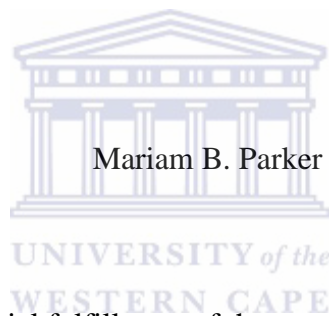


TITLE PAGE

PHARMACY PERSPECTIVES IN THE DESIGN AND IMPLEMENTATION
OF A MOBILE CELLULAR PHONE APPLICATION AS A
COMMUNICATION AID FOR DISPENSING MEDICINES TO DEAF
PEOPLE IN THE SOUTH AFRICAN CONTEXT



A thesis submitted in partial fulfillment of the requirements for the degree of
Doctor Philosophiae in the School of Pharmacy, University of the Western Cape.

Supervisor: Prof. Angeni Bheekie

Co-supervisor: Prof. William Tucker

November 2015

PHARMACY PERSPECTIVES IN THE DESIGN AND IMPLEMENTATION
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IN THE SOUTH AFRICAN CONTEXT

KEY WORDS

Deafness

Deaf culture

South African Sign Language (SASL)

Dispensing

Patient counseling

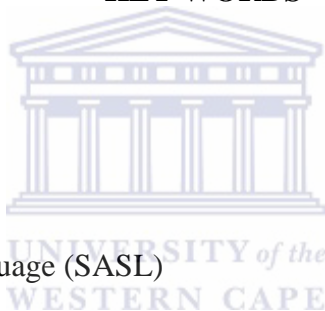
Social competency

Medicine instructions

Mobile phone application

Multi-disciplinary collaboration

Sign-language interpreter



PHARMACY PERSPECTIVES IN THE DESIGN AND IMPLEMENTATION
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COMMUNICATION AID FOR DISPENSING MEDICINES TO DEAF
PEOPLE IN THE SOUTH AFRICAN CONTEXT

ABSTRACT

MB Parker

Ph.D. thesis, School of Pharmacy, University of the Western Cape

South Africa's White Paper for the transformation of the health care system in South Africa (DOH, 2007) acknowledges major disparities and inequalities as a result of an imprint by apartheid policies. In its transition to democracy, health promotion strategies have been initiated to address these disparities. However, such strategies have been narrowed and "*favoured target audiences that are literate, urban-based and who have easy access to print and audio-visual media*" (DOH, 1997). This implies that many vulnerable and marginalised groupings in South Africa, including the Deaf community are excluded from health promotion endeavours.

Deaf people in South Africa communicate using South African Sign Language (SASL) and majority of the Deaf community exhibit poor literacy levels. Deafness is a significant communication barrier which limits a Deaf person's prospect to attain the best possible health care (Barnett, et al 2011). Various means of communication including spoken language, written instructions and the use of pictograms are used by healthcare workers to communicate health-related information. For many members of the Deaf community who communicate primarily in sign language, these methods are a sub-standard and prevent the attainment of optimum therapeutic outcomes. With regard to pharmacotherapeutic services, Deaf people cannot hear the spoken language used by pharmacists during patient counselling, and their compromised functional literacy hinders the ability to read instructions on medicine labels. With both the spoken

and written means of communication compromised, the Deaf patient's ability to comprehend instruction by pharmacists on how to use their medicines is inadequate and as a result, a Deaf patient may leave the pharmacy with medicine, but a poor understanding of how to use the medicine safely and effectively.

Previous researchers have worked on building a technology base, including industrial design and computer science expertise to conceptualize the groundwork of a mobile phone application called SignSupport to facilitate communication between medical doctors and Deaf individuals. The particulars of the pharmacy scenario however, require a pharmacy-specific device to be of use in the dispensing of medicines to a Deaf patient in a pharmacy. The over-arching goal of this thesis is to design and evaluate a mobile phone application to facilitate the communication of medicine instructions between a Deaf patient and a pharmacist.

Qualitative, participatory action research and community-based co-design strategies were directed toward Deaf participants, senior pharmacy students and pharmacists to create a prototype of the afore-mentioned mobile phone application. Preliminary results indicated that the application was suitable to pharmacists and Deaf community. Furthermore, both sets of users approved the overall design and were receptive to and keen on the practical uses of the application. Inadequacies pointed out by the Deaf community and pharmacists were addressed as an iterative modification to the prototype and culminated in version 2 which was deployed in an actual hospital pharmacy in 2015. Hospital usability studies generated largely positive results from both Deaf users and pharmacists, indicating that SignSupport is able to facilitate communication between pharmacists and Deaf patients. Next steps include advancing the application to a market-ready version that is downloadable and available as an application on the play stores of commercially available smart phones.

November 2015

DECLARATION

I declare that *Pharmacy perspectives in the design and implementation of a mobile cellular phone application as a communication aid for dispensing medicines to Deaf people in the South African context* is my own work (except where acknowledgements indicate otherwise), that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Mariam B. Parker

November 2015

Signed



DEDICATION

To my moms- Najmunissa and Zaibunissa, for your prayers, resilience and unwavering support.

To Mazhar- for filling my shoes as well as yours, and for letting me be me.



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To my Almighty creator, who gently nudges and pushes me in directions of which I can only dream, who has opened the doors of academia which so innately suits my very fiber, who has equipped me with the strength and capability to do this work.

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This research would not have been possible without my team members, Prang and Michael, my research assistants (B..Pharm. IV student research groups 2012, 2013 and 2015) and the participants who selflessly gave of their time and knowledge to bring SignSupport to fruition. Thank you for sharing of yourselves and for your dedication to deliver your best.

To the funders of this work, the National Research Foundation and University of the Western Cape, Deputy Vice Chancellor, for affording me the necessary resources to bring this thesis to completion.

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LIST OF ACRONYMS

SASL:	South African Sign Language
DeafSA:	Deaf Federation of South Africa
SASLI:	South African Sign Language Interpreter
UWC:	University of the Western Cape
TU Delft:	Delft University of Technology
DCCT:	Deaf Community of Cape Town
NRF:	National Research Foundation
WHO:	World Health Organization
FIP:	International Pharmaceutical Federation
US:	United States
SAPC:	South African Pharmacy Council
OSCE:	Objective Structured Clinical Evaluation
OSDE:	Objective Structured Dispensing Evaluation
WFD:	World Federation of the Deaf
WASLi:	World Association of Sign Language interpreters
SADA:	South African Disability Alliance
SANCD:	South African National Council of the Deaf
DOH:	Department of Health
NAD:	National Association of the Deaf
NDP:	National Drug Policy
SMCR:	Sender-Message-Channel-Receiver
SMS:	Short Messaging Service
HCD:	Human Centered Design
ICT:	Information and Communication Technology
OTC:	Over-the-Counter (medicine)
PC:	Personal Computer
GPP:	Good Pharmacy Practice
PAR:	Participatory Action Research

TERMS AND DEFINITIONS

deaf: (lower-case 'd') refers to individuals who experience hearing loss from moderate to severe, and use mainly spoken language to communicate.

Deaf: (uppercase 'D') refers to those individuals who experience profound hearing loss and use South African Sign Language as their main means of communication. They identify with Deaf culture.

Deaf culture: a cultural grouping associated with Deafness and the primary use of sign language as the main means of communication.

Dispensing Phase 3: *"Provision of information and instructions to the patient to ensure safe and effective use of medicines." (SAPC, 2010)*

Patient counselling: *"A one-to-one interaction between a pharmacist and a patient and/or caregiver. It is interactive in nature. It should include an assessment of whether or not the information was received as intended and that the patient understands how to use the information to improve the probability of positive therapeutic outcomes." (Beardsley, 1997)*

SignSupport: A mobile phone assistive technology to facilitate communication between a pharmacist and a Deaf patient.

Multi-disciplinary collaboration: the collective efforts of a pharmacist, computer programmer, industrial design

engineer and Deaf community toward realizing SignSupport.

Dispensing dialogue pattern: a collective order-of-sentences elicited from studying the communication between a pharmacist and patient.

Communication script: the dispensing dialogue pattern converted into a format to be coded in SignSupport.

Pharmacy student participants: final year pharmacy students as research participants selected on the basis of a non-randomized sampling strategy.

Research assistants: final year pharmacy students as research assistants selected on the basis of their curriculum requisites to complete a research project.

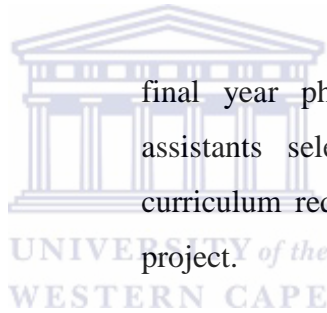


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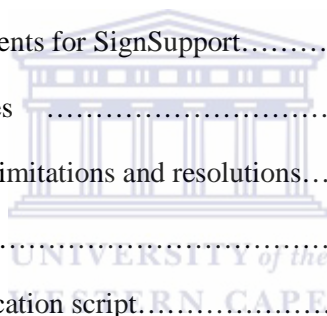
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CHAPTER 1

INTRODUCING THE RESEARCH

More than two decades into the emergence of a democratic South Africa, the aftermath of historical injustice and inequality lingers in the country's healthcare system. The public health sector in particular has inherited a highly under-resourced and fragmented state of affairs (Dayi & Gray, 2006). While the impoverished and needy are recognized daily as casualties of this fragmented system, marginalized groups may be at greater risk. In a health system fraught with a lack of resources and an over-stretched capacity (Dayi & Gray, 2006), the disabled become victims of poor service delivery and failure to address their special needs (DOH, 2007).

The need for effective verbal, written or electronic communication is imperative in the provision of healthcare. This is particularly important during a pharmacist-patient interaction in which the patient is given medicine dosage and administration instructions (Beardsley et al., 2008). If miscommunication occurs, patients may understand instructions incorrectly which in turn can have potentially dangerous consequences (Beardsley et al., 2007 in Tietze, 2004). Typically, the intended therapeutic outcome is compromised, which could result in a potentially life-threatening situation for the patient, placing a further burden on the already overstretched health system. On special needs and effective communication in a pharmacy setting, the Deaf community may be especially vulnerable.

South Africa is home to an approximated range of 600 000 to 1.5 million profoundly deaf people who use South African Sign Language (SASL) as a first language and identify with the Deaf culture (DeafSA, 2011). Deaf people often exhibit literacy impediments because they have not acquired spoken language at a pre-lingual age (Barnett, 1999). The absence of auditory stimuli impedes phonic development and is causal to their literacy insufficiencies (Fellinger et al., 2012).

Deaf individuals are often termed “functionally illiterate”, i.e. have marked limitations in their capacity to read and write. Functional illiteracy renders medicine labels and traditional verbal medicine instruction/counselling unviable options for Deaf patients, since neither option can be understood with sufficient accuracy required for medicine instruction (Steinberg et al., 2006). This communication difficulty may pose a significant barrier to achieving intended therapeutic outcomes of prescribed medicines. The challenges in communication between Deaf people and health care professionals have been widely shown to result in a poor medicine use (Reeves et al., 2002). The gravity of these problems creates a critical need for a concise and clear communication medium for the transfer of medicine instruction between a pharmacist and Deaf patient.

The past decade has seen an international and ever-expanding impetus toward looking to emerging technologies to counter social quandaries in every shape and form. The world of communication has been transformed by the emergence of networks and applications that allow for real-time relay of access to information. Many individuals, corporations and governments are employing technologies not only as a means of development but also as a medium to empower marginalised communities in areas of health, education and social reform. This dissertation presents a possible solution to enable the effective communication of medicine instructions between a pharmacist and a Deaf person collecting medicines at a pharmacy.

1.1 Personal interests and experiences

As a pharmacy student and intern pharmacist, I was naturally drawn to matters concerning effective communication between pharmacists and patients/clients. Working in a public tertiary hospital in a country diverse with eleven official languages, I was often privy to the bottlenecks which arose when a patient receiving medicine instructions was unable to understand the language the instruction was given in, for example an isiXhosa-speaking patient and an Afrikaans-speaking pharmacist. The possibility of a person being placed at risk of under-dosing or overdosing on medicines simply because they did not understand

instruction was an issue that needed urgent attention. This led to my first independent research endeavour which aimed to bridge the linguistic gaps in medicine instruction. The study involved crafting a manual solution as a dosage translation tool which allows pharmacists to translate medicine instructions dynamically between English, Afrikaans and isiXhosa (Parker & McCrae, 2008). This research directed me to academia which in turn led to social studies and qualitative research, in particular community-centred and participatory action research.

The umbrella project described in this thesis was not self-initiated, but referred to myself by a colleague who was aware of my background and interest. I was approached by an international research group to be the pharmacy arm of a multi-disciplinary project in which the expertise and professional training and experience of a pharmacist was needed. Since the project was aligned with my interests, participation was inevitable. Thrust into an unfamiliar world of sign-language, computer programming and android interfaces, the prospect of creating a solution for Deaf people to understand how to use their medicines without having to rely on interpreters, family or friends to administer doses was sufficiently enticing to ensure my continued efforts.

1.2 Multidisciplinary Collaboration

The final outcome of this research was envisioned to be a mobile phone prototype application that would allow communication of medicine instructions between a hearing pharmacist and a Deaf person, without the Deaf person having to rely on interpretation or assistance. Instead, medicine instructions would be available for the Deaf person in their preferred language i.e. South African Sign Language (SASL). For this outcome to be realised, a mobile phone interface would need to translate instructions keyed in by a pharmacist into SASL (e.g. Take two tablets three times a day after meals). To make this a reality, collaboration of various stakeholders with different expertise was crucial. In brief, the following expertise was needed:

1. **Pharmacist:** to contribute all pharmacy-related communication needs for implementation into the mobile phone application.
2. **Computer programmer:** to contribute technical expertise to code the application onto a mobile phone interface in a manner that was usable and functional.
3. **Industrial design engineer:** to design interface icons and flow in a manner that would be understood by the Deaf community. In addition, she advised the team with regard to suitable evaluation techniques to assess the usability of the application.
4. **Deaf community and interpreters.** The Deaf community were the drivers of the design; they dictated what would be suitable for them. Interpreters bridged the communication gap between the researchers and Deaf community at every step of the research.

1.3 Partners, affiliations and interests, funders

Since this collaboration involved team members from different fields of expertise, each team member was affiliated to different partners, funders, centers and co-researchers. Academic partners included the University of the Western Cape (UWC) School of Pharmacy and Department of Computer Science and the Delft University of Technology (TU Delft), Netherlands. Deaf community partners included the Deaf Community of Cape Town (DCCT) and the Deaf Federation of South Africa (DeafSA). During the research, three teams A, B and C (team details in Appendix A) of senior pharmacy students participated as research assistants working under my supervision during separate study phases. Table 1 below outlines the specific role of each member outlined in the study.

Table 1: Research partners and affiliations

Partner	Role	Affiliation	Co-researchers		
Pharmacy	Pharmacist Member	UWC School of Pharmacy	Assistant researchers:		
			Team A	Team B	Team C
Computer Science	Computer programmer	UWC Computer Science	n/a		
Industrial Design	Industrial design member	TU Delft (Netherlands)	n/a		
Deaf community	Input in design, preliminary testing	DCCT	n/a		
Paarl DEAFSA	Hospital testing	DEAFSA	n/a		

Funding for the study was granted by the South Africa-Netherlands Research Programme on Alternatives in Development (SANPAD), the National Research Foundation (NRF) and the University of the Western Cape (UWC) and used for costs incurred in running the experiments, research assistance and staff relief.



1.4 Research context

In order to realise the outcome of a purposeful mobile phone application prototype, the active engagement of two groups of study participants was necessary, viz. pharmacists and Deaf persons, who were the intended end-users of the mobile phone application. Participant groups were obtained at various centres within the Western Cape province of South Africa, with pharmacists being from the city of Cape Town and Deaf participants from both Cape Town and Paarl, a town on the outskirts of Cape Town.

1.4.1 Pharmacists

Pharmacists were needed in the study because ultimately, they are intended to use the application to key in medicine instructions for the benefit of the Deaf patient. For this reason, the application had to be designed to specifically meet their professional and practical needs at the point of care, namely the time required to

dispense, adhering to the pharmacist's code of practice and fitting in to their professional and work contexts. Their contribution on whether the application was user-friendly, applicable, accurate and complete was what would drive study iterations.

Since the Deaf communities we were working with mostly made use of public rather than private health services, and in particular tertiary hospital pharmacies to collect their medicine, we worked with pharmacy participants who were familiar with and had experience at tertiary hospital pharmacies. The final empirical procedures of this dissertation were also conducted at a tertiary hospital pharmacy since this was the site where Deaf participants would regularly engage with pharmacists to receive their medicine. Our main focus was to test the mobile phone application in a real-world context that mimicked the pharmacist-patient interaction in a hospital setting.

Public sector pharmacies are often fraught with severe human resource constraints, often being short-staffed and working over-time to meet patient load. In this way, the time commitment required from pharmacists would be minimised. The initial iterations used senior (fourth year) pharmacy students from the UWC School of Pharmacy in place of pharmacists, based on the criteria that they must have had prior experience in supervised dispensing at a public hospital pharmacy. Later in the study, pharmacists employed at Tygerberg hospital pharmacy were used to test the application with Deaf participants in a real-world setting.

1.4.2 Deaf participants

The mobile application was envisioned to be of use for South African Deaf persons. Thus, they were another target sample of the study. Deaf patients experience difficulties during a pharmacy consultation because traditional means of communicating medicine instruction are not feasible for them: spoken instructions are not audible and written or typed instructions on a medicine label present a problem to Deaf persons with limited literacy. The Deaf community primarily dictated the design of the application: what would suit their needs in a format that was most appropriate for them was at the forefront of the design process. Initial

design, subsequent iteration and final experimentation were conducted with Deaf people.

1.5 Research Origin

The main outcome of this study, a mobile phone application for Deaf persons, emerged from prior work by Looijestein (2009), Mutemwa (2011) and Chinithorn (2011). Looijestien designed a program on a personal computer that allowed a Deaf person and a doctor to communicate with each other using sign language videos. This program was called SignSupport (Version 1).

SignSupport was implemented on a mobile phone by Mutemwa (2011). He expanded on Looijestein's (2009) version by using an organised composite of SASL videos and English text. This format enabled a Deaf patient to communicate to the doctor which symptoms he/she was experiencing and the symptom duration. Testing of Mutemwa's version revealed that while the format was functional, it was not feasible to use in the context of a medical consultation. Chinithorn (2011) went on to investigate the way Deaf people use mobile phones to communicate with both hearing and Deaf people. With input from a local Deaf community, she re-oriented SignSupport toward pharmacy, and realised that they required the expertise and experience of a pharmacist to bring the pharmacy version of SignSupport to realisation. My involvement in this study, and the work presented in this thesis ensued.

1.6 Research problem

Deaf people identify with the Deaf culture and use South African Sign language (SASL) as their primary means to communicate (DeafSA,2011) . They also use modern mobile phone and computer technologies, including e-mail, short messaging service (SMS), Whatsapp® and Skype®, among others (Glaser & Tucker, 2004). While these technologies have proved useful in some contexts, limited text literacy hinders communication. Poor text literacy also renders medicine labels of little use. A medical communication exchange requires high levels of accuracy to avoid risk of incorrect diagnosis, treatment and correct

understanding of medicine administration. In Deaf persons, this risk can only be avoided using their ‘mother-tongue,’ sign language, to accurately and without ambiguity convey instructions in a manner that Deaf people can clearly understand. South African public healthcare facilities do not make provision for interpretive services for Deaf people; as a result they rely on the assistance of family and friends. Deaf people have reported a desire for the same autonomy and confidentiality in medical issues that their hearing counterpart’s experience. This can only occur if the pharmacist is able to communicate with the Deaf person in sign language, which is unlikely to be the case.

1.7 Research Approach

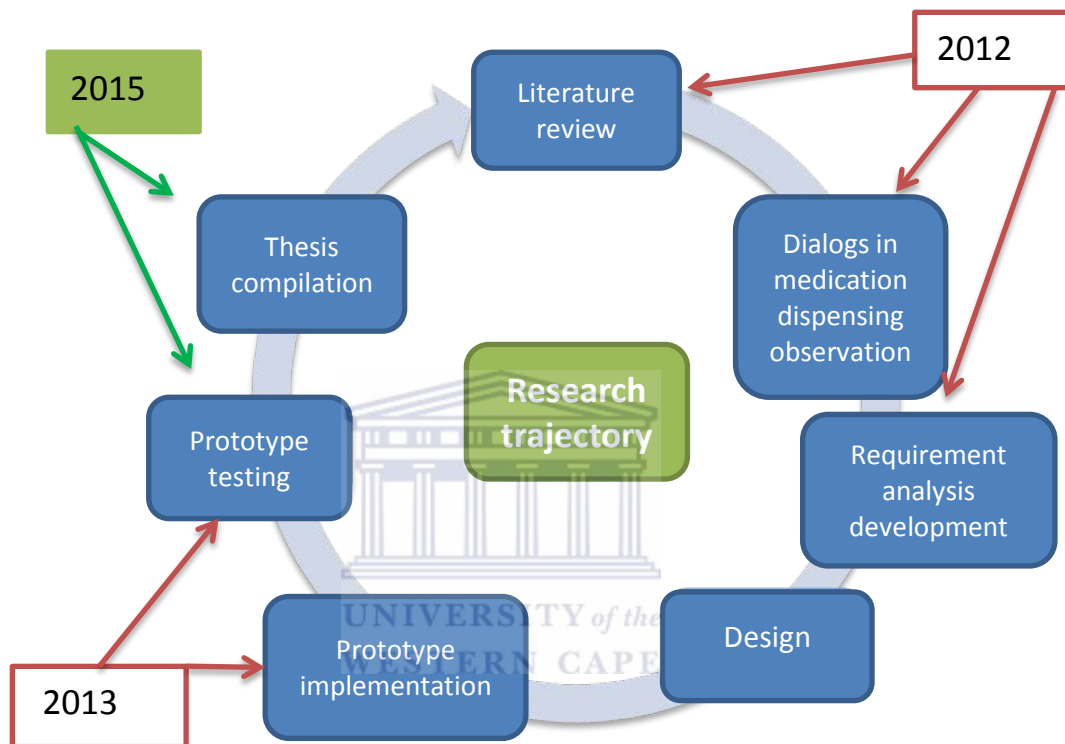
To enable the research team to fully immerse ourselves within the Deaf culture and to elicit their communication needs, qualitative and participatory research approaches suited the inquiry process and these strategies were employed throughout the stages of this research. Data collection was qualitative and data from each juncture of the study was incorporated into the subsequent phase, creating iterative cycles of research and subsequent design. A participatory action approach is well suited for innovation studies because it considers the requirements and input of the intended users of the product. Furthermore, participation and feedback at respective research sessions influenced subsequent design iterations of the mobile phone application.

1.8 Overview of the research

The iterative nature of the research necessitated a sequential pathway of events, outlined as research phases. The research team commenced work with a conceptual notion of a mobile phone application which would allow a pharmacist to communicate with a Deaf person in SASL. The concept was based on Looijestein’s (2009) computer model and Chininthorn’s (2011) work with a local Deaf community. Members from pharmacy, computer science and industrial design engineering backgrounds combined their expertise and agreed upon the design progression for the mobile phone application collectively, which in turn determined

the trajectory that my research would follow. Logically, research activities accommodated the design process in order to bring to fruition the overarching goal of a tangible, usable mobile phone application. Figure 1 outlines the sequence of research activities.

Figure 1: Sequence of research activities



1.9 Thesis outline

The iterative nature of this study calls for data to be reported on at each stage of the research. This dissertation is thus presented in narrative manner and deviates from the conventional manner in which thesis reports are structured. The first chapter has introduced the scope of research, the multi-disciplinary team members and their respective roles, my personal research background and the phases of this complex study.

Chapter two sets the backdrop for the proposed mobile phone initiative within the local Deaf community and its applicability in pharmacies in the South African public health care system. Insights into the pharmacist's crucial role in

communicating medicine related information substantiates the applicability of assistive devices in bridging communication gaps between pharmacists and vulnerable groups. A synopsis of health-related communication issues affecting Deaf persons portrays an immensely challenged community further subverted by a lack of resources and service facilities. The chapter proceeds to report on and analyse published local and international policy and legislative documents looking toward elucidating the theoretical underpinnings for the development of assistive technologies in healthcare communication. Furthermore, innovations in communication technology designed specifically for Deaf persons are explored, with a view to extract lessons of the successes and drawbacks of these technologies for incorporation into our own mobile phone application design.

Chapter three elucidates from the literature the focal aspects that establish the rationale for the study and details the research objectives designed to fulfil the main aim and outcomes of the study.

Chapter four (research design and methodology) presents the elucidation of the research plan and chosen methods, grounded in the underpinnings of the qualitative paradigm and of participatory action research. It further portrays the manner in which research theories are applied at each emerging phase of data collection and analysis. This is followed by a discussion of the manner in which quality and rigour were addressed in every phase of the study. The chapter concludes with presenting and applying ethical issues particular to working with vulnerable groups.

Chapter five presents the baseline study which comprises the first empirical processes of this dissertation. These processes, aimed at attaining the groundwork for the intervention described in this dissertation include a qualitative, explorative study with the Deaf community and a participatory action and qualitative study with senior pharmacy students.

This thesis reaches its climax in **Chapter six**, which presents the conceptual processes toward a mobile phone application which facilitates communication

between a pharmacist and Deaf patient. The application is presented as a pictorial series of screenshots of how it would appear on commercially available smart phones.

Chapter seven serves to present usability studies of the mobile phone application, targeted at pharmacists and Deaf patients. A pilot study is described subsequent to which the pilot study is implemented in a real-world hospital setting.

Chapter eight delivers a general discussion of the main themes emerging from this project, scholarly views of such themes and its implications on social redress for Deaf communities.

Chapter nine brings this thesis to a close, delivering a distillation of the research findings, author opinions and recommendations for future work.



CHAPTER TWO

LITERATURE REVIEW

The literature review is separated into three sections and examines legislature, policy and published research pertinent to underpinning a theoretical framework for the research. The opening section explores the concept of deafness and reviews definitions of deafness with a view to extract a single designation applicable to the research. I delve into the formal support structures for hearing-impaired communities both internationally and locally, and examine the constitutional rights of the Deaf community regarding health care provision and accessibility. The psychosocial and emotional impact of Deafness provides the landscape relating to the affective behaviour of Deaf people. The review further explores literature documenting the experiences of the Deaf community with healthcare communication, and specifically medicine instruction, thereby creating a case for the intended research.

The second instalment explores global and national policy recommendations pertaining to the roles of pharmacists within the healthcare system, focusing specifically on characteristics of effective communication in service delivery. Literature focusing on the communication experiences of pharmacists with hearing-impaired patients is analyzed.

The final segment reviews global trends in using assistive technologies to counter social problems experienced by the Deaf community, focusing on the area of information communication technology (ICT) for communication in healthcare. It reports on the foundational work done specifically in using assistive technology to assist the Deaf community in healthcare communication. The review culminates in lessons learnt from the literature that are central to this thesis.

2.1. UNDERSTANDING THE DEAF COMMUNITY

Deaf people experience a unique and complex set of circumstances that extend far beyond their physical disability. Not merely people who have impaired hearing, they are a multifarious community characterized by cultural and societal intricacies which are essential to understand when working with them. As a fairly isolated and marginalized minority group, they have a strong sense of kinship and loyalty to other deaf people. This section explores the fascinating characteristics of Deaf people and how they function in a hearing society.

2.1.1 Deafness and hearing loss

The word ‘Deaf’ (adjective) is largely defined as:

“Lacking the power of hearing or having impaired hearing”

Notwithstanding its Germanic roots, related to Dutch ‘*doof*’ and German ‘*taub*’, (from an Indo-European root shared by Greek *tuphlos* ‘blind’), the term ‘deaf’ is Old-English in origin (Oxford University Press, n.d.). While the general definition is expansive encompassing everything from mild hearing loss to zero hearing ability, in reality the term is far more complex with multi-faceted connotations.

In March 2015, the World Health Organization’s (WHO) media centre published updated indicators detailing key facts and statistics on the worldwide picture of deafness. Globally, 360 million people experience disabling hearing loss, the majority of who reside in low and middle-income countries (WHO, 2015). In the age group 65 years and older, 33 percent of people experience disabling hearing loss, the greatest prevalence occurring in Sub-Saharan Africa, South Asia and Asia Pacific (WHO, 2015). While Deaf prevalence in South Africa is contested, the statistics reflect numbers between 600 000 and 1.5 million people (DeafSA, 2011). Causes of hearing difficulties are either congenital or acquired. Congenital causes are present at or shortly subsequent to birth and include genetic factors, low birth weight of the infant, maternal rubella and birth asphyxia among others. Acquired causes lead to hearing loss at any age and include meningitis, chronic ear

infections, otitis media, ear or head trauma, ageing and exposure to excessive noise pollution (WHO, 2015).

2.1.2 “Hearing loss” versus “Hard-of-hearing” versus “deafness” versus “Deafness”

The degree of hearing impairment varies largely from one individual to the next; while one person may have zero ability to hear, another may experience only minor deficiency. For this reason, many different terms exist to describe hearing impairment (Middleton et al., 2010). These terms are often fluid, they are used interchangeably and vary across communities. While no single universally accepted definition for Deafness exists, I examine below the definitions presented by key organizations, with a view to elucidate therefrom a definition that applies to this study.

According to the WHO (2015), the term ‘hearing loss’ applies to persons who experience hearing thresholds of 25 decibels (dB) or better in both ears. Hearing loss can be unilateral or bilateral and ranges from mild, through moderate and severe to profound. Persons who are hard-of-hearing are characterized by hearing loss spanning the range from mild (difficulty in hearing conversations in a noisy area or hearing whispering) to severe (begin to hear sound between 71- 85dB, i.e. equivalent to the sound of a lawnmower). They are able to communicate using spoken language, and are represented by a lower-case “d,” i.e. “deaf”.

“Deaf” people denoted with an upper-case “D” experience profound hearing loss with very little or no hearing. They can only hear sound equivalent to or above 95dB (WHO, 2015), for example a gunshot (140dB) (Cambridge University Press, 2010). Instead of using spoken language, they use signed language to communicate. The WHO classification system of hearing impairment is based on objective clinical presentation (decibel count) and is classified in terms of presentation by the variables: mild, moderate, severe and profound. Conversely, the Cambridge University Press’s “Working with Deaf people: A handbook for healthcare professionals, (Middleton et al., 2010)” defines “deaf” persons as those having a

profound level of hearing loss and who use both signed language and spoken language in different contexts.

Figure 2: WHO hearing- impairment classification scale



The World Federation of the Deaf (WFD) serves as the international, non-governmental organisation for national associations of Deaf people and is recognized as the representing body for Deaf people who use sign language. While WFD does not classify varying degrees of hearing impairment, it embraces a concept of Deafness that mimics the WHO definition, with the common factor between the two being the usage of sign language (World Federation of the Deaf, n.d.).

In their constitution the Deaf Federation of South Africa (DeafSA, 2008), defines Deaf (uppercase D), as “*all persons with substantial hearing loss who may consider themselves Deaf*” and includes persons who are hard-of-hearing, deaf-blind and deafened persons who affiliate themselves with the Deaf culture and the use of SASL. The uppercase ‘D’ denotes adherence to a specific social grouping i.e. the Deaf culture (DeafSA, 2008).

Alternative constructs of the terms “deaf” and “Deaf” are based on the period of deafness in years, the individuals own perception of whether they are deaf, Deaf or hard-of-hearing, whether the person’s hearing impairment was congenital or acquired, and the literacy status and ability to communicate in the hearing world. For this research I have discarded these definitions due to the subjective nature of the variables.

2.1.3 Deaf community representation

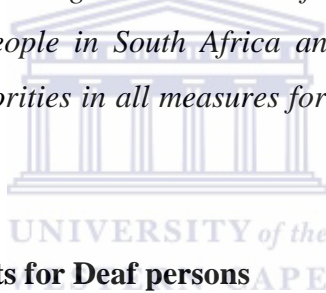
While hard-of-hearing and Deaf communities are often referred to as minority groups, substantial representation of deaf people by organized federations and societies is evident worldwide, with deaf community perspectives featuring in the work of the United Nations (UN) and WHO.

The WFD is an international organization representing approximately 70 million Deaf people worldwide. Established in Rome in 1951, WFD comprises an existing membership of associations in 133 countries globally (World Federation of the Deaf, n.d.). It is estimated that more than 80 percent of these 70 million live in developing countries, where authorities are rarely familiar with their needs. WFD works closely with the UN and its various agencies in promoting the human rights of deaf people. This is in accordance with the principles and objectives of the UN Charter, the Universal Declaration of Human Rights and other general acts and recommendations of the UN and its specialized agencies globally (World Federation of the Deaf, n.d.). WFD advocates for Deaf people in every country to have the right to preserve their own sign languages, organizations and cultural activities. Most important among WFD priorities are Deaf people in developing countries; the right to sign language; and equal opportunity in all spheres of life, including access to education and information. WFD's philosophy is one of equality, human rights and respect for all people, regardless of race, nationality, religion, gender, sexual preference, age and all other differences. WFD supports and promotes in its work the many UN conventions on human rights, with a focus on the aim of solidarity and unity globally (World Federation of the Deaf, n.d.).

The South African Disability Alliance (SADA) is a national board that comprises thirteen national organizations that represent various disabilities in South Africa, including Autism South Africa, Deaf-Blind South Africa and Down syndrome South Africa (SADA, n.d.). Serving as the voice of the disability sector in the country, SADA represents approximately 8% of the populace and advocate on behalf of disabled persons. The Deaf Federation of South Africa (DeafSA) is one of the thirteen members that constitute SADA. Formerly known as the South African National Council for the Deaf (SANCD), SANCD was founded in 1929

and in 1995 the former SANCD was transformed to a new democratically elected organization, DEAFSA. DEAFSA serves as the “national research, information and community action” association on behalf of an approximately 600 000 citizens that are culturally and linguistically Deaf (DeafSA, 2008). The vision of DEAFSA is “*a fully functional Deaf community with equality in society, empowered to utilise opportunities in order to create and sustain a high quality of life* (DeafSA, 2008).”

DEAFSA comprises of and represents nine provincial Deaf federations. Among their national objectives, DEAFSA seeks to “*formulate national policies regarding deafness, to promote the status of SASL, to initiate, develop, decentralize, co-ordinate and maintain structures and projects, to promote and assist standards of training of sign language interpreter services in South Africa, to be the official lobbying, representation and negotiation channel for the purpose of equalization of opportunities for Deaf people in South Africa and to co-operate with national, provincial and local authorities in all measures for the general well-being of Deaf people* (DeafSA,2008).”



2.1.4 Constitutional rights for Deaf persons

Embedded within the Human Rights Charter and in accordance with its constitution and international conventions, South Africa is obliged to provide equal rights, opportunities and services for Deaf and hard-of hearing persons. The constitution of South Africa advocates for equality for all people under Articles 9 (3), 10, 13 which declare the right to privacy of communication, access to information and the right to practice culture, religion and language freely (Constitution of the Republic of South Africa, 1996). In addition, South Africa is a signatory nation to a number of global treaties and declarations relating to protection of human rights, protection of people with disabilities and matters of equality for all. It is indisputable that Deaf persons should have access to and equally enjoy the provisions and facilities provided to their hearing counterparts. This notion has been entrenched in international policy and resonates in South African policy which is fairly well-developed in establishing constitutional rights for disabled people. Policy however

fails on an implementation level. South African legislation does not specify or obligate special services (for example sign-language interpretation) for Deaf people within healthcare facilities (Zulu, 2014). In addition, several circumstances arise for Deaf people which compromise their constitutional rights. These are outlined later in this review.

2.1.5 Epidemiology of Deafness in South Africa

Population numbers detailing the prevalence of Deafness in South Africa are inconsistent across various sources. Community survey data 1997 report a 0.4% prevalence rate of Deafness in the country (Statistics South Africa, 2007) while DeafSA (2011) reports a prevalence figure of 3.7 percent. The DeafSA numbers are closer to the WHO estimate of 5 percent Deafness prevalence in the world populace. Census data 2011 reflect a total disability incidence of 7.1 percent (Statistics South Africa, 2013), of whom 20% are estimated to have a hearing disability. The discrepancies of Deaf prevalence data may be due to varying subjective classification systems of hard-of-hearing, deafness and Deafness. DeafSA reports an expansive range of users of South African Sign language, between 600 000 and 1.5 million users (DeafSA, 2011), the lower interval mimicking the WFD number of Deaf users.

2.1.6 Deaf community profile in South Africa

South Africa's deaf community is well-established and experience strong support in terms of national and provincial representative organizations and non-profit organizations. The country's history of inequity and social injustice has resulted in a high incidence of unemployment and limited literacy levels among the South African deaf community (Chininthorn, 2011). An estimated 600 000 South Africans communicate in SASL, this number coincides with the prevalence of profoundly Deaf people (DeafSA, 2011). Sign language is not universal; each country has its own unique form, with further dialectal differences from one Deaf community to the next. The same is true for sign language in South Africa. SASL is a visual, natural language developed through its use by the local Deaf

community (DeafSA, 2008). The language has a unique syntax and uses a series of signs to communicate a message, as opposed to the series of words used by hearing people. DeafSA hopes to officialize SASL as the country's 12th official language in order to uphold the rights of the Deaf community (DeafSA, 2011).

The deaf education system in the country is robust with more than forty dedicated schools for the deaf countrywide (Berke, 2014). Deaf colleges include the Worcester-based Deaf College South Africa, which trains deaf people to enter the job market, and the Gauteng-based Bible College for the Deaf which provides training to work in deaf ministry (Berke, 2014). About a third of all Deaf adults are functionally illiterate (Conrad, 1977). Functional illiteracy would mean that Deaf people requiring healthcare would most likely be dependent on sign-language interpreters or assistive audiology devices rather than traditional means of spoken and written information. If such resources are not available, the quality of care of Deaf people could be compromised.

Sign-language interpreters in South Africa were recently in the spotlight when the authenticity of sign-language interpretation of the internationally broadcast former-president Nelson Mandela's memorial service was questioned and derided for using gestures meaning "rocking horse" and "prawns" in the bogus sign-language translation (Newling, 2013). While the fake interpreter's presence and proximity to world leaders drew much attention in terms of breached security, it also highlighted the importance of authentic sign-language interpretation services for Deaf people and the fine line they experience between access to information and a lack thereof.

Figures detailing the religious profile of the South African deaf community are not available. However, deaf Christians who prefer deaf churches are affiliated to one of 15 churches of fellowships associated with the Deaf Ecumenical Forum of South Africa (Smit, 2010). Several Deaf South Africans are Jehovah's Witnesses and are members of Jehovah's Witnesses sign language congregation, or are Muslims. Al-Waagah Institute for the Deaf is an Islamic institute providing services for the deaf community in Athlone, Cape Town (Smit, 2010). The South African deaf community enjoy a deaf-dedicated television series, Deaf TV which airs weekly on

the national broadcaster channel, SABC3. This privilege is one which is not ubiquitously available globally (Berke, 2014).

2.1.7 The social and emotional handicap of Deafness

Deafness is more than a physical disability. It is a physical, emotional, educational, social and psychological handicap (Arana et al., 1978; Ismail and Henderson, 2014; Mc Brien, 1982; Schlesinger, 1978), compounded by the reality that deafness is also an invisible handicap; often the general public do not recognize that a person is Deaf.

Understanding the implications and full extent of the handicap of Deafness is an exhaustive task. Mc Brien (1982) found it best explained by sketching the developmental implications of Deafness in an infant who lost their hearing pre-lingually over the infant's natural life span (from infancy into childhood, teenage years and adulthood). Mc Brien's approach, although dated more than three decades ago, is a useful approach to understand the gravity of Deafness and how it impedes the natural development of human beings causing its extensive social, emotional and psychological implications. I have chosen to follow his approach in my own sketch of Deafness, extracted from various literature sources.

Consider a comparison between a baby who is born profoundly Deaf or acquires Deafness in the first three years of life (before language acquisition) and a hearing baby who has normal auditory capability. Very early in life and in fact while still in the womb, a baby is able to hear its mother's voice which impacts the baby's brain development. Patricia Kuhl (Institute for Learning & Brain Sciences, University of Washington) reports that *"the mother has first dibs on influencing the child's brain. The vowel sounds in her speech are the loudest units and the foetus locks onto them."* (Kuhl, 2013). Equally important, is the bonding between mother and infant that occurs when the mom talks and sings to the baby. Seconds after birth, a baby will turn its head toward voice and moves *"in rhythm to his mother's voice"* (Woodward, 2015). Babies particularly respond to human voices (McBrien, 1982). Brain development and maternal bonding may be diminished for an infant

who is unable to hear. Very early in life, babies who are Deaf experience the mental, intellectual, psychological and emotional implications of deafness.

McBrien (1982) reports that in the first year of life babies begin to experiment with sounds through “babbling and cooing,” and begins to learn language and the meanings of simple words. As the baby learns more words and the meanings thereof, he experiences encouragement from others and starts to understand the effects of his own words on others. Use of words in this way begins to impart to the toddler, some “*control over his environment, and subsequently he becomes more secure, more independent of his parents and more socially integrated.*” (Mc Brien, 1982). However, in a deaf child, Schlesinger (1978) reports that mechanisms of internal control are not well-developed due to an inability to communicate feelings. Consequently, a deaf child struggles to stall or relinquish his desires, which manifests in impulsiveness and aggression (Schlesinger, 1978). Psychologists question whether a deaf child can connect normally to his parents in spite of the inability to communicate with them. The preclusion of normal bonding relationships with parents may impede the development emotional security and trustfulness. In addition, parents may further effect the child’s emotional security through denying or hiding the handicap, causing a delay in seeking appropriate help (Mc Brien, 1982). On the other hand parents may be unnecessarily over-protective (Kritzinger et al., 2014), causing the child to be “*withdrawn, timid and accustomed to having his every whim indulged and cannot live with others as an equal*” (McBrien, 1982). In early childhood, Deaf youth already experience social exclusion.

In addition to poor impulse control and aggression, Deaf children also experience marked frustration due their inability to communicate. Such frustration may manifest as temper-tantrums and even violent behaviour, causing the deaf child to be considered as “disruptive or unmanageable.” McBrien reports that this may be owing to the fact that due to their inability to hear, Deaf children may not be warned about inappropriate behaviour, and when they do transgress, learning the consequences of their behaviour and receiving punishment for it may not be easy to achieve. Investigations with deaf children have indicated diminished levels of emotional maturity and feelings of isolation (Farrugia and Austin, 1980).

Furthermore, a deaf child may experience feelings of rejection with family members who approach them cautiously and may not be as openly warm as they are normally, and with other children who may mock or taunt them (Mc Brien, 1982).

With regards to education, further disparities emerge. Linguistic ability facilitates the process of abstract, theoretical, conceptual and figurative thinking tremendously. Deaf children, who often have poor linguistic capabilities, tend to think in “concrete,” literal terms more constantly than hearing children. Vocabulary, reading and writing skills are suboptimal owing to the inability to communicate effectively. At four years old, a hearing child knows approximately 1500 words, while a Deaf child may only know one or two words (Mc Brien, 1982). Memory and concentration is also impaired.

As a result of all these obstacles, success in classes and examinations of traditional educational systems is so much more difficult to achieve, which in turn decreases the likelihood of advancing in education and securing well-paid employment. The inability to communicate manifests itself in the inability of the Deaf person to realize their full potential, which may negatively affect their confidence and sense of self-worth (McBrien, 1982), and often result in timid behaviour and insecurity (Kritzinger et al., 2014).

In adolescent-hood and early adulthood, the teaching of what is socially appropriate and tactful is left unattended. The same applies with teaching appropriate “courting and sexual behaviour.” As a result, Deaf adults are seen as abrupt and too frank and candid in their behaviour, not conforming to the norms and intricacies of social decorum (Mc Brien, 1982). Deaf adults may face problems in finding a life-partner and subsequently starting a family. The same applies in finding work. Even when they overcome these problems, their actions as a partner, as a parent and as an employee are subject to scrutiny (Mc Brien, 1982). This is in addition to people who may taunt their disability. ‘Deafness paranoia’ is a term coined to describe the paranoid tendencies of Deaf people in social situations (Bleckly, n.d) . Deaf people may erroneously assume that hearing people

are talking about them, scrutinizing their behaviour. *“Deafness paranoia can be as mild as feeling embarrassment when you make a mistake believing everyone thinks you’re stupid, through to delusions of persecution...that everyone is out to get you, talking about you, judging you and laughing at you”* (Bleckly, n.d.) In addition to Deafness paranoia, social exclusion, ostracizing, and a lack of self-worth are plausibly what results in the strong dependence of Deaf people on other Deaf people to interact and befriend, and the closeness of the Deaf community and their exclusion of the hearing society (McBrien, 1982).

In summary, Deaf people experience marked difficulties in their ability to communicate, this impacts heavily on their emotional, social, psychological and intellectual development. As a result, Deaf people are characterized by emotional immaturity, poor impulse control, aggression, inappropriate social behaviour, lack of confidence, inability to realize their full potential and a struggle to form meaningful relationships socially and in the workplace.

Unexpectedly, in comparison to hard-of hearing or deaf people, these findings are not unlikely, although the extent to which they occur may be lessened. Mc Brien (1982) reports that the distress of losing hearing later in life is comparative to being born deaf or losing hearing ability prelingually, with these individuals often becoming depressed and “paranoid” that they are being spoken about by other people.

In offering healthcare to Deaf and deaf people, one would therefore need to be cognizant of minimizing the social and emotional barriers. In terms of pharmaceutical care, this would mean that the deaf/Deaf person’s accurate interpretation of medicine instructions would be essential to optimize therapeutic outcomes. The pharmacist’s understanding and ability to embrace Deaf people’s sensitivity to their communication barrier is crucial.

2.1.8 Deaf Culture

Many definitions have been presented for Deaf culture, often varying with demographic profile and geographic location of the Deaf communities. For this reason, I circumvent the need to construct a single definition and instead seek to gain an understanding of what Deaf culture is and how it is experienced in the daily lives of Deaf people.

Deaf culture is not unlike other cultural groupings in that it embraces its own unique social features, including social etiquette, recreation, entertainment, humour and arts (Barnett, 1999). Central to association with the Deaf culture is the use of sign language. In addition, Deaf culture is used in a positive perspective, signaling communal identity, pride and belonging, as opposed to terms such as hard-of-hearing or deafness which do not imply belonging (Meador & Zazove, 2005; Barnett, 1999).

Deaf people who adopt a culturally “Deaf” identity compare themselves to members of other ethnic communities. Within Deaf culture, social norms differ from those of non-deaf people (Meador & Zazove, 2005; Barnett, 1999). For example, to get the attention of an individual or group, a Deaf person may repeatedly flick a light switch, stomp his/her foot, or bang on a table to communicate using vibration (Barnett, 1999). Touch is also acceptable; a Deaf person may tap on somebody’s arm or leg for attention. To the hearing world, all these means may appear rude or socially inappropriate belonging (Meador & Zazove, 2005; Barnett, 1999).

The Deaf culture is one of a proud social identity. Historically, Deaf people have resisted efforts by oralists to minimise the use of sign language and mobilise Deaf people into the majority group (Hunt & Marshall, 2012). Deaf people still prefer to socialize with their own kind (Hunt & Marshall, 2012). The Deaf community’s self-determination and strong sense of maintaining their own identity is indicative of their independence and allegiance to other Deaf people. The self-determined and isolated nature of the Deaf community would mean that health care practitioners’

ability to engage with sign-language interpreters would form a vital link to optimize service delivery. Assistive interventions aimed at Deaf persons must thus embrace Deaf culture with all its nuances, including sign language and cultural norms.

2.1.9 Deaf literacy

The heterogeneity of Deafness extends into the facets of linguistic ability and literacy, with marked variances in these aspects between Deaf persons. Within these variances Barnett (1999) observed that persons who (i) became deaf in the pre-lingual stage (before three years of age) and (ii) learnt sign language as their first language, are worse off in terms of literacy. For these members of the deaf community, written language is ineffectual. Onset of deafness before language is established occurs in 7 per 10 000 people (Fellinger et al., 2012). Furthermore, deficits in early auditory stimulation disturb neurocognitive processes including concentration and visual and aural memory, indicating that Deafness is more disabling than simply the inability to hear (Fellinger et al., 2012). Early exposure to linguistic and auditory stimuli is critical in the development of spoken language. People who experienced onset of deafness in early adulthood have better prospects in English proficiency than those who were born deaf or experienced pre-lingual onset of deafness (Marschark, 2001). In the ambit of healthcare service provision, this characteristic is of pronounced significance, especially where traditional means to convey messages rely on textual methods. This includes having to read and sign consent for treatment as well as receiving written directives on health advice or medicine instruction.

While a literacy impediment seems to be more prominent in Deaf as opposed to deaf persons, Barnett (1999) reports that literacy impediments comparably affect deaf people. In the United States, the average literacy aptitude of a deaf high school graduate equates to that of a 4th or 5th grade learner (McBrien, 1982, Barnett, 1999). Learning to read is an arduous task when you have a diminished ability to articulate sounds. This is causal to Deaf peoples' struggle with comprehending any text–

based message. Further causes of low literacy have been presented by Barnett (1999) and are summarized in table 2 below.

Table 2: Barnett’s multi-factorial causes of low literacy among Deaf people

Multi-factorial causes of low literacy
1. Delayed language acquisition by deaf children who have hearing parents
2. English is a second language, after sign language
3. Lack of consistency in educational approaches of a deaf child
4. Lack of access to general information

In light of their hearing and literacy difficulties, it is inevitable that Deaf people would become dependent on signed language interpretive services to engage meaningfully with the hearing worlds.

2.1.10 Interpretive services

Sign language interpreters are skilful professionals who are commonly registered with authorities that control their practice. Sign language does not depend on spoken word; it is a complex composite of gestures, inflections, facial expressions, attitude and body language (DeafSA, 2008). Unlike interpreters of other languages, sign language interpreters have the added responsibility of interpreting and decoding all these aspects, dissimilar to a linear transaction in which one language is translated directly to another. They must also be able to translate spoken language e.g. English into these complex gestures, in-so-doing ensuring that the Deaf person is able to fully understand the message intended by the sender. Interpreters immerse themselves in the Deaf culture and shift their social norms to those of a specific Deaf community.

The World Association of Sign Language interpreters, WASLi, report a universal shortage of sign language interpreters (WASLi, 2015). The same is true for South Africa which experiences a critical shortage of the same. Interpretive services are

very costly (average cost per hospital visit per person of R 2074.80) and can rarely be afforded by the South African community (Zulu, 2014), of whom the majority are not educated at a tertiary level and thus eligible only for low-waged jobs (Chininthorn, 2011).

2.1.11 Deaf people in relation to healthcare services

Published works relating to the experiences of Deaf people in health care facilities are largely and characteristically anecdotal. Based on the subjective experiences of authors working within Deaf communities, these studies are not generally representative of entire Deaf populations. Of the scanned literature, “hard-evidence” studies on the interactions of Deaf people in health facilities have emerged mostly from the United States and the United Kingdom (Reeves et al., 2002). The nature of sampling processes seem to be skewed toward opportunistic or convenience methods. While this may be a limitation in terms of producing data that is generalizable, it does provide depth and richness of description in reported findings. Furthermore, reports have produced congruent, consistent findings, augmenting the validity of assertions made (Reeves et al., 2002).

Deaf people report a number of difficulties in accessing healthcare services. These include sub-optimal quality of healthcare information (Steinberg et al., 2006; Kritzinger et al., 2014) lack of a clear understanding of where to proceed within facilities (Mathews et al., 2011; Reeves et al., 2002), the imposition of spoken and written instructions on treatment consent forms and in health-related information (Steinberg et al., 2006), and apprehension that they will miss treatment opportunities because they are not able to hear their names being called in waiting rooms (Reeves et al., 2002; Steinberg et al., 2006). Common adjectives describing the Deaf person’s experience emerge from several literature sources; these include fear, mistrust, disempowerment and frustration which is inevitably demonstrated through their aggressive facial and physical inflections (Mathews et al., 2011; Steinberg et al., 2006).

2.1.11.1 Communication with healthcare personnel

It is indisputable that the inappropriateness of traditional communication methods (spoken and written language) used in healthcare facilities cause Deaf people to utilize health care facilities differently than the hearing community (Barnett, 1999). Steinberg et al (2006) report ubiquitous difficulties in the interactions between health care practitioners and Deaf persons. This finding is corroborated in publications by Ferguson and Shan (2015), Kritzinger et al., (2014) Mathews et al., (2011) and Barnett (1999).

Speech, written messages and lip-reading (also called speech-reading) are the means most commonly relied on by healthcare personnel to communicate with Deaf people (Ferguson & Shan, 2015, Reeves et al., 2002). Speech cannot be relied on for effective communication because Deaf people, by definition, are profoundly deaf and unable to hear spoken messages (Steinberg et al., 2006). Furthermore, many Deaf people themselves have very limited to no intelligible speech (Reeves et al., 2002).

Lip-reading poses a number of problems. Firstly, lip-reading is viewed by some Deaf cultures as inferior to signing and has the negative connotation of being forced to conform to the language of the hearing world, thereby creating a psychosocial barrier in addition to a communication barrier. Secondly, lip-reading is not 100% intelligible and this intelligibility is affected by a number of variables, including the physical differences in peoples' lips (Steinberg et al., 2006), lighting in the area, word pronunciation and presence of a beard. The amount of speech understood by lip-reading is approximated by Steinberg et al., 2006 to be between 30% to 40 %. In a medical context this poses significant risks.

Written communication is cited by Deaf people to be the most common method used by healthcare personnel to transfer a message to deaf people (Ebert, 1995). The main problem with written communication is the limited literacy levels of the Deaf community, particularly those who became Deaf pre-lingually (Barnett, 1999). Speech and written communication are both dismissed by the Deaf community as inadequate. Harmer (1999) reports that such communication

inadequacies may dampen the Deaf patients' willingness to pose questions, and results in reduced confidence and suboptimal understanding of therapy. Health-seeking behaviours are consequently compromised (Harmer, 1999) unless Deaf people are able to access the services of sign language interpreters.

2.1.11.2 Sign-language interpretive services in healthcare

Communication via certified interpreters is positively received by Deaf people. Steinberg et al's (2006) USA-based study indicates that sign language interpreters effect superior communication in the healthcare ambit. The presence of interpreters for medical interactions is valued by the Deaf community and is viewed as symbolic of the healthcare provider's interest in their well-being (O'Hearn, 2006). Access to interpretive services may facilitate health care accessibility and receptivity to services as found in Pollard's (1994) investigation. He reports that patients are more likely to select therapeutic plans involving sign-fluent personnel and sign-language interpreters. Interpreters however are scarcely available and there is no legal provision for the inclusion of sign language interpreters in healthcare facilities in South Africa (Zulu, 2014).

In the absence of cost-estimate data on the use of sign-language interpreters in South African healthcare facilities, Zulu (2014) sought to estimate the costs of interpreter services at district health level. Cost estimates for the Cape Metro-pole district represented a range of 2.4-12.8% of the total budget for Western Cape district health services, indicating that the provision of interpretive services in South Africa would require significant capital investment by government.

Alternatives to using sign-language interpreters involve providing auxiliary aids for Deaf patients or using staff at the hospital to assist with interpretations. The monetary implications of providing auxiliary aids may be a significant obstacle. In addition, complexities arise when relying on healthcare staff to assist with interpretation. These may include breaches in confidentiality and autonomy for the Deaf patients, and their inexperience with medical terminology. Similar complexities arise when Deaf people rely on a family member or friend for

medical interpretation (Reeves et al., 2002). Building human resource capacity and skills development in training medical staff to interpret sign language is an opportunity to be explored. This would require interest and willingness by staff and planning to accommodate for the extra workload in an already resource constrained environment. Unavailability of interpreters at health care facilities across South Africa inhibits Deaf patients from expressing themselves correctly and this limits the ability of health care workers to share relevant information (Kritzinger, 2011).

2.1.11.3 Access to and assimilation of health information among Deaf people

Limited literacy precludes Deaf persons from the opportunity to access health information because much of the information at health facilities is in a textual format, including pamphlets, posters, labels, charts and consent forms (Mathews et al., 2011 & Reeves et al., 2002). Health information is also regularly acquired by the hearing community through radio, television, newspapers, magazines and the internet, all of which pose auditory or literacy obstacles for Deaf persons (Barnett, 1999). In the context of health-related information, medical jargon and context-specific terminology require Deaf people to possess a level of literacy which is beyond their capacity (Zazove and Doukas, 1994, & Huntington et al., 1995).

Highlighting their limited access to health-related information is Mohay & Kleinig's finding that Deaf people have been shown to possess reduced knowledge on health-related topics than hearing people, knowing little about basic first-aid, sexually transmitted diseases and sexual activity and its associated risk of pregnancy (Mohay and Kleinig, 1990; Miner, 1984, Chacko et al., 1987 & Van Biema 1994, cited in Reeves et al., 2002). Tamaskar et al (2000) report that Deaf people are less likely to believe the health benefits associated with reduced smoking, weight control and regular exercise. If the Deaf community is unable to take heed of health promotion information, then this would mean pharmaceutical care could pose an even greater challenge. Not only is the assimilation of health promotion information vital, but how health care professionals engage with the Deaf community is cornerstone to quality health care.

2.1.11.4 Attitudes of healthcare personnel toward Deaf patients

Steinberg et al's 2006 USA based study reveals perceptions of Deaf patients to be that they are treated unfairly in comparison to hearing patients. In the US, legal action has been sought by Deaf patients in filing a significant number of complaints of violation of rights and non-conformance to disability policy and legislation (Moore & Swabey 2007). Some hearing health care professionals display negative attitudes to Deaf persons, perceiving them to be obstinate and intellectually challenged (Meador and Zazove 2005; Scheieir 2009). This may impact on the willingness of Deaf individuals to seek healthcare. Abraham and Fiola (2006) have shown in a Canada-based study that healthcare professionals expect of patients that they either demonstrate fluency in the local language or have an interpreter present for the medical consultation. Such expectations may not be feasible in under-resourced countries such as South Africa.

Deaf awareness describes the recognition that a person is Deaf and understanding the communication impediments experienced by Deaf people. Huntington et al., (1995) and Lomas (1998) report that the Deaf community often complain about a lack of Deaf awareness by healthcare professionals. As a result they shout, fail to use plain English and often use medical jargon, do not mouth words clearly, speak very slowly and do not directly face the Deaf person during an interaction (Reeves, et al., 2002; Moola, 2010). These behaviours all create further communication barriers for a Deaf individual. Not only does this pose a problem for over-burdened health professionals such as pharmacists, it also alienates the Deaf community from seeking health services (Herring and Hock, 2000).

Kritzinger et al., 2014 describe the “pervasive disempowerment” attitude of deaf people, who may not want to think autonomously, but merely accept what they are told. In their article titled “*I just answer “yes” to everything they say,*” Kritzinger et al., (2014) report that even though deaf people may not understand what the healthcare professional is saying, they do not raise questions, and that from the healthcare professionals perspective, they may not realize that the deaf person does not know or understand unless the patient indicates a lack of understanding.

2.1.11.5 Deaf community experiences with medicine instructions

In orthodox medical practice, the correct use of medicines is central to achieving optimal therapeutic outcomes. A good understanding of the purpose of the medicine and administration instructions is requisite to correct medicine use. A Manchester-based study (Reeves et al., 2002) depicts how the absence of such information from the healthcare professional diminishes the prospects of positive health outcomes. Within the study periphery, outcomes described that Deaf people were given inadequate information regarding prescriptions and that a number of Deaf people were of the opinion that they were given incorrect medicines for their ailment. Others expressed anxiety that their inability to communicate effectively may result in receiving wrong medicines. Deaf people also reported not being told the purpose of the medicines. Two patients suffered illness after drinking a medicine that was intended to be used externally (Reeves et al., 2002).

In the South African milieu, Moola (2010) reported that pharmacists, when providing medicine related advice and counselling, often speak “louder, more slowly and their articulation is clearer”. Deaf patients who can lip-read understand the explanation from the pharmacist partially, but those who cannot do not understand the explanation well (Chininthorn, 2011). In addition, Deaf people have misconceptions about how to take their medicines.

2.1.11.6 Health risks for Deaf patients in a health care setting

Patient safety and risk minimization is a priority in modern health care systems. An adverse event is an unintended injury or complication caused in delivering clinical care (Bartlett et al, 2008). Patients with physical and sensory disabilities including Deafness and blindness face considerable barriers when communicating with health care professionals and are understandably at greater risk of healthcare-related errors including adverse events. Communication disorders are estimated to affect five to ten percent of the general population, and more than 155 of admissions to university hospitals involved patients with one or more disabilities severe enough to prevent any form of communication (Bartlett et al., 2008). In addition, patients

with communication disabilities are at increased risk for depression and other co-morbidities, and are three times more likely to experience a preventable adverse event than patients without such problems (Bartlett et al., 2008).

Anecdotal evidence indicates that communication impediments render Deaf patients more likely to over-use emergency medical facilities for routine health problems (NAD, n.d). Correspondingly, effective communication may result in achieving better healthcare outcomes, shorter stays in hospitals and fewer readmissions, better treatment adherence and higher patient-satisfaction levels.

Causal factors contributing to health disparities in public health care settings include inadequate health status information of the Deaf person, low literacy in Deaf adults, and healthcare deviations, impeding the Deaf person's opportunity to attain the best possible healthcare (Barnett et al., 2011).

Without interpretive services or auxiliary aids, healthcare personnel run the grave risk of misunderstanding patient symptoms, misdiagnosing illness and prescribing or administering inappropriate treatment. In light of limited access to interpretive services, accessibility to information and health-related advice is a significant concern.

Notwithstanding the social, emotional, cultural and literacy challenges facing the Deaf community, their reliance on a health service that can accommodate their needs is unquestionable. The question for researchers to ask is: what potential avenue in the health services could be explored that would enable healthcare workers to work together with the Deaf community to address their health care needs? If a portal could be established at the point of pharmaceutical service delivery, then a window of opportunity could be created for meaningful engagement with a vulnerable group of people who constantly remain on the periphery of the health care system. In the context of this study, the pharmacists' role and their experiences with the Deaf community serve as the basis for further exploration.

2.2 PHARMACISTS' ROLES IN HEALTHCARE PROVISION

This section commences with a depiction of the situation in South Africa's healthcare system, focusing on the practice of pharmacists within this role. I discuss the importance of communication by pharmacists during healthcare provision and critically analyze published literature on pharmacists' interactions with Deaf patients.

2.2.1 The healthcare system in South Africa

The South African health system is well-known for its inequities. It is divided into two separate streams: a majority-serving, under-resourced, over-used public sector which provides for eighty percent of the population, and a smaller, well-resourced private sector which serves the remaining twenty percent (Ntuli & Day, 2004). The allocation of healthcare personnel is concentrated in the private sector and urban areas, leaving the majority of the population dependent on public healthcare which utilizes a substantially smaller workforce (George, Quinian and Readon, 2009). Healthcare services are classified as either primary healthcare, secondary care or tertiary care (Haynes & Hall, 2002).

Primary healthcare refers to a set of prescribed services which are generally either the first point of contact for patient care, or the provision of follow-up care. In the Western Cape, primary healthcare services are provided by the Provincial Government of the Western Cape (PGWC) and City Health. A Community Health Centre (CHC) is an example of a primary healthcare facility (Department of Health, 2006). Secondary care refers to services which are generally beyond the scope of primary care and requires the input of a registered specialist. The intervention of specialists in addition to general medical services is required (Department of Health, 2006). Tertiary care is beyond the normal scope of specialists and requires an even higher level of specialization. Both specialist and sub-specialist care is provided (Department of Health, 2006b). An academic hospital, such as Tygerberg hospital is an example of a tertiary hospital (Cummins, 2002).

A global paucity of human resources for healthcare poses a significant hurdle to achieving positive health outcomes. (World Health Report, 2006). South Africa also faces a major crisis with regard to human resources for healthcare. There is a scarcity of healthcare professionals coupled with a skewed distribution to the private healthcare sector (Padarath, Ntuli, & Berthiaum, 2003/4). South Africa faces a considerable shortage of pharmacists, the number of pharmacists per population is 1: 3849, a ratio well below the WHO recommended norm of 1: 2300 (SAPC, 2011). This may have negative consequences for pharmaceutical service delivery. Reports of exhaustingly long queues at public sector facility pharmacies are common with hundreds of people standing in line. In the Western Cape, patient waiting times for medicine were found to be up to 12 hours in some cases. (Ntuli, 2007). In light of the human resource deficiencies and service-delivery inadequacies, people with special needs may be further disadvantaged through the system's inability to handle their specific needs.

Concerning healthcare services for special-needs patients, South African policy is fairly well developed, however this does not translate to specific legislation or implementation. For example, South African law does not necessitate sign language interpreters in health facilities, or the training of health professionals in sign language (Zulu, 2014). This is despite the well-documented inability of Deaf people to communicate using traditional methods. The critical need is entrenchment of specific legislation for all disabled groups and the implementation of policy, especially in light of high disease burdens and major skills shortages. This then begs the questions: what is the quality of care offered to special-needs patients in the Western Cape? How are healthcare professionals addressing the health needs of the Deaf community in particular? In the context of this study, I discuss the role of the pharmacist in the health care system.

2.2.2 Pharmacist's roles in the health care system

Traditionally referred to as the 'custodians of medicines,' pharmacists are a group of registered professionals who are responsible for the medicine-related needs of society. They commit their efforts to ensuring the safe and effective use of medicines toward the goal of optimal therapeutic outcomes. Historically called apothecaries, (derived from Latin word *apotheca*, meaning storehouse), their main function was preparing and providing medicines (Sonnedecker, 1976). The onset of industrialization and globalization launched the small scale preparation of medicines into a global industry, manufacturing medicines in large scale in factories and distributing these medicines through international and local channels, a service which we make use of today.

This advancement in medicine preparation called for transformation of the roles and practices of an apothecary into what we now know as the modern-day pharmacist (Anderson, 2007, Wiednmayer et al., 2006). The role of a pharmacist has expanded to currently include (among others) research, drug design and development, formulation and manufacture, selection and procurement, distribution, clinical pharmacy, dispensing, and monitoring the use of medicines (SAPC, 2010).

Pharmacy is a highly regulated profession, with international and national authorities the world over prescribing roles, scopes of practice and professional codes for pharmacists and pharmacy support personnel. Two global edifices, the World Health Organisation (WHO) and the International Pharmaceutical Federation (FIP) have been instrumental in establishing the roles and practices of modern-day pharmacists. Recognized by WHO for their unique skill set and credence in matters relating to medicine-related care, the most marked shift in practice from the apothecary to the pharmacist has been the shift in focus from the product to the patient. Based on the WHO premise that pharmacists serve in their greatest numbers within communities, their contribution can "*have the most immediate effect in patient welfare*" (WHO, 1994).

2.2.3 Global perspectives on the pharmacist's role

Since 1986, WHO and FIP have embarked on several initiatives to transform and influence the pharmacists' role in developing, developed and newly industrialized nations. These ideologies have been accepted by governments worldwide and are entrenched in administrative policy and academic curricula. WHO advises that community pharmacists should "*play a central role in the provision of advice and information to patients on the use of medicines*" (WHO, 1994). Ensuing from the WHO Consultative Group meeting (New Delhi, 1988), Tokyo Meeting (1993); and subsequent WHO collaborations with FIP and other groups, the consultancy agreed that modern-day pharmacists must assume the role of effective healthcare team members who are able to fulfil various functions. Their practice must be underwritten by note-worthy knowledge, attitudes, skills and behaviours. These traits ought to be considered as rudimentary, essential and minimum expectations held of pharmacists (WHO 1994a; WHO 1994b, WHO 1994c, WHO 1996). From the WHO-FIP deliberations emerged WHO's concept of the 'seven-star pharmacist.'

The seven stars refer to the basic roles of a pharmacist and include caregiver, decision-maker, communicator, manager, life-long learner, leader and teacher. While WHO does not emphasize any of the seven-star attributes as being more or less important than the others, one could plausibly assert that all the features that comprise the seven-star are dependent on effective communication. This insinuates that communication is the central and most important feature since the remaining six features will be difficult to achieve without it.

In addition to establishing communication as an important role of the pharmacist, FIP suggests standards for quality of services by pharmacists in their Good Pharmacy Practice guideline. This guideline requires that the "*core of pharmacy activity is supply of medication and other health products of assured quality, appropriate information and advice for the patient and monitoring effects of use*" (WHO, 1994a). Pharmacists are often the first port-of-call for persons requiring healthcare. In serving communities their roles involve identifying and interpreting the medicine-related needs of the patient, accurate and safe provision of medicines,

counselling patients at the time of dispensing and monitoring medicine usage, extemporaneous preparation of medicines, being a source of medicine and health-related information for health professionals and clients, responding to symptoms of minor ailments, health promotion activities and domiciliary services. (WHO, 1994a)

A common theme emerging from both the WHO and FIP perspectives of the pharmacist's role, particularly in servicing the public, is the provision of advice and information to patients to ensure the safe and effective use of medicine. This further signifies the importance of effective communication between a pharmacist and client. This review focuses on the role of the pharmacist in providing medicines and medicine-related advice to the domestic sector, concentrating specifically on patient counselling during the medicine dispensing process. Effective communication is crucial within this role, but may be precluded for persons who are unable to communicate in the same way as pharmacists.

2.2.4 Pharmacists' roles in South Africa

In line with national strategic goals, the professional practice of pharmacists in South Africa is rooted in the underpinnings of the White Paper for the Transformation of the Health System in South Africa (DOH, 1997) and the National Drug Policy (NDP) (DOH, 1996). The major thrust of the White Paper is to address the inadequacies in healthcare resultant from the apartheid regime through health reform by developing a “*unified health system capable of delivering quality healthcare to all citizens efficiently and in a caring environment*” (DOH, 1997). The White Paper sets out to achieve this through meeting a set of goals and objectives. Among others, the objectives highlighted below include:

- *To promote equity, accessibility and utilization of health services*
- *To extend the availability and ensure appropriateness of health services*
- *To foster community participation across the health sector*

While the White Paper for health system transformation prioritizes redress and social reform, there is little mention of specific disabilities and even less consideration of targeted strategies entrenched in legislation to cater for the special needs of disabled people.

The National Drug Policy (DOH, 1996) has as its overarching goal the ensuring of an adequate and reliable supply of safe, cost-effective drugs of acceptable quality to all citizens and the rational use of medicines by prescribers, dispensers and consumers. The NDP calls on pharmacists, in particular those who are practicing within communities to assume purposeful roles targeted at educating and instructing patients in the community on appropriate use of medicines, entrenching and promoting in the community the notions of individual responsibility for health and informed decision making. Pharmacists must collaborate with other members of the healthcare team toward the objective of rational medicine use, and must be significant players in primary health care and preventive health services. The NDP however, does not make mention of skills that pharmacists need to gain to meet its mandate with disabled people.

The South African Pharmacy Council (SAPC) is the regulatory and statutory body which controls the pharmacy profession and its functions in terms of the Pharmacy Act (Republic of South Africa, 1974), as amended. Pharmacists are registered with the SAPC who prescribe their scope of practice, code of conduct and other professional affairs (SAPC, 2010). The SAPC establishes the ethos of pharmacy as: ***“a dynamic, information driven, patient-orientated profession whereby the pharmacist, through his competence and skills is committed to meeting the health care needs of the people of South Africa by being the:***

- custodian of medicines;
- formulator, manufacturer, distributor and controller of safe, effective and quality medicine;
- advisor on the safe, rational and appropriate use of medicine;
- provider of essential clinical services including screening and referral services;

- provider of health care education and information;
- provider of pharmaceutical care by taking responsibility for the outcome of therapy and by being actively involved in the design, implementation and monitoring of pharmaceutical plans;
- provider of cost-effective and efficient pharmaceutical services” (SAPC , 2010)

The SAPC prescribes the roles and practice norms and standards for pharmacists through its publications the Good Pharmacy Practice (GPP) manual (SAPC, 2010). The GPP sets out professional norms and minimum standards for various practice scenarios and settings, including dispensing, therapeutic medicine monitoring, facilities and equipment and patient information and advice, among others. GPP rules and standards are obligatory as per Section 35A of the Pharmacy Act 53 of 1974 (Republic of South Africa, 1974).

Additional practice guidelines for pharmacists set by the SAPC are the Code of Conduct (SAPC, n.d) and Ethical Rules (SAPC, n.d.) for pharmacists. The Ethical Rules advises acts or omissions which are deemed to be unethical or unprofessional behaviour by pharmacist, e.g. failure to furnish advice or information for the safe and effective use of medicines supplied by the pharmacist. The Code of Conduct for pharmacists functions as the standard of professional conduct and fundamental duties (SAPC n.d.). A breach in the code of conduct by registered persons could fuel disciplinary action against the registered person. Principles presented in the Code of Conduct include: (i) Wellbeing of the Patient, (ii) Confidentiality and (iii) Continuing Professional Development, among others.

South Africa faces considerable shortage of pharmacists (SAPC), 2011. This shortage has a negative impact on pharmaceutical service delivery. Reports of exhaustingly long queues at public sector facility pharmacies are common, with hundreds of people standing in line. In the Western Cape, patient waiting times for medicine were found to be up to 12 hours in some cases (Ntuli, 2007). Inadequate pharmaceutical service delivery in the public sector has been the subject of media attention. Media reports have highlighted that long queues for medication cause

community frustration with long waiting times a seemingly insurmountable problem (Ryan & Peters, 2007).

Pharmacists in South Africa conform to global trends in their areas and fields of practice. These include community pharmacy, hospital pharmacy, academia, pharmaceutical industry, regulatory pharmacy and clinical pharmacy. WHO (1998) reports that pharmacists serve in their greatest numbers within communities, where the role fulfilled by pharmacists is the safe and effective provision of medicine and they fulfil this role through adhering to the GPP minimum standards for dispensing of medicines. The medicine dispensing process, and particularly patient information and advice, is the central context for this thesis and is discussed later in this chapter. I elucidate the importance of communication between the pharmacist and patient.



2.2.5 Communication between pharmacists and patients

Communication is the basis of all contact between human beings (Floyd, 2011) and consumes up to three-quarters of our daily activity. The etymology of “communication” implies that the word has its origins in Latin “communicare,” meaning “to share.” The benefits of effective communication in a social context are unlimited. It allows people to express themselves, to exchange important information, to establish relationships and achieve goals (Liu, Volcic & Gallois, 2011). In a healthcare context the importance of effective communication is further amplified. The success of a healthcare system relies on effective communication between healthcare professionals and patrons, and inter-collegial communication among healthcare professionals (Schwarz et al., 2010). Ambient information in the general media (magazines, newspapers, internet etc.), in addition to healthcare professionals’ advice influences people’s decisions on what is considered to be ‘healthy’ (Schwarz et al., 2010). Inadequate communication is a common causal factor in inadvertent detriment to healthcare system patrons (Leonard, Graham and Bonacum, 2004)

Communication is the transmission of information from one entity (person, data source) to be received by another. It is a process in which a message is generated, then directed toward and received and interpreted by another person. Various types of communication occur, including: (i) Interpersonal communication (transaction process between two or more persons in which both have a chance to speak), (ii) Impersonal communication (based on a specific role, for example a sale, people are treated in a detached manner), (iii) Cross-cultural communication (between persons of different social and cultural backgrounds encompassing different communication styles) and (iv) Health communication (purpose-driven communication in a healthcare context) (Beebe et al, 2001; Wood, 2007; Dutta, 2008; Duck & McMahan, 2010; Dainton & Zelle, 2011, cited in Knoesen, 2014).

Effective pharmacist-patient communication is cornerstone to appropriate medicine use and achieving optimal therapeutic outcomes (Beardley et al., 2008). Through successful transfer of medicine-related instructions and advice, pharmacists improve the use of medicines and patient adherence to therapy (Davis & Fallowfield, 1994). Since pharmacists rely on feedback from patients to assess whether they understand the medicine therapy and additional information, it is plausible to assert that pharmacist-patient communication should be interpersonal; rather than impersonal. This may be difficult to achieve in the context of a pharmacist providing medicine-related information to a Deaf person. Based on their difficulties with spoken language and literacy, Deaf people are unlikely to be able to provide feedback, thus negating the inter-personal characteristic. Communication in this situation may be cross-cultural instead. Cross-cultural communication involves different styles and patterns (Kai, 2005); this may create a communication barrier which generates uncertainty in whether communicated messages are properly understood by the recipient.

2.2.6 Models of communication

Numerous models exist for general communication. Shannon and Weaver's (1964) Linear Model implies that messages are sent from one unit (sender) to another (receiver). Berlo (1960) expanded on the Linear Model by inserting into the centre of the model, two additional features: the Message and the Channel, so that the model appeared as Sender-Message-Channel-Receiver, also dubbed the SMCR Model (Lee, 1993). In a pharmacy interaction in which feedback from the patient to the pharmacist is crucial to assess whether the patient has understood the information given, both the Linear Model and Berlo's expanded model are lacking as the one-way nature of these models do not acknowledge patient feedback and do not account for any interaction between persons or the transfer of messages to and from multiple persons involved in a communication process (Knoesen, 2014).

Wilbur Schramm's 1994 communication model introduces the element of interaction. Schramm recognizes that communication is not a one-way process, but instead encompasses feedback from the receiver (Croft, 2004; Floyd 2011, Johanson 2012). Such feedback is not simply passive listening, but rather active verbal and non-verbal reactions. Schramm further noted that the prime responsibility of the sender of a message is to convert the information (i.e. the message) that he/she wants to send into a words for the receiver to accept. This process is called 'encoding.' The prime responsibility of the receiver of the message is to understand what the sender is trying to say. This process is called 'decoding'. Encoding and decoding are vital processes of communication, and are influenced by the encoder and decoder's personal experiences. For messages to be interpreted accurately, the encoder and decoder must share a commonality, for example the same language or culture (Croft, 2004; Floyd 2011, Johanson 2012). This highlights the potential difficulties that Deaf people face in communicating with pharmacists, with whom they do not share commonality in neither language nor culture.

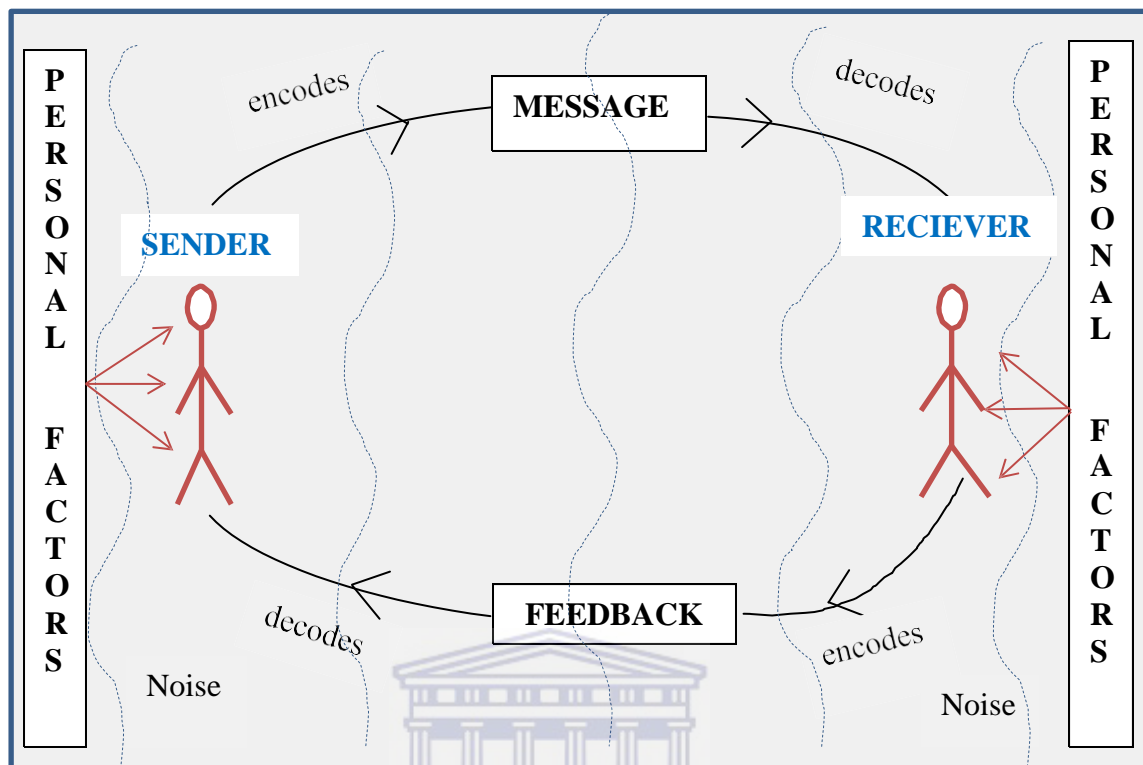
In 1970, Barnlund propositioned the Transactional Model of communication (Barnlund 2008), which implies the synchronized sending and receiving of messages in a reciprocal interaction. Communication moves in multiple manners

in a cyclical process. A further convoluted form, the model focuses on the manner in which an individual communicates, recognizing that this manner determines how the message will be interpreted. Communication occurs via a channel (e.g. air in the case of a spoken face-to-face conversation) and in the presence of “noise”. The interaction has also described as an “**encode-transmit-receive-decode**” interaction. It occurs in the presence of environmental noise and is influenced by personal factors including tradition, culture and gender. In summary, a person who wants to convey a message must first encode the message, (i.e. decide what it is he/she wants to say and how to say it) after which he/she then transmits the message by expressing it in words (or an alternative form). The message is received by the intended recipient and then decoded (interpreted and understood). The entire process is influenced by personal factors of the encoder and decoder.

This model is well suited to a dyadic communication context, dyadic referring to the inter-relationship between two individuals, as is the case of a pharmacist providing medicine information to a patient. Transaction communication models have been adopted by sectors of society for application in various contexts, particularly healthcare. Such models are well-suited to pharmacist-client interactions to achieve effective communication (Shah & Chewing, 2006). In summary transaction communication models comprise the following aspects which are ideally suited to pharmacist-patient interactions:

1. A dyadic, reciprocal process
2. A dynamic, cyclic process
3. Encoding and decoding influenced by personal factors
4. Environmental noise

Figure 3: A transactional communication model



Interactions between pharmacists and patients have been termed 'patient counselling', and to a lesser extent 'patient education' and 'pharmacist-patient communication' (Shah & Chewning, 2006). Patient counselling commonly occurs during (but is not limited to) the process of dispensing medicines and the primary goal is health promotion. In line with this, communication must yield the necessary patient history (e.g. presence of allergies), purpose of the medication, dose and duration of therapy, therapeutic goals, medicine specific issues (e.g., side-effects) and how to deal therewith. These activities constitute both patient counselling and dispensing and are contextualized further in the next section.

2.2.7 Medicine-related communication in pharmacy

Transactional models have been widely accepted as appropriate for interactions between pharmacists and patients. Since pharmacists are the custodians of medicine, such interactions normally involve the transfer of information related to medicines. This section describes specific types of information and the context in which it is relayed.

WHO reports that pharmacists serve in their greatest numbers within communities, where the role fulfilled by pharmacists is the safe and effective provision of medicine. In South Africa, pharmacists fulfil this role through adhering to the GPP standards for dispensing of medicines. The medicine dispensing process, and particularly patient information and advice, is the central context for this thesis.

2.2.7.1 Dispensing procedures

The task of dispensing medicines is a central function of pharmacists. The Republic of South Africa's Pharmacy Act 1974, as amended defines dispensing as:

The interpretation and evaluation of a prescription, the selection, manipulation or compounding of the medicine, the labelling and supply of the medicine in an appropriate container according to the Medicines Act, and the provision of information and instructions by a pharmacist to ensure the safe and effective use of medicine by the patient .

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- (GNR 1158 of November 2000) –

The GPP systematizes dispensing into a 3-part procedure:

- PHASE 1: Interpretation and evaluation of the prescription.
- PHASE 2: Preparation and labelling of the prescribed medicine.
- PHASE 3: Instruction and information to the patient to ensure the safe and effective use of medicines (SAPC, 2008).

Phase 1 entails the acceptance of the prescription and assessing of the integrity thereof by verifying the authenticity of the prescriber, confirming the identity of the patient to whom the medicine is prescribed, assessing the legality of the prescription. The prescription is also reviewed for dosage suitability, drug interactions, contra-indications and therapeutic duplication. Phase 2 encompasses accurately picking, preparing and labelling the medicine. Phase 3 comprises direct interaction with the patient. At the interface with the patient, the pharmacist must supply information and advice to patient on how to safely and effectively use their

medicines. This information must be personalized, taking into consideration the unique need of the individual patient. Accurate and individualized patient information is crucial to ensure the safety and efficacy of medicine therapy. (SAPC, 2010).

The SAPC's definition of the dispensing process mimics the omission of explicit and special solutions or skills to accommodate disabled people in healthcare provision. While the SAPC procedure for dispensing establishes the necessity to provide medicine-related information and advice and the responsibility of a pharmacist, it fails to elaborate on the importance of effective communication during dispensing and does not at all address the complexities of communication. The SAPC further fails to identify and mandate specific solutions for different disabled groups, including Deaf people.

2.2.7.2 Contextual circumstances in dispensing

In South Africa, dispensing of medicines to the general public occurs in two basic circumstances: (i) dispensing in accordance with a prescription from an authorised prescriber and (ii) dispensing medicines without a prescription which can legally and within limits, be supplied over-the counter (OTC) (Knoesen, 2014). These circumstances are hereafter referred to as prescription-only medicines and OTC medicines respectively. I differentiate between the two circumstances to highlight the differences in medicine-related information and advice between them.

2.2.7.2.1 Prescription only medicines

Patient-counselling in pharmacy typically follows a “sequence of instructions” including the provision of medicine-related information and advice (Rantucci, 2007; Berger, 2009). According to Nigussie (2014) patients typically take their medicines in a way correlating to the way in which it was dispensed and the type of information received during the dispensing process. Dickinson and Raynor (2003) report that, with regards to their treatment, patients regularly want more

information, and that the following medicine-related information is considered to be essential: instructions on how to use medicines, what it is used for, what it is intended to do, possible side effects and related warnings and recommendations (“do’s and don’ts”). Kreuger & Hermansen-Kobulnicky (2011) investigated community pharmacies in the USA over two years (2006-2008). The emphasis of their research was the type of information requested from patients with regards to new or repeat prescriptions.

Table 3: the significance (%) of five types of information requested from patients with regards to new and repeat prescriptions

(adapted from Kreuger & Hermansen-Kobulnicky , 2011)

	NEW PRESCRIPTION		REPEAT PRESCRIPTION	
1.	Basic instructions	33%	No new information required	30%
2.	Indications for use	19%	New facts(medicine-related)	15%
3.	Additional instructions	15%	Review of medicine information	15%
4.	Side-effects and allergic reactions	58%	Number of repeat prescriptions	24%
5.	Interactions	30%	Concern for patient’s well-being	8%

In a separate study on new prescriptions, Svarstad et al. (2004) cited in Knoesen (2014), focused on seven aspects of medicine-related information given to patients who visited 306 pharmacies in the USA. The patients were mystery shoppers to whom three medicines were dispensed; and antibiotic, an anti-inflammatory medicine and an anti-depressant. For each type of medicine, the authors investigated the number of mystery shoppers who received verbal instructions on seven aspects of medicine related information. In table 4 below, I illustrate the number of mystery shoppers who received the information in ranking order of

highest percentage to lowest percentage, expressed the average percentage over each the three medicine types.

Table 4: Percentages of mystery shoppers receiving aspects of medicine-related information (adapted from Knoesen, 2014)

	Information type	Average percentage of mystery shoppers who received verbal information
1.	Directions for use	56%
2.	Name of the medicine	55%
3.	Purpose	40%
4.	Adverse effects	28%
5.	Duration of treatment	26%
6.	Other precautions	23%
7.	When medicine will start to have an effect	7%

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Similarly, Berry et al (1997: 471) itemize medicine-related information to be covered in during dispensing as 16 information elements these 16 elements are ranked in order-of-importance as stated by patients and doctors.

Table 5: Patients' and doctors' ranking of importance of medicine information aspects (adapted from Knoesen, 2014)

Medicine-relation information aspect	Patient's ranking	Doctor's ranking
Potential side-effects	1	10.5
Action of the medicine	2	10.5
Lifestyle modifications	3	3
Questions regarding medicine use	4	2
What the medicine is (e.g. active ingredient)	5	15
Medicine interactions	6	1
Action to take if symptoms do/do not change	7	10.5
Effectiveness of treatment	8	14
Alternative treatment	9	16
Is it known to work	10	13
Does medicine treat symptom or cause	11	6.5
Action to take when over-dosed or dose was skipped	12	6.5
Interactions with OTC medicines	13	4
Consequences of not taking medicines	14	8
Interactions with other prescribed medicines	15	5
Signs that the medicine is having an effect	16	10.5

While the ranking order of importance differs between the studies, common elements of medicine-related information and advice are evident across all three studies. These are the basic directions for use, purpose of the medicine, side-effects, interactions, and additional information. Such studies have yet to be documented for dispensing to the Deaf community in South Africa. The dispensing process prescribed by the SAPC provides pharmacists with an opportunity to interact with patients/clients and provide the necessary medicine-related information. In the case of the Deaf community, salient medicine-related information could easily be overlooked or misinterpreted, compromising the quality of pharmaceutical care.

2.2.7.2.2 Over-the-counter medicines

In South Africa, certain medicines may be supplied to the general public without a prescription. Commonly referred to as OTC medicines, they are typically supplied in a community retail pharmacy where a client walks in with a health-related problem, seeking advice from the pharmacist and in-so-doing, allows the client to “self-treat” minor health problems (Bakic-Miric 2009 :41) Technically, according to the SAPC three-step dispensing process, the supply of medicine’s on an OTC basis is not dispensing because there is no prescription to fulfil phase 1 of the process (phase 1: interpretation and evaluation of the prescription.)

Bakic-Miric (2009:41) asserts that the following information must be provided to patrons to whom medicines are supplied on an OTC basis:

- Generic/brand name of the medicine
- Dosage form and route of administration
- Dosage amount and frequency of administration
- Storage instructions of the medicine
- Potential interactions and therapeutic contra-indications
- Techniques for self-monitoring therapy

In summary, the dispensing process requires mutual exchange of medicine-related information between the pharmacist and patient in order to optimize the patient's therapeutic outcome. For a patient with auditory and literacy capabilities this occurs as a largely natural and 'automatic' interaction. However, for a Deaf patient, the dispensing process could be seen as a dead end, with little hope of making any sense of what the pharmacist is trying to communicate.

2.2.8 Pharmaceutical care

Along with dispensing, pharmaceutical care is a philosophy centered around pharmacist-patient communication. This philosophy of practice has been embraced widely in the pharmacy profession (Burton, 2013) in line with its evolution from a product-focus to a patient-focus. It is a patient-centered, results-oriented ideology, aimed at improving the patient's health-related quality of life and attaining positive clinical outcomes. The philosophy has its roots in the work of Hepler and Strand, who advocate for "*the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life.*"

Along with the profession, Hepler & Strand's (1990) concept has also evolved from its emphasis on drug therapy to a stronger emphasis on the patient-centered *role* of a pharmacist. Such a patient-centered approach establishes the responsibility of both the pharmacist and patient to optimize therapeutic outcomes. The joint responsibility implies open communication channels between a pharmacist and patient where mutual understanding is established to arrive at a common goal. In this regard, the pharmaceutical care process is especially relevant for marginalized communities who may require pronounced levels of care. Pharmaceutical care comprises a number of essential elements, tabulated below:

Table 6: Elements of Pharmaceutical Care (adapted from APhA, 1995)

Pharmaceutical Care element	Description
Professional relationship between pharmacist and client/patient	A pharmacist-patient relationship based upon compassion, open communication, trust and mutual decision making is established and maintained. The patient is forthcoming with personal information and provided input in the therapeutic plan.
Patient-specific medical information is collated, organized and maintained	Pharmacists must elicit from the patient information regarding his/her health and well-being, medical history, dietary and activity habits, history of medicines taken and current medicines being consumed, and social financial and information pertaining to the patient.
Patient medical data must be assessed and a therapeutic plan jointly established with the patient.	The pharmacist assesses the complete case, including social, psycho-social and medical aspects of the disease and together with the patient, designs the therapeutic plan.
The pharmacist provides information and advice necessary to fulfil the therapeutic plan.	The pharmacist shoulders responsibility for the therapeutic outcome, thus ensuring that the patient has all the necessary drug and non-drug therapy and understands the disease and the therapeutic plan.
The pharmacist documents, reviews and amends the therapeutic plan with the patient and healthcare team.	Patient progress recorded Patient feedback on progress, inter-collegial collaboration. helping assure continuity of care as the patient

All the tabulated elements of pharmaceutical care above (establishing a relationship, collating patient information, assessing patient data, jointly establishing a therapeutic plan, providing information and advice and amending the therapeutic plan with the patient) involve effective communication between the pharmacist and patient. Surprisingly, the importance of communication is not

addressed in the concept of pharmaceutical care (Knoesen, 2014). If communication is not possible, the ability of a pharmacist to provide pharmaceutical care may be undermined and the level of care obtained by the patient is likely to be sub-optimal. This is supported by Beardsley et al (2008), who establish communication as a requisite to achieve success of pharmaceutical care.

In comparison with the SAPC's recommended standards for dispensing, pharmaceutical care is more complex and encompasses elements of mutual responsibility, the establishment of a relationship with the patients and social competency. Conversely, dispensing according to the SAPC is a one-way process by the pharmacist, and is largely product-focused. While various definitions of pharmaceutical care include an emphasis on medicine-related information ("ensures safe and rational drug use", "responsible provision of drug therapy" etc.), it also includes a patient-focus, joint responsibility for therapeutic outcomes and patient-centered care.

For marginalized populations who are often already disadvantaged, the lack of pharmaceutical care is potentially detrimental. To overcome this problem, pharmacists must obtain the skills required to provide services and care to people from different social backgrounds and with different social skill levels and communication abilities.

2.2.9 Cultural competency for pharmacists

Cultural competency describes the relationship of health professionals to diverse members of their community and, in relation to healthcare has been defined as "*the ability...to provide care to patients with diverse values, beliefs, and behaviours, including tailoring delivery to meet patient's social, cultural and linguistic needs.*" (Betancourt et al., 2002) In its aim to enhance service quality and improve health outcomes, the notion of cultural competency echoes the philosophy of pharmaceutical care. Cultural competency may thus be asserted as a necessary skill set for pharmacists to have.

Camphina-Bacote (2002) is the developer of the Volcano model for cultural competency that can provide healthcare professionals with a blueprint to attain the

skills to practice within multicultural communities. The volcano is depicted to illustrate a process involving five steps. The procedural nature of the model reflects Camphina-Bacote's assertion that cultural competency is an attribute to be developed through a course of progression, i.e. one "becomes" culturally competent rather than "being" culturally competent. The foundation of the model or the base of the "volcano" is the aspiration of the healthcare worker to develop cultural awareness and is the launching pad from which a pharmacist can progressively develop cultural competency. Figure 4 below illustrates the Camphina-Bacote Volcano model.

Figure 4: Volcano model for cultural competency (Camphina Bacote)



Apart from cultural desire, the model illustrates that the characteristics of cultural skill, cultural awareness, cultural knowledge and cultural encounters emerge from a developmental progression that comprises the process of becoming culturally competent. According to Camphina-Bacote (2002), cultural awareness is the healthcare professional's self-awareness of their own cultural background and their biases to other different cultures. Cultural skill is the ability to juxtapose a patient's cultural profile against his/her presenting medical problem on order to address his/her health problem. Cultural knowledge is the understanding of and familiarity

with different cultures and their unique beliefs and outlooks. Cultural-encounter is a construct which encourages healthcare professionals to participate in cross-cultural interactions with people of different cultural backgrounds in order to expel biases and identify and dismiss stereotypical views of that culture.

Cultural competency education has been entrenched in many pharmacy curricula worldwide. The American Colleges of Pharmacy Education (ACPE) has committed to cultural competency training through establishing accreditation standards that pave the way for schools of pharmacy to include cultural competency within their curricula (Smith et al., 2011). However, disability is not normally included as a component of cultural competency education, and disabled groups are generally under-represented. This may result in the inequities experienced by disabled people. (Smith et al., 2011)

The Volcano model is ideally suited to the unique South African milieu, distinguished by its rich heritage of numerous cultures and languages and extreme socio-economic differences. With eleven official languages and an even greater level of cultural diversity, the limitations in linguistic ability and literacy of a large numbers of South Africans may present a barrier to accessing medicine information.

Further compounding this problem is the reality that many pharmacists in South Africa are unable to speak African languages (Mansoor & Dowse, 2004). Consequently, patients use medication inappropriately, which results in failure of therapy and untoward effects. Pharmacy cases that have been observed include oral administration of suppositories, failure to complete antibiotic regimens and inability to use insulin pens (Parker & McCrae, 2008). Such situations may be even more magnified when pharmacists are required to dispense medicines to Deaf patients who are able to communicate only in sign-language, and may compromise their rights of access to information and medical care. In this regard, the constructs of the Volcano model are essential skills for pharmacists to develop and are important in the provision of pharmaceutical care to patients with diverse social and cultural backgrounds.

2.2.10 Traditional set-up of dispensaries in South Africa

Typically a South African pharmacy contains a dispensary from which pharmacists dispense medicines and provide patient counselling and medicine-related information. The SAPC prescribes Good Pharmacy Practice requirements for dispensaries and other pharmacy facilities. The size of the dispensary must allow a “safe and efficient workflow,” allow for adequate supervision of tasks by a pharmacist and reflect the number of prescriptions dispensed (SAPC, 2010). Factors to consider in dispensary size are prescription volume, workload and overall space allocation in the pharmacy. For each pharmacist, a space of 90cm x 1m must be allocated in the dispensary (SAPC, 2010). As a minimum standard where medicines are supplied to the public, there must be a “reasonably private” area where background noise is minimal for provision of information and advice. In addition, the area must have a professional appearance and sufficient space to promote counselling (SAPC, 2010). Other types of areas include a private area and a semi-private area. According to the SAPC, among the main concerns are the security of medicines and scheduled substances and ensuring patient confidentiality through allowing levels of privacy. To this effect, glass windows with an open hatch at the bottom through which medicines are dispensed are commonplace, especially in hospital pharmacies. While the window serves as a security barrier, it also isolates the pharmacy staff from patients whose needs require special attention.

Dispensary guidelines do not explicitly consider or account for disabled people including Deaf persons. The prescribed features of privacy and security in the form of glass windows may form further barriers for Deaf people who pay close attention to facial expressions and gestures and lip-read need an up-close face-to-face interaction to understand a message. In addition, public sector hospital pharmacies initiate contact with patients in the waiting area via a microphone system which serves no purpose for a Deaf patient.

2.2.11 Pharmacists and communication with deaf persons

Pharmacists are ethically and professionally duty-bound to communicate medicine instructions and health-related information relative to the particular needs of an individual patient. The profession has embraced the notion of a patient-centered philosophy of practice which further supports the provision of individualized care. To bring this notion to fruition, it is crucial that pharmacists become culturally sensitive and capable in their interaction with diverse communities, especially marginalized communities such as minority language groups who are often disadvantaged in healthcare provision. On communication in health promotion, South Africa's White Paper for Transformation of the Health system asserts that historically, "*communication strategies for health promotion have been restrictive and have favored target audiences that are literate, urban based and who have easy access to print and audio-visual media.*" This health disparity further validates the necessity for socially competent healthcare practitioners in South Africa.

Available literature on the pharmacist-deaf patient interaction is limited (Ferguson & Lui, 2015), with more studies having focused on the physician-deaf patient interaction. In both situations, study efforts are skewed toward how the healthcare professional experiences communication with the deaf person, with fewer studies focusing on how the deaf patient experiences communication with a healthcare professional. Even fewer studies are available on how Deaf people experience communication with pharmacists, with no published research thereof in the US existing in 2014 (Ferguson & Lui, 2015). Below I analyze pharmacist-perspective studies, while the deaf-perspective studies were appraised in the previous segment of this review.

A cross-sectional, survey-based study in Southern Illinois (Ferguson & Shan, 2015) surveyed pharmacists who practice in communities with a high prevalence of deaf patients. The study sought to probe pharmacists' experiences in communicating with the deaf community. Findings suggest that pharmacists generally experience discomfort and primarily use written material as the main methods to convey medicine and health related information. A separate study surveying published

research on the experience of deaf persons with their physicians corroborated this finding, with deaf persons indicating that writing back and forth is the most frequent mode of communication (Chaveiro et al., 2009). The South Illinois study further found that speaking in a manner that the Deaf person can read one's lips was the second most adopted manner of communication followed by relying on the assistance of a family member or friend. All three scenarios present problems specific for the Deaf community. These problems are explored in the subsequent section of this review.

In their "Introduction to Diversity" course, Wegman School of Pharmacy (New York), in collaboration with the National Centre for Deaf Health Research offer pharmacy students an exercise dubbed "Deaf Strong Hospital (DSH)." Adapted from the University of Rochester's School of Medicine and Dentistry program, Deaf Strong Hospital is a role-reversal exercise in which pharmacy students are asked to assume the role of a patient at a hospital (Mathews et al., 2011). At this hospital, all healthcare personnel are deaf and can communicate only in sign language. Aimed at raising student awareness of communication barriers in healthcare, the program uses an atrium, classrooms and study rooms to simulate a hospital setting. Personnel at the hospital are volunteers who are able to communicate in American Sign Language. Students must attend the hospital as hearing patients, but are not allowed to talk because the personnel are all deaf. Students receive instructions in sign language, similar to the way in which a deaf person would normally be given instructions in spoken language. Two days prior to their experience at DSH, students are given instructions on how to fingerspell the alphabet, some basic signs in American Sign Language and reading material on Deaf culture. On the day of the exercise, students are not allowed to use their voices in any way, but are encouraged to use alternative methods of communication (e.g. pantomiming). Students must navigate the waiting area, doctor's office, emergency room and pharmacy during the exercise. In the waiting room, they must wait for their name to be "called" using fingerspelling, mimicking the situation a Deaf-person would experience when a hearing person calls their name in spoken language. Students are instructed to communicate their symptoms including nausea, headache etc. without speaking. A volunteer, acting as a doctor,

would explain the diagnosis in American Sign Language. At the pharmacy, medicine containers are filled with different colour candies to mimic a real-world situation in which a patient would receive different medicines. Again, the students are not allowed to utilize their voice. As part of the hospital experience, students are also asked to complete a treatment consent form, except that the form is drafted in a language which they are unfamiliar with, to represent the textual language barriers encountered by deaf persons when they are asked to sign consent in English, while their mother-tongue is sign language. The exercise was designed to elicit feelings of frustration and disempowerment in students, in-so-doing instilling the value of cultural competency. Subsequent to the exercise, students participated in a panel discussion and debriefing session to allow them to reflect on the experience. Student reflections pointed to a number of problems experienced by deaf people in the provision of health services at a typical health center (Mathews et al., 2011).

Many students found the waiting room procedure to be unclear and frustrating. Several students reported that they feared missing their name being called and that would be left in the waiting area to be ignored (Mathews et al., 2011). Since students only had limited exposure to fingerspelling, many missed their doctor's appointment because they were unable to identify their name being "called." Further problems identified by the students were that they needed clarity in navigating stations as they were unclear of where to proceed to next. They also lacked clarity on the extent of their health problem, or the symptoms they reported were understood by the healthcare practitioner. In addition, students struggled to ask the pharmacist questions or highlight concerns. Students found communicating via an interpreter challenging, expressing difficulty in interacting with and focusing on the deaf healthcare provider as if the interpreter was not there. The consent form presented a language barrier, rendering students to be functionally illiterate. Several students signed consent, not understanding what they were signing for (Mathews et al., 2011).

Although this study did not survey the experience of pharmacists communication with deaf patients, the 'pharmacy-student-as-patient taking instruction from deaf healthcare provider' design delivers a fascinating insight into the pharmacist-deaf

patient interaction. It provides a realistic account of challenges experienced by the Deaf community. As adjectives to describe the experience, pharmacy students used the words “frustrating, eye-opening, thought-provoking and interesting” and several expressed an interest in taking a sign language course. Study findings highlight a need for pharmacists to be more proficient in interactions with Deaf people.

In another study, an analysis of the experiences of medical interpreters in interpreting interactions between nurse and deaf patient revealed inaccuracies in terms of perception, performance, memory and meaning (Cokely, 1982).

A non-systematic review of computer-databases spanning a decade was aimed at analysing aspects of interactions between physicians and deaf persons. The review found that physicians are generally underprepared to care for deaf persons as academic curricula preclude the skills-set needed to meet this minority group. (Chaveiro, 2009). A lack of awareness by healthcare workers about deaf people is one of the most significant factors that impact quality of care. This finding is corroborated for pharmacists by Moola (2010), who reports that pharmacists mistakenly assume that all deaf people can lip-read and prefer it as a means of communication, resulting in pharmacists talking in a slower and louder manner, taking care to pronounce words clearly for articulation by a Deaf person.

Published work indicates that when communicating with Deaf patients, pharmacists are challenged to provide individualized, patient-centred care. Their regular methods of communication are not always suitable due to their inability to communicate effectively in a manner that can be understood by the Deaf patient.

2.3 WORK RELATED TO THIS THESIS

A major outcome of the research is to collaboratively create an assistive device to facilitate communication between a Deaf person and a pharmacist. Expertise from a computer programmer and industrial designer is to be intricately linked to arrive at a mobile phone application. This final section of the review seeks to critically appraise technological interventions aimed at assisting Deaf people to communicate with healthcare professionals. While I had no part in the technical aspects of this collaboration (programming and construction of the technical architecture), I include this critical appraisal as a backdrop and further motivation for the mobile phone intervention.

The proliferation of technological advancements has caused a global ever-expanding impetus toward using technology to neutralize social problems. The world of communication has been transformed by the mushrooming networks and applications that allow for real-time relay of access to information. Society at large is employing technologies as a means of social and economic expansion. Its use has also been seen in marginalized communities and minority groups with the aim of social upliftment. Several interventions have been created for use specifically by the Deaf community. These interventions differ on the basis of the delivery medium, network requisite, inclusion of avatar versus actual interpreter, and use of text versus video (Motlhabi, 2014). The intervention envisaged as the outcome of this research would be a mix of the above variables that are suited to the unique needs of the South African Deaf community.

2.3.1 Information Communication Technology for deaf people

A **telephone type-writer (TTY)** is an apparatus with a QWERTY keyboard and a small screen that allows for communication transfer from voice to text with the use of an interpreter (Motlhabi, 2014). A speaking caller gives a message to an interpreter, who in turn types the message on the keyboard, for transfer to a Deaf person on the other end of the line. The Deaf person can respond in text to the interpreter, who voices the message to the hearing person. There are two major

shortcomings in this system: (i) it is text-based and (ii) it requires the services of a sign-language interpreter (Motlhabi, 2014). Text-based formats are not suitable for most of the Deaf community in light of their literacy problems (Zafrulla, 2008); and in South Africa, the monetary impact and scarcity of interpretive services pose an operative barrier for the TTY system to work.

Video-Relay Service (VRS) systems are naturally preferred to the TTY by the Deaf community as this system allows for transfer of messages in sign language. It works by sending a sign language video over a cellular phone network and requires broadband internet connectivity (Motlhabi, 2014). While VRS is superior to TTY in terms of communication applicability for Deaf people, it poses significant limitations in that it requires high-definition cameras, high speed internet connectivity and expensive devices. For Deaf communities outside first-world countries, VRS systems are inaccessible in terms of affordability (Motlhabi, 2014).

Mobile ASL is an American Sign Language based venture that solves many of the problems of TTY and VSR (Motlhabi, 2014). It enables Deaf people to use easily available mid-range mobile devices to send sign language videos over a mobile phone network, negating the need for specialized equipment and high-end devices. Video compression techniques are used to condense videos in order to reduce the cost of sending them over the network. The drawback with video messages lies in the perspective of the service provider of the mobile network. Service providers prioritize voice and text rather than video (Motlhabi, 2014). In-so-doing, service providers alter the bit-rates and frame-rates of transmitted videos at the nearest base-station. Altering videos in this manner almost always results in a diminished video quality, which may render sign language videos unintelligible and unusable for sign language communication. The Mobile ASL team have surpassed this drawback by pre-processing the video before it is sent over the network. Deaf people have been enthusiastic and receptive toward Mobile ASL, but poor video-handling infrastructure set up by providers to handle video requests remains an obstacle (Motlhabi, 2014).

Artificial Intelligence Techniques have also been applied in the attempt to translate spoken language into sign language. The **Automatic Speech Recognition**

and Augmented Reality (ASRAR) system uses a human signing avatar to alter voice messages sent by a hearing person into sign language, and sign languages messages sent by a Deaf person into text (Motlhabi, 2014). In computing, an avatar is a cartoon-like image that represents a person. The instrumentation of ASRAR means that the avatar communicates programmed signs that it recognizes from text, thereby negating the use of a sign language interpreter. Artificial intelligence techniques usually require infrastructure that is already included in many commercially available phones, and they have the added benefit of allowing Deaf persons to autonomously communicate with hearing persons without the need of an interpreter. The constraint of this system lies in the cost implication of creating the avatar. For the avatar to recognize sign language, highly sophisticated, intricate mechanics using sensors in headgear, gloves and a body-vest to record body motion and facial expression are required (Motlhabi, 2014). Furthermore, the specific language used medicine instruction and the accuracy required in conveying medicine-related information makes artificial intelligence methods unsuitable in communicating medicine instructions.

Automated Dispensing Systems (ADS) include the Baxter Dispensing System® and Pyxis Medstation® among others. The advantages of automated dispensing is that these systems often do the manual tasks of assimilating dosage units into patient-ready quantity packages, and seal and label the packages with printed instruction. In this way, most of the manual process-centred tasks are completed for the pharmacist without large human-resource demands (Motlhabi, 2014). Drawbacks of ADS are that the instructions are text-based, and therefore not appropriate for persons who have limited text literacy (Motlhabi, 2014). Furthermore, instructions are pre-programmed and finite, they cannot be altered based on the individual needs of the patient and preclude caring and empathy which is cornerstone to the pharmaceutical care philosophy.

Shared Speech Interface is a system designed to facilitate communication between a deaf person and their consulting physician. It involves a multi-touch table top display with speech recognition to facilitate medical conversations between doctor and patient, a standard keyboard and a microphone headset (Motlhabi, 2014). The system works by having the doctor and patient sit opposite

one another, on either side of a table with a large multi-modal touch screen interface. Messages are fed into the system in one of two ways: (i) text input or (ii) audio input. The doctor or patient is also able to add visual information, such as x-rays, and scans and these can be “discussed” collaboratively, by creating text-boxes or speech-bubbles of the input of either user that appears on the screen, to be seen by both users. The strengths of this system include the face-to-face orientation of the patient and doctor, allowing the communication of body language, facial gestures and non-verbal cues, and the size of the table top screen which allows the sharing of information on a platform that can be viewed by both users simultaneously (Motlhabi, 2014). The system was also designed using a participatory action approach with deaf persons and hearing persons who frequently interact with the deaf community. The drawback of this system is the reliability of transcription of natural language into text, which is problematic. Due to its heavy reliance on text, the researchers have also found this system to be of value only in certain sub-populations: deaf persons who are comfortable using English and those who are hard-of hearing, thereby precluding Deaf people.

2.3.2 Supporting Work



The intervention described in this dissertation was based on the conceptualisation and prior work of Looijestein (2009) and Chininthorn (2011), industrial-design engineering students from Delft University of Technology (TU Delft), and Mutemwa (2011), a computer science student from the University of the Western Cape.

Looijesteijn (2009) designed the first prototype which is the base-model for this work: a model of a mobile phone on a personal computer that enabled the transmission of messages between a Deaf person and a doctor using pre-recorded SASL videos. The program was set-up to question a Deaf person on medical issues in SASL. The Deaf person answered the questions in SASL, subsequent to which the answers were accessible to the doctor in English text. The doctor was able to read a symptom summary and respond; this response was translated into a SASL video to be watched by the Deaf patient. Looijestein dubbed his application **“SignSupport.”**

Mutemwa (2009) then implemented Looijestein's SignSupport on a Symbian phone and engaged web pages with an arrangement of both SASL videos and English text. Once again, the Deaf patient was able to communicate to the doctor their symptoms and duration of the symptoms. In a sequential series of patient medical history type questions presented in SASL, the Deaf patient's answers are translated in English indicating to the doctor how the patient is feeling. The real-world application of Looijestein and Mutemwa's collective work however presented a significant problem: in order for SignSupport to work, all possible aspects of the doctor-patient interaction had to be pre-recorded in SASL to enable the phone to translate messages entered by the doctor. This included all the imaginable symptoms, ailments and illnesses which presented an endless number of possibilities. The domain of the communication was simply too large to be video-recorded and stored on a commercially available phone.

Chininthorn (2011) recognized that the pharmacy context is more restricted than the doctor-consultation context and re-oriented Mutemwa's SignSupport prototype toward pharmacy. She commenced by investigating the manner in which Deaf people use cellular phones in their daily lives to communicate with both hearing and Deaf people. Since the pharmacist-patient exchange is more limited than the doctor-patient exchange, it is more viable to pre-record and store a restricted communication flow on a mobile phone. With input from a local Deaf community, Chininthorn (2011) set in motion a plan to craft a context-specific solution to be implemented on a mobile phone. She recognized that for this to come to fruition, the involvement of pharmacist and computer programmer was necessary. This marked the birth of this collaborative project which aimed to recreate SignSupport for use in a pharmacy.

2.4 LESSONS LEARNT FROM THE LITERATURE

Below I provide a synopsis of the lessons that have emerged from the literature review. These are mainly issues that affect a pharmacist-Deaf patient interaction and are further summarized comparatively in Table 1.

Global and national influences have endorsed patient-centered care in pharmacy practice activities and recognize the significance of effective communication in achieving optimal health outcomes. While human rights, health policy and disability policy are well developed, they fail to advocate for key elements which are essential for the Deaf community. No provision is made for SASL interpretive services at healthcare facilities. Similarly, international and national pharmacy practice guidelines establish communication as a key characteristic and important skill for pharmacists, but communication skills specific for the needs of the Deaf community are not prescribed. While global and local disability charters have been established to protect Deaf people, who are also affiliated to organized structures which advocate for equal rights and accessibility, the literature has revealed that in reality the Deaf community often do not enjoy the same level of healthcare service provision as hearing people.

Although the literature on pharmacist-deaf patient interaction is scant, all reviewed studies point toward communication complexities and impediments which potentially hinder patient adherence and understanding of therapy. Pharmacists use spoken and written language to interact with patients, but Deaf people communicate in sign-language and likely do not understand written or spoken language. In addition, transactional models of communication have widely been accepted for pharmacist-patient interactions, but such models are not appropriate for a Deaf person who is unable to formulate a response in written or spoken language. The ability to respond is an essential feature of transactional communication models; Deaf people are thus only able to experience linear communication when interacting with a pharmacist.

The applicability of the term 'Deaf' is not fixed but its most common associations include the use of sign-language and an affiliation with Deaf culture. Deaf people

experience a strong sense of culture. The nuances of Deaf culture are unique; affiliation to the culture not only implies pride and communal identity, but also a set of social norms which differ vastly to those of non-Deaf people. Furthermore, the cultural norms of one Deaf community may differ to that of the next, with dialectal variances in sign language and behavioural differences in social customs. Pharmacists, similar to other healthcare professionals have shown a lack of Deaf awareness, failing to realize that Deaf people may have limited literacy and prefer to not lip-read. Pharmacists are likely to be unaware of other Deaf-specific issues including difficulties in cognitive processes such as memory and attention.

Public healthcare facilities in South Africa face human resource shortages and high workloads. Pharmacies have come under scrutiny for long patient queues and extended waiting times. Such circumstances may be even more magnified for the Deaf community, who, in light of staff shortages may not receive the specialized attention they require. Furthermore, they are not able to voice their queries or concerns to staff about their prescriptions or appointments and are often left to keep waiting to be called in patient-waiting areas. In conforming to GPP requirements of security and privacy, the traditional set-up of pharmacies and dispensaries in South Africa may create a physical communication barrier for Deaf patients who struggle to see intricate facial gestures and lip movements (in lip-reading) over a dispensary counter and through a glass window.

Pharmaceutical care requires the establishment of a mutual relationship in which the patient is jointly responsible with the pharmacists to achieve optimal therapeutic outcome. There is a dependence on mutual interaction between a pharmacist and a patient. Deaf persons are not able to communicate effectively without a SASL interpreter. This may preclude the provision of pharmaceutical care to Deaf patients.

Several technological innovations have been created for the Deaf people. These interventions all differ substantially and have shown benefits to Deaf communities abroad. A critical analysis of a number of these interventions has revealed various incompatibilities with the local Deaf community. These incompatibilities are based on affordability, network access, network-provider infrastructure and suitability to

literacy deficits. In order to create a technological innovation appropriate for the local Deaf community we must extract from these prior innovations elements which are appropriate for them and exclude those which are not. Furthermore, such an innovation must accommodate Deaf culture, literacy capacity and South African Sign Language, in a manner that does not require large monetary investments, high-end devices or sophisticated network requirements. Pharmacy-related innovations have all been text-based and are thus inappropriate for Deaf persons due to the afore-mentioned reason of limited literacy.

Table 7: Summary of lessons elicited from the literature

	PHARMACIST	DEAF PERSON
Health policy	Access to information Access to medical care	No provision for sign-language interpreters at health facilities
Pharmacy practice guidelines	Communication as a central role and responsibility	No mention of communication for Deaf persons
Communication medium	Spoken e.g. English	SASL
Communication theory	Transactional	Linear (receiver)
Deaf definition	Lack of awareness	Strong sense of culture
Medicine–related	Verbal and Written instructions	SASL Limited literacy
Pharmacy unit	Staff shortages High workload Minimal time	Special needs, requiring additional attention
Dispensary set-up	Conformance to GPP	Physical communication barrier
Pharmaceutical care	Joint responsibility Reciprocal relationships	Unable to communicate effectively
Available technology	Text-based	Not appropriate for limited-literacy persons

In conclusion, the literature review has emphasized several problems pertaining to the interaction between pharmacists and Deaf patients. It has also shown how technology designed for Deaf patients are inappropriate for the unique South African Deaf-community backdrop. These problems influence my thesis tremendously through highlighting key concerns and lessons to consider in ensuing research activities.



CHAPTER THREE

STUDY RATIONALE

The literature review highlighted a labyrinth of interconnecting problems pertinent to medicine use in the Deaf community. A systematic summation of the dominating issues examined in the literature provides the causal factors and theoretical underpinnings of the study. Furthermore, lessons emerge from a dissection of similar and related work. These lessons pave the way forward and culminate in the over-arching study goal and specific research aims and objectives set out to achieve the goal. This is highlighted to bring lucidity to all ensuing study endeavours.

3.1 DEVELOPMENT OF RESEARCH QUESTIONS

In this chapter I provide an overview of obstacles to effective pharmacist-Deaf patient interaction to contextualize the research problems. I categorize these problems as:

- (i) Barriers to effective interaction;
- (ii) Health policy disparities;
- (iii) Perceptions of Deaf community
- (iv) Nonconformity to professional practice recommendations
- (v) Available technology

These problems are pertinent to conceiving more specific research questions and are systematically synopsisized below. Following collective synopses, the research questions are elucidated through further refinement of the problems. Refined problems and subsequent research questions are provided in shaded and bordered text.

3.1.1 Barriers to effective interaction

The literature highlights a complex set of barriers to effective interaction between a pharmacist and Deaf patient. These can be categorized as physical barriers, physiological barriers, and psychosocial barriers and emotional barriers and emphasize the need for an intervention to bridge communication gaps during the medicine dispensing process.

- 1. Physiological barriers: Lack of auditory ability
 Limited cognitive ability and memory
- 2. Physical barriers: Dispensary counters
 Dispensary window Pharmacist
 proximity to patient
 Lack of human resources
- 3. Psycho-social barriers: Language barriers
 Limited literacy
 Deaf cultural unawareness by pharmacists

Lack of independence in seeking healthcare
Lack of confidentiality in accessing care

4. Emotional barriers:
- Frustration, mistrust in the system
 - Fear of not receiving service
 - Anxiety associated with hospital visits

3.1.2 Health policy disparities

While human rights, health policy and disability policy are well developed, they fail at an implementation level resulting in circumstances which compromise the fundamental human rights of Deaf people. These circumstances include a lack of access to information in a medium that is suitable for their unique needs, a lack of awareness by healthcare professionals of their disability, a lack of privacy and confidentiality in medical interactions due to reliance on interpretation or assistance and the potential risks associated with not understanding medical communication. Policy also fails to specify and legislate essential services for the Deaf community. No provision is made for SASL interpretive services at healthcare facilities, compounding the communication barrier faced by Deaf people with health care providers.

3.1.3 Perceptions of Deafness

The literature review has emphasized that health professionals are unaware of the specific characteristics of the Deaf community and how these characteristics differ within each community from one Deaf person to the next. There seems to be a flawed perception that all Deaf people are the same: they are unable to hear, but can read and lip-read. Deafness however, is heterogeneous. Deaf people differ in terms of their physical degree of deafness, literacy, lip-reading ability, level of education, dialect, and culture and sub-groups of are different to ‘deaf’ people who experience reduced levels of deafness and higher levels of literacy. The WHO, WFD and DEAFSA each have separate, unique definitions of ‘Deafness.’ The coinciding element of all three definitions however, is the use of sign language. For

this reason, and for the purpose of this study, I have constructed the following definitions of ‘deafness’ and ‘Deafness.’

Defining Deafness

‘**deaf**’ (lower-case ‘d’) refer to individuals who experience hearing loss from moderate to severe, and use mainly spoken language to communicate.

‘**Deaf**’ (uppercase ‘D’) refer to those individuals who experience profound hearing loss and use South African Sign Language as their main means of communication. They identify with Deaf culture.

Deaf people have limited linguistic skills including literacy. Medicine instructions are traditionally given verbally and in a text format, neither of which are suitable for Deaf people. They prefer to communicate via an interpreter rather than receive instructions in a format that they do not understand, but interpretive services are inaccessible due to the cost implication and scarcity of interpreters. Interpretative services pose problems for a Deaf person who wants to communicate in privacy, and for a pharmacist who must interact via an interpreter, since the presence of an interpreter precludes patient confidentiality as prescribed in the pharmacists’ code of practice.

We are politically and socially obliged to uphold rights for Deaf people but significant barriers to meeting this obligation are evident. This is particularly the case with regard to the right to accessibility of health-related information. Failure to implement policy, lack of Deaf awareness and the absence of sign-language interpretive services all create circumstances which negate Deaf peoples' rights to access healthcare information. Deaf communities require solutions which can accommodate their unique and heterogeneous needs and characteristics.

What are the experiences of the local Deaf community with regard to medicine use and their interactions with pharmacists?

What are their specific challenges during their interactions with pharmacists and what would they like to experience during such an interaction?

3.1.4 Nonconformity to professional practice recommendations

Pharmacists have a professional and ethical responsibility toward maintaining levels of social competency in their interaction with patients. The philosophy of pharmaceutical care calls on pharmacists to assume mutual responsibility with patients to achieve optimal therapeutic outcomes; this is supported world-wide in codes of practice. In order for pharmacists to adopt these roles, effective communication with their patients is crucial. The literature reveals that pharmacists experience difficulties in communicating with Deaf people. This has been shown to undermine the patient counselling process, with anecdotal evidence of Deaf patients not understanding instructions by pharmacists resulting in incorrect use of medicines.

The SAPC organizes the process of dispensing medicines into three sequential phases and prescribes the responsibilities of pharmacists within each phase. According to the SAPC classification, direct interaction and communication with a patient mostly occurs during Phase 3 of the dispensing process, during which a pharmacist must provide instructions, information and advice to the patient to

ensure the safe and effective use of medicines (SAPC, 2008). However, in terms of pharmaceutical care, the SAPC definition is flawed as it implies a one-way process of giving information and advice, whereas pharmaceutical care philosophy focuses on mutual interaction and responsibility between pharmacists and patients. For this reason I have chosen to use the term patient-counselling to represent phase 3 dispensing which is the professional context of the research, and use the two terms interchangeably throughout this dissertation. Equating these terms and using them interchangeably is supported in the literature.

Equating ‘Dispensing Phase 3’ to ‘Patient counselling’

Dispensing Phase 3 is defined by the SAPC as:

“Provision of information and instructions to the patient to ensure safe and effective use of medicines.”

Patient counselling is defined as:

“A one -to-one interaction between a pharmacist and a patient and/or caregiver. It is interactive in nature. It should include an assessment of whether or not the information was received as intended and that the patient understands how to use the information to improve the probability of positive therapeutic outcomes.” (Beardsley, 1997)

Unless a pharmacist is sign-fluent or can ensure the assistance of a sign–language interpreter, they are not able to properly conduct patient counselling with patients who experience profound Deafness. Deaf people generally experience superior communication with the presence of a sign-language interpreter. SASL interpretive services however are inaccessible to the majority of Deaf South Africans. Pharmacists do not have the skills or sign-language interpretive facilities to communicate effectively with Deaf people. The traditional setup of dispensaries in South Africa may further impede their interactions with pharmacists, who operate behind a counter that offers a semi-private counselling area (a requisite for counselling prescribed by the SAPC). While such a semi-private counselling area

fulfils the SAPC's requirement, it hinders efforts to communicate with Deaf people who rely on close-up, clear, face-to-face interactions to be able to understand the message being conveyed.

Digital technology may offer an alternative option to interpretive services suited to the needs of Deaf people. Such a technological intervention in dispensing could eliminate the breaching of patient confidentiality which is expounded through the presence of a sign-language interpreter. By introducing technology to facilitate the pharmacist-Deaf patient counselling process, it is essential that professional practice codes would have to be followed.

In a real-world setting, a pharmacist needs a sign language interpreter to effectively conduct patient-counselling with a Deaf person. In the absence of sign-language interpretation, pharmacists are unable to sufficiently provide patient counselling and should find ways to replace interpreter services. Technology may be a plausible opportunity to explore. Such technology would need to accommodate all the obligatory features of the patient-counselling process and conform to professional practice stipulations.

What are the typical and obligatory features of the patient counselling process? What do pharmacists 'say' during this process, and what information is necessary to obtain from a patient to ensure the safe and effective use of medicines?

What are the specific pharmacy practice guidelines that a technological intervention must comply with in bridging the gaps in pharmacist-Deaf patient communication?

3.1.5 Available technology

In the previous chapter I have discussed several technologies created to overcome communication barriers for Deaf people. I have discussed reasons why these technologies are not suitable for the South African Deaf community. They may require sophisticated, high-end equipment or high speed data connections. Neither of these requisites is affordable for the South African Deaf community. A number of the technologies are text-dependent, precluding limited-literacy populations. Mobile phone technology which is ubiquitous in service sectors is yet to be introduced into the South African pharmaceutical services. A mobile phone application could be explored as an assistive device during pharmacist-Deaf patient counselling.

The South African Deaf community experience a unique socio-economic climate and demographic circumstances etched by historical injustice. Technology designed for their use would need to accommodate their unique characteristics including financial status, literacy level and level of education.

Are Deaf persons receptive to using a mobile phone technology in their interactions with pharmacists? Can such technology accommodate their unique needs?

Looijestein and Mutemwa developed a prototype for interaction between a doctor and Deaf patient during a medical consultation. This prototype, called SignSupport, demonstrated positive outcomes in using sign-language translation videos on a mobile phone for communicating with Deaf people. On the contrary, their prototype was not successful in the doctor-consultation context because the domain of possible communication between doctor and patient was too large to pre-record and store all possible interactions

The Looijestein-Mutemwa SignSupport prototype was successful in using sign-language translation videos in a doctor-consultation context but was unable to contain the expansive scope of the doctor-patient interaction. In comparison, the pharmacist-patient interaction is more confined. The research team therefore hypothesized that re-orienting SignSupport to a pharmacy context may result in better outcomes.

Are sign-language translation videos able to accurately and effectively translate medicine instructions to a Deaf patient in a way that is understandable for the patient?

The Looijestein-Mutemwa SignSupport prototype was not suitable for medical doctors because it was not physically and technically possible to record and store sign-language videos corresponding to all the terminology (symptoms, signs, illnesses and other medical terms) that doctors may require to effectively communicate with a patient, onto commercially available phones. Hence it did not suit their professional context or conform to their practice norms and was not able to communicate all the aspects that they wanted to say to the patient. While Deaf patients were enthusiastic about the prospect of communicating with their doctor through sign-language videos on SignSupport, it was ultimately not ideally suited because SignSupport's inability to capture all the doctor's messages would lead to Deaf patients receiving incomplete information. SignSupport could be an option to facilitate counselling on medicine use between a pharmacist and a Deaf patient. The use of such an assistive device would have to conform to both their needs in terms acceptability.

If pharmacists were to use SignSupport to aid their interaction with a patient, it would need to (i) conform to their practice contexts and (ii) be acceptable to pharmacists in terms of their ability to communicate what they want to say.

Pharmacists would also need to have confidence that there are no gaps in the Deaf patient's understanding of his/her medicine regimen when they conclude the patient counselling process.

Would pharmacists be keen to interact via SignSupport, and is SignSupport able to accommodate the features of the patient-counselling that pharmacists deem necessary?

Are Deaf patients able to better understand medicine instructions when using SignSupport as opposed to their regular interaction without SignSupport?

Will Deaf people incorporate SignSupport into their daily medicine-taking routines?



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The questions elicited above leads to the overarching research questions: What pharmacy-related information aspects can be incorporated into digital technology? How can technology-based pharmacy interactions be designed for use by pharmacists and Deaf patients during the patient counselling process?

3.2 AIM AND OBJECTIVES

In an attempt to answer research questions presented in the shaded boxes above, the following aim and objectives were elucidated:

3.2.1 Overall Aim

- To provide dispensing-related pharmacy expertise in the design and implementation of SignSupport: a mobile phone application to facilitate communication between a pharmacist and a Deaf patient.

3.2.2 Objectives

1. To qualitatively evaluate the experiences and challenges of the Deaf community regarding their experiences of the medicine dispensing process and using their medicines.
2. To extract a dialogue pattern representing the communication flow that would typically occur between a pharmacist and a patient during medication counselling, and to express this pattern as a series of ordered sentences.
3. To compile databases containing the standard medicine-related information features captured during the patient counselling process:
 - (i) Medicines and Symptoms/Illnesses database and
 - (ii) Prescription instruction database
4. To verify that recorded SASL videos which translate to medicine-related information features from text into SASL videos incorporated into SignSupport communicate the medicine-related information correctly and accurately.
5. To iteratively test SignSupport with Deaf persons and pharmacists to assess their acceptability and usability thereof.

CHAPTER FOUR

RESEARCH METHODOLOGY and DESIGN

In the preceding chapter, research questions were elucidated and cast as research aims. In light of these aims, I sketch a framework that led to the selection of the study methods and design strategies. The following parameters influenced my selection: research methodologies employed in previous Deaf community studies reviewed in the literature; the unique cultural value system of the Deaf community; pharmacist availability; methodological homogeneity with members in the multidisciplinary research team and restrictions faced in communicating via a sign-language interpreter.

This chapter serves to present the theoretical underpinnings of all the research techniques employed in this dissertation. Only a brief description is included of how they were applied in the study, with further details of the procedural application presented in the ensuing chapters (five, six and seven) which deliver the empirical processes of this thesis. Presented as two main sections, the first section reflects on the motivation for the chosen research paradigms and includes conceptualization of relevant study theories, data collection and data analysis methods, a description of how quality and rigour of findings were attained and ethical considerations.

The second instalment of this chapter details how the identified research strategies were applied in successive study phases by illustrating this application in a series of diagrammatic illustrations (the research design). This section culminates in a description of how findings are structured in the ensuing thesis chapters.

SECTION A: RESEARCH METHODOLOGY

In this section I provide an overview of the SignSupport prototype design requirements to establish motives for the selected research strategies. In developing SignSupport, qualitative and participatory research strategies were followed, both of which are discussed in this chapter. I describe a general overview of the research theories pertaining to these strategies and discuss the specific methods used and how they were applied to obtain data that would influence the development of SignSupport. In evaluating SignSupport, qualitative methods were used to assess the acceptability and usability of the intervention and participatory action methods were used to influence subsequent prototype iterations. Data analysis techniques are discussed followed by an explanation of how the validity and reliability of study findings was ensured. This section concludes with a description of the ethical considerations that were applied in the research.

4.1.1 Overview of SignSupport development requirements

SignSupport was conceptualized to transcend the communication barriers that exist between pharmacists and Deaf patients during patient counselling. The underlying hypothesis was that a collaboratively designed prototype would assist Deaf people to better understand their medicine instructions and empower pharmacists to communicate medicine-related information effectively to Deaf patients. Logically, SignSupport had to be developed in order for the hypothesis to be proven. The iterative development of SignSupport necessitated the following pre-requisites previously alluded to in chapters one and two:

1. Multi-disciplinary collaboration to converge different expertise to develop SignSupport
2. Participation from Deaf community and pharmacists to influence design features
3. SASL interpretive services for interactions between the Deaf community and the research team

4. An in-depth insight into the experiences of Deaf people with regards to the patient counselling process and medicine usage. These insights would inform the design of the Deaf-user interface of SignSupport.
5. Naturalistic behavioural patterns of pharmacists when providing medicine instructions. This would lead the design of the pharmacy interface.
6. Sign-language videos translating medicine instructions from text into SASL

Figure 5a illustrates the overall content requisites needed to build SignSupport. These requisites led to the selection of study methods and design strategies. Figure 5b, which follows on from Figure 5a, illustrates how the content requisites were interconnected to realise SignSupport.



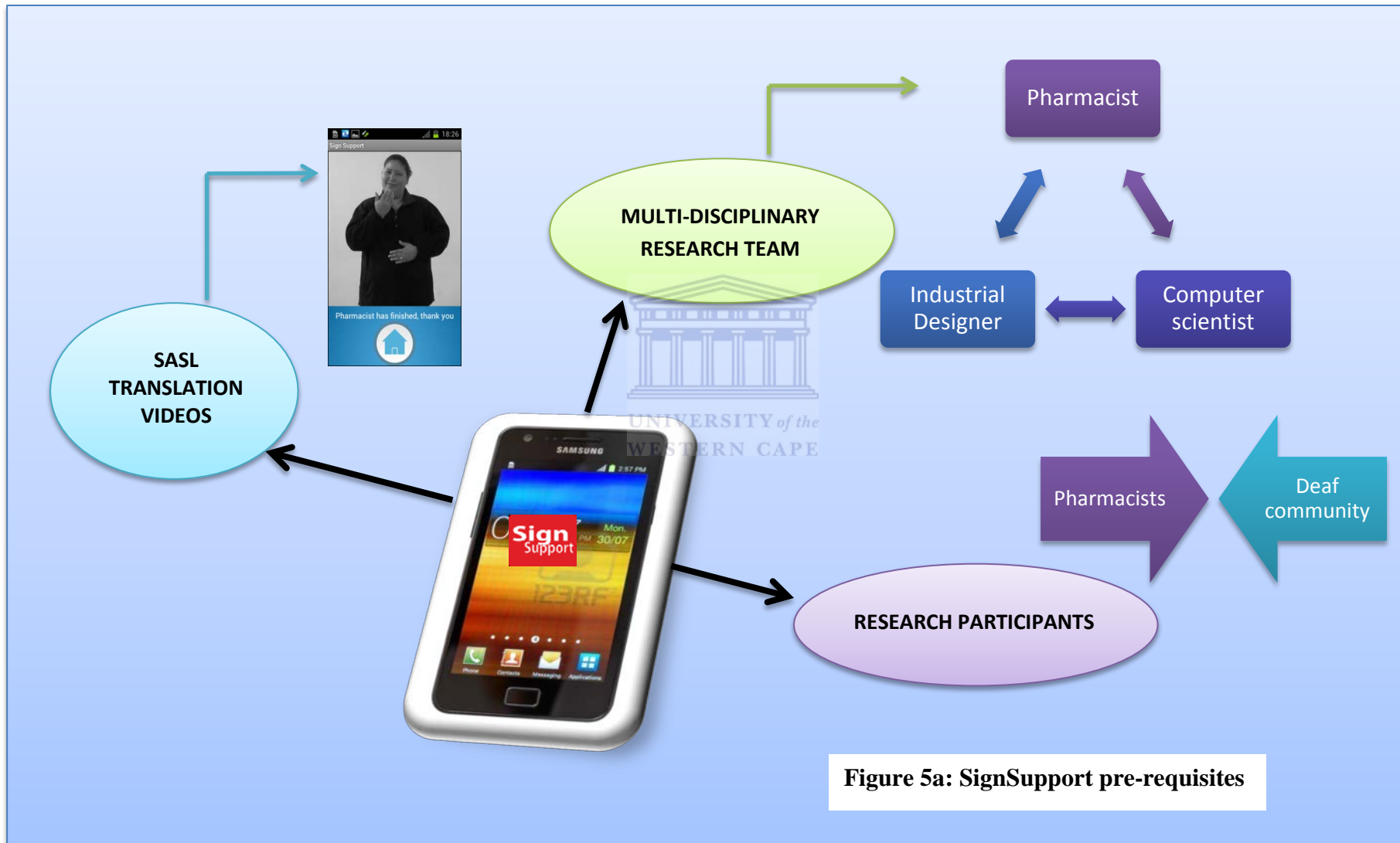
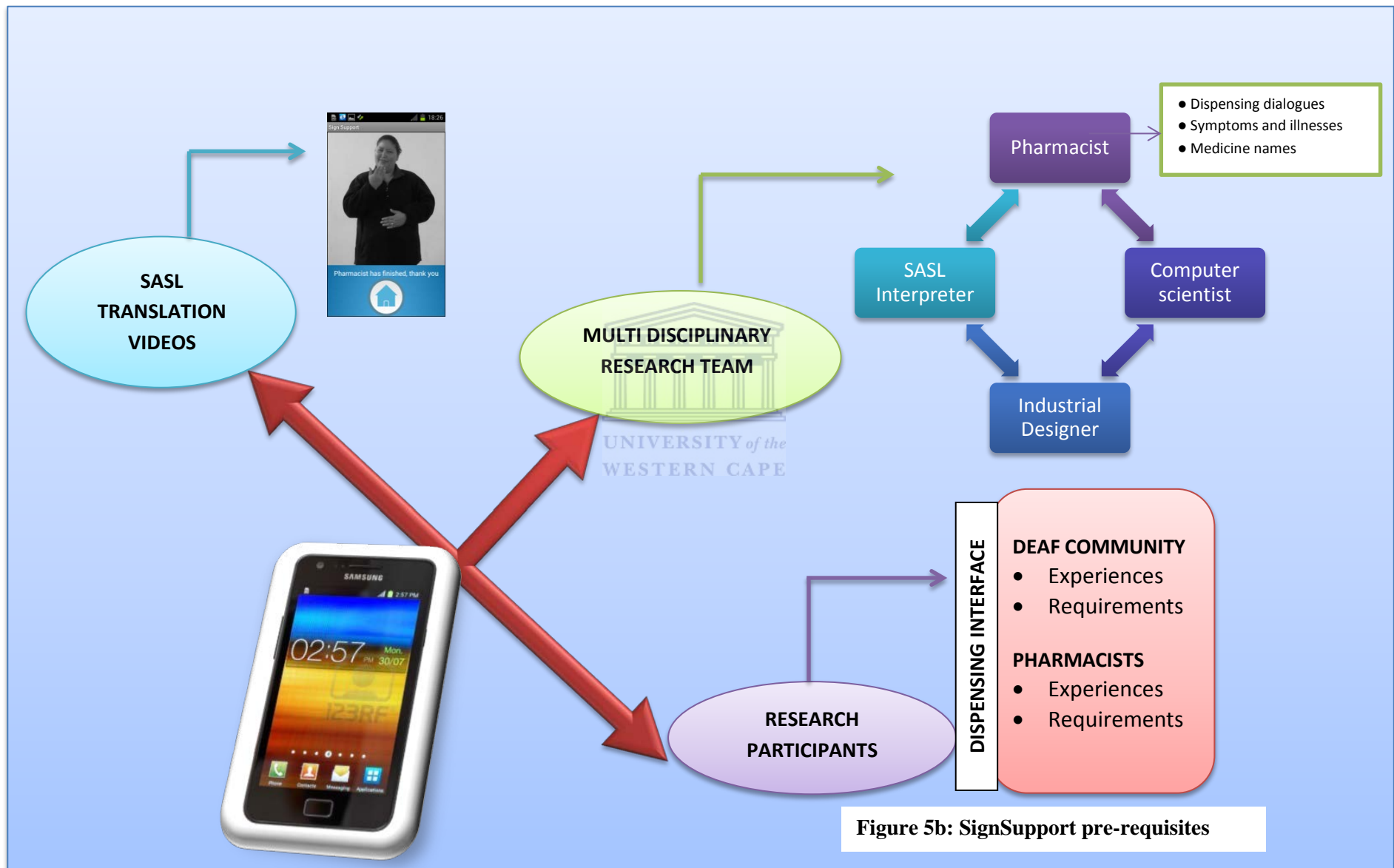


Figure 5a: SignSupport pre-requisites



In addition to SignSupport requisites, several considerations influenced selection of the study methods. These include (i) working within a multi-disciplinary team, (ii) conducting research with Deaf people (iii) conducting research with pharmacists and (iv) suitability of research paradigms. These considerations are discussed below.

4.1.2 Multi-disciplinary collaboration

A multi-disciplinary collaboration between various stakeholders was central to developing SignSupport. The specific duties and contribution of stakeholders comprising the multi-disciplinary team are the following:

1. **Pharmacist:** to construct the pharmacy dialogue pattern, to ensure accuracy and safety of medicine instructions, to ensure completeness of medicine-related information, to fulfil pharmacist's code of practice by respecting patient dignity and confidentiality.
2. **Computer programmer:** technical expertise to program the application onto a mobile phone interface in a manner that was usable and functional.
3. **Industrial designer:** to design icons for SignSupport and a system flow in a manner that would be cognitively acceptable for the Deaf community.
4. **Deaf community and interpreters:** The Deaf community were the drivers of the design; they dictated the features of SignSupport to be suitable for them. Interpreters bridged the communication gap between the researchers and Deaf community at every step of the research.

In addition, senior pharmacy students were employed as research assistants. As part of their fourth year curriculum requirement to engage in research, pharmacy students are invited to state their preference from one of four disciplines (pharmaceutical chemistry, pharmacology, pharmaceutics and pharmacy-practice). Students who had opted to undertake pharmacy-practice based research were randomly assigned to one of three staff members within the discipline. Three student groups (one group per year) consisting of five or six students per group were involved in this research for 2012, 2013 and 2015 (Appendix A).

In light of the research objectives of this thesis, the study techniques selected had to accommodate the participation of multiple members of the multi-disciplinary team, the inter-dependence of expertise and the dynamic interplay between team members required to develop SignSupport. The participatory nature of the collaboration led to the consideration of Participatory Action Research (PAR) as a methodological choice. PAR is explored later in this chapter. Particular research tasks were conducted collaboratively while others were done independently. Appendix A provides details of team members and Appendix B provides an outline of the scope of work and individual and group responsibilities mutually agreed on by all stakeholders in the multi-disciplinary team.

4.1.3 Deaf community research considerations

The literature review revealed that the preponderance of studies with Deaf communities is anecdotal rather than statistical, owing to the nature of the data that researchers were aiming to achieve. For SignSupport development we wanted to assess experiences, behaviours and attitudes of Deaf people. In order to accomplish this, the following was necessary for interactions with the Deaf community:

1. Availing SASL interpretation services
2. An understanding of the nuances of Deaf culture
3. Accommodating Deaf-specific needs (e.g. limited literacy)
4. Recognizing and planning for the heterogeneity between participants and different Deaf communities

Researchers needed to immerse themselves within the Deaf community to establish familiarity with participants and understanding of their cultural value system. Only once this was sufficiently achieved did research commence. Owing to the strong sense of cultural connectedness within Deaf communities, we aimed to recruit SASL interpreters with which the Deaf community already had an existing relationship and level of comfort. This was essential to establish a harmonious working relationship to initiate the research inquiry process. Other specific cultural considerations included Deaf participants' preference to sign-language, their impartiality to lip-reading and

accommodation of their socio-economic circumstances. For example, at the first contact session with the Deaf community, their main concern was how they would afford the transport cost to research sites. As a result, all transport needs of Deaf participants were pre-arranged and paid for by the researchers. In addition, meals were provided during research sessions to negate the participants having to prepare or buy meals on research days. With regard to Deaf community's cultural nuances, researchers were cautioned by staff at the Deaf community centre not to push participants by insisting that they respond to questions. Staff advised us that certain issues were very sensitive and that probing excessively on these topics would upset the Deaf community and even alienate them which would hinder research activities. Sensitive topics were not pre-known or predictable and researchers had to pre-empt our course of action should an issue arise that would cause distress to the Deaf community.

Foreseeably, Deaf people prefer to communicate in sign-language. In addition to sourcing interpretive services, researchers ensured that study materials accommodated sign-language translation (not excessively wordy or verbose) and allowed responses in sign language (for example participant consent was video-recorded as a show of hands). Their limited literacy meant that at no point would we require Deaf people to fill out forms, read text or cause them to feel that spoken language was imposed on them. Lastly, it was imperative that researchers recognised that what would work with and for one Deaf participant may be unacceptable for the next due their heterogeneity in language, literacy and culture. This required researchers to be dynamic and pre-empt study adaptations during data collection activities to ensure the success of the study.

4.1.4 Research considerations with pharmacists and pharmacy students

SignSupport development required pharmacists' input to obtain their user requirements and assess their acceptability and usability of the prototype. In order to obtain this requirement, key considerations in working with pharmacists were:

1. To minimise and be efficient with regards to the time required from them.
2. To accommodate their peak workload times

3. To obtain permission from their managers when research activities occurred within working hours.

Senior pharmacy students were used as a sub-sample in the initial study phases to represent practicing pharmacists in the required study phases. The reasons for using pharmacy students were: (i) senior pharmacy students would provide a freshly trained and updated insight into best-practice behaviours by pharmacists as they had been newly groomed at university as opposed to practicing pharmacists who may have inherited suboptimal practices, and (ii) due the shortage of pharmacists and their immense workloads, access to pharmacists at their workplace is limited. Senior pharmacy students were an appropriate and useful sub-sample to represent pharmacists. In the later research phases practicing pharmacists were recruited because they had protracted and more intense experiences in patient counselling. Cognisance was taken of their peak workload times and research activities were not scheduled during these times. The same applied to pharmacy students who also have busy academic schedules. With both groups, researchers avoided wasting time in dawdling and doing unnecessary tasks or tasks that could be done prior to the data collection session. All research with pharmacists was permitted by their manager and the pharmacy director.

4.1.5 Research methodology considerations

In the early stages of the research, quantitative methodology was considered as a strategy to achieve the aforementioned requisites for SignSupport. Quantitative research produces data which is objective, numerical and statistically significant, generating procedures which are likely to produce quantified and possibly generalizable conclusions (Bell, 1993). Quantitative data measures facts and focuses on variables (Neuman, 2003), and can be statistically analysed to test hypotheses (Armstrong, Calnan & Grace, 1990). For the purposes of this study, quantitative research approaches were rejected for the following reasons:

1. Quantitative inquiry produces objective data. For programming SignSupport, we required (i) in-depth insights into the experiences of Deaf people and (ii) natural behavioural patterns of pharmacists during

dispensing. Research of experiences and behavioural patterns require subjective, rather than objective data.

2. The literature reviewed on Deaf communities is anecdotal rather than statistical. This is attributed to the heterogeneity in culture and social norms from one Deaf community to the next. Such heterogeneity implies that it is unreasonable to expect generalizable results between different deaf communities whose social behaviours are dissimilar and unpredictable. Quantitative data is applied when generalizable results are sought.
3. Instead of generalizability of findings, the researchers aimed for transferability of findings to subsequent research phases and in SignSupport iterations. Further negating the requirement for quantitative inquiry.
4. Active participation of the target groups (Deaf community and pharmacists) was cornerstone to development of SignSupport. Such participation involved intense workshop sessions of small numbers of participants in order gauge their attitudes and preferences toward SignSupport. Smaller sample numbers and the investigation of attitudes, preferences and authentic experiences is difficult to achieve through quantitative inquiry.

The afore-mentioned reasons precluded the application of quantitative strategies in the research and led to deliberations on alternative methodological influences which are explored below.

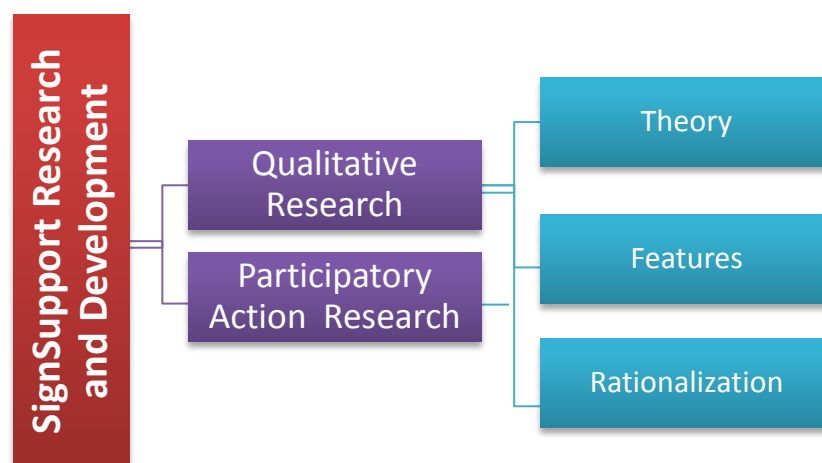
4.2 METHODOLOGICAL INFLUENCES

Dominant influences in selecting appropriate methods for this work emerged from the literature review, a newly-acquired familiarity with Deaf culture and the exclusion of quantitative methodology as an appropriate research strategy for this thesis. On commencing the literature review, I expected to find predominantly quantitative studies. Instead, previous work was largely anecdotal with rich descriptions and insights into the Deaf world. It was through this process that I realized that such insights could not be achieved through quantitative investigation and saw the value of qualitative inquiry for the research. This was the first major methodological decision which determined the trajectory of the ensuing research

progression. Further cementing the decision was my continued interactions with Deaf persons. As my understanding of their unique and fascinating cultural nuances evolved, it was evident that a one size-fits-all statistical inference based approach would not do justice to the overarching goal of crafting a solution for their communication difficulties at the pharmacy.

Crafting the afore-mentioned solution required collaborative action to bring to fruition a tangible prototype that could potentially achieve the research goal. The process of innovation and design depended not only on the collaboration of the professionals involved but substantially on the input and contribution of the Deaf community themselves. This reality lent itself to the second major methodological decision: the employment of a Participatory Action Research (PAR) approach. In PAR, data collection, action and reflection are aimed at reducing health inequities and improving health outcomes through the involvement of people who, through the research process take actions to improve their own health (Baum et al., 2006). Both qualitative doctrine and the notion of PAR resonated with the intent of this work and are presented below as research theory, research features and rationalization for the relevant methodological choice. This is illustrated in Figure 6:

Figure 6: Methodological influences for SignSupport research and development



4.2.1 Qualitative research theory

There is broad consensus among experts that research is typified by three major taxonomies: Positivism, Interpretivism and Critical Theory (Merriam, 2009). Qualitative methodologies are grounded in the philosophy of interpretivism which is typical of social science research. Interpretive ontology and epistemology adopts the notion of multiple realities owing to the subjective nature of knowledge (Creswell, 2013). Merriam (2009) describes this notion in the following quotation: “*There is not a single observable reality...rather multiple realities, or interpretations of a single event. Researchers do not find knowledge. They construct it* (Merriam, 2009, p. 9).”

Hence, interpretivism is also known as constructivism, (Mouton, 2001), and differs to positivism which assumes that reality is steady and is best observed through an objective understanding.



4.2.1.1 Features of qualitative research

The scope of qualitative research is broad and expansive. Straus and Corbin (1990) provide an inclusive definition of qualitative research as ‘*any kind of research which produces findings that is not arrived at by means of statistical procedures.*’ Merriam (2009) provides a different, narrower perspective: “*qualitative researchers are interested in...how people make sense of their world and the experiences they have in the world.*” (Merriam, 2009, p. 13)

Qualitative research seeks to find and express the subjective understandings of participants about the study subject and how they experience it. It provides detailed descriptions of occurrences and the functions of collecting, analysing and interpreting data is done by observing what people do and say (Neuman, 2000). “*Qualitative data is asserted, it can provide rich insight into human behaviour.*” (Guba & Lincoln, 1994, p. 106), Merriam (2009) describes four major characteristics of qualitative research as:

1. Process-, understanding- and meaning-directed research

2. The researcher is the prime instrument of data collection and analysis
3. The research process is emergent
4. The outcome is richly descriptive

The researcher aims to understand the experience from the participants' point of view by gaining an insider's perspective. Pauly (1991) describes qualitative research as a five-step procedure: defining a topic; constructing the research question; collecting evidence; interpreting the evidence and expressing the researcher's story. Direct observation, recorded speech or behaviour, video or audio tapes and interviews are qualitative research procedures. Data emerging from a qualitative inquiry include full field notes, interview and focus group transcripts, the researcher's jotted records, field journals and video recordings. (Pope et al., 2000). In this regard, qualitative research seemed to be an appropriate study option to meet SignSupport development requisites alluded to in Figure 5a.

4.2.1.2 Rationalization for qualitative research inquiry

Lessons emerging from the literature review and subsequent process of research question elucidation have lent itself to the qualitative, interpretivist characteristics of human inquiry described by Merriam (2009) in the following ways:

- The research sought to explore (i) experiences of the Deaf community with pharmacists during the patient counselling process and (ii) their typical use of medicines, thus drawing on the participants' perspective to understand these occurrences.
- Similarly, the research identified as an outcome a pattern of typical medicine dispensing dialogues extracted from the normal dispensing behaviour of pharmacists. Once again, there is a dependence on the participants' perspective to understand the subject. This research activity was also emergent in that the dialogue was central to subsequent research activities.
- Data appeared in the form of transcripts, video recordings, field notes and interview notes. The researcher was thus involved in "constructing

meanings” to the participants’ experiences in the form of words (Creswell, 2007, p. 38). The researcher is therefore the primary instrument of data collection and analysis.

4.2.2 Theory of Participatory Action Research

One of the many approaches in collaborative research investigations is participatory action research (PAR). It is a progressive research process which is gaining popularity in a wide variety of healthcare settings and has been shown to be ideally suited in innovation aimed at improving healthcare and developing new professional skills and roles. PAR is apportioned to the broader genus of action research modalities (Reason & Bradbury, 2008). Action research seeks to pursue action outcomes and research outcomes simultaneously and has components which resemble both field inquiry and change interventions. It differs from most research approaches which conventionally focus on “acquiring knowledge” (Reason, 2006; Waterman et al., 2007). In addition it is unlike quantitative deductive research or qualitative interpretive techniques in that it is underpinned by a “moral dimension,” focusing on societal improvement through “*engaging people in dealing with issues in their lives*” (Greenwood & Levin, 1999; Reason, 2006). Meyer (2001: 173) describes this notion in the following quote: “*Essentially action research is concerned with generating knowledge about a social system, while, at the same time, attempting to change it*”. Most action researchers hold the view that their primary goal is the service to their participants (Dick, 2009).

No single established definition exists for PAR, instead many research experts agree on a number of common features: (i) participation, (ii) a cyclic process (iii) the emergent nature of the engagement and (iv) reflection (Reason & Bradbury, 2008). Other researchers have contested this standpoint, instead favouring the term “collaborative action research” (Kemmis & McTaggart, 2003). Hughes, (2008) describes PAR as including three elements: “*systematic inquiry, a professional practice intervention and participation in decision making by key stakeholder*” (Hughes, 2008: 385). He represents these elements as an interconnected web of overlapping features:

Figure 7: Hughes's concept of Participatory Action Research



For this research I have adopted Hughes's concept of PAR for research endeavours With the Deaf community and pharmacists. Hughes's model encompasses all the essential features required for the inquiry process to achieve the envisioned prototype.

4.2.2.1 Features of Participatory Action Research

Aforementioned features of PAR include: (i) participation, (ii) a cyclic process (iii) the emergent nature of the engagement and (iv) reflection (Reason and Bradbury, 2008). Below I discuss each feature in relation to this study.

Participation is central to a PAR approach. Fals-Borda and Rahman's (1991) work (cited in De Koning & Martin, 1996) emphasized the rights of people to contribute to decisions which affect them and is underpinned by liberation theology and the neo-Marxist approach to community development (De Koning & Martin, 1996). Some researchers connect such contribution by the people with democratic/egalitarian values. Interestingly, South Africa's disability movement adopts a slogan which aptly represents such democracy-inclined community participation:

“Nothing about us, Without us.”

In PAR, participation can occur in all or certain stages of the research process spanning from the stages of exploring the research emphasis to utilising the study results. Varying degrees of participation have been endorsed by some researchers who hold a pragmatic view that participation should be included in the most relevant research areas, not necessarily in all stages (Reason, 2006; Laws et al. 2003). Others are of the view that participation by researchers and participants must be evident across all stages of proper PAR.

A high level of participation was needed throughout this study. At each stage, from conceptualization to implementation, the input of Deaf persons, pharmacists and research partners was crucial. The very idea for SignSupport was sketched out by the Deaf community, whilst all pharmaceutical elements were contributed through research with pharmacists. Subsequent to initial conceptualization and development of version 1 of SignSupport (incorporating the pharmacists' contributions), the prototype was evaluated by both Deaf participants and pharmacists. Their feedback was incorporated into the first iteration, resulting in SignSupport version 2. The process was repeated, again with both participant groups to inform the second iteration: SignSupport version 3.

The cyclical process is another characteristic typical of PAR. The cyclical process can be explained as cycles of research activities which converge to form a continuum of cycles of reflection. Overlapping of circles occur when findings from the reflections of one research cycle are incorporated into the subsequent cycle. Each cycle may comprise interventions or changes in understanding or behaviours (Waterman et al, 2007). The idea of a cyclical process resonated with the iterative design cycles of SignSupport. Data emerging from initial research cycles was incorporated into SignSupport as a component or design feature. The completed prototype was then evaluated by participants in the second iterative cycle, and adjusted according to their feedback, which in turn shaped the second iterative cycle.

Reason (2006) describes the third characteristic of PAR: the emergent process of engagement. It begins with situational knowledge and develops with the process of inquiry:

“Good PAR emerges over time in an evolutionary and developmental process, as individuals learn skills of inquiry, as communities of inquiry develop, as understanding of the issues deepens and as practice grows and shifts change over time.” -Reason, 2006-

Reason’s stance illustrates emergence which refers to possible modifications in research questions, approaches and the purpose of research due to the generation of knowledge during the inquiry. This feature of PAR was particularly appropriate in a context where the researchers did not know much about medicine instruction in the Deaf community, owing to a scarcity of published literature. In addition, the researchers had limited experience with the nuances of conducting research with the Deaf community.

Reflection is a cornerstone feature of action research and was central to the research-related and SignSupport design-related study objectives. The value of reflection has been noted in assisting professionals in complex health systems where there is a need to solve multifaceted problems. The literature on reflection is immense; the concept has been dissected by many scholars. Overall, it is considered as a process of learning from experience; that which is learnt is then used to develop practices (Loughran, 1996, Leitch & Day, 2000). In the literature, reflection is predominantly associated with the cognitive processes involved in conceiving and solving a problem. Loughran (1996), defines reflection as *‘the deliberate and purposeful act of thinking which centres on ways of responding to problem situations.’* In the context of this study, the complex problem situation is the communication barriers between pharmacists and Deaf patients. It is complex in the sense that neither has the skills or ability to communicate with the other and the well-being of the Deaf patient is dependent on how the pharmacist engages meaningfully with the patient. The cognitive processes involved in arriving at a practical solution comprised the collaborative creative efforts of the primary researchers and participants, each contributing to the design aspects and SignSupport refinement in each successive iteration.

4.2.2.2 Rationalization for participatory action research

The characteristics of PAR have been explored in detail earlier in this chapter. Within the discussion of each characteristic, I provided a description of how that specific characteristic was applied in the study. This is summarised below:

- The development of the pharmacy version of SignSupport depended hugely on the specific naturalistic behaviours of both Deaf persons and pharmacists. These behaviours were noted and contributed by the participants themselves. Participation was key; without it this research would be a futile exercise.
- Action was evident in each stage of the research: action to solve the problem motivated the creation of SignSupport, and each step in the fabrication of SignSupport was accomplished with the researchers and participants.
- Actions were reflected upon; these reflections formed the data sets which was, in turn, the launching pad for subsequent modifications and iterations.
- The research and SignSupport design processes were cyclic rather than linear. Research activities were often repeated with the intent of learning from one cycle lessons to apply in the next cycle.
- The emergent process of engagement was necessary in a context where not much was known by the researchers about the specifics of medicine instruction in the Deaf community or how to conduct research with Deaf people

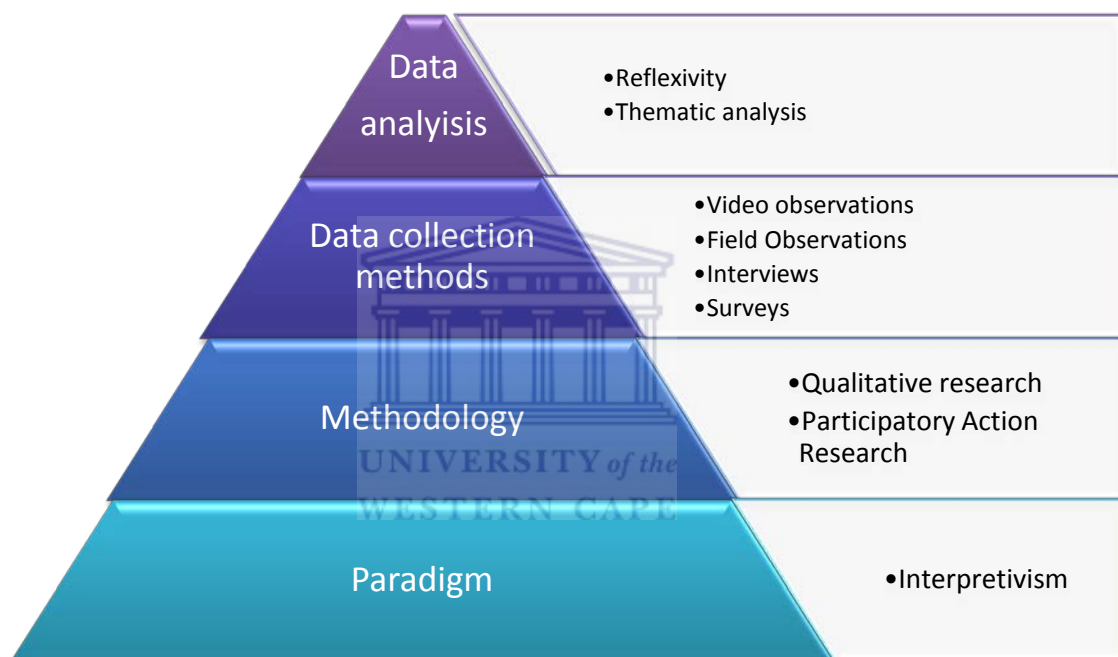
The choices of research paradigm (interpretivism) and methodology (qualitative research and PAR) formed the foundation of the study and paved the way for selection of specific methods and techniques which comprise the research framework.

4.3 RESEARCH FRAMEWORK

The research framework illustrates how the dominant research influences were applied in the study. In Figure 8, a pyramid representing the framework illustrates how the interpretivist approach shapes the foundation for this research, which in

turn determined research approaches and the chosen methods of data collection and analysis. Methods based on interpretivist methodology included video recording of role-plays and user tests to construct elements of SignSupport and usability ideas and recommendations thereof. To ensure sound validity, a reflexive framework (Srivastava & Hopwood, 2009) for interpretation was combined with thematic analysis of data in the form of transcribed verbatim. Specific data collection methods and data analysis techniques are explored later in this chapter.

Figure 8: Research framework



4.4 DESCRIPTION OF THE TARGET POPULI

SignSupport is intended for 2 user groups: Deaf persons and pharmacists. More specifically, target groups for this study were Deaf people and pharmacists from the Western Cape Province who were acquainted with the medicine dispensing process at a public hospital pharmacy. Study samples were not chosen to be representative of the larger samples for either target group (600000 -1.5 million Deaf persons and 11000 pharmacists) and findings are not intended to be generalizable. Instead, findings were intended to be transferable, i.e. to feed into the successive design cycles of SignSupport with a view to realize it as a mobile

phone application that can bridge the communication gap between the 2 target groups.

The Deaf sample numbers differed throughout the various phases of the research and the total samples for each phase is described in detail in the forthcoming chapters (five, six and seven) which present the empirical activities of this thesis.

The Deaf samples were small due to a number of reasons:

- Deaf sample size was influenced by the literature review which revealed that the preponderance of Deaf study findings are anecdotal in nature and have a qualitative underpinning. Qualitative studies seek a rich understanding of the subject being studied, rather than results representative of large numbers.
- Secondly, each Deaf community is unique and complex; tenets within one Deaf community may differ from the next, which in turn may produce different study results, making it unreasonable to expect results that are generalizable.
- The nature of the data we were hoping to extract necessitated in-depth, intense examination of the thoughts, impressions and attitudes of participants, further cementing the requisite for qualitative inquiry.
- The complexity of ensuing research undertakings via a sign language interpreter limited research time and as a result, sample size.
- Participants numbers were determined by the number of Deaf people who were affiliated with the communities which we were studying: DCCT and DeafSA PAARL.
- Lastly a significant component of this work is design-oriented (designing features of SignSupport). This was done in line with the tenets of PAR and community-based co-design, both of which closely mimic the qualitative paradigm in that they produce results that reflect an understanding of peoples' needs, how they interact and what they perceive and experience.

Albeit small, the Deaf participant sample size is not viewed as a limitation but is instead seen as an opportunity to gain an in-depth insight required in qualitative investigation.

The sample size of the pharmacist participants (also detailed in the forthcoming thesis chapters five, six and seven) mirrored that of the Deaf sample. Once, more this was in part due to the qualitative and PAR study orientation. While the reasons of cultural uniqueness and interpreter-assisted communication do not apply to the pharmacist group, the sample size was dictated by the Deaf participant sample size. This is because majority of the research activities involve an interaction between a Deaf person and a pharmacist to assess the communication between them assisted by SignSupport. In essence, if we were studying 5 Deaf persons, we needed 5 pharmacists. More pharmacists would be of no use unless we also had the Deaf numbers to match them. Furthermore, pharmacists in South Africa are scarce-skill professionals and public healthcare facilities are fraught with human-resource constraints. In light of staff shortages, pharmacists and their managers are reluctant to make the time for research-based activities. The study was designed with the intent of placing minimum demands on the time required from pharmacists.

Senior (final year) pharmacy students from the UWC School of Pharmacy were used as a sub-sample in the initial study phases to represent practicing pharmacists. As a pre-requisite, that had to have experience in dispensing at a public hospital pharmacy. The reason for using pharmacy students is bi-fold: (i) senior pharmacy students would serve as exemplars for dispensing practice needed in Phase 1 of the study to construct dispensing dialogues because they have been freshly groomed at university as opposed to practicing pharmacists who may have inherited suboptimal practices over time and (ii) due the shortage of pharmacists and their immense workloads, access to pharmacists at their workplace is limited.

4.4.1 Sampling and Recruitment strategies

Non-random sampling methods are applied in this qualitative, iterative study which sought data that is transferrable as opposed to data that is generalizable. Three non-random methods were used: (i) Purposive sampling for Deaf community, Purposive Expert sampling for key informants and (ii) Convenience sampling for pharmacy students and pharmacists.

4.4.1.1 Purposive sampling for Deaf participants

Purposive sampling (alternatively called selective or subjective sampling) draws on the judgement of the investigator to select study participants. The sample being investigated is typically small and the aim is not to randomly choose participants from a population to create a sample with the intent of making statistical conclusions from that sample to the larger population (Purposive sampling, Laerd Dissertation, n.d.). The goal is instead to focus on particular characteristics of a target group which will best enable one to answer research questions (Merriam, 2009). For researchers pursuing qualitative research inquiry this is not considered to be a weakness. Literature reveals up to fourteen different purposive sampling strategies, each differing with the nature of the researcher's intent. I applied different types of purposive sampling techniques to the successive study phases. These are outlined below. For some study groups I found that 2 different strategies were applicable.

In Homogeneous sampling, participants are selected on the pre-requisite that they have similar characteristics which are of certain interest to the researcher. A homogeneous sample is often chosen when the research question that is being addressed is specific to the characteristics of a particular sample. The homogenous characteristics in our Deaf sample are the following:

- (i) All participants are Deaf and
- (ii) All participants became Deaf pre-lingually and
- (iii) They were affiliated to DCCT (Cape Town) and DeafSA (Paarl) where research activities took place

In phase 1, a study objective was to evaluate the experiences and challenges of the Deaf community regarding the medicine dispensing process and using medicines. In this regard, their characteristic of probable impaired literacy due to pre-lingual Deafness onset was of interest since it would affect the level of comprehension during the medicine dispensing process. Affiliation with DeafSA in Cape Town was of interest because later in the study, I aimed to compare an urban-based

group with a rural-based group on the basis of their comfort with the mobile phone technology.

In **Typical case sampling**, the researcher is interested in the typicality of participants (i.e. their normal behaviour). The interest in typicality is not to infer generalization but rather investigate such typicality in terms of its comparison with other similar samples (Purposive sampling/Leard Dissertation, 2012). In this study I tested SignSupport with one group of urban-based participants and tested it a second-time with a rural-based group. Typical case sampling can be used exclusively, or as I have done, used with another type of purposive sampling technique which can help in exploratory inquiry.

Maximum variation sampling is a sampling practice used to enable an investigation of a wide range of viewpoints relating to the study subject. Participants may exhibit a wide range of characteristics, behaviours, experiences etc. The idea of maximum variation sampling is to gain deeper comprehension of an occurrence by observing at it from different angles. This can help in the thematic identification of findings which are evident across samples (Purposive sampling/Leard Dissertation, 2012). In the final segment of the research, I digress from the Deaf community with whom I conducted the initial research phases, to a community in a rural town with a different mother-tongue and schooling system, with a view to investigating whether they would experience and use SignSupport differently to those in an urban-based area that is predominantly English speaking.

Purposive sampling strategies are useful in instances where qualitative study comprises multiple phases as it allows for a wide range of non-probability sampling techniques to be used in successive phases. Such sampling techniques that draw on researcher judgment and subjectivity can be prone to researcher bias. (Purposive sampling/Leard Dissertation, 2012). This bias is however only a significant drawback where judgements have not been based on well-defined criteria. Such criteria may appear as a theoretical framework, expert elicitation, or some other accepted criteria. It can be difficult to defend the representativeness of a sample based on purposive methods, but that is not of major concern in this study as I am not aiming for generalization of findings.

Participants were recruited based on their affiliation with DCCT and DeafSA, and were accessed via telephone calls to their community representatives, who assisted in selecting samples based on the afore-mentioned criteria. Community representatives also introduced us to sign-language interpreters who were appropriate for the purposes of the study. Most study activities occurred within the Deaf community centres on days that were convenient for the Deaf community, for example if they were present at the centre for some other reason such as a class. Deaf participants were only studied outside of their community centres on the trial experiment and hospital experiment days. On these days, researchers fetched and escorted participants to study sites. All data collection was via a DeafSA-affiliated and certified interpreter.

4.4.1.2 Sampling strategies for pharmacy students and pharmacists

Expert sampling is a purposive technique used to glean understanding from persons that have particular expertise, the 'expertise' in this case being (i) deafness or Deafness, (ii) familiarity with dispensing services to the Deaf community. Expert sampling was used in the initial phase of this study when I sourced key informants who were able to give insight on both being Deaf and being a pharmacist (ideally, somebody who had both characteristics). DeafSA staff members who provide healthcare services to Deaf people or accompany them to health facilities were also considered in key informant selection.

As is the case in this study, such expertise may be required during the exploratory phase of qualitative research; the particular expertise being explored may shape the foundations of the study or influence the study design. Expert sampling is particularly useful where there is a lack of empirical evidence and high levels of uncertainty in a research area.

Convenience sampling is another non-probability sampling method that draws on the judgement of the researcher to select study participants. As the name implies, a convenience sample is one where the participants who are chosen for inclusion in the sample are convenient and simple to access. Logically, findings do not imply

generalization. Convenience sampling is however a suitable method to use when a researcher encounters obstacles in accessing participants and requires easier access to qualitative data. Convenience sampling was applied to this study with pharmacists, who were difficult to access due to their work commitments and time limitations, and pharmacy students for similar reasons. Advantages of convenience sampling methods are the ease of sample collection and the possibility of extracting useful findings that may not have been possible using probability methods which require more strict access to populations. The disadvantage of these techniques is the possibility of bias and the risk of under-representation or over-representation of specific groups within the sample. The sample is also unlikely to be representative of the larger population being studied.

Key informants were accessed through telephonic appointments and met at their places of employment for research activities. Pharmacy students were accessed at UWC School of Pharmacy and research activities took place during their recess period over lunch hour. Access to pharmacists at a public hospital pharmacy was granted via their director and deputy director. Research activities took place at in the pharmacy boardroom and dispensary at their place of employment.

4.5 DATA COLLECTION METHODS

This section delivers the theoretical underpinnings of the specific data collection techniques employed in this study to obtain the data sets required for SignSupport development. Only the theoretical aspects are described, while a detailed application thereof in the empirical processes of this study is delivered in the ensuing thesis chapters (five, six and seven).

4.5.1 Theory of data collection

The process of data collection is undertaken to secure sound, reliable information that will assist in answering research questions and achieving research objectives. Creswell (2007) distinguishes the functions of data collection as site identification, securing site access and establishing relationships, recruiting a sample, recording

information, collating and storing data and overcoming field issues. Data is the chief outcome of data collection activities, and is described by Merriam (2009): *“Data is nothing more than ordinary bits of information found in the environment. They can be concrete and measurable, as in class attendance, or invisible and difficult to measure, as in feelings.”*

There are several methods of data collection. Creswell (2007) classifies these methods into 4 groups: (i) observations, (ii) interviews, (iii) audio-visual materials and (iv) documents. All four categories were used in this study in the following order ranking highest use to lowest use:

- Observations and audio-visual materials
- Interviews
- Documents

Deaf people rely largely on gestures, inflections and the presence of a sign-language interpreter to communicate; as such written or spoken data sets are not realistic outcomes in conducting research with Deaf people. This being the case, one would expect mostly audio-visuals material as data sets. In the list above, observations and audio-visual materials are ranked together at the highest position of use because they were the most frequently obtained forms of data and because all observations were video-recorded. Interviews were used to a lesser extent, and applied to key-informants and focus-group attempts with the Deaf participants via a sign-language interpreter.

The focus group method was later abandoned due to non-feasibility; the sign-language interpreter was unable to manage multiple responses and questions simultaneously.

Lastly we used simply structured surveys (documents) with both participant groups (Deaf participants and pharmacists). This was not done to achieve generalizability; the sample groups remained small and generalizability was not a study objective. Instead, surveys were used as a means to allow participants to highlight issues or problems they had with SignSupport that they were not easily able to articulate (especially the Deaf participants). With Deaf participants, a SASL interpreter

signed the questions; they marked their responses as crosses or ticks with the SASL interpreter's assistance.

4.5.2 Observations and audio-visual materials

Observation is an orderly way of viewing and listening to people's actions and interactions, and the recording, analysing, and interpreting of their behaviours (Gray, 2004). Types of observation include participant observation and non-participant observation. In participant observation the researcher becomes part of group being studied, participating in the same activities as the members of the culture under study in an attempt to experience the view and perspective of a participant rather than an outsider. This produces narrative accounts as data (Mertler, 2005). In non-participant observation the researcher assumes a non-active, on-looker type role and does not get involved in the activities of the group. (Patton, 2002).

Observation is either overt or covert. In overt observation, participants are cognisant of the reality that they are being observed (Gray, 2004). A shortcoming of this method, known as the *Hawthorne effect*, is the possibility of a change in the behaviour of participants owing to awareness that they are being observed (Kumar, 2005). This may result in inaccurate data; what is observed may not mimic typical behaviour. On the contrary, in covert observation participants are not aware that they are being observed. The data produced should provide a naturalistic, real reflection of the phenomenon under study. (Gray, 2004). Covert observation may be a useful technique to assess the receptivity of an intervention.

Observations were used to extract the pharmacy dialogue patterns in a role-play enactment of a pharmacy student acting as if they were dispensing medicines to a (simulated) client in a 'role-play room' which imitates a public hospital pharmacy setting. The interactions and dialogues were observed via live video in another room which had a screen connecting to a camera in the role-play room by research team members. The reason for this was that we wanted to construct a pattern of typical, naturalistic dialogues that a pharmacist would have with a patient. We did

not feel confident that we would get this natural communication by observing as a third party in the same vicinity where the role-play was taking place. Instead we wanted to observe covertly, hence the use of video cameras.

The simulated client approach is an internationally accepted tool for gauging outcomes in pharmacy practice research (Watson *et al.*, 2006). This approach was used to simulate clients that hand prescriptions to pharmacists at public sector pharmacies. In the role-play, prescriptions were given to final year pharmacy students (representing pharmacists) in the role-play room. Pharmacy students dispensed medication from a prescription to a simulated client. Their dispensing dialogue and communication flow was observed and structured as dispensing dialogue patterns.

All data banks with the Deaf community comprise video recordings which yielded the outcome of video observation notes made with the assistance of a SASL interpreter who translated all interactions during research sessions. In addition, comprehensive field notes were taken regularly. This allowed the researchers to observe body language, gestures and other non-verbal cues. Field notes are the 'backbone of collecting and analyzing field data' (Bailey, 1996, p.80). Gray (2004) recommends that field notes be written up instantaneously after the observation. Field notes are the fundamental data from which the analysis will surface and comprises everything the fieldworker believes to be important (Lofland, & Lofland, 1984).

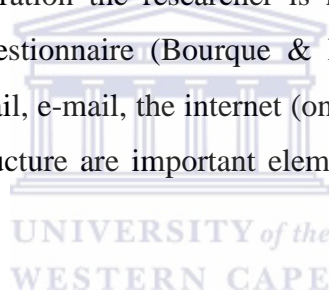
4.5.3 Interviews

Two types of interviews were employed in the research: key informant interviews and focus group interviews. Key-informant interviews were conducted as per structured interview guideline. They comprised face-to-face interactions with participants who were able to share specialized insight on medicine use by Deaf persons, and were audio-recorded. The guideline was adapted as required during the interview session.

A focus group is an exploratory approach in which an assembly of participants is selected to discuss a subject being researched (Miller & Brewer, 2003). A typical feature of focus groups is the interaction between research participants. In this interaction, the sharing of views, stories and experiences between the respondents is what produces the 'rich, insightful data' (Miller & Brewer, 2003).

4.5.4 Questionnaires

Questionnaires are among the most prevalent methods for data collection in research. Questionnaires may be filled out either with or without supervision by the researcher (Bourque & Fielder, 2002). Supervised administration involves face-to-face interviews where the participant is in a one-to-one position with the surveyor. The surveyor is able to answer any questions that the participant may need to ask. In unsupervised administration the researcher is not with the participant whilst he/she completes the questionnaire (Bourque & Fielder, 2002), which may be directed via traditional mail, e-mail, the internet (online) or by the drop-and-collect system. Wording and structure are important elements of a questionnaire as they affect the data obtained.



The questions which make up a questionnaire may be asked as either open-ended (a possible response is not provided, participants write an answer in their own words) or closed-ended (possible answers are provided in the questionnaire (Kumar, 2005). The respondent selects one answer from a set of given answers, for example Yes-No or True-False type answers (Gray, 2004). An attitudinal scale is another manner of posing questions, it useful for the researcher who wants to gauge the participant's attitude about a topic (Kumar, 2005). A Likert scale is a type of attitudinal scale which allows the participant to select a category which best describes their attitude toward a statement (Kumar, 2005). For example, participants may be required to select one of the following responses: agree, neutral or disagree, to express their attitude toward a particular statement (Miller & Brewer, 2003). Likert scales show the strength of one respondent's attitude in relation to another (Kumar, 2005). All survey instruments used in this study included Likert scales. This was done for ease of selecting a response to a question

which was posed in SASL and to avoid requiring the Deaf participants to write wordy responses.

4.6 DATA ANALYSIS

Data extraction from research in which the data was largely in sign-language and appeared as gestures, body language and other non-verbal cues was challenging. The researchers initially intended to transfer all data into transcripts for analysis, but found that direct transcripts of what was signed in SASL excluded crucial non-verbally communicated data. Instead, we depended on raw data (videos) and video observation notes detailing the videos for analysis. Where applicable in data collection with pharmacists, direct transcription yielded data sets. The two main methods of data analysis were (i) Thematic analysis and (ii) Reflexive analysis.

4.6.1 Thematic analysis

Thematic analysis is a suitable method for exploratory research that produces copious amounts of data where rigorous, methodical analysis is required. Plentiful data requires thoughtful reduction to extract "big ideas" from the data (Ayres, 2008). Thematic analysis has been defined as *"a systematic approach to the analysis of qualitative data that involves identifying themes or patterns of cultural meaning, coding and classifying data (usually textual) according to themes and interpreting the resulting thematic structures by seeking commonalities, relationships, overarching patterns, theoretical constructs or explanatory principals."* (Lapadat, 2010, p. 926). Essentially, it is the extraction of common themes emerging from data sets.

Thematic analysis includes analysis of both discernible, apparent data and underlying obscured data and allows for condensation of qualitative data through separation, classification, summation and subsequent restructuring to represent the most important concepts embedded in the data. Thematic analysis is beneficial in sketching a narrative of the data and finding patterns whilst maintaining contextual perspectives. (Ayres, 2008). Boyatzis (1998) states five purposes for using thematic analysis: it allows one to see data patterns; uncover relationships; analyse data; systematically observe a situation and measure qualitative findings. Additional

advantages of thematic analysis is that it serves as a means to focus data interpretation, reduce large volumes of data without losing the context and it allows the researcher to immerse oneself in the data. (Lapadat, 2010, p. 926).

The pattern-finding feature of thematic analysis was used in the objective of a constructing a dialogue pattern of typical pharmacist-patient counselling interactions in the role-play scenarios. It also was useful in analysing data on experiences of the Deaf community with medicine use. Thematic analyses were later applied in usability tests for the emerging versions of SignSupport. Responses from focus groups, observation of pharmacists and Deaf participants and survey responses were classified as being positive, negative or neutral responses. This helped to identify significant themes and patterns that emerged from the analysed data.

4.6.2 Reflexive analysis

Reflexive analysis is an outcome of reflexivity-orientated methodology. In qualitative inquiry, it is not possible to remain independent of the subject matter; the researcher's presence inevitably has some effect on the study subjects and subsequent data. Reflexive research methodology emphasizes the researcher's involvement as a major operative factor. In reflexivity, the researcher's awareness of the effect of his/her presence on the progression and products of the research resonates with Steedman's (1991) view that 'knowledge cannot be separated from the knower.' A clearly articulated research design is crucial to establish balance and the researcher's awareness that while the he/she may be closely involved in subject matter and co-constructing meaning, he/she must remain conscientious and uphold a level of professional detachment (Johnson and Duberley, 2000). Furthermore, the researcher must be clear about his/her perspective and epistemological and ontological views in to order to attain truly reflexive research.

Srivasta's (Srivasta & Hopwood, 2009) framework for reflexive analysis comprises three questions to ask in the data analysis process:

1. What is the data telling me?
2. What is it that I want to know?

3. What is the relationship between what the data is telling and what we want to know?

Srivatsa's reflexive analysis framework (Srivasta & Hopwood, 2009) was applied throughout the research process which required a high level of subjective interpretation. Reflexive questions were applied in data collection activities and were used to shape the final discussion and develop study recommendations.

4.7 VALIDITY AND RELIABILITY

Literature puts forward several different terms for research validity including credibility, authenticity, trustworthiness and quality (Herr & Anderson, 2005, Marti and Villasante, 2009). Reasons for introducing different terms are owing to the dissimilar nature of research paradigms. Qualitative research is aimed at acquiring an understanding; hence what makes it "valid" will differ from that of quantitative study (Nieuwenhuis, 2010). As such, positivists generally prefer the notion of validity, while "trustworthiness" is adopted by naturalistic researchers. Both terms have been contested in action research as they do not take into account participation and action. Since this study is influenced by qualitative and PAR methodologies, and generalizability or statistical significance of findings is not a research aim, I have chosen to discard the term "validity" and instead use the term "quality", favoured by a number of experts (Reason et al., 2001, 2006 and Marti and Villasante, 2009). Reliability refers to the consistency of data obtained if the same study were repeated under very similar conditions (Neuman, 2003). Several researchers have recommended criteria for ensuring quality in research. I have selected a targeted set of criteria which applies to this study.

4.7.1 Criteria applied to ensure quality

Several criteria were applied to enhance quality in the research. These include perspective, doing-what-is-right, repetition, member checks, triangulation, redundancy, critical reflexivity and transferability.

Perspective is a criterion I developed to help me ensure that I kept my personal opinion and stance separate from that of the participants, with the intention of

accurately and truthfully depicting their feelings, opinions experiences and points of view. Throughout the research, I was cognisant of keeping my perspective separate from their perspective. This was grounded in the interpretivist view of multiple realities: *“there is not a single observable reality. Rather multiple realities, or interpretations, of a single event.”* Researchers do not find knowledge, they construct it.” The purpose of applying “perspective” as a research criterion was to ensure that I consistently represented the participants’ view instead of my own. This was achieved through direct transcription of data and using raw data in the form of video recordings to extract themes and draw conclusions.

The second criterion applied by the researchers was a composite of Herr and Anderson’s (2005) “democratic” validity and Reason’s (2006) criteria of “democracy and participation” and “pursuing worthwhile purposes.” For this study, we adopted these criteria as **“doing what is right.”** This meant many different things: it meant social responsiveness; it meant confining our design outcomes to what was needed and requested by the Deaf community and pharmacists and it meant basing our work on best practices and human rights recommendations of policy frameworks and good practice advices. It also meant insisting on a high level of collaborative participation to ensure entrenchment of participant contribution in all study endeavours, producing work that is applicable to and for the context in which we were working, and not in any manner inconveniencing participants or breaching confidentiality. This criterion was applied through always achieving consent and input from participants, being transparent in all research undertakings, caring for participants’ needs during research activities (meals, intervals, transport etc.) and establishing and maintaining a relationship with participants through feedback on findings and regular contact.

Repetition and Member checks: Repetition was applied by repeating research activities to gauge whether outcomes were similar when studies were duplicated, and also through posing the same questions in different data collection activities (e.g. focus groups and questionnaires). Findings were always directed back to participants and co-researchers so that they could verify it. Feedback was easy to achieve since most activities were conducted in a work-shop style, negating the

need for participants to write or e-mail back verification and member-check responses.

Triangulation of methods means to employ different methods for the same aim with a view to achieving a comprehensive understanding the research topic (Creswell, Fetters & Ivankova, 2004). Looking at an object of research from multiple perspectives provides researchers and theorists with more comprehensive understanding about the object of study (Silverman, 1997). Methodological triangulation is used to exploit the strengths of qualitative and quantitative approaches (Miller & Brewer, 2003) and has the advantage of producing understanding of the topic under investigation in ways that cannot be realized by use of a single method (Bernard, 1994). Triangulation was achieved by using multiple data collection methods and multiple researchers to answer research questions.

Redundancy was a criterion agreed upon by all research members regarding the aspects of the study which was aimed at testing the usability of SignSupport. We aimed to repeat usability tests and iterations until the point of saturation or redundancy when the findings of one set of experimentation resembled the results of the previous experiment. The disadvantage of this was that we did not know how long it would take to achieve redundancy; it could be two or twenty experiments. Redundancy was also applied by comparing findings from one researcher to that of the next in the multi-disciplinary collaboration. Whilst I do not report on the findings of the other members of the multi-disciplinary team, I do refer to them in the discussion of my results and conclusions.

Critical reflexivity is the practice in which the researcher acknowledges the biases of his/own perspectives in the subject matter and critically reflects on these biases throughout the research process. I maintained this criterion in the research through application of Srivastava's three question framework when analysing all data and shaping the "big ideas" and conclusions from study findings.

Transferability: As afore-mentioned, results were not intended to produce generalizability, instead I aimed for transferability of data. Such transferability was

applied in the sense that data emerging from the initial study stages was incorporated into, or “transferred” to the design aspects of SignSupport and validated in the usability experiments. For example, the first SignSupport prototype incorporated aspects given by both pharmacists and Deaf participants. The prototype was then tested with both sets of users. If it incorporated their aspects incorrectly, or not at all, their dissatisfaction would surface in usability experimentation where participants were afforded the opportunity to verify that their suggestions were incorporated and to comment on the overall acceptability of the prototype. In addition, data from usability experiments were expressed as modifications to subsequent iterations on the prototype.

4.7.2 Criteria applied to ensure reliability

Reliability is a term used to describe the extent of reproducibility of the study findings under identical experimental conditions (Merriam, 2009). While this concept is widely accepted in positivist research, it is contested in studies with human beings as participants because human behaviour cannot be definite. Instead the terms “consistency” or dependability have been used in qualitative inquiry. Rather than reproducibility of findings, the question is “are results reflected consistent with data collected” (Lincoln and Guba, 1985 in Merriam, 2009). To this effect, we have used member checking and an audit trail. I kept an audit trail by maintaining consistently a research log of all undertakings and recording analysing and organizing data in research iterations.

4.8 ETHICAL CONSIDERATIONS

Ethics approval was applied for from UWC Senate Research Ethics Committee and was approved as per registration numbers 12/2/15 and 15/3/37. Further approval was attained from the director of DeafSA Western Cape, the manager of DCCT and the principal pharmacist at Tygerberg hospital pharmacy. Participants were informed of the voluntary nature of this investigation prior to the commencement and that they may leave the study at any point should they feel the need to do so.

The ethical principles of non-maleficence, beneficence, respect for autonomy and justice and principles promoted by the MRC (Guidelines on Ethics for Medical Research, 4th edition 2001) were applied consistently throughout research proceedings. Deaf individuals are a vulnerable group and particular care was taken to uphold ethical principles. Participant information sheets (Appendix C) and consent forms (Appendix D) were applied with all study participants, the details of which is described in the study procedure of each empirical activity of this thesis, presented in the forthcoming chapters (five, six and seven). Informed consent implies that participants know what they are involving themselves in, the risks and benefits of their involvement, and what is expected of them. The same informed consent was applied to the sign language interpreters. The researchers ensured that no harm came to the participants and their wellbeing was the dominant consideration in making decisions pertaining to the study. This was established through carefully considering and respecting participants' time, providing meals and transport, frequent checks with participants during research activities that they were comfortable, and efforts to meet any participant needs that arose during research activities. In addition, researchers were cognisant of the nuances of Deaf culture and made efforts to appreciate and respect their culture at all times. Furthermore, participants were communicated with in a language with which they felt comfortable. All Deaf interactions were via a certified SASL interpreter with whom the Deaf community had an existing relationship and understanding. Deaf participants were at no point forced to read or write, participant information was signed to them in SASL, they indicated their informed consent through raising their hands (this was video-recorded) instead of signing forms.

The researchers did not identify any foreseeable risks as the study was conducted using mock prescriptions and involved role-plays between Deaf participants and pharmacists. Usability questionnaires and videos were recorded, analysed and kept confidential as per the participant-information and informed-consent documents. Each participant was assigned a random research code only known to the primary investigators involved. All other personal information used to identify participants was assigned a separate code and kept separately from the other data. The data obtained for the investigation was entered into a research database and is

identifiable only by the research codes. Researchers of the multi-disciplinary team and research assistants reached mutual agreement on roles and responsibilities of different stakeholders:

Responsibilities of the research session leader, investigators and facilitators

- To keep the data collected confidential
- To review scientific literature to ensure that research guidelines are consistent with current research practices and do not place participants at unnecessary risk;
- To respect fellow investigators, participants and supervisors
- To maintain professionalism at all times during study research
- To adhere to the ethical obligation, i.e. honesty, loyalty
- To keep the data as true and accurate as possible

Confidentiality

Data collected and recorded was of a visual nature in the form of videos containing the observations. These were protected in the following way: videos are stored on a password protected computer system known only to the investigators involved in the research. Upon completion of this study, all information emerging from the study was locked away with access allowed only to the primary investigators.

Risk and benefit

No threat or risk was involved due to the role-play nature of the study. The main concerns involved with this research were confidentiality of the participants and the special regard for the Deaf participants. Information obtained was captured via electronic (videos) means and was password protected and the written material kept safe in a locked cabinet. All symptoms or diseases mentioned in the play are simulated and are not the real conditions which Deaf participants have. Thus SignSupport will not cause any confusion or misconceptions to a participant who is on concomitant treatment. The experiments were conducted under controlled conditions. This was beneficial since the researcher and other stakeholders were able to observe how a Deaf patient experiences interaction with pharmacists. Another benefit is that, due to the participatory nature of the study, participants are

able to give valuable input to the researcher as the researcher learns from the experience of the participant.

The use of an interpreter

Study purposes necessitated the use of certified SASL interpreters to communicate between the investigators and the Deaf participants. The interpreter had to be adequately proficient in signing in SASL to the Deaf participants and also be fluent in English to communicate to the investigators. Furthermore, we aimed to use interpreters who had an established relationship with the Deaf community we were surveying to ensure a level of comfort. Interpreters assisted in notifying Deaf participants of all the study-related information and signed as witness of the Deaf participants' consent to research proceedings.

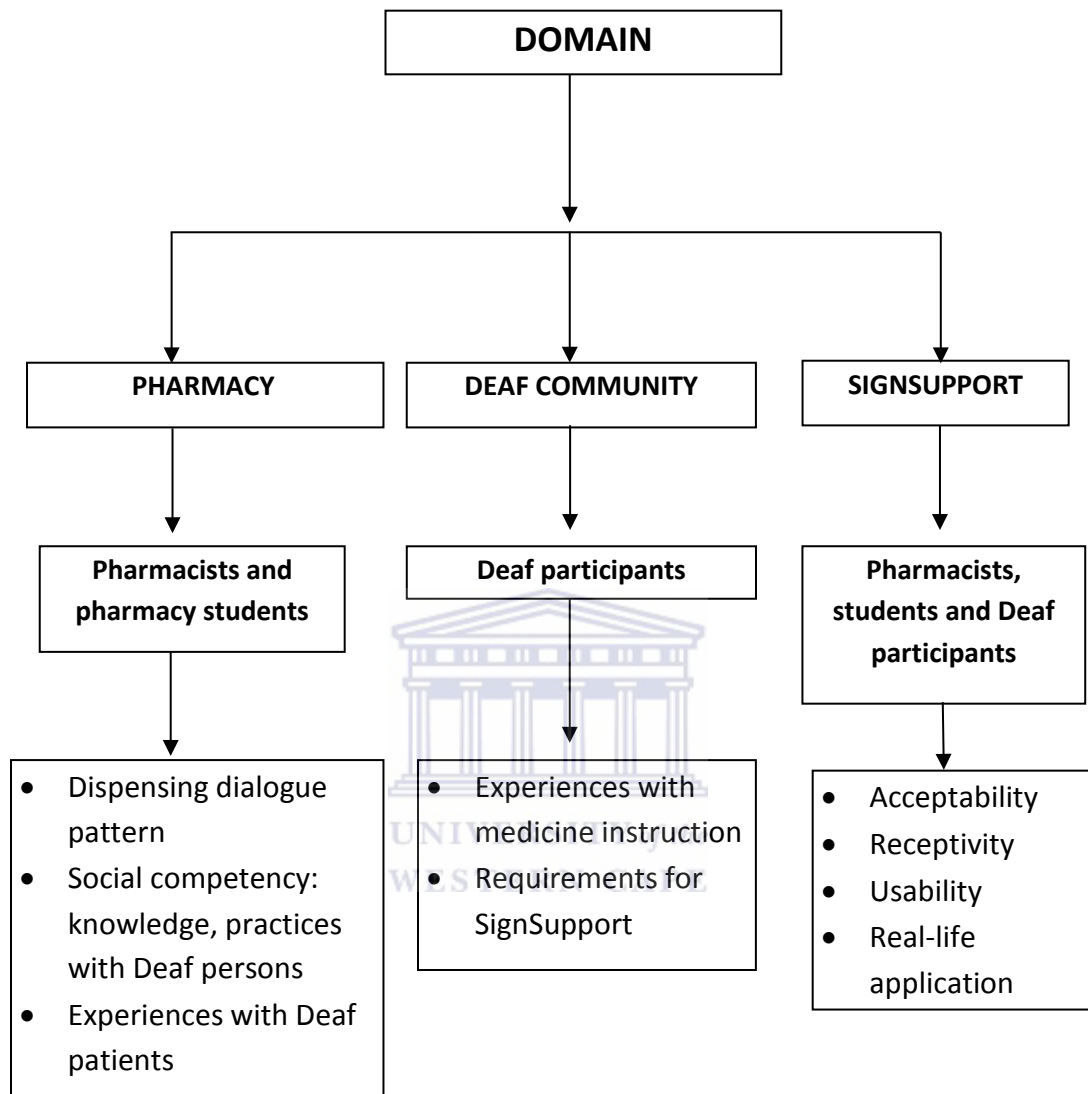
SECTION B: RESEARCH DESIGN

4.9 RESEARCH PLAN

In this section I provide a series of schematic representations to illustrate how research theories discussed in the previous section are implemented in a logical and sequential manner to establish the research design. Furthermore, I outline the experimental sites and timeline.

Three main subject matters were studied to present this thesis. These are represented as three study domains: Pharmacists, Deaf community and SignSupport. Pharmacists and the Deaf community were studied to reveal user elements that would inform the design of SignSupport. SignSupport was then studied as an intervention in terms of how it would impact on the medicine dispensing process experiences of both pharmacists and Deaf participants. This is illustrated in further detail in Figure 9 below:

Figure 9: Domains to be evaluated in this study



Data collection occurred prior to, during and after implementation of SignSupport. The data collected prior to designing SignSupport formed the baseline data of this inquiry and was done to obtain: (i) a dialogue pattern typical of a pharmacist-patient interaction during patient counselling, (ii) pharmacist’s experiences and (iii) Deaf patients’ experiences with the medicine dispensing process and medicine use. These aspects were incorporated into stage 2 in which all aspects were collated to program SignSupport, which was tested with pharmacists and Deaf persons iteratively in stage 3. Figure 10 further illustrates the study design.

Figure 10: Outline of study design and research methods used

Stage 1 : Pre-intervention/ Baseline Study		
Objectives:		
<ol style="list-style-type: none"> 1. To extract a dialogue pattern representing pharmacist-patient communication 2. To evaluate Deaf community experiences/challenges regarding the medicine use and the dispensing process 		
Research Method	Pharmacists	Deaf community
Qualitative and PAR	Participant observation	Focus groups
↓		
Stage 2: Collation of elements needed to program SignSupport		
Objectives:		
<ol style="list-style-type: none"> 3. To compile the databases of medicine information aspects 4. To verify recorded SASL videos on SignSupport 		
Research Method	Pharmacists	Deaf community
PAR, Qualitative	Practice guidelines, literature	-
PAR	-	Participant observation
↓		
Stage 3: Post-intervention Study		
Objectives:		
<ol style="list-style-type: none"> 5. To obtain user data on and acceptability and usability of SignSupport 6. To modify /iterate SignSupport based on user feedback 		
Research Method	Pharmacists	Deaf community
PAR	Participant observation	Participant observation
Qualitative	Questionnaire	Questionnaire

4.10 RESARCH SITES

The following locations represent study sites in chronological order and correspond to research phases:

1. UWC School of Pharmacy
2. Deaf Community of Cape Town (DCCT), Claremont
3. Deaf Community of Cape Town (DCCT), Heathfield
4. UWC School of Pharmacy
5. Deaf Community of Cape Town (DCCT), Heathfield
6. UWC School of Pharmacy- Pharmacy Practice laboratory
7. Tygerberg Hospital Pharmacy

4.11 RESEARCH TIMELINE

This study was registered and approved by April 2012. Research activities commenced immediately with pharmacy students, with subsequent research activities ensuing thereafter. In 2012 the exploratory phases were completed. In 2013, the pharmaceutical aspects and design features were prioritized. Corresponding video translations in SASL were recorded, after which the first fully functional version of SignSupport was realized. The year 2013 closed with the first SignSupport user experiment and subsequent first iteration. The New Year (2014) saw no research activity due to personal reasons that necessitated my withdrawal from the research field. January 2015 commenced with a proposal submission for permission to conduct studies at a public hospital, after which ensued the second user experiment and subsequent iteration. This timeline corresponds to the research phases in chronological order.

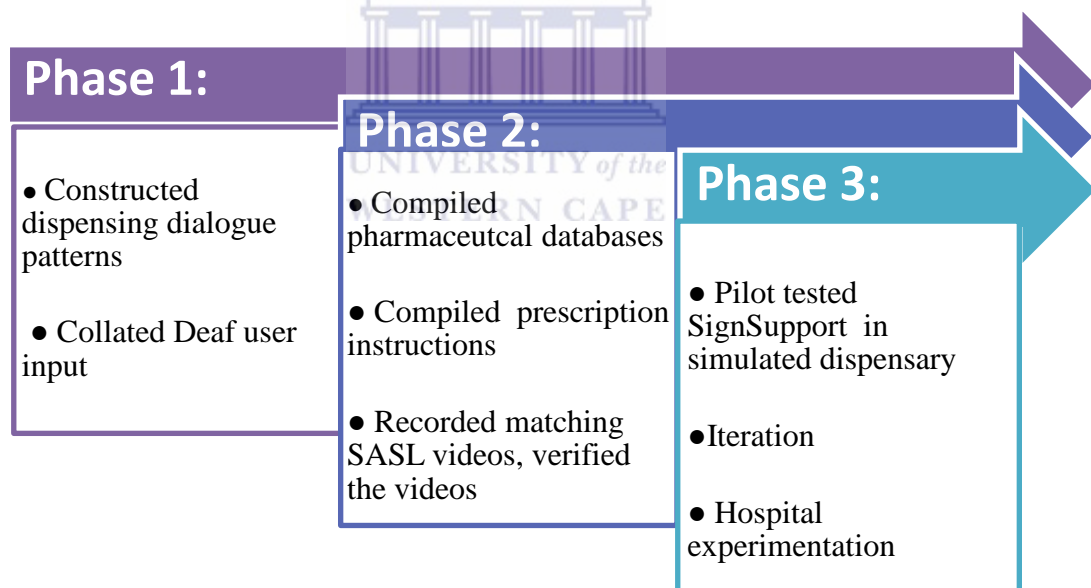
Figure 11: Research timeline



4.12 REPORTING THE FINDINGS AND STRUCTURING THE THESIS

Until this I have presented this dissertation in a manner that follows typical thesis protocol. The ensuing chapters deviate from the conventional format in that I have chosen to represent the findings from each research phase in a narrative style as isolated chapters. Within each chapter I deliver actual sample size(s), research site(s), method(s), data collection instrument(s), results, discussion and a conclusion. I have chosen this arrangement because the research trajectory was such that one set of results was fed into the subsequent research phase, making it more logical to present as a chronicle. The upcoming three chapters are presented according to the research phases illustrated in the phase progression diagram below:

Figure 12: Research phase progression



Chapter five presents and discusses findings from the pre-intervention/baseline study. A description of how the dispensing dialogues were constructed is given together with findings from Deaf community focus groups and key informant interviews.

This baseline data was used to inform research processes in **Chapter six**, which presents the intermediate phase in which SignSupport was completed. During this phase, pharmaceutical databases of medicine names, diseases and prescription instructions were collated to export into SignSupport's program. Thereafter, the process of recording videos in SASL to match the pharmaceutical elements was recorded using a SASL interpreter to sign. For example, if we loaded a disease or symptom that a pharmacist would say (e.g. headache), we had to record an interpreter "saying" headache in sign language, in order to achieve the text-to-sign capability we were aiming for. The videos were then incorporated into SignSupport and tested for accuracy. This culminated in a complete prototype (SignSupport Version 1) that was ready for user testing.

Chapter seven presents the post-intervention stage in which SignSupport is tested iteratively with Deaf users and pharmacists, first in a simulated dispensary and thereafter in a real-world hospital pharmacy.

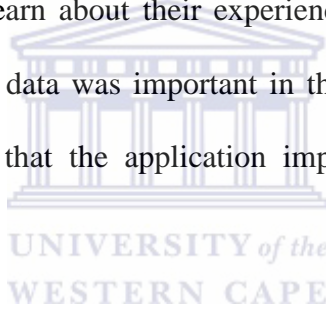
Chapter eight delivers a general discussion of the main themes emerging from this project, scholarly views of such themes and its implications on social redress for Deaf communities.

Chapter nine brings this thesis to a close, delivering a distillation of the research findings, author opinions and recommendations for future work.

CHAPTER FIVE

RESULTS AND DISCUSSION: BASELINE STUDY

This chapter presents findings from research phase one, the baseline investigation, which was conducted to yield data to inform the design of SignSupport. Two main study undertakings were conducted and are presented as Section A and Section B respectively. In Section A I deliver the findings of a qualitative investigation with the Deaf community to learn about their experiences of the medicine dispensing process at hospitals. This data was important in the development of SignSupport because it was intended that the application improve the medicine dispensing process for Deaf persons.



In Section B I present the findings of an empirical investigation with senior pharmacy students who were asked to role-play a dispensing interaction with a simulated client to their best ability. The objective was to observe their interaction in order to extract a dialogue pattern of what pharmacists say and ask during the dispensing process. This dialogue pattern was necessary for incorporation in SignSupport programming architecture, since the application aims to facilitate the communication between a pharmacist and Deaf patient. The chapter culminates in a compilation of data from the baseline phase that will be incorporated in the imminent intervention phase.

Introduction

The exploratory baseline study was conducted to meet research objectives 1 and 2 presented earlier in chapter three:

1. To qualitatively evaluate the experiences of the Deaf community regarding the medicine dispensing process and the use of such medicines.
2. To extract a dialogue pattern representing the communication that would typically occur between a pharmacist and a patient during patient counselling, and to express this pattern as a series of ordered sentences.

Separate research activities were conducted to fulfil the two research objectives. These are presented separately as Section A and Section B to represent objectives 1 and 2 respectively. Each section is described in detail under the following sub-headings:

1. Linkage to research objective
2. Actual sample and study site
3. Methodology
4. Materials
5. Study procedure
6. Results and discussion of findings.

The chapter concludes with the extraction of relevant data that will be used in the design of SignSupport.

SECTION A: DEAF COMMUNITY EXPERIENCES WITH THE MEDICINE DISPENSING PROCESS

5.1.1 Qualitative evaluations with the Deaf community

An insight into Deaf community's experiences with medicine instruction was an important consideration for SignSupport because the researchers intended to design the prototype with input from the users. To gain this insight I led two empirical activities:

- i. Focus group sessions with Deaf participants
- ii. Key informant interviews with individuals who had expertise in the area of medicine use in the Deaf community.

The focus groups and key informant interviews were linked to the same objective and since both are qualitative techniques that were undertaken to meet the same objectives, they produced similar data. As such, it was logical to analyse the data sets emerging from these research activities together. For this reason, and to avoid repetition, I have chosen to present the focus groups and key informant interviews together under each of the afore-mentioned subheadings.

5.1.2 Research objective linkage

Focus groups and key informant interviews were conducted in order to achieve the first research objective:

- To qualitatively evaluate the experiences and challenges of the Deaf community regarding the medicine dispensing process and using medicines.

Specific research questions connected to this objective are:

1. What are the experiences of Deaf people when they collect their prescription medicines at a public sector pharmacy?
2. How do staff members at the facility and at the pharmacy communicate with Deaf people?
3. How do Deaf people perceive their interactions with pharmacy staff and other healthcare workers?
4. Are there any challenges they experience? If so, what are these challenges and what can we do to overcome these challenges?
5. What are their experiences of the patient counselling process and of using medicines?

5.1.3 Study site and participants

Focus groups

Focus groups were directed to the Deaf community and staff at DCCT, Heathfield. All participants were informed about the study and all its criteria and that participation was voluntary. They had the opportunity to withdraw from the focus group at any time. Deaf participants were informed via a SASL interpreter who also communicated to them the informed consent procedures. Homogenous purposive sampling and typical case purposive sampling was used to target participant samples for focus groups. Focus group participants (n=16) were split over two focus group sessions, both of which were held at the DCCT on separate days. Inclusion criteria were that the participants should be Deaf, have a connection with the DCCT and must have used/are using medication. The exclusion criterion was hearing participants and those with no connection to the DCCT.

All focus group participants were long-standing residents of previously disadvantaged areas in the Cape Town metro-pole, with most residing in the Cape Flats, a lower socio-economic housing plain in Cape Town. The majority of participants were in their senior years, older than 60 year of age, with 81% of the total sample having a pre-lingual onset of Deafness (i.e. born deaf or before age of 3), implying that they are Deaf and thus may experience problems in literacy. This is reflected in their level of schooling, with most participants not having entered secondary schooling (grade 7-12). Figure.14 reflects the number of participants using the public and private sectors for healthcare. The graph shows that only 1 participant used private healthcare services, with the rest using public healthcare services.

Demographic profile of focus group participants

GENDER		AGE GROUP			ONSET OF DEAFNESS (age)			
Male	Female	30-59	60-69	70-79	Born Deaf	Pre-lingua 1 (<3)	4-6	>18
4	12	5	6	5	10	3	2	1

Figure 13: Highest completed educational level of participants

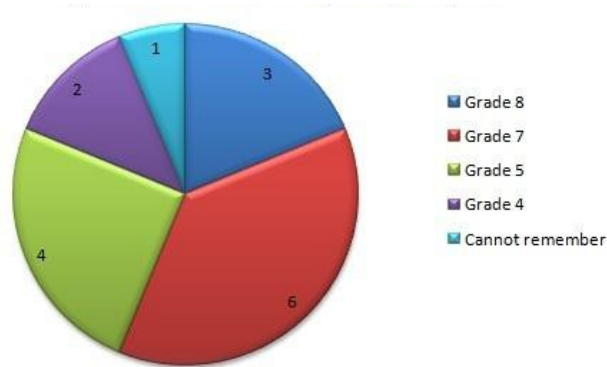


Figure 14: Use of public versus private healthcare services



Key informant interviews

Four interviews were conducted, three at the DCCT and the fourth at Groote Schuur hospital. All key informant interview sessions lasted 1 hour. Expert purposive sampling was used to select participants (n=4) for key informant interviews. Inclusion criteria were that key informants should have specialized knowledge and insight of medicine use within the Deaf community, with the exclusion criteria being those with no such knowledge or insight.

All key informants were female. One was a pharmacist who is deaf and had done prior research with the deaf community. The other three participants were deaf staff members who are community workers, working with the Deaf community at DCCT and have particular experience in healthcare service delivery to Deaf people.

Demographic profile of key informant interview participants

GENDER		AGE GROUP	
Male	Female	20-35	36-50
0	4	2	2

5.1.4 Methodology

Qualitative methods (focus group interviews and key informant interviews) were used to explore the experiences of Deaf people at public sector pharmacies when they collect their medicines. For both methods, participants were informed about the study by way of participant information sheets and informed consent documents (Appendices C and D). They were asked to sign consent forms (Appendix D) to indicate their voluntary participation. In cases where they were unable to sign, they indicated their informed consent with a cross (X). Focus group interviews and key informant interviews were conducted according to structured protocols which comprised a list of questions which guided the discussion (Appendices F and G).

Since the researchers did not have any experience in conducting research with Deaf people, and particular via a sign-language interpreter, the only considerations in the development of the focus group and key-informant protocols were (i) the research questions and (ii) lessons about Deaf culture and social behaviour that was gleaned from the literature review. Data collection activities were recorded and transcribed verbatim, then double checked for accuracy with co-researchers.

5.1.5 Materials and resources

The materials and resources used in executing the afore-mentioned study tasks are tabulated below:

FOCUS GROUPS (n=2)	KEY INFORMANT INTERVIEWS (n=4)
Focus group protocol	Key informant interview protocol
Video recorders	Audio and video recorders
SASL interpreter	SASL interpreter (where appropriate)
Notepads and pens	Notepads and pens

5.1.6 Study procedure

Focus groups

In preparation for the focus groups, the researchers requested permission from DCCT to conduct the study at their premises and with the staff members. On the first visit to DCCT we were introduced to the staff and familiarised ourselves with the facility with a view to present the proposed study and to recruit participants. On the second visit a preliminary information session was held to present the proposed study and obtain study approval. The participant information was explained to the study participants in order to elaborate the purpose of this study. Participants were asked to indicate informed consent as proof of voluntary participation in this study. This was done by raising their hands to indicate their consent (this was video-recorded), or writing a cross (X) on the document, whichever method they preferred. In addition we recruited a certified interpreter proficient in SASL and known to the DCCT community. Both focus groups were conducted at the DCCT: the first with 5 Deaf participants lasted for 1 hour and the second with 11 senior (age) Deaf participants for an hour and forty minutes. The focus groups were video-recorded, transcribed verbatim and double-checked for accuracy by member-checks with the SASL interpreter and co-researchers. All communication was via a certified SASL interpreter. Focus groups were conducted according to a focus group protocol (Appendix F). Responses were coded together with key informant responses for thematic and reflexive analysis.

Key Informant interviews

Key informants were selected based on their specialized expertise in the study area. Key informant interview participants and timeslots were secured through telephonic appointments. Three key informants were staff members at DCCT who had direct experiences in healthcare service to the Deaf community. On the first visit we were introduced to the staff and familiarized ourselves with the facility with a view to recruiting key informants. At the following visit, a preliminary information session was held to present the proposed study and obtain study approval. The participant information sheet was explained to the study participants in order to elaborate the purpose of this study. Participants signed an informed consent document as proof of voluntary participation in this study. The interviews followed a structured key informant guide and lasted one hour per interview and took place in a private, enclosed environment. The interviews were conducted via a sign-language interpreter, who signed a modified version of the informed consent. The interviews were recorded, transcribed verbatim and double-checked for accuracy. The fourth key informant was a deaf pharmacist who was working at a public hospital in Cape Town. She had prior experience in conducting research with deaf people. A telephonic appointment was made with her and the interview was conducted at her workplace during her break. The interview lasted fifty-five minutes. Responses were combined with focus group responses, then coded and analyzed thematically and according to Srivatsa's three question framework.

5.1.7 Overall impression of data collection activities

Focus groups

At first, the participants were noticeably uncomfortable and apprehensive about the focus group procedure. The researchers asked whether they would prefer to abort the intended procedure but participants indicated, albeit reluctantly, that they would go ahead. In this first interaction with the Deaf community, we were privy to their social connectedness with and loyalty to other Deaf people and realized that this may obstruct research procedures. In addition, the circumstance of having to conduct the focus group via a SASL interpreter appeared as a further impediment

to the process. The researchers approached the focus group questions cautiously and at a slow pace, hoping to establish rapport. At first, participants were reluctant to share their opinions and views but as the discussion progressed they became more relaxed and were more open to sharing their experiences. Although all participants were involved in the discussion some were more willing to speak their mind while others remained reserved throughout the session. Some questions were not answered well and at other times, participants refused to answer treatment-related questions as they felt that it was personal information. Nevertheless, the focus group discussion served as a platform for Deaf participants to express themselves as they responded to the pre-arranged topics in the focus group protocol, and the researchers were able to glean an understanding of the experiences of Deaf people at public sector pharmacies.

Key Informant interviews

Key informants were more open to sharing their views as they were more informed and interact with hearing individuals on a regular basis. They were forthcoming in sharing their experiences and openly offered advice and recommendations for working with Deaf communities. They also provided insights into the challenges faced by the deaf patients with medicine usage and their knowledge and behaviours.

5.1.8 Data analysis

Early on in the data analysis process, it became apparent that it was more logical to analyze focus group data and key-informant interview data together since common themes were emerging across the two data sets. As a result thematic analysis and Srivasta's reflexive framework was applied to both data sets collectively to achieve a composite analysis. Prior to analysis, each interview was transcribed (with the assistance of the SASL interpreter where applicable) and additional points of interest (burning issues) was noted. After transcripts were generated, they were read with the intention of assigning codes to common responses. Codes appeared in

the form of a short descriptive phase summarizing the gist of what the code represented. When a code became apparent during the focus group or key-informant interviews, it was mentioned to the participant(s) as a theme during the interview with a view to apply member-checks, reflexivity and elicit further responses. Data analysis occurred after each focus group and key informant interview in two stages:

- (i) Thematic analysis
- (ii) Application of Srivasta's reflexive question framework.

5.1.8.1 Steps of analysis

Data analysis occurred in a step-wise format which comprised a sequence of analysis tasks for each set of data. Figure 15 below illustrates the stepwise data analysis process. Individual sets of data (e.g. a focus group record) converge with other data sets in the 'categorization-of-coding' step. During this step, codes are refined through either grouping sub-codes into a bigger code or minimizing a code through its dissolution into a related/similar code.

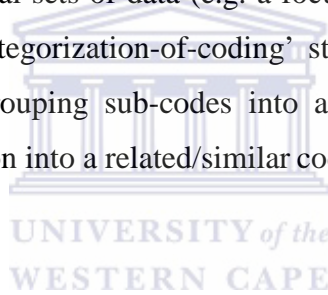
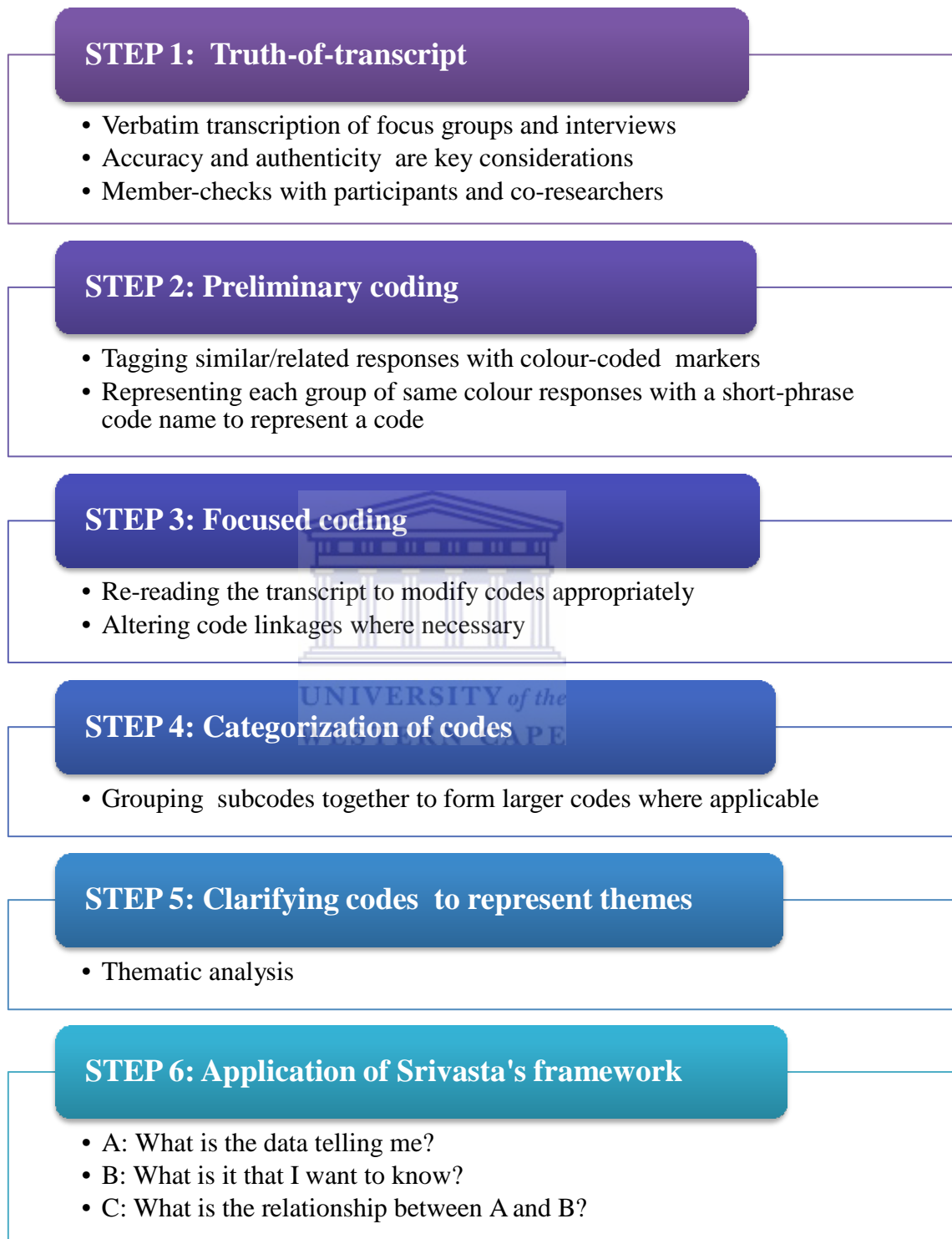


Figure 15: Steps in the data analysis process for focus groups and key informant interviews



5.1.8.2 An example of coding to illustrate coding process

In the text-box below I illustrate the coding process with an example of how I coded a participant's quotation from the raw data (transcript) into a preliminary code, focused code and theme (adapted from Theunissen, 2014). To illustrate reflexivity, I also provide a link to the relevant research question.

Transcript quotation:	<i>“You know I get cross after a while and then I’m rude and I grab my bag and then I leave. Then I go home and cry. And I’m asked by my family why I’m crying and then I explain, because, you know, I’m stressed, I cannot communicate at the day hospital, I’m sick, I don’t know what to buy at the pharmacy for myself even if I have to self-medicate... that’s a big stress in my life.”</i>
Preliminary code applied:	Failure of the healthcare system to provide services to Deaf people
Focused code applied:	Dissatisfaction with healthcare service delivery
Theme applied:	Pharmaceutical services experienced by Deaf patients
Sub-theme applied:	Dissatisfaction with pharmacy services
Research question link:	What are the experiences of Deaf people when they collect their prescription medicines at a public sector pharmacy?

5.1.9 Results and Discussion

5.1.9.1 Thematic analysis of focus groups and key informant interviews

Themes representing similar responses were extracted across two focus groups with Deaf participants groups (n=5) and (n=11) and four key informant interviews (n=4). In total, six themes were elucidated according to the afore-mentioned coding procedure. These themes are represented below:

THEMES	SUB-THEMES
Communication challenges during healthcare service delivery	<ul style="list-style-type: none"> • Lack of effective communication • Attitudinal barriers of healthcare personnel • Infrastructural challenges • Comparisons with hearing patrons
Pharmaceutical services experienced by Deaf patients	<ul style="list-style-type: none"> • Dissatisfaction with pharmacy services • Suggestions for improvement
Strained relationship between Deaf patients and pharmacists	<ul style="list-style-type: none"> • Inadequate pharmaceutical care • Lack of Deaf awareness • Request for increased levels of social competency by pharmacists
Communication methods employed by pharmacists with Deaf patients	<ul style="list-style-type: none"> • Common methods employed
Limitations in knowledge and purpose of medicines	<ul style="list-style-type: none"> • Misconceptions regarding medicine use • Insufficient information regarding medicine use • Challenges in using medicines
Need for autonomy in healthcare	<ul style="list-style-type: none"> • The need to be independent or self-reliant

A total of six broad themes with sub-themes (14) have been represented in Table 1. Reflexive questions allowed the sub-themes to be categorized in relation to research questions. Below I present each elicited theme and expand on the theme and subthemes (presented within the main theme in bold text) through substantiation with raw data quotations (*italics*) and a juxtaposition of these study findings with related findings in published literature. Quotations are from key informant interview participants (K1–K4) and focus group participants (F1-F16).

5.1.9.1.1 THEME 1: Communication challenges during healthcare service delivery

A plethora of healthcare policy exists which advocate for quality in healthcare service delivery and equal rights to access and care for all citizens. However, participant responses indicate that this is not upheld for Deaf persons in local healthcare facilities. This finding is supported extensively in the literature. Haricharan et al. (2012) and Kritzinger's (2011) investigations in the Western Cape province of South Africa have shown multifarious complexities in accessing the right to healthcare, a finding echoed in studies worldwide (Steinberg et al 2006; Moore & Swabey, 2007; Abraham & Fiola, 2006; Reeves et al., 2002). In the USA, Deaf patients have sought legal action by filing a significant number of complaints of violation of rights and non-conformance to disability policy and legislation (Moore & Swabey, 2007). One of the main problems identified was **the lack of effective communication with Deaf patrons**, who often feel excluded and despair that will not be seen to, which results in them having to return again the next day. This inconvenience is represented by the quotations below.

FG 12: "It's a very difficult situation...showing people I can't hear, I can't speak and then they just smile at you and then they'll ask for your name and I'll write down my name on a piece of paper and then they just say "Tomorrow, tomorrow." So even though I'm very sick, I go back home and come back the next day...and the same thing happens."

FG 4: “You know I get cross after a while and then I’m rude and I grab my bag and then I leave. Then I go home and cry. And I’m asked by my family why I’m crying and then I explain, because, you know, I’m stressed, I cannot communicate at the day hospital, I’m sick, I don’t know what to buy at the pharmacy for myself even if I have to self-medicate... that’s a big stress in my life.”

FG 7: “nobody is interested (in me)...and I can’t go the next day again and the next day again.”

KI 3: “The health department must remember that there are people who are Deaf. There is a shortage of interpreters in Cape Town. It would be preferable if there are pharmacists who can sign.”

FG 4: “When I go to the clinic, I’ll be meeting the doctor...there are communication problems. I don’t understand the doctor. It’s very hard to explain.”

The finding ‘**lack of effective communication**’ with Deaf patrons in healthcare facilities is well supported in local and international research. In a case-study based investigation of a Deaf patient in Cape town, Haricharan et al. (2012) illustrate how the healthcare rights of a deaf person is compromised through a lack of “informational access”, the cause of which is the inability of a Deaf person to access health-related information in sign-language. As a result, their right to healthcare is violated. Bat-Chava et al., (2005) assert that communication and language are the main barriers experienced by deaf people in accessing healthcare information. This is corroborated by Kritzinger (2011) who found that communication barriers are the most significant barrier to healthcare services and information. Comparable findings are reported by Iezonni et al., (2004), Law et al., (2005) and Steinberg et al., (2006). The implications of a lack of effective communication in a healthcare setting are substantial. Haricharan et al., (2012) argue that deaf people suffer tremendous detrimental consequences due to a lack of effective communication. These consequences include “misdiagnosis, incorrect/inappropriate treatment or a lack of treatment, problems with treatment adherence, missed appointments,” and ultimately, a violation of their right to

healthcare. Draioni et al., (2006) identify a lack of effective communication between disabled people and health care providers as a structural barrier faced in the healthcare system. From a pharmacy perspective, such a lack of communication may cause patients to take their medicines incorrectly or not at all. Providing medicines is the last link in the chain of healthcare service delivery and appropriate treatment with medicines is often the outcome of a series of efforts expended in diagnosis and medical consultations. Medicines not taken properly due to a lack of understanding negates the effort, time and cost incurred in medical consultations and diagnostic procedures and puts the patient at risk of not receiving treatment essential to solving their health-related problems. For marginalized and disabled people who often require increased levels of medical attention, this is unacceptable. Pharmacy professionals must learn to bridge communication gaps with patients to ensure that people know how to take their medicines and receive the appropriate care from health care facilities.

Attitudinal barriers of healthcare personnel emerged as a second subtheme. Two main issues arose: the taunting of Deaf patrons by healthcare personnel and their lack of Deaf awareness resulting in indifference to their special needs. These are illustrated in the quotations below:

FG 8: “They (staff members) will be like “aah, I can’t sign,” and do a negative gesture to kind of make a joke about it which really makes me cry...because like really nobody is interested in interpreting for me. Plus you’ll find the hospital staff are kind of making fun of the fact that I cannot speak and cannot hear...”

KI 2: “Greet the person, be respectful, do not show that you do not want to help the Deaf patient or that you are put off by helping them. Work on the facial expressions.”

FG 4: “I don’t like that the staff call me ‘deaf and dumb’. I don’t like that word. I am Deaf, I am not stupid, I am just Deaf.”

KI 1: “If the pharmacist uses spoken language, Deaf people are treated as being stupid. They are shouted at or spoken down to.”

Poor attitudes of healthcare personnel and a lack of Deaf awareness are also seen in the literature. Kritzinger reported that healthcare workers “misuse” deaf people and are afraid of them. Furthermore, healthcare workers find it simpler to ignore deaf people and do not provide all their treatment and diagnosis-related information or pay attention to their concerns. This is corroborated by Steinberg et al., (2006), whose study reveals that Deaf patients feel that healthcare workers have an aversion to working with deaf people. Health care providers may show “insensitivity or a lack of respect” to disabled people, and people with disabilities believe that healthcare workers treat them as if they are unworthy of receiving optimal, high quality care (Draioni et al., 2006). The following quotations from a deaf patient in Haricharan et al’s case-study further corroborate these findings:

“I did not receive any counselling...I did not have a chance to ask questions when I tested (for HIV)”

“They (clinic staff) scolded me...I explained the situation. They scolded me.”

Some hearing health care professionals display negative attitudes to Deaf persons, perceiving them to be obstinate and intellectually challenged (Meador & Zazove 2005, Scheier, 2009). While the perception of negative attitudes of healthcare professionals toward deaf people is a common finding in the literature, it is important to note that this perception is based on the Deaf patient’s reality. Deaf people cannot hear what is happening around them, they are only able to see. As a result, they may perceive situations to be negative toward them while this may not actually be the case. For example, if a pharmacist is frowning or has a discouraging expression, it may be due to a number of reasons; perhaps an error on prescription, unclear handwriting, by the prescriber, missing information etc. The pharmacist cannot communicate this to the Deaf person, who erroneously assumes that the pharmacist is frowning at them or because of them. Deafness paranoia was described in the literature review as a deluded view of persecution by a Deaf person; that people are gossiping about them and have an intention to “get” them (Bleckly, n.d.) This is in addition to their existing social exclusion and lack of self-worth. Deafness paranoia and a perception of a bad attitude on the part on healthcare professionals may result in a further psychological barrier to treatment

and care. Deaf people are unlikely to accept care from a person whom they believe acts negatively toward them. Healthcare professionals must be made aware of this situation and be taught the skills to be self-aware and cognizant of their behaviour toward Deaf people to minimize the possibility of bad perceptions.

Abraham & Fiola (2006) have shown in a Canada-based study that healthcare professionals expect patients to have fluency in the local language or have an interpreter present for the medical consultation. Such expectations may not be feasible in under-resourced countries such as South Africa. Deaf awareness describes the recognition that a person is Deaf and understanding the communication impediments experienced by Deaf people. Huntington (1995) and Lomas (1998) report that the Deaf community often complain about a lack of Deaf awareness by healthcare professionals. As a result they shout, fail to use plain English and often use medical jargon, do not mouth words clearly, speak very slowly and do not directly face the Deaf person during an interaction. These behaviours all create further communication barriers for a Deaf individual. Not only does this pose a problem for over-burdened health professionals such as pharmacists, it also alienates the Deaf community from seeking health services.

KI 1: “if a deaf person is not recognized (acknowledged) then they won’t take you seriously because you were neglecting them in the first place.”

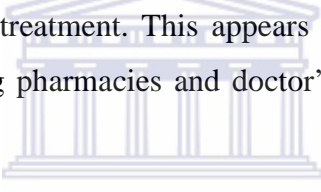
FG 7: “...I’m getting help (only) because I’m the last one there (at the day hospital). Didn’t they realize that this person is Deaf...we’ve missed this person down the queue. Sometimes they say come back tomorrow because we closed already. Major thing, major thing.”

KI 1: “I was in the hospital, the nurse used to come at night...and she would ask me to give her my hand but I could not hear her...then she got angry because she did not know I was deaf.”

The lack of Deaf awareness points to an absence of training on Deaf culture in healthcare and pharmacy curricula. It is unreasonable to expect healthcare professionals to be sensitive to specific nuances of a small marginalized society

when they have no knowledge or understanding of that society. Schools of medicine and pharmacy should incorporate training of Deaf culture in their curricula to prevent a lack of Deaf awareness.

Infrastructural challenges were described by participants. The most common barrier was not being able to hear when their name was called for their doctor's consultation or collect their medicines. Public healthcare services rely on patients being able to hear their name or card number being called while they sit in the waiting room so that they know when it is their turn to be seen to. In this type of setting where patients and healthcare providers rely strongly on hearing and their voices, it is very difficult for the Deaf patient to function optimally. Most Deaf patients find waiting rooms to be particularly stressful and frustrating. They are anxious while they wait for their number/name to be called as they are fearful that they will not hear their name, which leads to missing their appointments and an opportunity for receiving treatment. This appears to be a problem with waiting areas in general, including pharmacies and doctor's rooms. The following quotes illustrate this:



FG 8: "It is a major struggle to know when it's your turn, they will call you because you're there, but you're not going because you don't know that you have to go and then they think you're not there."

FG 7: "...I'm getting help (only) because I'm the last one there (at the day hospital). Didn't they realise that this person is Deaf...we've missed this person down the queue..."

FG 2 "I always show someone (in the waiting room) my patient card and ask them if they heard my name being called."

FG 16: "Once I sit with patients I ask them to tell me when they hear my name."

FG 7: "If somebody is a new mother and you've got to take your baby to the day hospital to be weighed etc. and there are problems, one does not know what is happening with your own child because you cannot communicate. You will not know, people (staff) will just

write things down and move on to the next person. I have had that problem myself and many others in the community have the same problem. When you have to take your new-born baby, that first couple of years to the clinic...a lot of communication is missed there, a lot of information is missed.

The problem of missed appointments due to not being able to hear their name being called is a common finding in the literature. In a role-reversal exercise where pharmacy students are asked to assume the role of a patient at a hospital where all the workers are deaf and can communicate only in sign language (including calling patients for their appointments), hearing “patients” missed their appointments because they did not realize when they were being called in sign-language. Further findings by Reeves et al., (2002), Iezzoni et al., (2004), Ubido et al., (2002) and Kritizinger et al., (2014) all point to the afore-mentioned problem of missing appointments or treatment opportunities for the lack of hearing their name being called. Valios and Vale (2004) provide a quotation similar to those presented in the finding of this thesis to illustrate the waiting room situation of a deaf patient:

“You’re sitting in your GP’s surgery and your name is called over the tannoy system. Unaware, you continue flicking through a magazine, after waiting for some time; you approach the receptionist to ask whether the doctor is running late, only to be told that you’ve missed your appointment as your name was called 15 minutes earlier. The receptionist had forgotten that you were deaf...(pg 30)

Not receiving treatment simply because of the inability to hear one’s name being called out is attributed to poor institutional planning, alienating the Deaf community from seeking care in the public sector. Healthcare institutions must establish technological solutions for Deaf people. Simple attention in recognizing that the person is Deaf and may not hear their name when being called for treatment is not unreasonable to expect from healthcare providers, however it does not occur.

Deaf people often compare healthcare services provided to themselves with those provided to the hearing community. **Such comparison with hearing people is**

largely negative and negates the promotion of equality and non-discrimination of persons who have disabilities. This is corroborated in Steinberg et al's 2006 USA based study which reveals that the perceptions of Deaf patients are that they are treated unfairly in comparison to hearing patients. It is also a plausible reason for the significant number of complaints of violation of rights and non-conformance to legislation (Moore & Swabey, 2007). The following quotes illustrate how study participants viewed their services compared to those provided to hearing people:

FG 13: "I also have problems getting assistance, but I can speak a little, so that gets me through at the end of the day, a little bit...but I'm still not getting the full service that the other people are getting."

FG 1: "I go to the hospital early, as early as possible in the morning and I see Hearing people next to me who came later than me, going home and getting help."

FG 7: "...I'm getting help (only) because I'm the last one there (at the day hospital) Didn't they realise that this person is Deaf...we've missed this person down the queue. Sometimes they say come back tomorrow because we closed already. Major thing, major thing."

Literature pertaining to health service provision to Deaf people yields similar findings of inferior service provision to Deaf people. Ralston et al., (1996) in an investigation with 165 doctors, found that all the doctors were lacking in their knowledge of their professional obligations to deaf patients. Shapiro (1993) reports that many deaf people complain that health care workers fail to see them as people; instead they see the disability and may even have difficulties in dealing with patients' health problems unrelated to that disability. In addition, Harmer (1999) asserts that healthcare providers may experience "disincentives" in deciding to provide care to deaf people. These disincentives include the need to spend more time with deaf peoples who may in turn result in negative financial implications for institutions and the possibility of having to incur costs for sign language interpretive services adds a strain to the health system. Furthermore, healthcare professionals may experience psychological barriers when suddenly having to work with deaf peoples. They feel a level of uneasiness that may cause ineffective help

to the deaf patient (Schlesinger & Meadow, 1972, cited in Harmer, 1999). Solutions should be explored to empower healthcare professionals to feel less uneasy and more confident in providing services to Deaf people. These solutions may lie in the inclusion of Deaf awareness in healthcare curricula, or alternatively in exploring technological solutions which can facilitate communication to Deaf people and diminished the reluctance and uneasiness of healthcare workers to interact with Deaf peoples.

5.1.9.1.2 THEME 2: Pharmaceutical services experienced by Deaf patients

There is very little literature reporting on Deaf peoples' experiences at a pharmacy. Only one study (Ferguson et al., 2015) exists regarding Deaf patient's experience with pharmacists in the USA. In South Africa, no studies exist apart from the research done within the context of SignSupport development. Instead, studies have focused on the use of medicines by Deaf people. The findings of this study regarding deaf people's experiences at pharmacies echo the literature on their experiences at healthcare facilities in general, with communication barriers and a lack of deaf awareness constituting the main findings.

Deaf peoples' dissatisfaction with pharmacy services

Hearing patients have many complaints when it comes to the waiting time to receive their medicines at the pharmacy. This is a predictable finding as waiting times at public sector pharmacies in South Africa are known to be problematic. Reports of tiresomely long queues at public sector facility pharmacies are commonplace. Queues are considered to be outrageous with hundreds of people standing in line. In the Western Cape, Ntuli (2003/4) reports that patient waiting time for medicine were found to be up to 12 hours. Ferguson & Liu (2015) report that Deaf people perceive that pharmacists are always rushed and impatient, which may imply high workloads and limited time. Deaf patients often experience even longer waiting times as they are not identified as being Deaf by healthcare providers, owing to a lack of Deaf awareness. Therefore Deaf patients are often overlooked in

the waiting room. This leads to Deaf patient dissatisfaction with public healthcare. The following quote illustrates this:

FG7: “We are living in a hearing world; pharmacists only seem to worry about the hearing patients, so when it comes to the deaf there is a struggle.”

FG 1: “I go to the hospital early, as early as possible in the morning and I see hearing people next to me who came later than me, going home and getting help.”

FG 7: “...I’m getting help (only) because I’m the last one there (at the day hospital). Didn’t they realize that this person is Deaf...we’ve missed this person down the queue. Sometimes they say come back tomorrow because we closed already. Major thing, major thing.”

Another issue identified in this study is the way the Deaf community perceives the attitude of pharmacists. Deaf people believe that pharmacists are frustrated in working with them and as a result are not patient and caring, instead in a rush to do the minimum that is required of them. The rushed and impatient behavior of pharmacists was also a finding in Ferguson & Liu (2015) study. Shapiro reports that many deaf people complain that health care workers fail to see them as people; instead they see the disability and may even have difficulties in dealing with a patient’s health problems unrelated to that disability. In addition, Harmer (1999) asserts that healthcare providers may experience “disincentives” in deciding to provide care to deaf people. These disincentives include the need to spend more time with deaf people who may in turn result in negative financial implications and the possibility of having to incur costs for sign language interpretive services. Furthermore, healthcare professionals may experience psychological barriers when suddenly having to work with deaf people, causing a level of uneasiness that may cause ineffective help to the deaf patient (Schlesinger & Meadow, 1972, cited in Harmer, 1999). The following quotations from study transcripts illustrate Deaf patient’s perceptions of pharmacists:

KI 4: “The majority of the pharmacist just focuses on giving the medicine, they do not focus on the needs of the deaf patient, the communication needs, they focus on the quantity and not the quality of information and only want to get done, they do not think the deaf patient cannot understand, that is why they need to make time for the deaf. They must ensure that when the person leaves they fully understand and know what to do. Most pharmacist talk even though they know you are deaf, hence no, there is no relationship.”

FG 15: “It seems that they are always pressured for time or they always ask you to bring a hearing person, always frustration.”

A very prominent finding of this study is that Deaf people want pharmacists to understand them and learn to use sign-language. This is their most common **suggestion for improvement in pharmacy services**. This suggestion is not surprising. The literature indicates that Deaf people prefer to use sign-language over any other form of communication, and in fact that they find lip-reading and all other methods to inferior to sign-language. Furthermore, they dislike the imposition of spoken and written language by healthcare professionals. In spite of the importance that Deaf people assign to pharmacists being able to communicate in sign-language, this is probably an unrealistic expectation. In reality, pharmacists already have immense workloads and face human resource shortages, it is unlikely that they can and will be trained to be fluent in a new language. Instead pharmacists should look toward other ways to provide sign-language services, perhaps through interpretive services at healthcare facilities or through drawing on technological innovation solutions that are able to provide sign language translation services. The following quotations represent participants preference to and need for sign-language communication from the pharmacist:

KI 2: “The pharmacist must learn the deaf culture. This will put the deaf patient at ease as this is something he can relate to.”

FG 12: “Also, why can’t the pharmacist learn sign language, it would be easier and instil more confidence for the deaf patients on the pharmacist.”

FG 16: “The pharmacist needs to understand that the deaf people are not children; they need to learn to communicate with them.

FG 3: “Also, why can’t the pharmacist learn sign language, it would be easier and instil more confidence for the deaf patients on the pharmacist.”

FG 8: They must learn how to communicate with us so they can sign back to us.

5.1.9.1.3 THEME 3: Strained relationship between Deaf patients and pharmacists

Pharmacists often feel uncomfortable when having to deal with a patient who is disabled to such an extent that it affects their ability to communicate with that patient effectively (Ferguson & Shan, 2015). This does not only affect the communication from the pharmacist to the patient, but is reciprocal. The Deaf patient can easily pick up from the providers’ expression and body language that they are uncomfortable or irritated with the fact that they cannot communicate effectively (Harmer, 1999). Consequently, not only does the pharmacist feel uncomfortable, but the Deaf patient may feel even worse. Due to their inability to communicate with Deaf patients, pharmacists may not establish relationships with them, precluding the provision of **adequate pharmaceutical care**. In pharmaceutical care, establishing relationships with patients enables the joint responsibility to achieve optimal therapeutic outcomes. Understandably, if there is no relationship, pharmaceutical care is impossible to achieve. The health care system is failing in its mandate to serve Deaf patients, especially on their pharmaceutical needs. The following quotes illustrate the lack of relationships of Deaf patients with pharmacists:

KI 3: “There is no relationship” (between a deaf patient and pharmacist)

KI 4: “There is a void” (with regard to a relationship with their pharmacist)

KI 1: “it should be more caring...more, more caring...because a deaf person they look at your face. If it’s sour then they won’t take note

because a deaf person goes according to emotion, facial expressions, so if you have a sour face they won't take notice of you because they're afraid to ask anything. That's why your facial expression should be like a smiley face and you should just be approachable

FG 12: "The majority of the pharmacist just focuses on giving the medicine, they do not focus on the needs of the deaf patient, the communication needs, and they focus on the quantity and not the quality of information and only want to get done. They need to make time for the deaf."

Deaf people requested **increased levels of social competency** by pharmacists. Apart from wanting pharmacists to learn sign-language, they expressed a need for awareness of the challenges experienced by Deaf people, and that pharmacists must exercise patience in their interactions with them. This alludes to the lack of Deaf awareness similarly allotted to healthcare workers in general by Huntington et al., (1995), Lomas (1998) and Haricharan et al., (2012). Many schools of pharmacy have included cultural competency in their curricula (Smith et al., 2010). However, disability is not normally included as a component of cultural competency education, and disabled groups are generally under-represented. This may result in the health inequities experienced by disabled people in pharmacies (Smith et al., 2010). Improving the skills capacity of pharmacists to work with disabled people, including Deaf persons can limit the health inequities they experience (Smith et al., 2010). The gaps in social competency by pharmacists emphasized in study findings include a frustration when working with Deaf people, a lack of patience and a lack of awareness about the inability of deaf people to read and write. These are illustrated in the following quotations:

KI 2: "There is frustration from the pharmacist's side when working with a deaf patient."

KI 4: "Pharmacists do not know that the deaf patients might not know how to read their instructions, and take it for granted that all deaf or people can read."

KI 3: “Pharmacists themselves think it’s easier to write to a deaf patient or think that deaf people can lip read, but when the deaf person goes home, they do not know exactly what that is all about, there are a lot of misunderstanding.”

FG 3: “They do not think the deaf patient cannot understand, that is why they need to make time for the deaf. They must ensure that when they leave they fully understand and know what to do. Most pharmacists talk even though they know you are deaf.”

5.1.9.1.4 THEME 4: Communication methods employed by pharmacists

Communication problems are a certainty for Deaf patients in a pharmacy setting (Iezonno et al., 2004; Law et al., 2005 ; Steinberg et al., 2006; Kritzinger, 2011; Bat-Chava et al., 2005). This has resulted in pharmacists using alternative forms of communication. The most commonly used alternative forms found in this study are writing and lip reading.

This is likewise a common finding in the literature (Ferguson & Shan, 2015; Iezonni et al., 2004; Reeves et al., 2002; Steinberg et al., 2006; Huntington et al., 1995). There is a misconception amongst pharmacists that all Deaf patients are able to read instructions. Limited literacy however, negates their ability to read, and even Deaf people who have some literacy capability, find the complex words used by pharmacists difficult to understand (Ferguson & Liu, 2015). There is a general assumption that all Deaf people are able to lip-read, which likely stems from a lack of Deaf awareness. Lip-reading is an acquired skill which is made more difficult by the fact that many similar words appear the same on a person’s lips (Reeves et al., 2002; Kritzinger, 2011). Despite its wide-spread use by pharmacists, relying on lip-reading and written communication have both found to be inadequate for the Deaf community (Steinberg et al., 2006, NAD, n.d. ; Ferguson & Liu, 2015). Deaf people prefer to have the pharmacist sign back to them instead of written or verbal instructions. All sixteen participants mentioned signing as their first preferred method for medicine instruction. This was followed by six participants mentioning that

they preferred written instructions second to sign language for the reason of having a record that they could ask somebody to read it to them should they forget how to use the medicines. Only two participants preferred lip-reading second to signing. The strong preference for health-related information in sign language is supported in the literature, with most patient preferring sign-language interpretive services and experiencing higher levels of patient-satisfaction with the presence of a sign-language interpreter (Reeves et al., 2002; Steinberg et al., 2006). However, in under-resourced settings, technology may be deemed an alternative assistive service for Deaf patients.

5.1.9.1.5 THEME 5: Limitations of medicine knowledge and its purpose

A sub-theme that emerged from this theme is **‘misconceptions regarding medicine use.’** Spoken language (requiring a Deaf patient to lip-read) and written instructions are the most commonly used methods of instruction used by pharmacists in their interactions with Deaf patients. However these are inadequate methods of instruction as very few Deaf people have sufficient literacy and can effectively lip-read. They rely strongly on visual instruction rather than spoken or written instruction, preferring sign-language over other method. Deaf participants in this study felt that medicine instructions are often very vague, not specific and clear as they need it to be. This ambiguity leads to uncertainty about the medication and Deaf patients feel that they would rather abstain from taking the medication than being unsure about its indication and dosage. The majority of the participants complained that when providers supplied them with medication, they were not adequately counselled and therefore they were unable to use their medication in an optimal manner. Participants would not take medicine at all if they did not know what its purpose was. The following quote illustrates this:

FG 9: “I couldn’t understand what the medication was about so I had to take it. My reading levels are not great. Which lead me to a point where I was not going to take the medication and be sick for a while, but I’d rather be sick than not knowing what medication I’m taking.”

FG 5: "...words (as instructions) are difficult for me and I do not want what I don't know"

This finding is established in the literature. In a case-study based approach with a Deaf woman in Cape Town, Haricharan et al., (2012) also found that Deaf patients may not take their prescribed medicine if they do not know or understand its purpose. A quotation from Haricharan et al's publication is very similar to the quotations by FG 9 and FG 5 above:

"I threw the tablets away when I came back home because I did not know what they were for and I did not feel sick...I did not know what I had. If I had known, I would have taken them."

The context of this quotation illustrates the gravity of not understanding the purpose of medicines. In this case, the Deaf patient was raped and the medicines were for post-exposure prophylaxis of HIV/ AIDS. This patient subsequently contracted HIV, although the authors cannot definitively prove that contraction of the disease was from the rape incident. Patients' non-adherence to pharmaceutical therapy due to a lack of understanding the purpose of the medicine is a problem that requires urgent attention. Non-adherence to therapy can have detrimental consequences and pharmacists must make every attempt possible to communicate to a Deaf patient the purpose of their medicine.

Understandably so, Deaf patients are likely to vehemently refrain from taking medicines for which they have no understanding of the clinical indications. Such a situation clearly calls for imminent communication strategies to address the needs of the Deaf community which is often overlooked at health care facilities. As a start, concerted efforts are needed from role-players to introduce visual communication alternatives since it is the Deaf community's most preferred mode when trying to engage with hearing society.

Additional misconceptions and confusion regarding medicine use is illustrated in the quotations below:

KI 3 "...when the deaf person goes home, they do not know exactly what is that all about, there are a lot of misunderstanding."

KI 4: “When its three times a day, they think you take 3 tablets not necessarily morning, midday and afternoon. This is very confusing for the deaf.”

KI 2: “Some deaf people are confused with before meals and after meals, there is misconception with that.”

KI 1: “The thing is in the deaf community, they rely more on instructions. If they see on TV or read that Panado® is taken two tablets, three times a day, they’ll only take two tablets, three time a day and they won’t recognise that it’s only for pain, unless somebody tells you “Listen, Panado® is only for pain,” you have to explain that to them properly in order for them to use it that way.”

Again, analogous verdicts appear in the literature. Ferguson & Liu’s (2015) paper implied similar findings, with study participants requiring more clarity in medicine instructions, and commenting on their lack of understanding of the instructions. A number of participants in Ferguson & Liu’s (2015) study experienced an adverse effect as a result of the lack of understanding. One participant took two tablets at once, when they should have taken 1 tablet twice a day, while another drove after taking a medicine that causes dizziness but he was unaware thereof. Another participant took aspirin which interacted with treatment for a common cold and got ill as a result (Ferguson & Liu, 2015). Reeves et al., 2002, describe how Deaf people were given inadequate information regarding prescriptions and that a number of Deaf people were of the opinion that they were given incorrect medicines for their ailment. Others expressed anxiety that they were not told the purpose of the medicines. Two patients suffered illness after drinking a medicine that was intended to be used externally. Deaf participants in this study also experienced the following **challenges when using medicines**. These were based specifically on (i) the colour of the medicines and (ii) the medicine name:

KI 1: “Deaf people do not look at the name of the medicine, they look at the colour e.g. Red tablet, when the person ask what medicine they use, they would say the Red tablet, and not the name, hence the person would not know the tablet.”

FG 14: “I don’t know green and yellow pill, what does that mean? It’s confusing because I don’t know what it is for but I take it anyway because the doctor said I should but I couldn’t understand him. I don’t know what green and yellow means; I know what the vitamins are and the pain tablets.

FG 7: “Different names are confusing”

FG 3: “small names and words are easy but big words are difficult. E.g. flu is easy.”

The problems with the names of the medicine are easily understandable. Deaf people experience limited literacy and medicine names are often long, complicated and often chemistry based. For example, flucloxacillin is a common antibiotic, and is likely to be a difficult name to read for an individual who has limited literacy. Similar findings are reported by Ferguson & Liu (2015), with words being “too big, too complicated” and “words are specific and I don’t understand”. With regards to colours of medicines, some participants preferred to identify medicines using colour, while others did not. One participant was very frustrated with being told to use the green and yellow tablet, stating he/she does not know colours. This was not found in the literature, but may be explained by the fact that some Deaf people have a corresponding sight disability and commonly known as being deaf-blind, which may compromise their ability to see colour, For SignSupport design purposes, the problems with medicine names and colours are a significant finding which was noted by the researchers as important consideration in designing SignSupport.

5.1.9.1.6 THEME 6: Need for autonomy in healthcare

Deaf participants in this study showed a strong need to be self-reliant and do not want to be a burden on friends and family members to help them communicate in a hearing world. The Deaf participants indicated that being independent means that the feeling of being an invalid and incapable of functioning in society falls away

and enables them all to feel free to make their own decisions regarding their health. It also eliminates the negative connotation surrounding being “disabled.” Confidentiality regarding their treatment was also a significant issue. This was similarly found in the focus group, during which many participants refused to answer specific –treatment related questions, saying that “it is personal.” The following quotes illustrate **the need to be independent or self-reliant** and the need for confidentiality:

- KI 3: “The pharmacist needs to understand that the deaf people are not children; they need to learn to communicate with them, why should they always bring someone with them? Where is the confidentiality? Deaf people are very worried about their confidentiality.”*
- FG 12: “There must be someone for us to communicate through. I am tired of asking other people to help me to communicate.”*
- FG 9: “There must be someone that is able to help us to communicate with us...there must be...I don’t like to ask other people at the clinic for help...I am tired of asking other people.”*
- FG 7: “The major and most common issue for us is that we don’t like to ask other people to help.”*
- FG 16: “ When there is no signing there is no privacy, confidentiality is an issue as pharmacist tends to shout instructions’, e.g. getting ARVs, the pharmacist will shout “ARVs” and other people will hear.*

According to the literature, a lack of confidentiality is also a problem that the Deaf people find with the use of sign-language interpreters in healthcare interactions, and would prefer to avoid having their medical information known by an interpreter. Harmer (1999) suggests that healthcare providers resist using sign-language interpreters to avoid violation of a patient’s privacy. The same is true for

Deaf patients who choose not to use interpreters for reasons of privacy and confidentiality (Glickman, 2003).

5.1.9.1.7 Summary of focus group and key informant interview results

There were no anomalies in the findings of the baseline study. Even though there is marked paucity in the available literature on pharmacist-Deaf patient interactions, all study findings were confirmed in published research focusing largely on doctors' or health-workers' interactions with Deaf people. I have extensively presented the literature findings alongside my findings within the text.

Shortfalls in the provision of effective health-related information and medicine instruction are evident. Pharmacists mostly use spoken language and written instructions to communicate, both of which are inadequate for Deaf people. Among the challenges in using medicines are uncertainty about the purpose of the medicine, the inability to identify lengthy generic names, poor understanding of verbose instructions and problems in identifying medicines based on the colour of the tablets or capsules. Consequently, Deaf people have used medicines incorrectly, thus experiencing untoward effects, or have not taken medicines at all, implying non-adherence to prescribed therapy.

In addition, Deaf people experience negative attitudes from healthcare professionals, including pharmacists and believe that they are not given an equal level of care as hearing patrons. Participants have requested increased levels of social competency from pharmacists in interacting with Deaf people. This is a finding that needs to be considered in pharmacy curricula. When asked to suggest strategies of improvement to counter these problems, all participants advocated for pharmacists to communicate with them in sign-language, but this is understandably an unreasonable expectation. It would require pharmacists to become fluent in another language, mastery for which, in light of their high workloads, they are unlikely to have the time. Lastly, Deaf people are concerned about their confidentiality when relying on family or a sign-language interpreter for health-

related problems. The lack of privacy may affect their health-seeking behaviour, precluding essential treatment.

In our attempt to consider a design for a potential technological intervention which aimed to bridge the communication gap between a pharmacist and Deaf patient, it was incumbent for the research team to consider the challenges and suggestions emergent from the focus groups and key informant interviews. This information is presented as challenges below, accompanied by proposed suggestions to resolve these challenges:

Challenges emergent from the qualitative study with the Deaf community:

- Deaf people must be communicated with in sign-language. For them, it is not an option; it is their language, and the only means they have to communicate in the world.
- There is significant lack of Deaf awareness from healthcare professionals including pharmacists.
- Waiting rooms are a particular problem for Deaf people, often resulting in missed opportunities for treatment.
- Specific challenges in medicine instruction are the use of words and colours. If possible, these would need to be avoided in using SignSupport.
- Deaf people are concerned about their confidentiality in healthcare interactions. They resist the assistance of a third person during the interaction for a fear of violation of their privacy. If possible, SignSupport needs to be an intervention that offers Deaf people independence.

In addition, we need to take cognizance of the context in which pharmaceutical care is offered at facilities. It is inevitable that capturing common pharmaceutical phrases that are shared routinely during a pharmacist-patient interaction would serve as a framework for the next logical step, which is the extraction of a dialogue pattern that could be translated into sign language.

SECTION B: DIALOGUE PATTERNS FOR DISPENSING

Pharmacists are intended to be significant users of SignSupport. They will dispense medicines to Deaf people using the prototype to ‘say’ that which they would normally say during patient counselling (for example, take one tablet three times a day). Instead of using words, the ‘saying’ would occur by selecting the medicine instructions on SignSupport which are subsequently converted into a corresponding sign-language video that can be watched and interpreted by a Deaf patient.

Understandably, for pharmacists to be receptive to using SignSupport, it would need to be set up in such a manner that it could be intuitively and instinctively used by pharmacists. It can reasonably be asserted that intuition and instinctiveness during a process comes from continuous and protracted experience of the process. For example, if pharmacists typically habitually day after day say “take 1 tablet three times a day after meals,” then the words and the word order are intuitively spoken; he/she does not have to think about what words to use or which order to use the words in. An analogy of such intuitivism is seen in the process of driving a motor vehicle. Drivers steer the wheel, apply the brakes, accelerate and decelerate etc. instinctively and without having to pause and think about what to do. In the same way, we aimed that the communication flow on SignSupport be intuitive for pharmacists. To achieve this, the researchers wanted to design the patient counselling dialogue structure in such a manner that it mimics as closely as possible the dialogue which pharmacists would typically say and the order in which they say it.

5.2.1 Research objective linkage

This component of the study was conducted to achieve the second research objective:

- To extract a dialogue pattern representing the communication that would typically occur between a pharmacist and a patient during patient counselling, and to express this pattern as a series of ordered sentences.

Specific research questions connected to this objective are:

1. What are the sentences that pharmacists typically speak during the patient counselling process?
2. What is the sequential order of these sentences?
3. If pharmacists ask questions, what are the possible answers that they are trying to elicit?

5.2.2 Study site and participants

Final year pharmacy students were invited (convenience sampling) to participate in the study as a substitute for pharmacists. The benefits of using students to investigate the dialogue patterns are (i) that students were freshly trained in patient counselling at university as opposed to practicing pharmacists who may have inherited suboptimal practices over time, and (ii) that accessing students was easier than the limited access to pharmacists at their workplace (due to shortage of pharmacists and high patient loads). The study occurred at UWC School of Pharmacy to ensure convenience for and close proximity to the participants (n=9). All the participants were English speaking and in the age group twenty to thirty years. The majority were female (n=7) and two participants were male. Participants were informed about the study in person and via participant information sheets. They were asked to sign consent forms to indicate their voluntary participation.

5.2.3 Methodology

Dialogue patterns were investigated qualitatively through covert observation and role-play techniques. The objective was to study the typical dialogue that occurs between a patient and a pharmacist during patient counselling. To accomplish this objective, the pharmacist is represented by the pharmacy student and a patient is a simulated-patient actor. A role-play room was set-up to resemble a dispensary located in a hospital pharmacy, typically resembling a scenario where Deaf people normally collect medicines. A mock patient identification card, pseudo prescriptions for acute and chronic treatment (influenza, and hypertension

respectively) and the medicines for treatment of these conditions were prepared. The simulated patient was given the mock patient identification card and the prescription and was briefed to act as a patient presenting the prescription to the pharmacist at the dispensary. The pharmacy students were given only the medicines and were asked to dispense the medicines to the simulated patient during the role-play in the best way that they could (i.e. adhering to professional requirements). The reason for having both acute and chronic treatment prescriptions was to investigate dialogues that would adequately represent patient counselling for both short-term and long-term medicine use. The role-plays were observed covertly through video transmission via an adjacent room setup with television screens.

5.2.4 Materials

The following materials were used in executing the afore-mentioned study tasks:

- Video-relay system (video cameras and television screens)
- Mock patient identification card
- Pseudo prescriptions for treatment of influenza and hypertension
- Medicines to dispense from the prescription (amoxicillin, enalapril, hydrochlorothiazide and paracetamol)
- Medicine counting tray and spatula
- Brief for the simulated patient
- Stopwatch

5.2.5 Study procedure

Each pharmacy student was asked to dispense two prescriptions in total, one each at separate patient counselling sessions. One prescription was for influenza and the other, for hypertension. The study procedure occurred as the following successive steps:

1. A pharmacy student entered the role-play room, stood at the 'dispensary' (to represent a pharmacist) and was approached by the simulated patient who handed over a prescription to the pharmacy student.

2. After handing over the prescription, the simulated patient sat down in the waiting area (as per the briefing instructions).
3. The student evaluated and interpreted the prescription and selected and prepared the medicines.
4. The student called the simulated patient to receive the medicine.
5. The student dispensed the medicines on the prescription.
6. The student concluded the interaction and both the student and simulated client exited the role-play room.
7. Steps 1-6 were repeated eighteen times, each student (n=9) completed 1 session for acute treatment and another for chronic treatment.

The interaction was observed covertly through video transmission to an adjacent room setup with television screens. Researchers recorded the dispensing time per prescription, sentences which were spoken, questions asked by the pharmacist and the chronological order of the sentences and questions.

5.2.6 Data analysis

Srivasta's 3-question framework was used as the main method of analysis. It was applied in the process of constructing and interpreting an OSCE (Objective Structured Counselling Evaluation) checklist which was used as a data analysis instrument. An OSCE is a widely accepted training tool that is utilised to teach and assess the competency of students in the practice of patient counselling. It is used to evaluate whether students have the skills to practice professional counselling and comprises a series of patient counselling parameters as checklist points. The checklist points are grouped into consecutive steps that make up a counselling session. While OSCEs are not formally known to be a data analysis tool, the researchers found it to be a useful instrument for analysis because it resembles a communication flow that occurs during patient counselling. In addition, it comprises all the compulsory medicine information parameters required to be covered during the course of such counselling. An example of an OSCE used at UWC School of Pharmacy is illustrated below:

Figure 16: Example of an OSCE

STEP 1: Clarification of the presenting problem	✓
STEP 2: General history	
2 Age	✓
3 Physiological status(e.g. pregnant)	✓
4 Previous allergies and reactions to drugs	✓
5 Previous and Current illness	✓
6 Current medication	✓
STEP 3: History of present illness	
7 Onset of Symptoms (duration?)	✓
8 Accompanying symptoms to current condition	✓

To suit study purposes, the researchers modified an OSCE from the undergraduate curriculum at UWC School of Pharmacy. The modified OSCE (Appendix H) was used as a data collection and analysis instrument and allowed us to tick off checklist points representing the parameters of patient counselling that the pharmacy student did/did not cover. Adjacent to each checklist point that the student communicated, researchers wrote the associated sentence (verbatim) that was spoken by the pharmacy student.

5.2.7 Results and Discussion

The modified OSCE is a consecutive checklist of patient counselling parameters that a pharmacist is obligated to cover during the medicine dispensing process. Nine pharmacy students were each asked to dispense two prescriptions (one each for acute and chronic treatment) to a simulated patient. This generated a total of eighteen dispensing sessions.

Participants did not always conform to the same order of the checklist points for each of the 18 sessions. The researchers however, noted that for 13 of the 18 sessions, the same order of checklist points was followed. From this majority incidence (72 %) the sentence order was subsequently adopted as the dialogue pattern. The literature supports the sequential order of medicine instructions. Rantucci (2001) and Berger (2009) refer to a common “sequence of instructions” followed during the provision of medicine-related information to patients.

Researchers collated the sentences which were spoken by participants during their interaction with the simulated client. These sentences were not identical for all the students but the differences between them were negligible as they were all essentially communicating the same aspect of patient counselling. For example, one student would say “*this is your medicine, panado,*” while another would say “*doctor prescribed the medicine, panado, for your problem.*” It became evident to the researchers that, more important than the exact words in the sentences, was the content it represented and the order in which the sentences were spoken.

The complete dialogue pattern and sentences are represented in Figure 17 as study results. Adjacent to each sentence and allocated in brackets is the frequency (total number of times the sentence was spoken) expressed as a total number out of 18 (the total number of dispensing sessions). Note that the sentences reflected in Figure 16 are not a verbatim reflection of what the student said, instead each sentence represents a group of similar equivalent responses that were expressed in different ways. For example, in all 18 sessions the students greeted by saying “hello,” or “hi” or “good-day” or “good afternoon.” These are represented collectively in the results by using a generic term, “hello” as it communicates the same patient-counselling parameter. Figure 17 below presents the frequency scores of similar sentences or phrases used during the role-play session between the pharmacy students and simulated patient.

Figure 17: Frequency scores of similar sentences/phrases spoken during the role-play session between the pharmacy students (n=18, 100%) and simulated patient

Patient Greeting	
•Hello	(n=18)
•How are you?	(n=15)
•I am (name), the pharmacist for today	(n=12)
Patient Identification	
•What is your name?	(n=16)
•Show me your identification card or date of birth	(n=11)
General history	
•Where do you live?	(n=4)
•Do you have allergies to food or any medicine?	(n=14)
•Are you using any medicines currently?	(n=14)
•Have you used medicines in the past 6 months?	(n=14)
•Do you have clean water and access to three daily meals?	(n=12)
•Do you smoke or use alcohol?	(n=10)
•What is your weight?	(n=8)
•What do you do for a living?	(n=4)
Clinical reasoning	
•Advice about medical problem (causes and lifestyle considerations)	(n=10)
Medicine decision-making	
•This is (medicine name) and it is for your (illness/symptom name)	(n=18)
• Medicine instructions (dose and frequency)	(n=18)
[e.g. You must take (n) tablets ___times a day ___meals]	
•Recommendations	(n=18)
[e.g. take it only when necessary/ take it everyday at the same time/complete the treatment]	
•Warnings	
• Reduce smoking and alcohol when you take the medicine	(n = 18)
• If you experience side effects call your doctor	(n = 14)
Feedback and closing	
•Do you understand?	(n=14)
•Can you tell me how to use your medicines?	(n=4)
•Do you have any questions?	(n=14)
•Thank you/ Bye	(n=18)

Pharmacy students commenced all eighteen sessions by greeting. They asked the patients “how are you?” in fifteen sessions and introduced themselves as the pharmacist in twelve sessions. Since these sentences were used in the majority of sessions, they were considered important in the pharmacist-Deaf patient interaction. Sentences were grouped as “patient greeting” and constructed for SignSupport as:

- *‘Hello, I am the pharmacist (...name.....). How are you?’*

Students asked the patient for their name (n=16) and requested to see an identification card eleven times. Once again, due to the frequency that these questions were asked, they were considered important to use in SignSupport, and was constructed as:

- *“Could you state your name please, and may I see your patient card?”*

Interestingly, none of the studies reviewed in the literature reported that establishing a patients’ identification is an important part of medicine-related information. This may be due to the fact that asking for a patient’s identification is a function specific to the context of hospital/institutional pharmacy.

During all the sessions, students asked questions about the patient’s general medical history. However, all eight questions regarding general history reflected in Figure 17 were only asked in ten of the eighteen sessions. In addition, the order of these sentences varied largely between sessions. Only two sessions included an enquiry into where the patient resides. This was asked to ascertain living circumstances, for example an urban or rural area which would indicate access to water, sanitation etc. In a country such as South Africa where poverty levels are high and it is common for people to live in informal settlements where basic water and sanitation services are often compromised, this is important information for pharmacists to elicit.

The experience of allergies was enquired about in sixteen of the eighteen sessions (89 %). This was possibly due to the presence of an antibiotic on some of the prescriptions. Pharmacy students are trained to be sensitive to the possibility of

allergic reactions when dispensing medicines. This finding is corroborated in the literature, with allergic reactions and side effects receiving the highest significance (58 %) with regards to information requested from patients for medicines in accordance with a new prescription. Furthermore, in Berry et al's (1997) study of the ranking of sixteen information types by patients and doctors, patients ranked adverse effects (including allergic reactions) to be the most important (ranking number 1).

Fourteen sessions included questioning of current and past medicine use while twelve sessions incorporated questioning of access to clean water and regular meals. Meals and water are important considerations to pharmacists who often advise patients to take medicines with, before or after meals to ensure the safety and efficacy of medicines and are even more important in South Africa where the high levels of poverty often preclude people's access to meals and clean water. Questioning of meals and water is not seen in the literature, perhaps because the reviewed studies were not done in resource constrained countries.

For similar reasons of safety and efficacy, the patient was asked about whether he smokes and uses alcohol, which interacts negatively with some medicines causing untoward effects or negating the efficacy of the medicine. Patients were asked about their weight during eight sessions. This is supported in Berry et al's (1997) ranking study where patients ranked lifestyle modifications as the third most important aspect of patient counselling. Most of the questions posed on general medical history were asked in majority of the sessions and thus seem to be an important part of the dialogue. For incorporation into SignSupport, these questions were constructed as the following:

- *Do you have allergies to food or any medicine?*
- *Are you using any medicines currently?*
- *Have you used medicines in the past 6 months?*
- *Do you have clean water and access to three daily meals?*
- *Do you smoke or use alcohol?*
- *What is your weight?*

The afore-mentioned questions posed a significant challenge for the research team. These are crucial questions to ask in a pharmacy context, but from a SignSupport programming perspective, and taking into consideration that Sign Support translates text (input by the pharmacist) to sign-language for the Deaf patient, it is not able to translate sign-language from the patient into text for the pharmacist. We identified a problem in that we would need to preclude aspects of the dialogue which would require the Deaf person to formulate lengthy answers. Alternatively, researchers would have to find a way to incorporate these questions into SignSupport in another, less problematic manner.

‘Clinical reasoning’ was the next section of the dialogue pattern and involved the pharmacy student providing advice to the patient about the medical condition that the prescription was intended to treat. This advice included causes of the medical condition and lifestyle behaviour modifications to improve the condition. Clinical reasoning is another important feature of the dialogue pattern, but does not feature prominently in any of the reviewed studies on medicine information. This may be due to the fact that pharmacist and patients concentrate on information directly linked to the medicine, and not the medical condition it is intended to treat. The dialogue that emerged from the ‘clinical reasoning’ section was reminiscent of the reasons why the Looijestein-Mutemwa SignSupport prototype was unsuccessful. It would be impossible to record sign language videos to translate the causes and lifestyle modifications regarding every possible symptom and illness, and store these on commercially available phones which simply do not have the storage capacity to handle multiple, large videos. As a result, no dialogue was constructed for SignSupport featuring illness/symptom specific clinical reasoning.

Medicine-specific instructions followed the ‘medical issues’ section. The findings from this section differ to those previously presented in that four of the five sentences were said by all the pharmacy students. In addition, the sequence of sentences was identical for the eighteen sessions. The strength of the findings for this section is indicative of the medicine-specific biases of the pharmacy students. Pharmacists are seen as the custodian of medicines and it is their duty to advise patients about how to use medicines. This finding is supported in the literature with

basic medicine instructions featuring prominently in the lists of medicine information that must be communicated. It also features as a pharmacist's responsibility in the SAPC definition of dispensing: *"Provision of information and instructions to the patient to ensure safe and effective use of medicines."*

The strength of the results in this section also indicated to the researchers that this section was crucial to pharmacists and that if SignSupport failed to present the intended dialogue pattern properly, pharmacists may not be receptive to using the prototype. We expressed these sentences in the following manner for incorporation into SignSupport:

1. *This is your medicine, ... (name)*
2. *You have to take ... (number) tablet(s)/capsule(s) ... (number) times per day.*
3. *That means take it in (the morning and/or afternoon and/or evening.*
4. *Take it (in relation to meals) before meals/with meals/after meals.*
5. *Recommendations*
 - a. *Take this medicine only when necessary*
 - b. *Take this medicine every day at the same time*
 - c. *Complete the treatment*
6. *Warnings*
 - a. *Reduce smoking and alcohol when you take the medicine*
 - b. *If you experience side effects call your doctor*
 - c. *This medicine may cause drowsiness. Avoid driving or operating machinery*

In closing the session, majority of the pharmacy students asked participants whether they understood what was said and students allowed the participant to ask question multiple times until they were satisfied that the participant understood sufficiently. Conversely, the participant asked to explain the instructions they were given back to the pharmacist only during four sessions. The dialogue in this circumstance was *"would you please tell me how you will take this medicine"*

(holding up a particular medicine container). Interestingly, feedback and questioning do not feature on any of the reviewed studies regarding medicine instructions, even though joint interaction is cornerstone to pharmaceutical care. At the end of all the sessions, the pharmacy student handed over the medicine with general greeting dialogues (bye, thank you, have a good day etc.). Since SignSupport is intended to largely allow a one-way communication flow, we excluded questions from the closing sessions of dialogue and constructed the sentence as:

Thank you, goodbye.

The sentences elucidated from the role-plays and reconstructed for SignSupport appear in bold, italicized font above. These sentences were collated and formed the dialogue pattern for incorporation into SignSupport. The complete communication structure is presented in Table 9 below:



Table 9: Communication script for SignSupport

ORDER	DIALOGUE
1.	Hello, I am the pharmacist (...name...).
2.	How are you?
3.	Could you state your name please, and may I see your patient card?
4.	Do you have allergies to food or any medicine?
5.	Are you using any medicines currently?
6.	Have you used medicines in the past 6 months?
7.	Do you have clean water and access to three daily meals?
8.	Do you smoke or use alcohol?
9.	What is your weight?
10.	Doctor has prescribed medicine for your(illness/symptom) (Here include a complete list of all possible symptoms and illnesses)
11.	This is your medicine, ... (name) (Here include a complete list of all possible medicine names.)
12.	You have to take ... (number) tablet(s)/capsule(s) ... (number) times per day. (Here include all possible dosage forms (e.g. tablets, syrups etc.) and dose units (milliliter, spray, puff, pump etc.)
13.	That means take it in ... (the morning and /or afternoon and/or evening).
14.	Take it ... (in relation to meals)...before meals /with meals /after meals.
15.	Recommendations
16.	<ul style="list-style-type: none">• Take this medicine only when necessary
17.	<ul style="list-style-type: none">• Take this medicine every day at the same
18.	<ul style="list-style-type: none">• Complete the treatment
19.	Warnings
20.	<ul style="list-style-type: none">• Avoid smoking and alcohol intake while using this medicine
21.	<ul style="list-style-type: none">• If you experience side effects call your doctor
22.	<ul style="list-style-type: none">• This medicine may cause drowsiness. Avoid driving or operating machinery
23.	Thank you, goodbye

5.3 CONCLUSION: BASELINE STUDY

The research objectives outlined for the baseline investigation were successfully achieved. Findings from the focus group discussion and key informant interviews offered in depth insight into the Deaf community's experiences at healthcare facilities and delivered valuable information to be incorporated in the design and development of SignSupport.

The dialogue pattern elucidated from role-play sessions between a simulated patient and pharmacy student generated a communication structure that will be used as the foundation of the programming architecture for pharmacist-patient interaction via SignSupport.



CHAPTER SIX

RESULTS AND DISCUSSION: INNOVATION PHASE

This chapter presents the second and most intensive research phase which comprises development of key components needed to build SignSupport. It is divided into two main sections, the first of which describes the theoretical underpinnings influencing the design of SignSupport, and incorporates three conceptual processes and one empirical activity (Section A). The conceptual processes include the compilation of prescription instructions, a database of symptoms/illnesses and a comprehensive list of medicine names. The empirical process involves video verification testing to evaluate the accuracy and correctness of the sign-language translation videos used in SignSupport.

The thesis reaches its apex with Section B which presents the first completed version of SignSupport incorporating the dialogues, user input, databases and verified videos. A description of how a pharmacist would use SignSupport is provided with an annotated pictorial illustration of the application.

SECTION A: SIGNSUPPORT DESIGN DETERMINANTS

The previous chapter concluded with a communication script for SignSupport and Deaf user experiences which influence the design of SignSupport. The logical forward progression is to collate the other components needed in SignSupport's programming, these components include (i) databases of medicine names and disease/symptom names and (ii) sign language videos which accurately translate the instructions and symptom/diseases from English text into SASL.

This section details the innovation of SignSupport. Firstly, the theoretical foundations on which SignSupport are grounded are described. Thereafter, the development of specific components required to build SignSupport is explained. During such development, a conflict arose which caused the research team to suspend our efforts and re-strategize before the project could continue. This conflict and the resolution thereof are also described in this section.

6.1 Theoretical underpinnings for design of SignSupport

A significant part of this dissertation is aimed at research, and an equally significant part is innovation. Chapter four detailed the theoretical paradigms for the research aspect. Below I discuss the selected paradigms (Human-centred design and Community-based co-design) for the innovation of SignSupport.

6.1.1 Human Centred Design

Human-centred design (HCD) has been placed alongside Technology-driven design and Environmentally-sustainable design as one of the three major discourses for design and innovation (Giacomin, 2012). With origins in semi-scientific arenas including computer science, artificial intelligence and ergonomics, HCD focuses on incorporating human factors, usability knowledge and techniques in design and innovation. It is essentially design for the human user, taking into account human factors and based on pre-determined user aspects. International standard ISO 9241-210 presents six features of HCD (Giacomin, 2012):

1. The adoption of multi-disciplinary skills and perspectives
2. Explicit understanding of users, tasks and environments
3. User-centred evaluation driven and refined design
4. Consideration of the whole user experience
5. Involvement of users throughout design and development
6. Iterative process of development

Many experts have written on the benefits of HCD as elevating the usability of an innovation since design is centred on user aspects. All six of the above characteristics were design intentions among the multi-disciplinary team and were applied in the design process of SignSupport. HCD has however also been criticised. The main basis of such criticism is that HCD leads to design that is skewed toward one or more predetermined user patterns, thereby presenting limitations in levels of interactivity and exploration (Giacomin, 2012). Experts who are critical of HCD have suggested elevated levels of design: designers should aim to determine design requirements based on what they know about the people involved and the environment in which they interact. Furthermore, designers must consider their users' emotional engagement and identify what the product means to and for intended users. Krippendorf (1989, 2004) cited in Giacomin, (2012) describes this as: *"...the use of artefacts is inseparable from how users conceive them and engage with them in their world...humans do not respond to the physical qualities of things but to what they mean to them."* It was apparent that if we wanted to achieve noteworthy benefits for the Deaf community in using SignSupport, we had to extend our view beyond the notion of design for humans (HCD), and elevate it to include "emotional" and meaningful elements.

6.1.2 Community-based co-design

Community-based co-design is a multifactorial approach developed by Blake et al., (2011) and integrates "action research, industrial design approaches, education and other societal elements". Blake et al., (2011) describes community-based co-design as:

“a way of exploring a design space in a way that alleviates the restrictions of the designer's own viewpoint and bias. In a cyclical fashion the designers develop according to their skills and learning and according to the users' expressed requirements and their learning. The researchers and the users end up being the design team.”

Blake et al., (2011) who conceptualized community based-co-design, are our predecessors in research with the Cape Town Deaf community and much of this work was based on their prior work with, and input from joint meetings with the Deaf community. Furthermore, Blake et al. were also pioneers of SignSupport with their involvement in conceptualization of Mutemwa's (2011) doctor-Deaf patient prototype on a Symbian phone.

By making users significant players in the design process, community-based co-design extends beyond the boundaries of human-centred design in that it establishes design with human users, rather than for human users. I incorporated all the elements of human-centred design in the medicine-information communication elements and also entrenched the concept of community-centred design as the principal theoretical inclination for my contribution in this multi-disciplinary venture.

6.2 A recap of SignSupport design requirements

The iterative development of SignSupport necessitated the following pre-requisites previously alluded to in preceding chapters:

1. A multi-disciplinary collaboration to contribute different areas of expertise.
2. An in-depth insight into the experiences of Deaf people with regards to the patient counselling process and medicines usage. These insights would inform the design of the Deaf-user interface of SignSupport.
3. Naturalistic behavioural patterns of pharmacists when offering medicine instructions. This would lead the design of the pharmacy interface.
4. Sign-language videos which translate medicine instructions from text into SASL.

6.3 Development of components for SignSupport

The following list of items was needed to build SignSupport:

1. A pharmaco-therapeutic communication script (dispensing dialogue patterns)
2. Information regarding Deaf user experiences at the pharmacy
3. Medicine information databases
 - a. Symptoms and illnesses database
 - b. Database of medicine names
4. Recorded and verified SASL videos to translate items 1 and 3 above into sign language.

6.3.1 Conflicting perspectives

In the previous chapter, empirical activities which yielded the pharmaco-therapeutic communication script and information regarding Deaf user experiences at the pharmacy (items 1 and 2 on the list above) were presented. These were intended to be the first building blocks in the architecture of SignSupport. However, the research team immediately encountered technical problems which altered the course of SignSupport's design. These technical problems involved a conflict between that which was considered to be essential from the pharmacist's perspective, and that which was possible, from the computer programmer's perspective. What was 'possible' related to the coding limitations of commercially available mobile phones. For example, in the pharmacists' dialogue pattern, the first item is "*Hello, how are you?*." Pharmacists greet the patients to establish rapport and as a matter of courtesy. Furthermore, a key feature of the dispensing process is that a patient is able not only to receive messages, but also to encode a response, which is usually feedback on their understanding or questions they may have with regard to their medicine. The pharmacist was of the opinion that without an opportunity for the patient to pose questions or provide feedback, the patient counselling session was not truly fulfilled.

The computer programmer however, was of the opinion that greetings and other courtesies, including feedback and questioning, were unnecessary to incorporate into SignSupport for two reasons: (i) a Deaf patient is unlikely to answer the question of how they are, and (ii) the words “*Hello, how are you?*” would need to have a corresponding SASL video to be translated to the Deaf patient. Since a code (computing) needed to be written for all the communication elements on SignSupport, the ‘unnecessary’ script and videos would also require coding. Furthermore, with regard to the feedback and questioning, SignSupport would need to be able to translate sign-language (‘spoken’ by the Deaf patient) into text for the pharmacist, in order to enable such functions. This would require highly sophisticated and expensive equipment, including hand- and facial sensors and intricate connectivity to be possible. This was simply not feasible due to the cost implications thereof.

Moreover, the computer programmer felt that only elements of the dialogue that was absolutely crucial should be included. If this was not done, the unnecessary script elements would complicate the coding process and may introduce avoidable glitches in the programming architecture. In addition, the extra space required by the additional videos files, which are typically large and occupy significant capacity, may cause a delay in uploading and playing of the videos (i.e. it would take considerably longer for the videos to be viewed). The computer programmer was of the opinion that glitches in the system and a possible delay in playing videos would cause Deaf people to not use SignSupport, while the pharmacist felt that it was necessary to include all professionally required aspects of the interaction in SignSupport. This led to an impasse, causing design operations to cease until members of the collaborative team resolved this conflict. The conflict resolution is described in the next section.

6.3.2 SignSupport practical limitations and resolutions

In an effort to find resolutions for the afore-mentioned conflict, members of the collaborative team called a strategizing meeting to state their perspectives and the importance thereof. The perspectives of the team-members are elaborated on below:

Pharmacist: was unwilling to compromise the pharmacist's code of practice. All professional and legally required items needed to be included in SignSupport to ensure my continued involvement in the project.

Computer-programmer: asserted that it was unreasonable and impractical for SignSupport to include unnecessary items. He was of a pragmatic view that the research team had limited time and funds and that our efforts and time should be expended only on what was essential and would allow Deaf person to understand medicine instructions. He was of the opinion that "*they* (Deaf people) *do not need a hello to understand how to use their medicines.*" More importantly, he explained that SignSupport is a "***limited communication domain***" system. Limited in the sense that it contains preloaded communication elements, thus the system is only able to translate into sign-language that which has been programmed into the system. As such, fluid communication in the case of questions and feedback, which may include words or phrases that are not within the limited communication domain, would not be possible.

Industrial designer: was in Netherlands at the time, but advised that the members above mutually decide on how to build SignSupport in a way that was practical, meets

professional stipulations and most importantly, would accommodate Deaf community needs.

Further input from the computer science study promoter was the following:

“We are building a prototype, not a market-ready system (yet). We eventually will get it to be commercially ready, but for now, we must design a prototype, a system that can carry a medicine interaction from start to finish that will have the capability to cause the Deaf patient to leave the pharmacy knowing clearly how to use their medicines because they were given instructions in sign-language by SignSupport”. We must get the communication flow right on a prototype, once we get it right it is then easy to populate the program with additional features.”

-William Tucker, study promoter (UWC, Bellville, Cape Town, 2012)-

As a result of the study promoter’s position and the strategizing meeting, the collaborative team took the decision to build SignSupport as a prototype. A prototype, by definition is *“a first, typical or preliminary model of something, especially a machine, from which other forms are developed”*(CourseHero, n.d.) The decision to build SignSupport as a prototype had significant implications: that we would design a complete (start-to-finish) communication flow for a pharmacist-patient interaction, with a view that once it is designed and functioning in an acceptable and usable manner for Deaf people and pharmacists, that it could then be easily populated with additional aspects. This was a major decision in the trajectory of SignSupport’s design, and resulted in the following mutually agreed practical limitations of the prototype version:

1. SignSupport would only include what was absolutely necessary in line with legal and professional requirements for a pharmacist-patient interaction. If during usability tests a burning issue arose that required another aspect to be added, the team would do so accordingly. This meant that we needed to revise the communication script elicited in the previous chapter, by selecting from that communication script only sentences which are absolutely essential.

2. SignSupport would be a **'limited communication domain system.'** As such, only communication elements agreed on by the team would be pre-loaded into the system, precluding the possibility of feedback and questions from the deaf patient. The prototype would be designed to facilitate medicine instructions from the pharmacist to the Deaf patient with no option for the patient to reply. Communication via SignSupport would not be dyadic, but one-directional.

3. At this stage in the design of SignSupport, we would structure the prototype to contain all the medicines possible for only one dosage form (*see note below); the selected dosage form would be the most commonly used by adults). For the reasons that it is the "most common type of dosage form in contemporary use" (Aulton, 2007) and frequently used by adults, we chose to design SignSupport for tablets/capsules, with the view that once we get the system operating smoothly for the selected dosage form, it would be an easy task add the additional dosage forms.
 - *A **dosage form** refers to "*the physical manifestation of a drug as a solid, liquid and can be used in a particular way. Examples of dosage forms include tablets, capsules, creams, ointments, solutions, injections, and aerosols.*"

4. As much information as the phone's storage capacity would allow, would be translated into SASL videos for the patient to watch, interpret and understand. It was not enough to merely record the videos. We would independently verify the content of each sign-language video for correctness (i.e. does it say what it is intended to say). The team agreed that we would not take any risks in medicine instruction; we needed to verify the videos to be certain that they would communicate the correct information to a Deaf patient.

5. The computer programmer would, if possible, add a Skype®-call feature onto the prototype. Skype®-call would allow a Deaf person to call an

interpreter during the patient counselling process should any critical issues arise during the interaction which necessitated SASL interpretive services.

6.3.3 The way forward

In light of the afore-mentioned resolutions and SignSupport requirements, the developmental progression of SignSupport changed. Along with these planning changes, the communication structure elicited in the previous chapter had to be modified to accommodate the resolutions. Once this was completed, the ensuing design functions could be executed. Design functions were executed in the following sequential order:

1. Modify communication structure elucidated in the previous chapter (five)
2. Compile medicine information databases:
 - a. Symptoms and illnesses database
 - b. Database of medicine names
3. Record SASL videos to translate 1 and 2a above into sign language
 - a. Independently verify recorded videos
4. Collate 1-3 above into SignSupport and finalize SignSupport version 1

6.4 Modifying the communication script

In Chapter five, results of role-plays simulating interactions between pharmacists and patients to elicit the naturalistic dialogues of pharmacists were presented. These dialogues were organised in a pattern reflecting the sequence in which pharmacist participants spoke. This sequential order of sentences was accepted as a generic pharmacists' communication script for SignSupport. However, in light of the previously discussed resolution to only include what was absolutely necessary in line with legal and professional requirements for a pharmacist-patient interaction, this communication script had to be altered. Table 10 below illustrates how the initial communication script was modified. Communication points 1-3 and 23, highlighted in red, were completely removed from SignSupport because, while they help to establish rapport, they are not absolutely necessary or a legal requirement. It was also felt that these points could be replaced by the pharmacist

acknowledging the patients presence. Communication points 4-9, which are questions to the patient about his/her general medical history, were also removed, but not completely. Instead they were kept in SignSupport but transferred to another programming location and would still be sufficiently addressed. This is discussed later in the chapter. Table 10 below illustrates how the communication script was modified by presenting the communication points which were removed in red font. This is followed by Table 11, which presents the finalized communication script, after the modifications were effected.



Table 10: Modifying the original communication script

ORDER	DIALOGUE
1.	Hello, I am the pharmacist (...name...).
2.	How are you?
3.	Could you state your name please, and may I see your patient card?
4.	Do you have allergies to food or any medicine?
5.	Are you using any medicines currently?
6.	Have you used medicines in the past 6 months?
7.	Do you have clean water and access to three daily meals?
8.	Do you smoke or use alcohol?
9.	What is your weight?
10.	Doctor has prescribed medicine for your ...(illness/symptom) (Here include a complete list of all possible symptoms and illnesses)
11.	This is your medicine, ... (name) (Here include a complete list of all possible medicine names.)
12.	You have to take ... (number) tablet(s)/capsule(s) ... (number) times per day. (Here include all possible dosage forms (e.g. tablets, syrups etc) and dose units (millilitre, spray, puff, pump etc)
13.	That means take it in ...(the morning and /or afternoon and/or evening).
14.	Take it ... (in relation to meals)...before meals /with meals /after meals.
15.	Recommendations
16.	Take this medicine only when necessary
17.	Take this medicine every day at the same time
18.	Complete the treatment
19.	Warnings
20.	Avoid smoking and alcohol intake while using this medicine
21.	If you experience side effects call your doctor
22.	This medicine may cause drowsiness. Avoid driving/ operating machinery
23.	Thank you, goodbye

Table 11 below represents the newly adapted communication script that was used for SignSupport. It was modified from the original script by removing communication points 1, 2 and 23, replacing communication point 3 and relocating communication points 4-9.

Table 11: SignSupport communication script

ORDER	DIALOGUE
1.	May I see your patient card?
2.	Doctor has prescribed medicine for your ...(illness/symptom) <i>(Here include a complete list of all possible symptoms and illnesses)</i>
3.	This is your medicine, ... (medicine name) <i>(Here include a complete list of all possible medicine names.)</i>
4.	You have to take ... (number) tablet(s)/capsule(s) ... (number) times per day. <i>(Here include all possible dosage forms (e.g. tablets, syrups etc.) and dose units (millilitre, spray, puff, pump etc.)</i>
5.	That means take it in ... (the morning and /or afternoon and/or evening).
6.	Take it ... (in relation to meals)...before meals /with meals /after meals.
7.	Recommendations
8.	Take this medicine only when necessary
9.	Take this medicine every day at the same
10.	Complete the treatment
11.	Warnings
12.	Avoid smoking and alcohol intake while using this medicine
13.	If you experience side effects call your doctor
14.	This medicine may cause drowsiness. Avoid driving or operating machinery

6.4.1 Relocating communication points 4-9: General medical history questions

The general medical history questions elicited from the dialogue patterns were:

- *Do you have allergies to food or any medicine?*
- *Are you using any medicines currently?*
- *Have you used medicines in the past 6 months?*
- *Do you have clean water and access to three daily meals?*
- *Do you smoke or use alcohol?*
- *What is your weight?*

These questions were removed from the pharmacists' conversation script in SignSupport for two reasons (i) they were questions (SignSupport facilitates the communication of medicine instructions from the pharmacist to the patient, it is not set up for questions because it converts text to sign-language not vice-versa as would be the case when the patient asks questions in sign-language, and (ii) the researchers felt that it was background information that could be recorded and stored by the Deaf patient prior to their interaction with the pharmacist. Instead of appearing as part of the dialogue, these general medical history questions were to be included on the phone as a section where Deaf patients are taught to upload their medical history based on a series of questions asked to them on a SASL translation video. This was called the 'Patient profile' section, and is one of the initial screens a pharmacist would encounter in their interaction with a Deaf patient while using SignSupport. The screen shows the presence of allergies, concurrent medicines, patient weight, whether they smoke or drink alcohol, and whether they have clean water and three meals daily. As a result, the pharmacist would still have this important information without having to ask the patient for it. Instead, it would appear on SignSupport.

At this juncture in the study, and in relation to SignSupport design requirements, we have finalized the modified communication script and questions regarding a patient's general medical history. Items 3-6 in Table 12 below will be addressed as this chapter progresses under the forthcoming subheadings.

Table 12: Progressive development of SignSupport components

1. Modified communication script	√
2. Patient general medical history questions	√
3. Incorporate Deaf user experiences	
4. Compile medicine information databases: a. Symptoms and illnesses database b. Database of medicine names	
5. Independently verified SASL videos to translate 1, 3 and 4 above into sign language	

6.5 Incorporating Deaf user experiences

From focus group interviews with Deaf people and key informant interviews with persons who had both Deaf knowledge/experience and pharmacy knowledge/experience (Chapter five), specific information was elicited regarding the Deaf community that we would use to inform the design of SignSupport. The following information (1-3) was specifically addressed by solutions A-C below, respectively.

1. Deaf people must be communicated with in sign-language only. For them sign-language is not an option; it is how they communicate in the world.
2. Specific challenges for Deaf people in medicine instructions include the use of verbose, complex words and colours. If possible, these would need to be avoided in using SignSupport.
3. Deaf people are concerned about their confidentiality in healthcare interactions. They resist assistance from a third person during the interaction for a fear of violation of their privacy. If possible, SignSupport needs to be an independent system.

- A. All communication on SignSupport aimed at the Deaf user appears as sign-language videos. This was done through the use of icons (designed with the Deaf community and by the industrial design engineer) and SASL translation videos recorded with an interpreter. At no point on the application does a Deaf patient encounter text. This includes the section in which he/she is required to upload information pertaining to their general medical history (i.e. the patient profile section).
- B. No words or colours are used to communicate medicine related information to the Deaf patient. Instead, a photograph of the medicine (taken by the pharmacist) appears as an image on the sign-language translation video to indicate to the patient which medicine to take. This will be explained more clearly in the second section which presents SignSupport.
- C. To maintain privacy and patient confidentiality, SignSupport will be set up as far as possible to preclude the use of an interpreter or any other third party to assist with medicine or health-related information.

At this juncture in the study, and in addition to the modified communication script and questions regarding a patient’s general medical history, we have incorporated Deaf user experiences. Table 12 below demonstrates the progress thus far.

Table 12: Progressive development of SignSupport components

1. Modified communication script	✓
2. Patient general medical history questions	✓
3. Incorporate Deaf user experiences	✓
4. Compile medicine information databases: <ul style="list-style-type: none"> a. Symptoms and illnesses database b. Database of Medicine names 	
5. Independently verified SASL videos to translate 1, 3 and 4 above into sign language	

6.6 Compiling medicine information databases

Following on from Table 12 above, the next requirement for SignSupport is compilation of a database including all possible symptoms or illnesses which a pharmacist could communicate to a patient in order to indicate the purpose of the medication. This is required to be included in point 2 on the conversation script presented earlier:

“Doctor has prescribed medicine for your (Illness/symptom)”

(Here include a complete list of all possible symptoms and illnesses)

6.6.1 Database of symptom/illness names

A pharmacist is required to include the symptom/illness name in their selection on SignSupport, and their selected symptom/illness name will be converted into a SASL translation video. For this to be realized, it was necessary to compile a database of symptoms and illnesses. In my approach to this, my first instinct was to be as inclusive as possible and be cognisant not to exclude any symptom or illness name. As a result, the **Merck Manual of Diagnosis and Therapy (1992)** was used to extract all possible symptoms/illness disease names. Commonly referred to the Merck Manual, the first edition was published in 1899 and it has since been used extensively by medical doctors, pharmacists and healthcare faculty as a reference to reach clinical and medical information. *“Within the confines of a single publication, the Merck Manual remains unparalleled in its scope and detail”* (de Korte, 1992). The strategy to achieve a full and comprehensive list of all conceivable symptoms/illnesses was to thoroughly elucidate it from the Merck Manual. Simultaneously, the computer programmer would contract a sign-language interpreter to provide SASL translations of each itemized symptom and illnesses in the database. The SASL translation would be video-recorded and added to SignSupport. The practical implications would be that pharmacist would select on SignSupport the text equivalent of *“This medicine is for your...(Illness/symptom name),”* which would then be translated into a SASL video for a Deaf patient to watch and interpret.

When the computer programmer commenced the process of recording sign language videos, a significant setback was encountered. Most of the medical symptoms/illnesses extracted from the Merck Manual to indicate to the patient the purpose of the medicine, could not be translated in SASL because a sign-language translation equivalent 'word' for many symptoms/illnesses simply does not exist. For example, if the pharmacist would select on SignSupport to say to a patient "this is for your auto-immune disease, multiple sclerosis," a sign-language equivalent for the word 'auto-immune disease' or for the word "multiple sclerosis" could not be recorded because these words simply do not exist in SASL vocabulary. The SASL interpreter who was contracted to translate the symptoms/illnesses advised that we adhere to simple symptoms and illnesses that Deaf patients could easily identify with. As a result, the strategy to use the Merck Manual to elicit symptom and illness names was aborted.

The next strategy was to use the Standard Treatment Guidelines (STG) for primary healthcare South Africa (2012). The STG is targeted at doctors and pharmacists who use it as an information resource of the standardised treatment approaches for illnesses and ailments. The STG contains a section "Index of Disease conditions." This was the primary resource for the list of symptoms/illnesses for SignSupport. I compiled the list through consultation with the SASL interpreter who advised us of the symptoms/illnesses for which there was an equivalent SASL translation, or in which cases an alternative could be used. For example, there is no SASL sign for 'peptic ulcer', the interpreter advised we use the word 'heartburn' instead, which she could easily sign to be understood by Deaf people. Table 13 below contains the list of symptoms/illnesses which comprises the database transferred to SignSupport. These are all words which can be translated into SASL to be understood by a Deaf patient.

Table 13: Symptoms and illnesses list for SignSupport

SYMPTOMS AND ILLNESSES		
Arthritis	Kidney problems	Ringworm
Bleeding	Lice, head	Rubella (German measles)
Common cold	Lice, pubic	Scabies
Cough	Malaria	Shock
Diabetes	Measles	Snakebite
Dental problem	Meningitis	Strains and sprains
Ear infections	Mood disorders	Sinusitis
Eye problem	Mumps	STI
Fever	Nappy rash	Tonsillitis and pharyngitis
Heartburn	Nausea and vomiting	Tuberculosis
Heart problems	Nose bleeds	Ulcers, mouth
HIV prophylaxis (PEP)	Pain	Bladder infection
HIV/AIDS	Pneumonia	Vitamin deficiency
Hormone replacement therapy	Prophylaxis in adults	Worm infestation
Hypertension	Prophylaxis in children	
Insomnia	Psychosis	
Itching	Poisoning	
Jaundice	Prevent child transmission of HIV	

6.6.2 Database of medicine names

Findings from the baseline study indicated that Deaf patients have an aversion to complex words including medicine names. Nevertheless, medicine names needed to be included in SignSupport for 2 reasons: (i) for pharmacists to identify which medicines to link their instructions with and (ii) it is both a professional obligation and a healthcare right of the patient to know which treatment they are taking for a particular condition or symptom.

Despite inclusion of medicine names in the prototype, patients would not be put in a position in which they need to identify a medicine by name, which we know they are uncomfortable to do. Instead, the research team overcame this by inserting a feature on SignSupport which requires the pharmacist to take a photograph of each medicine dose unit (for example tablet/capsule). This picture appears immediately prior to the sign language video which instructs the patient on how to use the medicine.

Three considerations were pertinent to compiling the database of medicine names:

1. Use of generic medicine name versus brand name
2. Which medicine names to include
3. Translation of medicine names to SASL

Regarding the decision to use generic or trade (brand) medicine names on the prototype, I decided to use generic names only and exclude brand names. A generic name refers to the active ingredient within a medicine and is typically a universally used name, while trade/brand names are specific to the pharmaceutical manufacturer who is licensed to produce a certain brand of medicine. There are several reasons for the decision to use generic names.

Firstly, SignSupport was intended for use in a public sector pharmacy, where medicines are dispensed using generic names instead of the trade name. To adhere with the norms at public facilities, generic names were selected. Secondly, multiple trade names exist for one generic name, based on how many pharmaceutical manufacturers produce different brands of the same medicine. To simplify the process in which a pharmacist would have to select medicine name, it can logically

be asserted that it is simpler to select an option of one name instead of multiple options. In addition new brands may be manufactured every year, implying that SignSupport would need to be updated continuously. In addition, pharmacists may not be familiar with brand names and would have better familiarity with trade names.

Once a decision was made to use generic names only, a question arose of which medicines would be included on SignSupport. Public sector healthcare facilities procure medicines based on provincial code lists which include all the medicines that may be used in a facility. The first consideration was to include all medicines on the provincial (Western Cape) code list. Problems with this decision were that the code list excludes many medicines which may be added at a later stage, implying that SignSupport would need to be updated. Another issue was that SignSupport was not being developed for the Western Cape Province exclusively; if we chose only medicines on Western Cape code lists then the widespread usability of the prototype would be limited. As a result, I chose to include all medicines, based on generic names that are registered in South Africa by the Medicines Control Council (MCC) of South Africa.

Since medicine names would not be translated to SASL, the problems encountered with sign-language translation of symptoms/illnesses are not applicable. This allowed the researchers to incorporate the MCC list of all generic medicine names. The list was copied directly from the MCC list (Republic of South Africa, 1965) into a Microsoft Excel® and imported into SignSupport. The use of the entire medicines list implies that the application is as inclusive as possible of all medicines that a pharmacist can possibly dispense to a patient in South Africa. As new medicines are added to the MCC list, they will be incorporated into SignSupport as well. Apart from excluding some items from the list (usually chemical entities), there were no alterations in the MCC list. The author has chosen not to include the medicines register in this thesis as it is an exhaustive list, instead it is included as a reference. The list was extracted from the MCC's Consolidated Schedules document. (MCC, 2015).

At this juncture in the study we have added to SignSupport a symptoms/illnesses database and a database of medicine names. Item 5 in the table below is the only component remaining for SignSupport to be complete and is addressed in the next section.

Table 12: Progressive development of SignSupport components

1. Modified communication script	✓
2. Patient general medical history questions	✓
3. Incorporate Deaf user experiences	✓
4. Compile medicine information databases: a. Symptoms and illnesses database b. Database of Medicine names	✓✓
5. Independently verified SASL videos to translate 1, 3 and 4 above into sign language	

6.7 SASL videos for SignSupport

In order to record sign-language videos which translate all the afore-mentioned components into SASL, the computer programmer converted the communication script and symptoms/illnesses database collated by the pharmacist into a series of corresponding sentences which he used as a script for a SASL interpret. Below I provide an example of how a sentence from the pharmacy communication script was converted into a corresponding sentence:

Example of sentence conversion for SignSupport:	
Sentence in pharmacy conversation script:	<i>May I see your patient card?</i>
Corresponding sentence for SASL video:	<i>The pharmacist would like to see your hospital card. Please show it to him/her.</i>

The interpreter read each corresponding sentence in the script, and then signed the equivalent sentence in SASL. The computer programmer recorded (video) a SASL

translation for each sentence. As a result, each sentence has an equivalent sign-language video which was then programmed into SignSupport. The author's role during this process was to advise whether the script made sense, whether it was presented in an acceptable order and adequately reflected the communication script elucidated from the dialogue patterns. This led to the next empirical activity which involved testing the videos for correctness and accuracy. We called this activity 'video verification testing,' and it was conducted by the computer programmer and me, the author of this dissertation. I present the study below.

6.7.1 Video verification testing

SignSupport is a system which is intended to convey medicine instructions to a Deaf patient in sign-language videos. To ensure safety and efficacy, medicine instructions require a hundred percent level of accuracy with no compromises. If the sign-language videos were not accurate, or did not communicate what we expected it to communicate, a patient would receive incorrect information which may have potentially dangerous consequences. To avoid this risk, it was important to verify that the videos articulate that which we expect of them. The computer programmer and myself, the pharmacist, had different perspectives in testing the videos. As a result, during the process of testing the videos, they investigated different parameters. The different approaches of the pharmacist and computer programmer to video verification testing are presented below:

Pharmacist: Do the SASL videos articulate what we expect them to say in terms of medicine instructions?

Are they sufficiently accurate for medicine instructions?

Computer programmer: Are all the videos contained in the SignSupport system?

Are the videos in the correct place on the application?

Do the SASL videos match the script?

The collaborative aim of video verification testing is to ensure that SignSupport provides accurate information to the Deaf patient. The pharmacist's and computer programmer's perspectives to address the above will uncover any errors on SignSupport with regard to translation of the medicine instructions from text format into SASL.

6.7.1.1 Research objective linkage

Video verification testing was conducted in order to achieve the research objective 4 presented in chapter 3:

- To verify that recorded SASL videos incorporated into SignSupport communicate the medicine-related information correctly and accurately.

A specific research question relating to the aforementioned objective is:

- Are sign-language translation videos able to accurately and effectively translate medicine instructions to a Deaf patient in a way that is understandable for the patient?

6.7.1.2 Study site and participant

Video verification testing was conducted at the DCCT, Heathfield in Cape Town. The only participant was a certified SASL interpreter affiliated to DCCT. Since she was not the same interpreter who was initially contracted to record the SASL translations and had no prior involvement in the study, video verification was thus conducted independently. The researchers were the pharmacist and computer programmer members of the multi-disciplinary team. As is often the case with qualitative research, the researchers were also participants in the empirical activities.

6.7.1.3 Methodology

Video verification testing was both qualitative (observations of the SASL interpreter and role-plays) and PAR (contribution of the SASL interpreter with regards to the best way to express sentences in the dialogue in sign-language). Video verification testing occurred in three separate ways; all tested the same afore-mentioned parameters of accuracy, correctness, and position on the prototype.

The first manner of testing involved basic playing of SASL videos, which the SASL interpreter translated into English. The second and third testing activities involved role-plays to simulate how a Deaf patient and pharmacist would use SignSupport in a real-world context. The testing procedures are described in the 'study procedure' section.

6.7.1.4 Materials and resources

The following were essential to the video verification testing experiment:

1. A computer (laptop)
2. Computer screens (x 2)
3. Pre-recorded SASL videos
4. A mobile phone (Android smartphone) on which SignSupport is installed
5. A video recorder
6. A conversation script (from the computer programmer)
7. Mock prescriptions
8. A certified South African sign-language (SASL) interpreter

6.7.1.5 Study procedure

The main purpose of this study task was to run the SASL videos on SignSupport for an interpreter and have her translate the SASL videos into English. This was achieved by conducting the following three video-verification tests:

- i. SASL interpreter translates played SASL videos into English
- ii. Role-play: the SASL interpreter assumes the role of a Deaf patient attempting to retrieve medicine instructions on SignSupport and translates the videos she encounters into English
- iii. Role-play: dispensing role-play during which a pharmacist enters mock prescriptions presented by the patient (played by the SASL interpreter) into SignSupport. The patient (SASL interpreter) retrieves the instructions and translates it into SASL, comparing it to the instructions on the mock prescription

All testing was conducted in the course of one day. The procedure for each video verification process is described below.

The first test involved playing the videos for the interpreter who voiced the content of the video in English. The researchers recorded whether the video was accurate by passing or failing the video based on its comparison to the English script. The procedure followed is described in steps 1-7 below:

- Step 1: All SignSupport SASL videos are uploaded onto a computer which is situated on desk. The computer screen is connected to a second screen on the opposite side of the desk for the interpreter to watch.
- Step 2: The SASL videos are played for the interpreter to watch on the opposite screen.
- Step 3: The interpreter verbally translates the SASL video content into English for the researchers.
- Step 4: While the interpreter voices the English translation, the researchers look at the corresponding English sentence on the script in order to compare what the interpreter is saying to what we want her to say.
- Step 5: If a match is found in step four we 'pass' the video; if the interpretation does not match we 'fail' the video. The result for each video is recorded on a checklist.
- Step 6: We also document comments from the interpreter on how some of the content could have been expressed in sign language in a better manner.

Step 7: We repeat Step 3 to Step 6 till we have viewed and ticked off all the videos that are on the system.

The second video verification procedure comprised a role-play exercise. In this role-play, the interpreter was asked to assume the role of a Deaf person who retrieves medicine instructions from SignSupport. The researchers navigated the SignSupport screens together with the interpreter. Each time a SASL video was encountered, the interpreter provided the corresponding English translation for the video and we confirmed that the video content is accurate and appears in the correct order. The procedure followed is described in steps 1-4 below:

Step 1: A SASL interpreter is asked to simulate a Deaf patient who is viewing instructions for his/her medicines on SignSupport.

Step 2: The interpreter is required to navigate through the SignSupport screens in the same way a Deaf patient would when receiving instructions from a pharmacist.

Step 3: The interpreter provides the English translation of each video.

Step 4: The researchers confirm the correctness and accuracy of the video by passing or failing the video on a checklist.

The third video verification procedure was conducted to simulate the real-world application of SignSupport in which a Deaf person collects medicines at the pharmacy and the pharmacist provides medicine instructions for the dispensed medicines using SignSupport. For use during the role-play, I prepared mock prescriptions that cover all the possible medicine instructions on SignSupport and permutations of these instructions. Prescriptions were selected randomly. The pharmacist entered the medicine instructions corresponding to the selected prescription. The SASL interpreter was asked to view the corresponding SASL videos on SignSupport and interpret it in English. In this experiment, researchers were testing whether the English text selections made by the pharmacist are consistent with the medicine instructions being given on the videos (researchers also referred to the conversation script for confirmation). The procedure followed is described in steps 1-7 below:

- Step 1: Prepare mock prescriptions which cover all possible prescription permutations on SignSupport.
- Step 2: Select prescriptions randomly.
- Step 3: A pharmacist enters medicine instructions on a mobile phone containing SignSupport software.
- Step 4: The pharmacist hands the phone to the SASL interpreter to view and interpret the medicine instructions selected by the pharmacist.
- Step 5: The SASL interpreter translates the selected medicine instructions in English.
- Step 6: The researchers compare the English translation to instructions on the prescription. If a match is found we 'pass' the video; if the interpretation does not match we 'fail' the video. The result for each video is recorded on a checklist.
- Step 7: Repeat Step 3 to Step 6 for each selected prescription.

6.7.1.6 Data analysis

Data was input into a Microsoft Excel® spread sheet and frequency scores were tallied for videos that passed the video-verification procedures and videos which were considered unusable for SignSupport (failed the verification procedures). The failed videos were classified as being ambiguous, unclear or unsuitable.

6.7.1.7 Results and Discussion

During the video verification procedure, 180 videos were recorded in total. Of the 180 videos, 35 videos were found to be unsuitable and were rejected for use in SignSupport. Reasons for rejection of videos included ambiguity, poor video clarity or incorrectness. These videos were subsequently re-recorded and tested in the same video verification procedure.

Videos that were of poor clarity were unclear due to lighting or that one could not clearly see the sign-language hand signals. Videos that were incorrect means that the translated English meaning did not match the meaning intended on the conversation script. For example, the illness of 'worm infestation' was translated by the interpreter as 'an acidic stomach'. Of the total number of videos, 47 were videos explaining the medical condition/symptom that the medicine was intended for. Of these 47 videos, nine were incorrect as a consequence of the limited medical vocabulary in sign-language. Many illnesses simply do not have a SASL equivalent 'word.' The SASL interpreter suggested that more time be spent to explain the condition in a way that a Deaf person could understand. This implied longer videos, which in turn implied more storage capacity on the phone. At this stage, the researchers were unsure of the feasibility of this suggestion.

Videos that were classified as ambiguous were mostly those that dealt with the frequency of taking medicines. For example, the instruction to "take 1 tablet 6 hourly after meals" was interpreted as "Take 1 tablet after meals after that every 6 hours and after that 6 hours and after that 6 hours and after that 6 hours." Similarly, the instruction to "take one tablet once a day after a meal every 24 hours" was translated as "take 1 tablet every morning after meals and after 24 hours and after 24 hours and after 24 hours". The repeated hourly instruction is due to the way that Deaf people indicate time, using a motion that involves moving their forearms and hands (from the elbow to the fingertips) in a clockwise fashion to represent time on a clock, This was found to be problematic for the 6 hourly and 24 hourly instructions but not for any other time connotation.

All 35 videos that were incorrect were discarded and subsequently re-recorded. Medicines instructions require a high level of accuracy and risks of a patient misunderstanding the instructions must be eliminated. The 145 remaining videos "passed" all of the three verification tests and were assessed by the computer programmer to appear in the correct place on SignSupport. These videos were consistent with the communication script and were used in SignSupport.

6.7.1.8 Conclusion

Although the task of modifying the original communication script arose from a conflict situation, the altered script suited the technological and communication features of SignSupport well. Apart from discarding non-essential sentences, the relocation of the patient's background information to a section where Deaf people are personally responsible for uploading their past medical information may empower them to feel more in control of their own healthcare. In addition, the researchers were able to include Deaf user experiences gleaned from the focus groups and key informant interviews and incorporate it into SignSupport in a manner that is potentially meaningful for Deaf patients.

Professional requisites for pharmacists including databases of symptoms/illnesses and medicine names were elicited in a way that is suitable for Deaf patients by avoiding medical jargon and the use of colour identification of medicines. In the compilation of both databases, researchers were cognisant to be as inclusive as possible, of both Deaf community needs and professional pharmacy stipulations.

Video verification testing concluded that most of the SASL videos were correct and ready to be used in SignSupport. The majority of videos were understood immediately and without hesitation. Those that were not understood immediately were rejected, re-recorded and tested in the same manner. The outcome was a complete set of videos to be incorporated in SignSupport.

Table 12: Progressive development of SignSupport components

1. Modified communication script	✓
2. Patient general medical history questions	✓
3. Incorporate Deaf user experiences	✓
4. Compile medicine information databases: a. Symptoms and illnesses database b. Database of Medicine names	✓✓
5. Independently verified SASL videos to translate 1, 3 and 4 above into sign language	✓

At this stage in the thesis, I have presented all the components that were required to develop SignSupport. These components, itemised above in Table 12 culminate in the final collation and programming of SignSupport which I present in the next section.



SECTION B: PRESENTING SIGNSUPPORT

In this section SignSupport is presented as an assistive technological device which can potentially bridge the communication gaps between Deaf patients and pharmacists during patient counselling. I commence by providing a brief recap of SignSupport specifications alluded to in preceding chapters. The format of SignSupport including how it is structured specifically to suit the needs of each user group (Deaf persons and pharmacists) is described together with a synopsis of the contents of SignSupport. A chronological and pictographic illustration of SignSupport with screenshot pictures of how the application appears on a mobile smartphone closes this chapter.

6.8 Recap of SignSupport specifications

In building SignSupport, the researchers agreed upon a number of specifications which defined the format and style of SignSupport. These include:

1. SignSupport comprises a text-based English format for pharmacists, and an exclusively SASL format for Deaf people.
2. The mobile phone onto which SignSupport is installed as an application, is intended to belong to the Deaf patient, who takes it along to the pharmacy on the day they that they collect medicines.
3. SignSupport has been developed for the circumstance in which medicine is dispensed in accordance with a prescription from an authorised prescriber at an institutional pharmacy. It has not been developed for medicines dispensed on an OTC basis or for in-patient hospital use.
4. SignSupport has been built on an Android smartphone with touch-screen capability, and is compatible with most smartphone technology. During the research we have used Samsung Galaxy S2®, Samsung Galaxy S4®, Samsung Galaxy S5® and Huawei P7® phones.
5. SignSupport will include a Skype®-call feature which will be activated in the event of a critical communication situation of communication breakdown during the pharmacist-Deaf patient interaction. This feature is wholly the responsibility of the computer-science team member.

6.9 Description of SignSupport

SignSupport comprises three main sections; (i) Background (patient profile), (ii) Pharmacist's interface and (iii) Deaf patient interface. Collectively, these three sections contain all the previously elicited components of SignSupport. Below is a description of the three sections.

6.9.1 Background setup (Patient profile)

This section is for the Deaf patient and contains 18 short sign language videos which function to elicit general medical history from a Deaf user. Earlier, during compilation of the communication script for SignSupport, the general medical history questions extracted from the dialogue patterns were removed and relocated to the 'patient profile setup' position on SignSupport. This allows a Deaf patient to upload and update their medical history before approaching the dispensary counter. Since all the questions are presented as SASL videos, the Deaf patients are capable of entering the information according to sign-language prompts. Consequently, the pharmacist is able to see the weight, whether the patient has a food or medicine allergy, is using any concomitant medicine therapy, or smokes and uses alcohol at the dispensing point and before providing medicine instructions.

6.9.2 Pharmacist user interface

The pharmacists' user interface contains only English text and is seen and used solely by a pharmacist to select medicine instructions from a touch screen menu which is structured to resemble a logical dispensing sequence. The screens encountered by the pharmacist in chronological order include:

- a. A general menu screen which contains an icon for the pharmacist and a separate icon for a Deaf patient. To access their interface, pharmacists would touch on the icon which represents a pharmacist.
- b. A password screen, using the pharmacist's registration number with the SAPC as the password. This was done to ensure that non-pharmacists

could not enter medicine instructions, thereby ensuring a level of patient security and safety.

- c. An introduction screen which directs the pharmacist to commence the interaction with the Deaf patient.
- d. A screen prompting the pharmacist to establish that the patient's identification card matches the patient's details on the prescription.
- e. A screen entitled 'Get ready to dispense.' This screen prompts the pharmacist to check where the prescription contains 'conflict,' the conflict being a drug-interaction, a contra-indication, insufficient information on the prescription or any other situation which would cause the pharmacist to not dispense the medication. In the event that a conflict is found, the pharmacist selects 'X' on the screen, which plays a SASL video directing the patient to either (i) wait at the counter while the pharmacist resolves the issue; (ii) go back to being seated in the waiting room or (iii) return to the doctor to rectify the error. Alternatively, the pharmacist does not find a conflict and selects '✓' on the screen. This allows the pharmacist to proceed to the next screen for dispensing.
- f. A 'Patient Background' screen where the pharmacist can view the patient's profile including general medical history.
- g. A screen prompting the pharmacist to select the symptom /medical condition corresponding to the medicine being dispensed.
- h. A screen prompting the pharmacist to select whether the treatment is acute or chronic.
- i. A screen prompting the pharmacist to select the medicine name from a pre-loaded drop-down tab.
- j. A screen prompting the pharmacist to take a photograph of the dose unit (tablet/capsule) and medicine package for the patient to identify when taking the medicine.
- k. A series of screens pertaining to medicine instructions (dose, frequency, time of administration and duration of treatment).

- l. Screens prompting the pharmacist to select pre-loaded warnings (e.g. do not use alcohol while taking this medicine and recommendations (e.g. take the medicine at the same time every day.)
- m. A menu screen which presents options to (i) review the selected instructions; (ii) dispense another medicine, or (iii) close and save the selected instructions.
- n. On the afore-mentioned review screen, the pharmacist is given a summary of all the selected instructions and is able to view in text, that which will be communicated to the patient in sign-language.
- o. The final screen prompts the pharmacist to hand the phone back to the Deaf patient, who is able to view all the selected instructions on a sign-language video.

6.9.3 Deaf user interface

This section contains a total of 170 sign-language videos, permutations of which match the medicine instructions selected by the pharmacist. In addition, a photograph of the medicine is stored for the Deaf patient to view together with the instructions corresponding to the medicine in the photograph. In addition, Deaf patients are able to protect the confidentiality of their information through setting a password, and are able to program reminders on the phone that correspond to medicine administration times.

6.9.4 Real-world application of SignSupport

As previously mentioned, SignSupport was developed to facilitate medicine instructions between a pharmacist and a Deaf patient in accordance with a prescription from a public sector institutional pharmacy. SignSupport is installed onto the Deaf patient's phone, who, when called to collect their medicines, approaches the pharmacist with the phone in hand. The phone is handed to the pharmacist in order to commence the patient counselling process. Figure 18 below provides a pictorial illustration of how SignSupport will be used by a Deaf person and a pharmacist at an institutional public sector pharmacy.

Figure 19 depicts be a stepwise annotated pictorial illustration of the pharmacist interface on SignSupport. I have not included the Deaf interface for two reasons (i) the scope of this thesis was to provide pharmacy perspectives in the development of SignSupport; the Deaf interface was the scope of the industrial design engineer and computer programmer, and (ii) the Deaf interface comprises a series of SASL videos; a reader would not be able to interpret these pictures and would thus be redundant in this dissertation. I do however; include examples of the Deaf interface where appropriate. In addition, green arrows are used in the illustration to depict a forward progression on SignSupport, while red arrows indicate that the pharmacist stops navigating the application. Multiple coloured arrows are used to indicate several selections from one screen.



Figure 18: Application of SignSupport in an institutional pharmacy

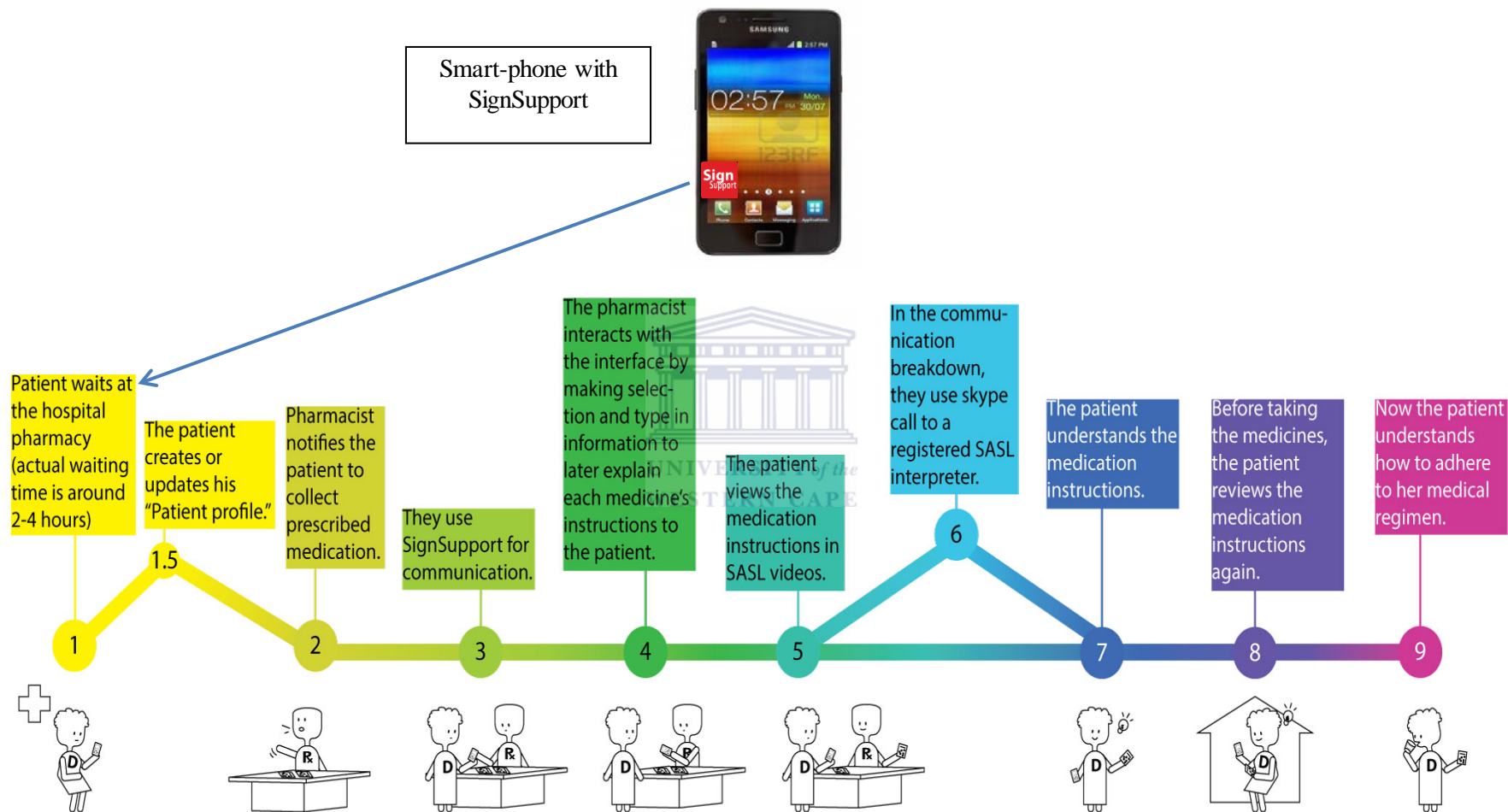
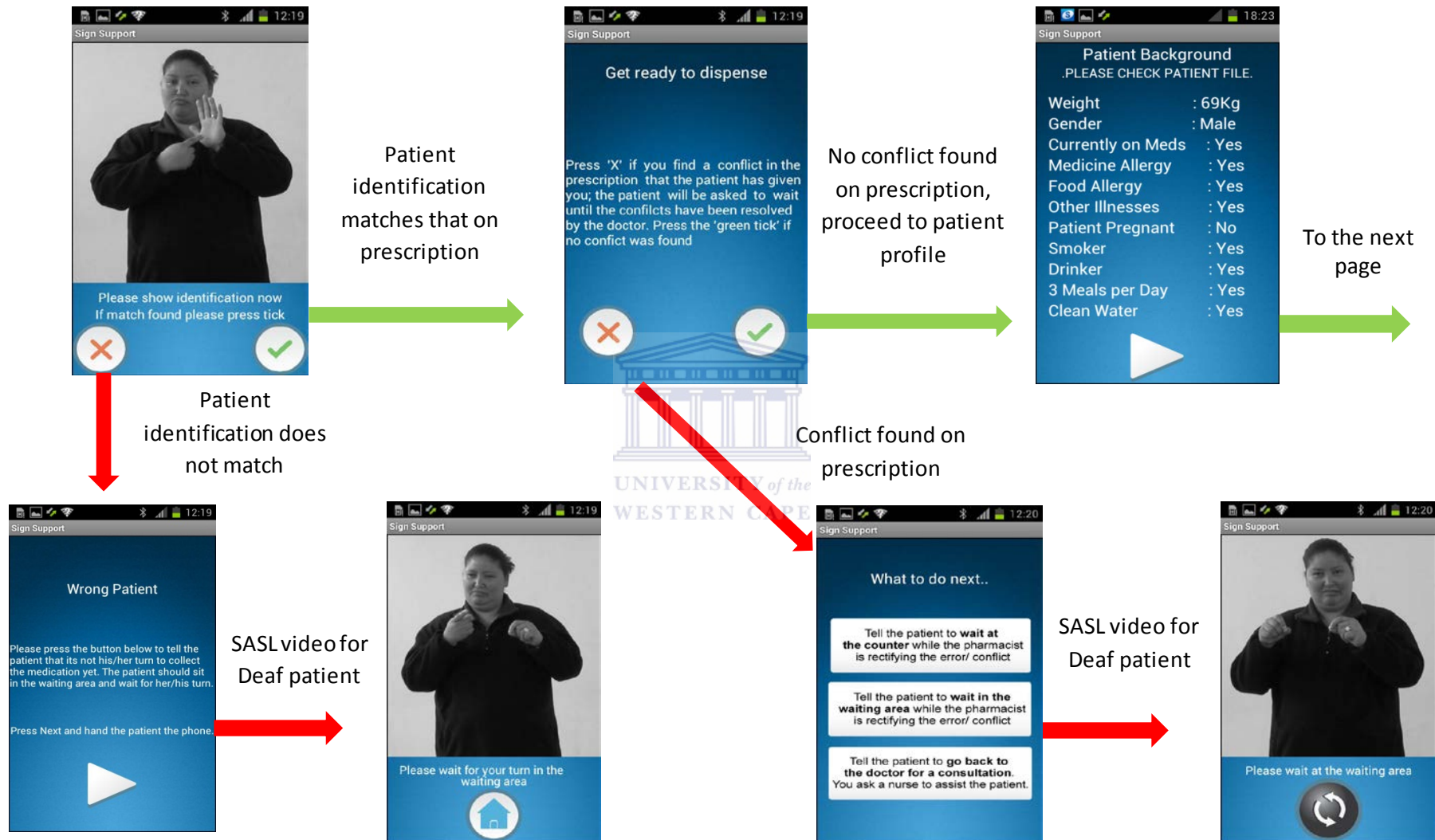
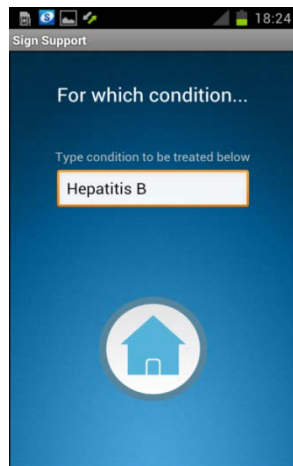


Figure 19: SignSupport communication flow: Pharmacist interface

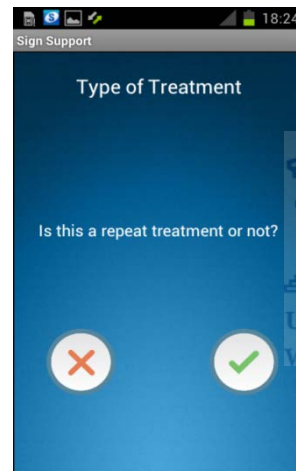




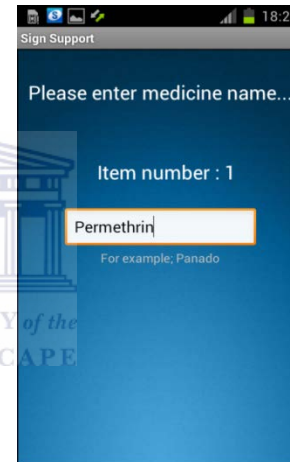
Pharmacist enters the symptom/medical condition



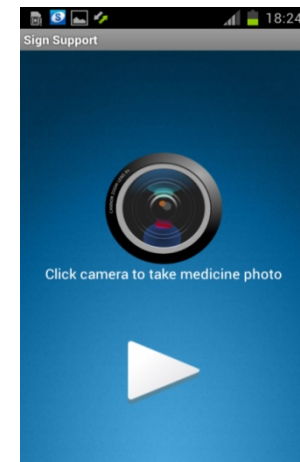
Pharmacist selects whether the treatment is acute or chronic



Pharmacist enters first two letters of the pre-loaded medicine names



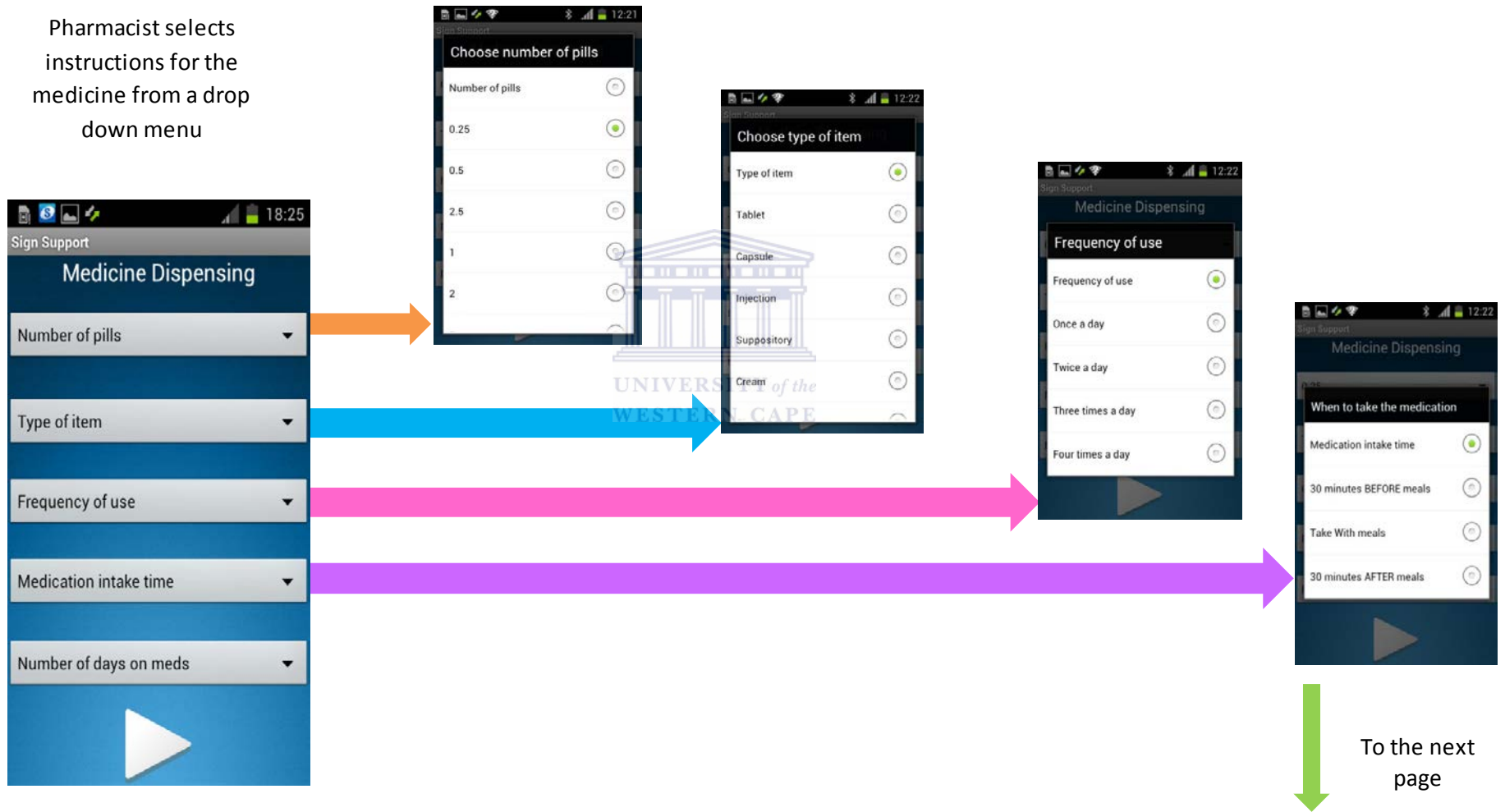
Pharmacist takes a photograph of the medicine dose unit for the patient to identify



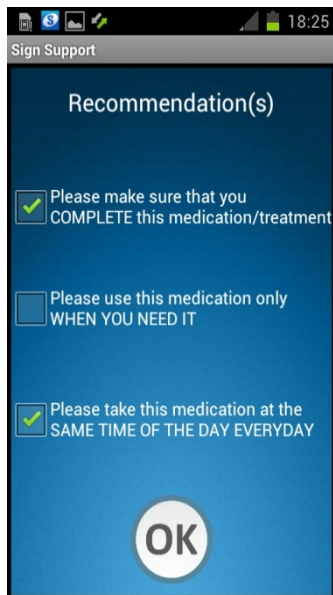
To next page



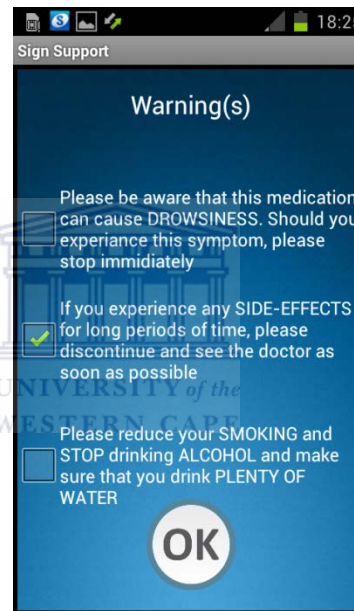
Pharmacist selects instructions for the medicine from a drop down menu



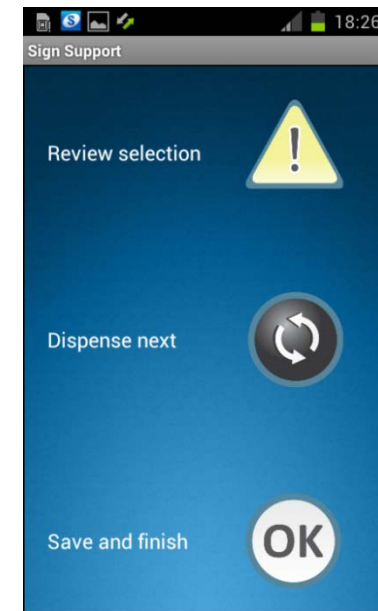
Pharmacist selects the appropriate recommendations



Pharmacist selects appropriate warnings

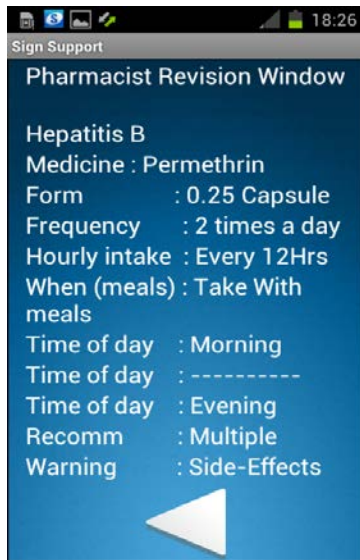


Pharmacist selects the appropriate item on the menu screen

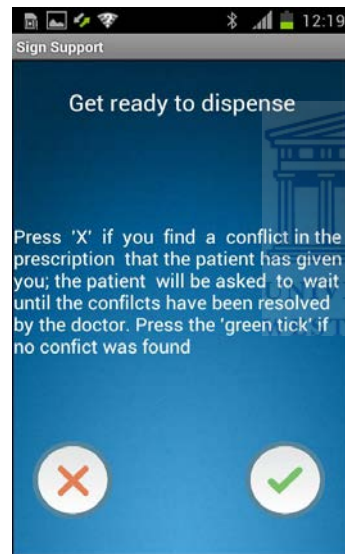


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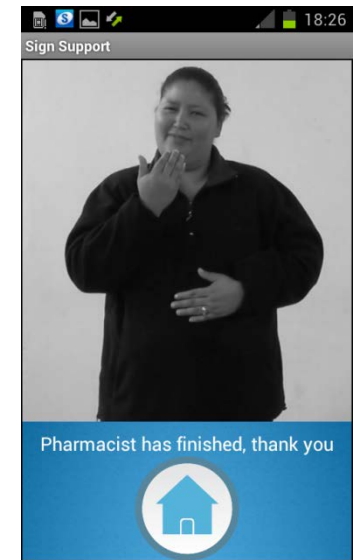
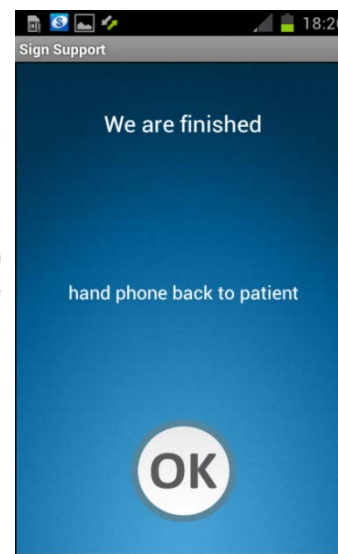
This screen appears when pharmacist selects 'Review selection'



This screen appears when pharmacist selects 'Dispense next'



These screens appear when pharmacist selects "Save and finish"



This is the end of the pharmacist interface. Videos are now available to be viewed and interpreted by the Deaf patient.

CHAPTER SEVEN

RESULTS AND DISCUSSION: POST-INTERVENTION STUDY

The preceding chapter presented the first complete version of SignSupport. This chapter presents the evaluation of SignSupport in terms of participant experiences of the usability and acceptability to pharmacists and the Deaf community in a dispensing context. This was achieved by way of two experimental procedures, presented within the chapter as Section A (Pilot study) and Section B (Hospital study) respectively.

In the pilot study, SignSupport was tested in a simulated dispensary where a pharmacist dispensed medicines to a Deaf patient using SignSupport to communicate medicine instructions. During and after the pilot experiment, participants were asked to assess how they had experienced SignSupport and whether they had any suggestions for improvement of the application. This data culminated in the first design iteration which modified SignSupport by incorporating feedback and suggestions from the pharmacist and Deaf patients.

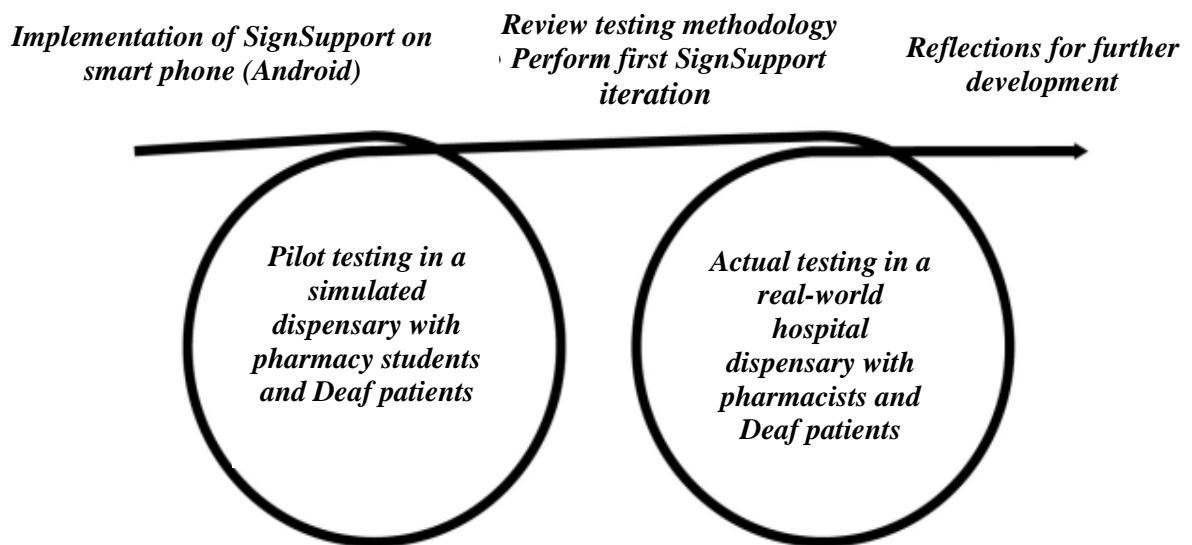
The hospital study implemented the pilot study in a public hospital pharmacy in Cape Town, where pharmacists employed at the pharmacy dispensed medicines to Deaf patients using SignSupport. In line with the iterative process, data was once again collected to ascertain how users experience SignSupport and whether they had suggestions for improvement. This data culminated in the second design iteration. Each experiment is described in terms of actual sample, study site, materials and methodology, study procedure, results and discussion of findings. The chapter brings to close the empirical activities of this thesis.

SECTION A: SIGNSUPPORT EVALUATION: PILOT STUDY

At this stage of its developmental trajectory, SignSupport is a fully operational prototype which has the capability to facilitate the communication of medicine instructions (for oral solid dosage forms) from a pharmacist to a Deaf patient. Logically, the next step would be to introduce the prototype to pharmacists and Deaf persons and evaluate it in the context for which it is designed. This would allow the researchers to assess how users experience SignSupport and whether they are receptive to using it. User feedback is crucial for the iterative process as subsequent modifications to SignSupport would be based on such feedback.

The research team unanimously agreed that SignSupport was ready to be tested with pharmacists and Deaf people. It was thus decided to conduct a preliminary evaluation in a simulated dispensary in order to learn an appropriate experimental procedure for testing the prototype. This preliminary testing would constitute the pilot usability experiment. If the pilot study was found to be feasible in terms of experimental procedure, the same experiment would be applied in a real-world hospital dispensary. Subsequent to each experiment, SignSupport would be modified by incorporating user feedback from the experiment. Such iteration would establish the next version of SignSupport which would subsequently be subjected to the same experimental conditions. The iterative process for evaluating SignSupport is represented in Figure 20 below:

Figure 20: Iterative process for evaluation of SignSupport



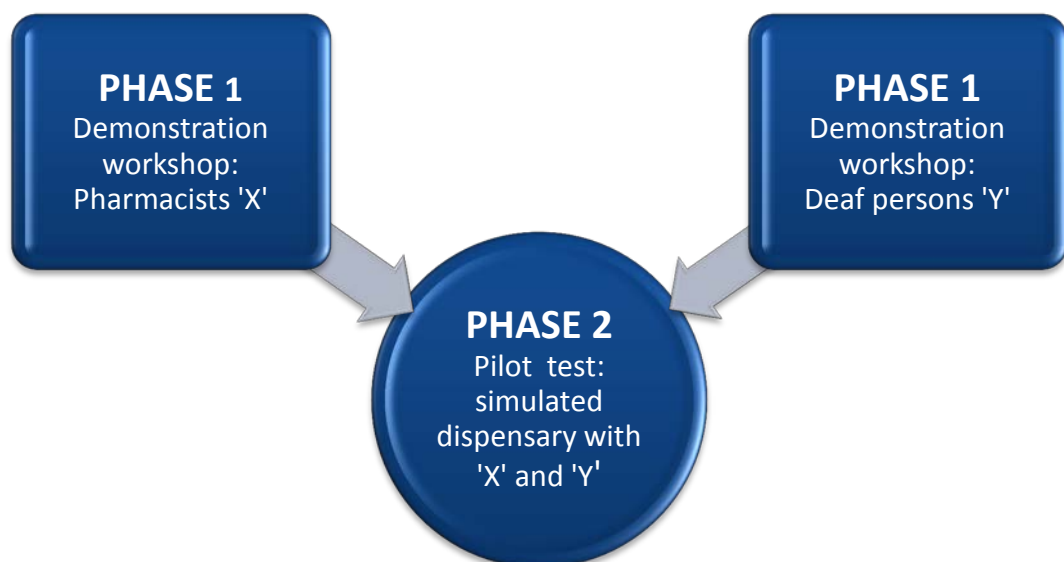
This chapter presents two usability evaluations of SignSupport: (i) a pilot study in a simulated dispensary and (ii) a hospital study in a real-world hospital pharmacy. The hospital study was based on the pilot study; thus the experimental procedures were reasonably similar. The two evaluations differed however, in terms of study sites and participant profile. Below I discuss the pilot study in terms of research objective linkage, study site and participants, methodology, materials, study procedure and results and discussion. Subsequently, the hospital study is described in the same succession.

7.1 Usability evaluation 1: Pilot study in a simulated dispensary

The pilot study was conducted for two reasons: (i) to determine an appropriate experimental procedure for testing SignSupport with Deaf people and pharmacists in a dispensary context and (ii) to obtain preliminary results with regard to how the users (pharmacists and Deaf patients) experience SignSupport. Pilot testing required two research phases. The first phase involved a demonstration workshop each for pharmacists (participant group ‘X’) and Deaf persons (participant group ‘Y’) to introduce and demonstrate SignSupport. The aim of the demonstration workshops for pharmacists and Deaf participants was to present SignSupport to

both groups and allow them to ‘play’ with the application in order to establish familiarity therewith. A level of familiarity was necessary for the second phase, during which the same pharmacists and Deaf persons who participated in the workshops would also participate in the usability experiment. If participant familiarity with SignSupport was not established, it could reasonably be expected that participants would fumble and hesitate during the experiment because it would be the first time they would have seen the application. This could potentially influence usability results. I led the demonstration workshop with pharmacist and this is discussed in this chapter. The computer programmer led the workshop for Deaf participants which occurred parallel to the pharmacists’ workshop. In this thesis the Deaf participant workshop alluded to but not discussed in terms of results as it is not within the scope of this research (my focus was the pharmacist’s perspective). These workshops ran parallel to one another and culminated in phase 2, which entailed testing SignSupport in a simulated dispensary with the same participants (‘X’ and ‘Y’) from phase 1. Figure 21 below illustrates the study design.

Figure 21: Study design for usability evaluation 1



Phase 2, which comprised the experimental phase was set up in a simulated dispensary and involved a role-play exercise to replicate the scenario in which a

Deaf patient collects medicine from a hospital pharmacy, except that in the role-play, the pharmacist would use SignSupport to communicate medicine instructions to the Deaf patient. This experiment was conducted subsequent to and in the same week as the demonstration workshops. The reason for doing so was that the literature review revealed that Deaf persons may have problems with memory and recall. In order to ensure the afore-mentioned familiarity of Deaf participants with the application it was essential to conduct the experiment in a close time-proximity to the demonstration workshops. Both research phases of the pilot experiment are described below.

7.1.1 Research objective linkage

The pilot user experimentation was conducted in order to achieve research objective 5 presented in chapter three:

- To iteratively test SignSupport with Deaf persons and pharmacists to assess their acceptability and usability thereof.

The following aims were necessary in order to achieve this objective:

1. To design a Microsoft PowerPoint® presentation for use in the demonstration workshop for pharmacists.
2. To conduct a pilot demonstration workshop with pharmacist participants.
3. To conduct a pilot experiment with pharmacist participants and Deaf patients in a simulated functional dispensary.
4. To qualitatively assess the usability of application for pharmacists and Deaf users.
5. To evaluate feedback from the pharmacists on the use of the mobile application.

7.1.2 Study site and participants

The study involved two participant groups; (i) senior pharmacy students (n=8) to represent pharmacists and selected on the basis of a convenience sampling strategy,

and (ii) Deaf persons (n=8) who are familiar with the medicine dispensing process at public health facilities in Cape Town and selected on the basis of a purposive sampling strategy. Inclusion criteria for the pharmacy students include:

- a. That participants are final year pharmacy students
- b. That participants have experience in dispensing in a public hospital pharmacy environment
- c. That participants are unable to communicate in SASL

Inclusion criteria for Deaf participants include:

- a. That participants are Deaf in terms of the definition presented in chapter 3
- b. That participants are affiliated with the DCCT from which consent was obtained to access the Deaf community
- c. That participants must all have had experience in using medicines

Participation in the study was voluntary and all participants were informed of study details and expectations via participant information documents (Appendices I, J, K, L). Participants were asked to indicate their informed consent (Appendices J and L). A registered SASL interpreter was used to translate the participant information and consent documents into sign language for the Deaf participants who indicated informed consent by raising their hands. This indication of agreed participation was video recorded.

The demonstration workshop for pharmacy students and the pilot experiment both occurred at UWC's School of Pharmacy. The workshop occurred in the school's seminar facility and the pilot experiment occurred in the pharmacy practice laboratory which was set up to simulate a hospital pharmacy dispensary. This included setting up a computer with dispensing software, placing health-promotion posters in the 'pharmacy' area, and positioning pharmacy-related paraphernalia on the 'dispensary' counters (tablet counters, typical reference books kept in a pharmacy). In addition, a patient waiting area was set up in close proximity to the dispensary to mimic a waiting area at a hospital pharmacy. Figure 22 below illustrates the simulated dispensary that was created for the pilot study.

Figure 22: Simulated dispensary for the pilot study



7.1.3 Methodology

Pilot evaluation of SignSupport employed both qualitative and PAR methodologies. Qualitative techniques included demonstration workshops, role-play exercises and video observations of pharmacy students and Deaf participants during the role-plays in which pharmacy students were asked to dispense prescription medicines to Deaf patients using SignSupport. PAR methods comprised contributions of the pharmacy students, Deaf participants and SASL interpreters with regard to their input for conducting the experiment and suggestions for modifying SignSupport. Both methods were incorporated in a community-based co-design strategy which facilitates the participation of multiple groups toward crafting a solution that suits their varying needs. The first research activity comprised the demonstration workshop for pharmacists followed by the second research activity which was the user experiment in a simulated dispensary.

7.1.4 Materials and resources

The following materials/resources were used in the two research activities: demonstration workshop and pilot experiment respectively:

DEMONSTRATION WORKSHOP	PILOT EXPERIMENT
1 laptop computer	A simulated dispensary
Microsoft PowerPoint® software	Video cameras on tripod stands x 4
SignSupport demonstration presentation	Mock prescriptions
8 Samsung® Galaxy SII phones on which SignSupport is installed	Medicines: amoxicillin, paracetamol, indomethacin
A digital projector	Mock patient folders
	Chairs for the patient waiting area
	SASL interpreters x 2

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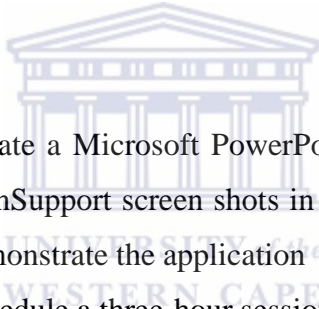
7.1.5 Study procedures

Separate procedures are described for the demonstration workshop and pilot experiment.

7.1.5.1 SignSupport demonstration workshop for pharmacists

To conduct the demonstration workshop, I created a Microsoft PowerPoint® presentation (Appendix O) which incorporated screenshots from the SignSupport application as they were presented in the preceding chapter. Screenshots refer to images of the application on the phone in the same way that it would appear to the user when they are working with the application. The screenshots were placed in a step-by-step format to illustrate how the application should be used.

The demonstration workshop was conducted over a three-hour session. During the first forty-five minutes, the PowerPoint® slides were presented, after which students navigated through the screens on SignSupport in a stepwise process (the next forty-five minutes). Thereafter, the students were asked to pair with a partner and practice in a role-play format by using SignSupport to communicate medicine instructions (one hour). During the role-plays, each pharmacy student took a turn to act as both the pharmacist and the Deaf patient. Feedback regarding the interface, usability and functionality of the application was taken both by covert observation and in a group feedback session (thirty minutes) which concluded the workshop. Recommendations from the pharmacy students for future modification were also noted. Steps 1 – 13 below describe the sequential process pertaining to the demonstration workshop for pharmacists.

- 
- Step 1: Create a Microsoft PowerPoint® presentation incorporating SignSupport screen shots in a sequential stepwise fashion to demonstrate the application
- Step 2: Schedule a three-hour session with pharmacy students during which to conduct the demonstration workshop
- Step 3: On the workshop day, seat all participants in a venue with a laptop and digital projector
- Step 4: Project the afore-mentioned PowerPoint® presentation to conduct the demonstration presentation.
- Step 5: Hand each pharmacy student participant one Samsung® Galaxy phone on which SignSupport is installed.
- Step 6: Allow participants time to ‘play’ with the application on the phone.
- Step 7: Once participants have indicated that they have had enough time to explore the application, ask them to partner with another participant to form a pair.

- Step 8: Ask the participants to role-play by pretending that one participant is a pharmacist and another is a Deaf patient to whom the pharmacist is dispensing medicines.
- Step 9: The ‘pharmacist’ pretends to dispense medicines to the ‘patient’ using SignSupport.
- Step 10: The pharmacist and patient switch roles and repeat step 9.
- Step 11: Repeat steps 8-10 at least three times.
- Step 12: Conduct a group feedback session and record participants perceptions of their experience in using SignSupport, feedback and suggestions for modification/improvement.
- Step 13: Conclude the demonstration workshop by thanking participants for their time.

Subsequent to the demonstration workshop and within the same week, the computer programmer conducted a similar demonstration workshop with the Deaf community. Two days thereafter the pilot experiment ensued. The study procedure for the experiment is described in the next instalment.



7.1.5.2 Pilot experiment: SignSupport usability

The pilot experiment occurred three days after the demonstration workshop for pharmacists. To conduct the pilot experiment, a simulated dispensary was set up using various pharmacy-related items to mimic a real-world dispensary setting. The simulated pharmacy included a patient-waiting area, dispensary counter, a computer with dispensing software and several typical pharmacy paraphernalia. Each pharmacy student dispensed one mock prescription to a Deaf patient by using the SignSupport application as demonstrated in workshop.

Video cameras recorded the dispensing interaction between the pharmacy student and Deaf patient from various angles, positioned to capture closely the hand-coordination of the pharmacist-user with the application, and the facial gestures of the Deaf patient to indicate acceptability and understanding of instructions given. After

all participants had completed their duties a short group interview was held between the pharmacy students, Deaf participants, study project members and interpreters in order to obtain feedback on the experience with regard to the usage of SignSupport . Thereafter, pharmacy students and Deaf participants were each asked to complete a short questionnaire (Appendices M and N) regarding their opinion of SignSupport. Deaf participants completed their questionnaires with assistance from the SASL interpreters. Steps 1-13 below describe the sequential process pertaining to the pilot usability experiment.

- Step 1: Set up a simulated dispensary and patient waiting area to resemble a pharmacy and patient waiting area at a public hospital pharmacy
- Step 2: Schedule an experiment day with Deaf persons and pharmacy students.
- Step 3: Prepare mock prescriptions and mock patient identity cards. Place the mock prescriptions on the dispensary counter ready to be dispensed by the pharmacy students. Collate the medicines corresponding to the prescriptions and place it in the mock dispensary.
- Step 4: On the experiment day, ask Deaf participants to be seated in the patient waiting area and hand each participant a mock patient identity card and one Samsung® Galaxy smart-phone on which SignSupport is installed.
- Step 5: Ask Deaf participants to input their general medical history on the background information screen as they have been demonstrated to do by the computer programmer during their demonstration workshop.
- Step 6: Direct pharmacy students to take a turn to, one at a time, behind the dispensary counter, at the computer to get ready to dispense one of the prescriptions placed on the prescription counter.

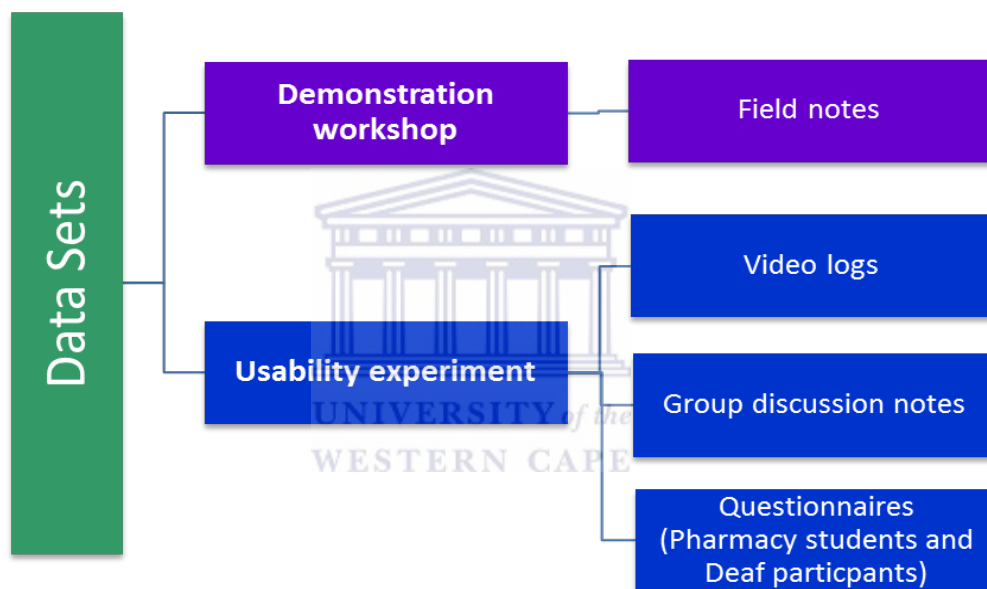
- Step 8: Each pharmacy student processes a prescription and selects and labels medicines corresponding to the prescription.
- Step 7: Once the medicines have been prepared, the pharmacy student calls out the patient name on the prescription.
- Step 8: A SASL interpreter communicates to the Deaf patient whose name was called, that their medicine is ready and they can now proceed to the dispensary counter with their patient identity card and phone in hand. When they reach the dispensary, the phone is handed over to the pharmacy student.
- Step 9: The pharmacy student is asked to dispense the medicines to the Deaf patient using SignSupport.
- Step 10: When the pharmacist concludes the interaction, the Deaf patient is directed by the interpreter to return to his/her seat in the waiting room.
- Step 11: Steps 7-10 is repeated 8 times, one time with each pharmacy student and a different patient.
- Step 12: The entire process is recorded on video by placing video cameras in strategic positions to record the participants' hands on the mobile phone to assess how they navigate through SignSupport screens.
- Step 13: A group interview (via a SASL interpreter) is held with the Deaf participants to assess their opinions on the dispensing experience and SignSupport. In addition, they are asked to complete a questionnaire on SignSupport.

Data emerging from the demonstration workshop for pharmacists and pilot usability experiment included group discussion transcripts, video-recordings and questionnaire responses.

7.1.6 Data analysis

Data analysis occurred separately for each data set emerging from the research activities. The demonstration workshop activity yielded workshop field notes as a data set, while the usability experiment activity yielded three data sets: (i) video logs, (ii) group discussion notes and (iii) usability questionnaire responses for both pharmacy students and Deaf participants. Figure 23 below illustrates the data sets generated by each research activity.

Figure 23: Data sets generated by usability evaluation activities



Field notes, video logs and group discussion notes from the demonstration workshop and usability experiment were analysed in terms of Srivasta's (2009) three question framework. Furthermore, the author noted common themes emerging from these data sets. Questionnaire data was input into Microsoft Excel® to obtain frequency scores for responses that indicate positivity, negativity and uncertainty/neutrality toward SignSupport.

7.1.7 Results

Results are presented separately for each data set emerging from the demonstration workshop (which yielded field notes) and pilot user experimentation (which generated video logs, group discussion notes and questionnaires).

7.1.7.1 Demonstration workshops: pharmacists

The Microsoft PowerPoint® presentation used in the demonstration workshop was understood and well-received by all the pharmacy student participants. No confusion or hesitation was evident and questions raised were minimal. All students were enthusiastic about the technological approach, with one student suggesting that the application be modified to apply to situations to breach communication gaps existing between pharmacists and patients who only understand other indigenous spoken languages. When asked to ‘play’ with the application and role-play in pairs, all the pharmacy students (n=8) found SignSupport easy to use and commented that the procedure on the application mimics a logical dispensing sequence with which they could easily identify. All the participants were able to navigate from the start to the end with minimal hesitation. Uncertainty arose in three areas:

- a. **Omitted medical conditions.** Students (n=3) recognized that several medical conditions (symptoms/illnesses) were excluded on the application. When attempting to select a medical condition pertaining to the purpose of medicine therapy, pharmacy students encountered a situation in which the medical condition they were attempting to type was not available in the preloaded menu of symptoms/illnesses on SignSupport, and they could not proceed to subsequent screens. Several medical conditions do not appear in SignSupport for the reason that no SASL equivalent exists for the word representing that condition (e.g. for peptic ulcer, SignSupport uses the word ‘heartburn’ since the SASL interpreter was unable to sign the phrase ‘peptic ulcer’. Refer to the previous chapter (five) which elicits symptoms/illnesses database). While sound reasons exist for not including several medical

conditions in SignSupport, one cannot reasonably expect pharmacist to predict those which are/are not in the application since they would not know which terms have equivalent SASL 'words.' This creates a practical bottleneck of the application for which the research team needed to find a solution.

b. Erroneous spelling of the medicine names and medical conditions.

Students (n=4) identified incorrect spelling of medicine names and therefore could not find certain medicines in SignSupport. It could be expected that medicine names would be spelt incorrectly since the computer programmer, who has no pharmaceutical background and had not encountered these names before, was responsible for typing the names into SignSupport program. Each name was typed from the medicine database that was provided by the pharmacist into the SignSupport program. Medicine names are often long and complex and within the exhaustive medicines list, it can reasonably be expected that the computer programmer would incur spelling errors in typing such complex medicine names. This was a problem which could be resolved in the first iteration of SignSupport.

c. Not receiving any feedback.

A chief concern identified by majority of the pharmacy students (n=6) was the aspect of concluding their interaction with the patient and not receiving feedback on whether they understood the instructions or had any additional questions. SignSupport does not enable a dyadic communication process and hence does not facilitate the provision of pharmaceutical care. Pharmacy students are taught to establish joint relationships with patients and dyadic interactions are cornerstone to achieving these relationships. While it can reasonably be expected that this would be a professional issue for pharmacist participants, it remains nearly impossible to establish a two-way conversation with a patient who cannot speak or understand the same language as a pharmacist. Although SignSupport cannot facilitate mutual interaction and joint relationships, it can facilitate the communication of medicine instructions which is a component of pharmaceutical care.

All the pharmacy students indicated that the PowerPoint® presentation was an appropriate manner to demonstrate SignSupport and that the presentation was informative, useful and sufficient to lead them into the role-playing exercises. Seven of the eight students said that they would not be confident to use SignSupport in an experiment had they not attended the demonstration workshop. This implies that, in a real-world context, practicing pharmacists would need similar introduction and orientation to the application if they would be required to use it in their workplaces.

Four days after the demonstration workshop the pilot experiment ensued. Findings obtained from this experiment are described in the next instalment.

7.1.7.2 Pilot experimentation

Data from the pilot experiment included video logs of the experiment, a group interview transcript and questionnaire data from Deaf participants and pharmacists. Results emerging from each data set are discussed separately below.

Video logs

On the video footage of the pilot experiment, all pharmacy student participants appeared confident when dispensing to the Deaf patients using SignSupport and navigated the application easily. Hand-to-screen co-ordination with the phones proceeded smoothly and with minimal hesitation for pharmacists and Deaf persons. Facial expression and hand-co-ordination indicated confidence and assurance when navigating SignSupport. The transition from the paper prescription to selecting instructions on SignSupport occurred effortlessly and without indecision. Students (n=4) hesitated briefly when encountering the screen on which they are asked to take a photograph of the medicine, but soon and without intervention realized what they needed to do and proceeded to subsequent screens. A possible explanation for their hesitation at this point is that taking a photograph of the medicine being dispensed is not a typical feature of the dispensing process and would not normally be done by a pharmacist. It thus would not occur intuitively to the pharmacy student as would the other features on SignSupport which are all typical dispensing procedures.

The average dispensing patient-interaction time using SignSupport was 4 minutes 34 seconds. This is expectedly longer than published dispensing time for patient counselling during normal dispensing without SignSupport, which was estimated in South Africa to be 1 minute, 14 seconds (Lubbe and Steyn, 2010). All the pharmacy students indicated that the time taken to dispense on SignSupport was reasonable and would be feasible in a pharmacy practice setting as it was only a few minutes longer than regular dispensing. Table 14 below depicts the dispensing time per medicine and total prescription dispensing time using SignSupport.

Table 14: SignSupport dispensing time per item and per prescription

Pharmacy student participant (code name)	Time taken to dispense (minutes: seconds)		
	1 st item	2 nd item	Total
Ph A	02:27	01:43	04:10
Ph B	02:38	02:01	04:39
Ph C	02:16	01:45	04:01
Ph D	03:04	02:32	05:36
Ph E	02:26	01:53	04:19
Ph F	02:55	02:12	05:07
Ph G	02:41	02:06	04:47
Ph I	02:17	01:43	04:00
Average dispensing time	02:35	01:59	04:34

On the video footage, all pharmacy student participants appeared enthusiastic with regard to using the application to communicate with Deaf patients and closed the patient counselling session with a stance of self-assurance. Deaf participants also seemed enthusiastic and appeared to understand the SASL videos on their phones pertaining to instructions for their medicines. This positivity toward SignSupport was also evident from the group discussion during which all participants were given the opportunity to express their opinions of and experience with SignSupport.

Group discussion

A short group discussion was held between all participants, interpreters and researchers subsequent to the pilot experiment to glean an overall impression of their experience of the dispensing interaction using SignSupport. All the students (n=8) reported that the dispensing process using SignSupport was easy; however none of the students had prior experience with dispensing to Deaf patients and were thus not able to draw a comparison between dispensing interactions with a Deaf patient with and without SignSupport. Pharmacy students (n=8) commented that the communication flow was easy to follow and made sense to them in terms of dispensing.

They indicated that they particularly appreciated the patient background information screen (n=7), commenting that they often do not know whether a patient has a medicine allergy or is on concomitant treatment, and that the screen serves as a reminder to follow up on the allergy condition or drug interaction possibilities with other medicines being taken by the patient. All the students (n=8) commented that the review screen was necessary as it provided a summary of all the instructions they had selected on the screens. All students agreed that they would rather dispense to Deaf patients using SignSupport than not having any other means of communication with the Deaf community. Students identified two areas of concern with regard to the dispensing process using SignSupport:

- a. **Not receiving any feedback:** The previously mentioned concern with regard to not receiving any feedback on whether the patient understood the instructions or had any questions was raised once again. The only way to alleviate this problem on SignSupport would be via the Skype®-call function alluded to in the previous chapter, which would allow the Deaf patient to video-call an interpreter who would translate the signed question into English for the pharmacist, and the pharmacist's response into SASL for the patient. At this stage in development, the Skype® feature was not yet programmed into SignSupport.
- b. **The “awkward silence.”** Students (n=5) found that the “awkward silence” during the dispensing interaction using SignSupport with a Deaf patient

made them feel uncomfortable as they are accustomed to engaging mutually with a patient during the patient counselling process.

All Deaf participants (n=8) reported that they understood the instructions on the SASL videos and that the videos would diminish uncertainty with regard to when and how to use medicines. All Deaf participants also indicated that the experimental procedure was a success and hence they had no suggestions for improvement. Deaf participants (n=2) commented that the SASL video should be brighter or appear in color, rather than the black and white format. Even though the Deaf participant's feedback regarding SignSupport was largely positive and optimistic in terms of whether it could facilitate the communication of medicine instructions, there was an evident aloofness seen in facial expression and body language of the Deaf participants. Further probing by the researchers as to the reason for this resulted in a dead end, as the Deaf participants continued to report the same aforementioned positive opinions of SignSupport. Consequently, the researcher decided to conclude the session by asking all the participants whether they had any further questions or comments. When none were raised, participants were thanked for their time.

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After the session I engaged with the SASL interpreter to enquire whether she knew the reason for the detached stance of the Deaf participants. She replied that she was not aware that they had any problems with SignSupport or the study, but that she would enquire whether they were experiencing any issues. After a short closed session with the Deaf participants (approximately 7-10 minutes) the SASL interpreter reported that the Deaf community felt that even though SignSupport works well and can communicate to them how to use their medicines, it does not help them in a primary care situation where they need to approach a pharmacist in a community pharmacy seeking assistance for a minor ailment. Furthermore, the application does not provide health information which they often need. Deaf participants also indicated that they have been taking medicines prior to SignSupport in a way that was told to them by fellow Deaf people, and often the advice was generic for all different medicines and seemed to work for them. An

example is the notion that all medicines should be taken at night after a meal. They felt conflicted that SignSupport instructs them differently.

The implications of these problems for SignSupport are minimal, as neither are directly related to the operational functionality of SignSupport. It does however highlight significant problems experienced by Deaf people which are not within the scope of SignSupport. These problems include a lack of access to general healthcare information and the lack of primary healthcare services as a result of their communication difficulties. In addition, it highlights the cultural misconceptions Deaf people experience with regard to medicine instructions. The reluctance of the Deaf participants to share the finding in the open group discussion is indicative of their cultural connectedness; even with probing the researchers were not able to establish the reasons for their aloofness which they only shared with the SASL interpreter. This highlights yet another issue; that data may not be credible and a true reflection of the Deaf community's experience of SignSupport unless the researchers immerse themselves within the community and become a member of the Deaf culture.

Another implication is that misinterpretation or lack of health information could lead to deeply ingrained medicine use practices and beliefs which could result in untoward effects. Pharmacy practitioners and pharmacy faculty should engage meaningfully with marginalized communities about their medicine use patterns to alleviate such misconceptions. After the group interview session, pharmacy student participants and Deaf participants were each asked to complete a short usability questionnaire about their opinion of SignSupport.

Questionnaire results

All the participants completed usability questionnaires which were based on Likert-scale type closed-ended questions which measured positive (yes), negative (no) or uncertain/neutral (unsure) responses to questions related to SignSupport. Separate questionnaires were created for the pharmacy student participant group and the Deaf participant group. The questions were structured in a simplistic manner to allow the participants to concisely and confidentially articulate their perception of

SignSupport to compensate for the possibility that they may not want to have shared this perception in the group discussion.

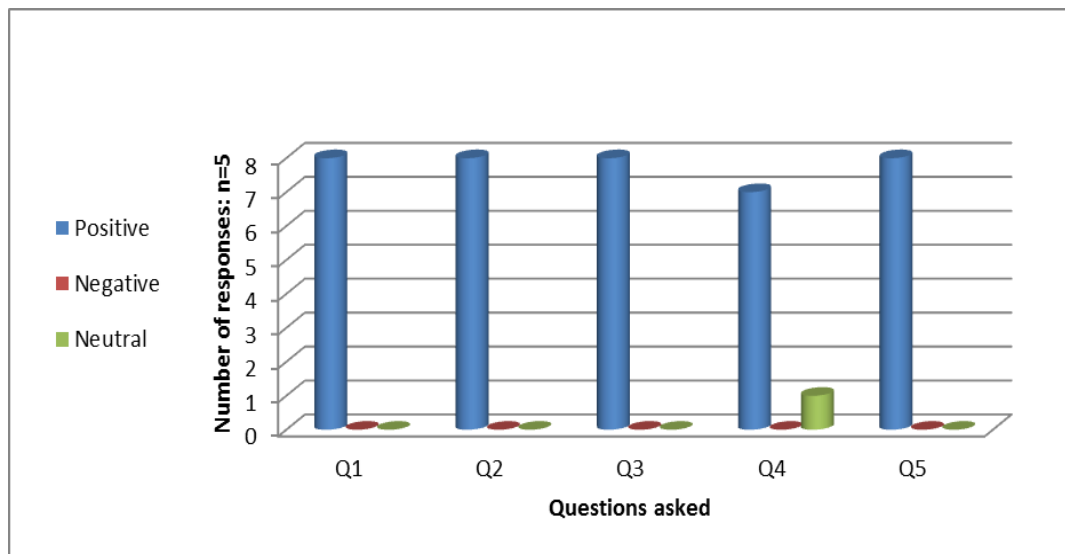
Pharmacy student questionnaire responses

All the pharmacy students (n=8) indicated that SignSupport was a useful intervention in dispensing to Deaf patients, that the application made it easier to assist Deaf patients and that they will recommend the application to their colleagues. Seven out of eight pharmacy senior students felt that SignSupport would improve patient adherence and all eight agreed that it will facilitate the communication between the pharmacist and the deaf patient. Overall, there were no neutral responses and only one negative response across a total of forty questions (from all five questions posed in eight questionnaires), indicating that the pharmacy students were positive about using SignSupport and would likely be willing to use it in their professional practice in the future. The overwhelmingly positive response is encouraging as this was the first evaluation of the practical usability of SignSupport. Table 15 below depicts questionnaire results from the pharmacy students; this is followed by a graphical presentation illustrating a comparative analysis between positive, negative and neutral questionnaire responses.

Table 15: Usability questionnaire responses: Pharmacy students

Questions		Pharmacy student responses (n=8)			
		YES		NO	
		n	%	n	%
1	Do you find SignSupport useful for dispensing to Deaf patients?	8	100	0	0
2	Do you feel that SignSupport would make it easier when dealing with Deaf patients in the future?	8	100	0	0
3	Do you think that SignSupport would facilitate and improve patient adherence?	7	87.5	1	2.5
4	Would you say that the way which SignSupport works is an effective way to facilitate communication between the pharmacist and the Deaf patient?	8	100	0	0
5	Would you recommend SignSupport to your colleagues?	8	100	0	0

Figure 24: Graphical representation of positive, negative and neutral responses: pharmacist questionnaire



Deaf participant questionnaire responses

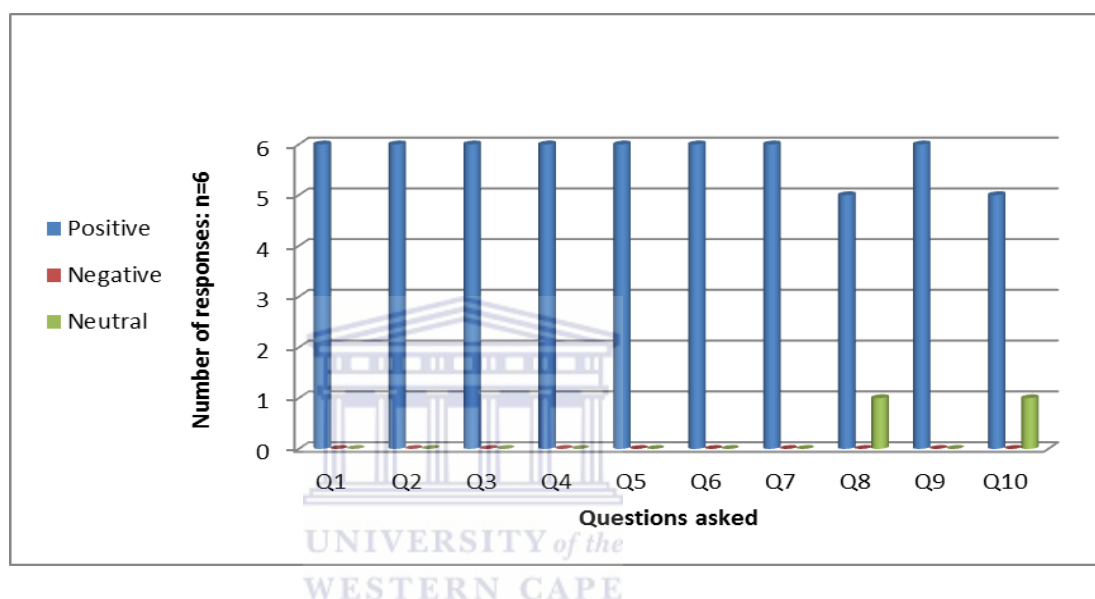
All eight (100%) Deaf participants agreed that the usability of SignSupport was acceptable, found the application easy to understand and indicated that it could assist with their adherence by making it easier to receive information. Seven out of the eight Deaf participants felt that their confidentiality was being protected, that SignSupport was useful and that the experimental session was successful. As was the case with the pharmacy students, opinions of the Deaf participants were largely positive, indicating no uncertain/neutral responses and 4 negative responses across all ten questions posed to all eight participants (total of eighty responses). Table 16 below presents questionnaire results from the Deaf participants followed by a graphical presentation illustrating a comparative analysis between positive, negative and neutral questionnaire responses.

Table 16: Usability questionnaire responses: Deaf participants

Questions		Pilot experiment Deaf user responses (n=8)			
		YES		NO	
		n	%	n	%
1.	Do you like SignSupport?	8	100	0	0
2.	Do you feel that your confidentiality is being protected when using SignSupport?	7	87.5	1	12.5
3.	Do you think SignSupport® will make it easier for you to understand how to take your medication?	7	87.5	1	12.5
4.	Do you feel that the application was easy to understand?	8	100	0	0
5.	Will this application help assist your adherence to your medication?	8	100	0	0
6.	Do you feel that it was easier to receive information with the use of SignSupport?	8	100	0	0
7.	Do you feel this session was a success?	7	87.5	1	12.5
8.	Will you tell others about this application and research study?	8	100	0	0

9.	Did you enjoy this application?	8	100	0	0
10	Did you find SignSupport useful?	7	87.5	1	12.5

Figure 25: Graphical representation of positive, negative and neutral responses: Deaf participant questionnaire



7.1.8 Discussion

The usability evaluation commenced with separate demonstration workshops targeted at pharmacy student participants and Deaf participants, followed by a pilot usability experiment during which the two participant groups merged in a role-play simulation exercise to test SignSupport in a simulated dispensary. The demonstration workshop for the pharmacy students was successful and well received by all participants, who commented that the stepwise Microsoft PowerPoint® presentation incorporating screenshots of SignSupport was easy to follow and provided the necessary orientation to the application. The strategy to conduct the presentation before allowing participants the freedom to explore the application and role-play dispensing scenarios of their choice was appropriate and positively handled by the participants. Due to the positive response of pharmacy

students to the demonstration workshop process, a decision was taken that the same PowerPoint® presentation and same procedure would be followed in all subsequent demonstration workshops for pharmacists in subsequent usability evaluations.

At this preliminary session students recognized that not all symptoms/illnesses were loaded onto SignSupport and commented that it would create a problem in a real-world context if a pharmacist was attempting to use SignSupport but was not able to find the medical condition pertaining to the purpose of the medicines. In addition, incorrect spelling of certain terms on SignSupport was observed by the students. These errors are accounted for due to lack of familiarity of the computer programmer (who entered the medicine names into the application) with long and complex medicine names.

The pilot usability experiment was conducted in a simulated dispensary which was set up to resemble a public hospital pharmacy. The experiment comprised a simulation exercise in which participants were briefed to role-play a situation in which Deaf patients would present a prescription at the pharmacy and wait for their name to be called before their medicine was dispensed by a pharmacist working at the pharmacy. The only difference to this role-play was that a practicing pharmacist would be using SignSupport to communicate the medicine instructions to the patient. Both pharmacy student participants and Deaf participants commented that the simulation exercise method was successful and had no suggestions for improvement of the experimental session. There were no significant hurdles encountered during the session; consequently the researchers agreed that the same experimental procedure would apply to subsequent usability experiments of SignSupport.

Video logs and the group discussion notes indicated that pharmacy students and Deaf participants experienced a positive dispensing interaction using SignSupport. Pharmacy students felt that the time take to dispense using SignSupport was not unreasonable and would be acceptable in a real-world context. All students indicated that they would prefer to dispense to a Deaf patient with the SignSupport rather than without. Pharmacy students once again noted spelling errors on the

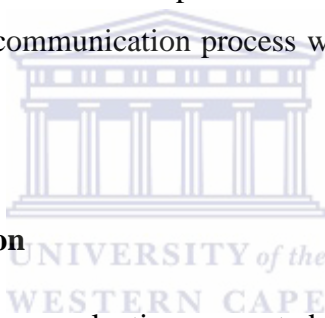
application with regard to medicine names, and the omission of certain symptoms and medical conditions. These were noted by the researchers who planned to rectify these problems in the first design iteration of the application.

Students mentioned their discomfort with the awkward silence that occurred during their interaction, as normally they would be speaking the medicine instructions to patient if the patient was Deaf. Pharmacy students were taught to interact with patients while counselling to building patient relationship. Models of communication relevant to pharmacist-patient interactions are dyadic in nature and include the features of sender, receiver, message, feedback and interference. If one juxtaposes SignSupport in the context of a communication model for a pharmacist-patient interaction, the 'sender' in the model relates to the pharmacist who inputs information into SignSupport and the 'receiver' relates to the Deaf patient who receives the information entered by the pharmacist in the form of SASL videos. The message refers to the SASL videos which are compiled on the application containing the relevant instructions. The missing element is the feedback which is not obtained since the Deaf patient is not able to ask any other queries which they may have. Pharmacy students were not comfortable that the patient did not have an opportunity to pose questions or indicate that they understood the instructions. This implies that while SignSupport can deliver medicine instructions, it is not able to facilitate pharmaceutical care in which the establishment of a joint relationship between patient and pharmacist is crucial in achieving optimal therapeutic outcomes. This inability of SignSupport to offer pharmaceutical care is discussed further in the following chapter of this dissertation.

All Deaf participants indicated that SignSupport was easy to understand, that it facilitated their understanding of how to use their medicines and that it would assist them to adhere to their medicine regimens. They appreciated the sign language format and did not experience any problems specific to the medicine administration instructions. Furthermore, they were able to input their medical history questions without difficulty. Concerns were raised by the Deaf participants with regard to the color of the SASL videos. The addition of color videos on any mobile application software requires more software storage space than those appearing in a black and

white format due to an increase in pixels required for color images, the computer programmer was tasked to assess the feasibility of changing the videos to a color format. Further concerns expressed by Deaf participants were not directly related to SignSupport. These concerns include the lack of access to general healthcare information and restricted access to primary health services as a result of the communication barriers they face in attempting to seek primary healthcare services.

Overall, pilot user evaluation results indicate that the communication of medicine instructions, confidentiality and autonomy of the Deaf community can be improved with the utilization of SignSupport. The application is able to bridge communication gaps that exist during the medicine dispensing process and enables a pharmacist to provide stipulated information regarding medication usage. The application is not able to facilitate the provision of pharmaceutical care as it does not allow for a two-way communication process which incorporates questions and feedback by the patient.



7.1.9 First design iteration

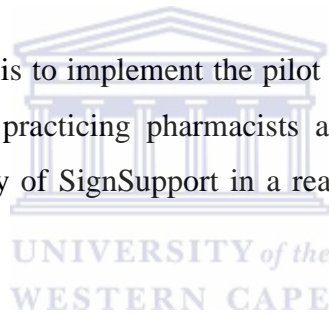
Findings from the pilot user evaluation generated the following recommendations to the research team for modification to SignSupport:

- Rectify medicine spelling errors by comparing the medicines list in SignSupport to the Medicines Control Council list of scheduled medicines.
- Expand the list of symptoms/medical conditions to include additional common symptoms/illnesses.
- At the section in SignSupport where a pharmacist is required to enter the name of the medication, provide an indication that pharmacists should enter the generic medicine name.
- When a medicine needs to be taken only when required, include an option to avoid the reminder, currently this is not possible.
- Enhance video clarity and assess the feasibility of full-color SASL videos.

7.1.10 Conclusion

All study objectives articulated for the pilot usability evaluation of SignSupport were achieved. Presentation materials for the purpose of demonstrating SignSupport for pharmacists was designed appropriately and was found to be useful and easy to understand. A simulated dispensary was created for pilot testing and was appropriate for the purpose of the experimental procedure. Pharmacy students and Deaf patients were able to effectively and efficiently operate SignSupport on the Samsung Galaxy SII mobile phones when they were required to partake in a simulated dispensing interaction. The usability of SignSupport from the pharmacy students' and Deaf participants' perspectives were evaluated and generated largely positive results. Data generated from the pilot usability evaluation informed the first design iteration of SignSupport.

The forward progression is to implement the pilot usability evaluation in an actual hospital pharmacy with practicing pharmacists and Deaf patients to assess the applicability and usability of SignSupport in a real-world context i.e. the hospital study.



SECTION B: SIGNSUPPORT EVALUATION: HOSPITAL STUDY

The hospital study aimed to investigate the applicability of SignSupport in a real-world context at the interface between practicing pharmacists and Deaf patients who collect their medicines from a public hospital pharmacy. In particular their first-hand impressions and experiences of using SignSupport were evaluated. The research design was based on the pilot study and was thus conducted in a similar fashion. However, this study differed from the pilot experiment in terms of study site and participant profile.

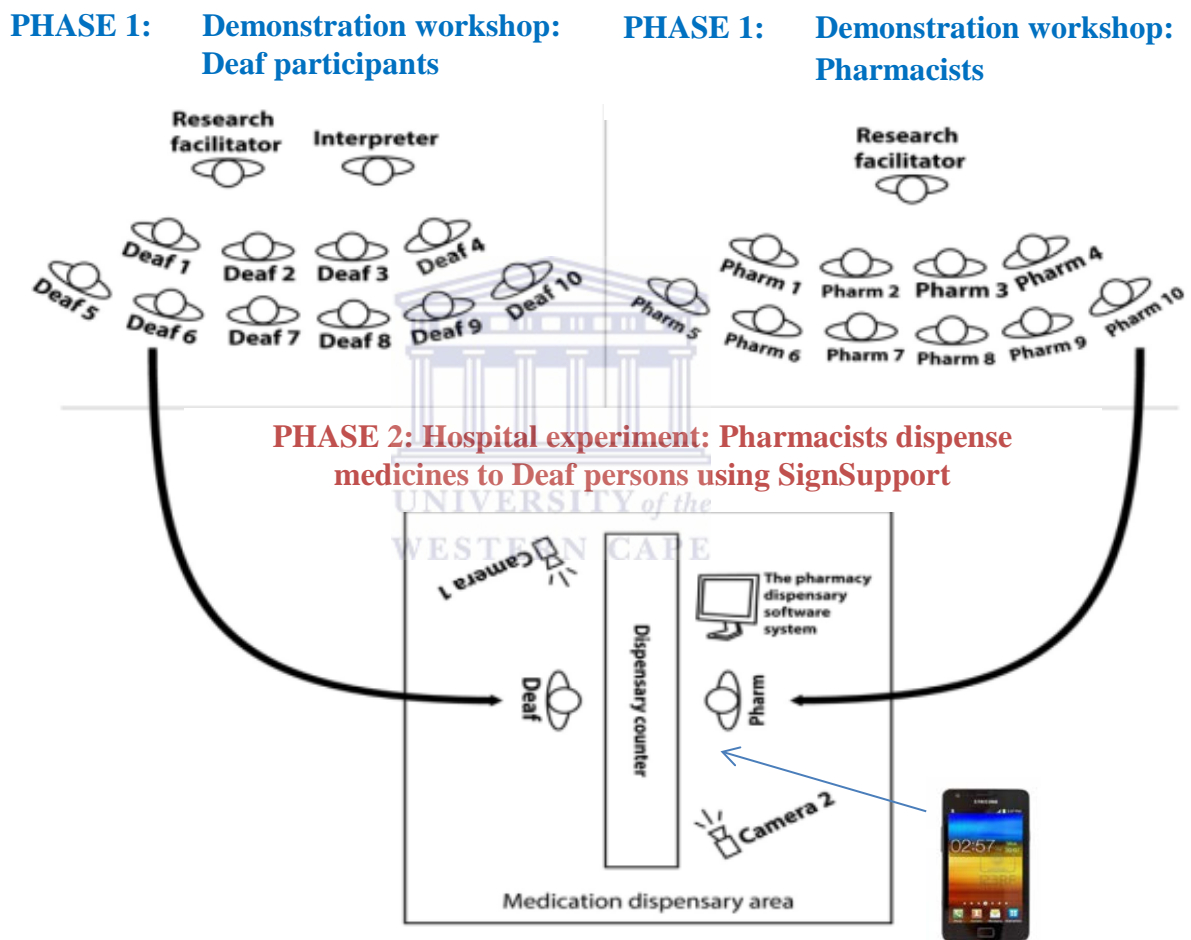
7.2 Hospital study

As was the case in the pilot study, the hospital study comprised two phases; (i) demonstration workshops and (ii) a usability experiment. During the first phase, demonstration workshops were conducted separately for pharmacists and Deaf participants. Neither of the participants groups had seen the completed version SignSupport prior to the demonstration workshops. The aim of these workshops was to introduce SignSupport to both groups and allow them to ‘play’ with the application in order to establish familiarity therewith. During the pilot phase, I led the demonstration workshop for pharmacists, while the computer programmer led the workshop for the Deaf participants. For the hospital study however, I conducted the workshops for both pharmacists and Deaf persons, presented in this section. For the hospital study, a group (n=5) of final year pharmacy students (Appendix A) who selected pharmacy practice as a research area for their mandatory research projects, acted as my research assistants. They were especially helpful in handling the many logistical issues associated with simultaneously managing research protocol with pharmacists and Deaf persons, and in light of the fact that I was the only member of the multi-disciplinary research team involved in the hospital study.

Phase two, the usability experiment, was conducted subsequent to and in the same week as the demonstration workshops to ensure a close time-proximity between the two phases, which was necessary to ensure that SignSupport was fresh and familiar in the minds of the participants. During the experiment, a pharmacist was asked to

dispense medicines to a Deaf patient using SignSupport. This dispensing interaction was recorded by video cameras which were strategically positioned to capture the hand-screen co-ordination of the participants with the mobile phones. Figure 26 below illustrates the general study design for the hospital evaluation and incorporated both demonstration workshops and the usability experiment.

Figure 26: Study design for hospital usability evaluation



The demonstration workshops for pharmacists and Deaf participants and the hospital experiment are described below under the following subsections: research objective linkage, study site and participants, methodology, materials, study procedure and results and discussion

7.2.1 Research objective linkage

The hospital usability evaluation was conducted in order to achieve research objective 5 of this thesis:

- To iteratively test SignSupport with Deaf persons and pharmacists to assess their acceptability and usability thereof.

The following aims set out in order to achieve the afore-mentioned objective:

1. To recruit a sample of pharmacists practicing in a hospital pharmacy setting.
2. To recruit a Deaf participant sample from a rural town on the outskirts of Cape Town which had a different linguistic demographic than the Deaf participant sample in the pilot usability experiment
3. To conduct demonstration workshops with the Deaf participant sample and the pharmacist sample
4. To conduct a usability experiment including both participant samples in an actual hospital pharmacy
5. To qualitatively assess the usability of application for pharmacists and Deaf users
6. To evaluate feedback from the pharmacists and Deaf participants on the use of the mobile application
7. To use the results obtained from the hospital usability evaluation to iteratively modify SignSupport

7.2.2 Study sites and participants

The study was directed to two participant groups: (i) pharmacists working at a public healthcare facility dispensary (n=5) and selecting on the basis of a convenience sampling strategy and (ii) Deaf participants who are familiar with the medicine dispensing process at public health facilities in Cape Town and are selected on the basis of a purposive sampling strategy.

For the pilot study, senior pharmacy students were substituted for pharmacists due to the non-availability of pharmacists. In this experiment I aimed to include practicing pharmacists who have extensive experience in working at a public hospital facility. This would allow insight into whether SignSupport can accommodate specific pharmacy practice requirements and whether it would be acceptable to practicing pharmacists. Inclusion criteria for the pharmacists include:

- that participants are employed at a public hospital pharmacy in Cape Town
- that participants are unable to communicate in SASL

The sample population was a total of 5 pharmacists. This sample was considerably smaller than what I had aimed for. However, as the primary researcher for the pharmacy component, I was dependent on the hospital pharmacy's director to allow as many pharmacy staff as she could afford to partake in the study during working hours and to use the facilities of the hospital pharmacy. Furthermore, Nielsen (1994) reports that a number of five users is sufficient to uncover 85% of the problems of a system. Pharmacists were recruited to attend the demonstration workshop where they were introduced to SignSupport. The same pharmacists were used to dispense medication to the Deaf in the hospital experiment.

The second group of participants for the study comprised Deaf individuals (n=6) and one SASL interpreter from DeafSA Paarl. A maximum variation sampling strategy was used to recruit this sample; 'maximum variation' in that this was a rural based community whose linguistic demographic was Afrikaans, compared to the pilot study group from a mixed-language based urban community. Urban versus rural was a significant variable in that the use of smart-phone technology may not have strongly infiltrated a rural based group as it would an urban group. I aimed to test SignSupport in groups who were both familiar with technology and those who were not. The language was a significant variable because the linguistic demographic in which a Deaf community is resident may affect the dialect of SASL specific to that community. Furthermore, Deaf people who are able to lip-read different languages may have varying understanding of the SASL videos on SignSupport. Testing the application with a Deaf community from different

linguistic backgrounds would allow the researcher to test this possibility. Inclusion criteria for Deaf participants included:

- that participants were Deaf in terms of the definition presented in chapter 3
- that participants are affiliated with the DCCT from which consent was obtained to have access to the Deaf community
- that participants must all have had experience in using medicines

Participation in the study was voluntary and participants were informed of study details and expectations on participant information and informed consent documents (Appendix I-L). A registered sign language interpreter facilitated communication between the Deaf participants, myself and the pharmacists. Informed consent was obtained from the Deaf participants via the interpreter who signed the participant information and informed consent documents to the participants. Participants agreed and indicated informed consent by raising their hands in a closed consent session. This indication of agreed participation was video recorded.

The study comprised three research activities:

- i. Demonstration workshop for pharmacists
- ii. Demonstration workshop for Deaf participants
- iii. Hospital experiment

The demonstration workshop for pharmacists took place in the pharmacy boardroom at their place of employment, Tygerberg hospital pharmacy. A venue that was located as closely as possible to the hospital pharmacy was deemed most appropriate to minimize the duration of time which the pharmacist was needed to attend study activities. For Deaf participants, the demonstration workshop occurred in the boardroom at the DeafSA offices in Paarl, Western Cape. The usability experiment was conducted at Tygerberg hospital pharmacy where the participants occupied one semi-private dispensing area in the pharmacy. Permission to utilize each of the venues was obtained from the respective authorities, namely the pharmacy director and DeafSA manager.

Figure 27 below illustrates the experimental procedure occurring between a pharmacist (dressed in a white coat) and Deaf patient at a semi-private counselling area at Tygerberg hospital pharmacy. In addition, Deaf participants occupied a section of the pharmacy waiting room while they were waiting for their names to be called for collection of their medicines by the pharmacy participants, who occupied a section within the pharmacy.

Figure 27: Experimental procedure: dispensing interaction between a pharmacist and Deaf patient at Tygerberg hospital pharmacy



7.2.3 Methodology

Hospital usability experimentation employed both qualitative methods (demonstration workshops, role-plays and video observations) and PAR techniques (contributions of the pharmacists, Deaf participants and SASL interpreter with regard to suggestions for improving SignSupport). Although the experiment tested SignSupport in a real-world context, role-plays were used to mimic a scenario in which a Deaf person collects medicines from the pharmacist. The medicines were not on actual prescriptions that belonged to the Deaf patient for medicines that they would actually use. At this stage SignSupport was still in the process of being

evaluated. To forego risks associated with Deaf patients taking medicines as instructed on a device that was still in a testing phase, I chose to conduct the experiment on a role-play basis even though it was in a real-world context. The hospital usability experiment occurred in line with a community-based co-design strategy which facilitates the participation of multiple groups toward creating a solution that suits their needs.

The first research activity comprised a demonstration workshop for pharmacists, followed by a demonstration workshop for Deaf participants. The final research activity entailed the usability experiment at Tygerberg hospital pharmacy.

7.2.4 Materials and resources

The following materials were used in the two research activities: demonstration workshop and hospital pharmacy experiment respectively:

Demonstration workshops	
Pharmacists	Deaf community
1 laptop computer	6 laptop computers
Microsoft PowerPoint® software	Microsoft PowerPoint® software
SignSupport demonstration presentation for pharmacists	SignSupport demonstration presentation for Deaf people
5 Samsung® Galaxy SII phones on which SignSupport is installed	6 Samsung® Galaxy SII phones on which SignSupport is installed
A digital projector	SASL interpretive services
1 video camera on a tripod stand	1 video camera on a tripod stand

Hospital pharmacy experiment

- A public hospital dispensary setting
- 2 video cameras on tripod stands
- Mock prescriptions
- Medicines corresponding to the afore-mentioned prescriptions
- Mock patient identity cards
- Mock patient folders
- SASL interpretive services

7.2.5 Study procedures

Separate procedures are described for the demonstration workshops and hospital pharmacy experiment. The workshops for Deaf participants and pharmacists each lasted 3 hours respectively and were conducted on separate days. The hospital pharmacy usability experiment occurred a few days later, in the same week. Results were obtained via video recordings and from my field notes. In addition, Deaf participants and pharmacists were asked to complete usability questionnaires after the experiment.

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7.2.5.1 Demonstration workshop with pharmacists

The same Microsoft PowerPoint® presentation used in the pilot study to demonstrate SignSupport to pharmacy students was used in the demonstration workshop for pharmacists. The presentation entailed a detailed explanation on the entire process of dispensing with SignSupport and included screen shots of the application. The screenshots were placed in a step-by-step format to illustrate how the application should be used. A three hour workshop was held during which the pharmacists navigated through the screens on SignSupport in a stepwise process. After the presentation pharmacists were asked to practice in pairs by means of a role-play from various pharmacy situations using the application. Feedback regarding the interface, usability and functionality of the application was taken both by covert observation, and a group feedback session held subsequent to the workshop. Pharmacy recommendations for future modification were also noted.

Steps 1-13 below describe the sequential process pertaining to the demonstration workshop for pharmacists.

- Step 1: Use the Microsoft PowerPoint® presentation from the pilot study which incorporates SignSupport screen shots in a sequential stepwise fashion to demonstrate the application.
- Step 2: Schedule a demonstration workshop with pharmacists for 3 hours
- Step 3: On the workshop day, seat all participants in a venue with a laptop and digital projector
- Step 4: Project the afore-mentioned PowerPoint® presentation to conduct the demonstration presentation.
- Step 5: Hand each pharmacist one Samsung® Galaxy phone on which SignSupport is installed.
- Step 6: Allow participants time to 'play' with the application on the phone.
- Step 7: Once participants have indicated that they have had enough time to explore the application, ask them to partner with another participant to form a pair.
- Step 8: Ask the participants to role-play by pretending that one participant is a pharmacist and another is a Deaf patient to whom the pharmacist is dispensing medicines.
- Step 9: The 'pharmacist' pretends to dispense medicines to the 'patient' using SignSupport.
- Step 10: The 'pharmacist' and 'patient' switch roles and repeat step 9.
- Step 11: Repeat steps 8-10 twice.
- Step 12: Conduct a group feedback session and record participants perceptions of their experience in using SignSupport, feedback and suggestions for modification/improvement.
- Step 13: Conclude the demonstration workshop by thanking participants for their time.

Three days after the demonstration workshop for pharmacists, a similar workshop was held for the Deaf participants.

7.2.5.2 Demonstration workshop with Deaf participants

A demonstration workshop was conducted for Deaf participants to introduce and provide instruction on how to use SignSupport. The workshop involved a detailed explanation on the entire process of receiving medicine instructions on SignSupport and included screen shots of the application. The duration of training was approximately 3 hours. During this time the Deaf participants were able to ask questions via the interpreter and were given the opportunity to familiarize themselves with the application. Steps 1-13 below describe the sequential process pertaining to the pilot usability experiment.

- Step 1: Use the Microsoft PowerPoint® presentation for Deaf persons from the pilot study (prepared by the computer programmer) which incorporates SignSupport screen shots in a sequential stepwise fashion to demonstrate the application.
- Step 2: Schedule a demonstration workshop with Deaf participants and a SASL interpreter for 3 hours
- Step 3: On the workshop day prepare six demonstration stations; each with a chair for the Deaf participant, another chair for a research assistant, a laptop on which the afore-mentioned PowerPoint® presentation appears and a smart phone on which SignSupport is installed.
- Step 4: Have one Deaf participant seated at each research station and a research assistant next to each Deaf participant.
- Step 5: Each research assistant navigates through the presentation screens while a SASL interpreter translates the principal researcher's (author) explanation of SignSupport for the Deaf participants.
- Step 6: Once the presentation is completed, conduct a question and answer session via the SASL interpreter.

- Step 7: Allow participants time to ‘play’ with the application on the phone.
- Step 8: Once participants have indicated that they have had enough time to explore the application, ask them to practice uploading their background medical history information with the assistance of the research assistant.
- Step 9: Ask the participants to role-play where the research assistant mimics a pharmacist’s role and the participant is a Deaf patient to whom the pharmacist is dispensing medicines using SignSupport
- Step 10: Repeat steps 8-9 thrice
- Step 11: The entire process is recorded on video by placing video cameras in a position to record the participants’ hands on the mobile phone to assess how they navigate through SignSupport screens.
- Step 12: A group interview (via a SASL interpreter) is held with the Deaf participants to assess their opinions of SignSupport, feedback and suggestions for modification/improvement.
- Step 13: Conclude the demonstration workshop by thanking participants for their time.

Two days after the demonstration workshop for Deaf participants, the usability experiment was conducted at Tygerberg hospital pharmacy.

7.2.5.3 SignSupport usability experiment: hospital pharmacy

The last empirical activity of this thesis is the usability experimentation of SignSupport with pharmacists and Deaf participants during routine operational procedures at a public hospital pharmacy. This testing occurred through a simulation exercise during which pharmacists who are employed at the hospital pharmacy dispensed medicines to a Deaf patient who was called from the waiting room, in the same way that they would normally do during their day to day dispensing activities, except that they used SignSupport to provide medicine instructions to the patient. During the simulation exercise, mock prescriptions, and

pseudo patient identity cards were used to preclude the possible risks associated with patients taking medicines as per a dispensing device that was still in the evaluation phase. Video recorders were set up at strategic positions to capture the dispensing interaction between the pharmacy student and Deaf patient from various angles. This was done to capture closely the hand-co-ordination of the pharmacist-user with the application, and the facial gestures of the Deaf patient to indicate acceptability and understanding of instructions given. I conducted group discussions with pharmacists and Deaf participants in order to obtain feedback on the experience with regard to the usage and other aspects of SignSupport. Steps 1-13 below describe the sequential process pertaining to the hospital usability experiment.

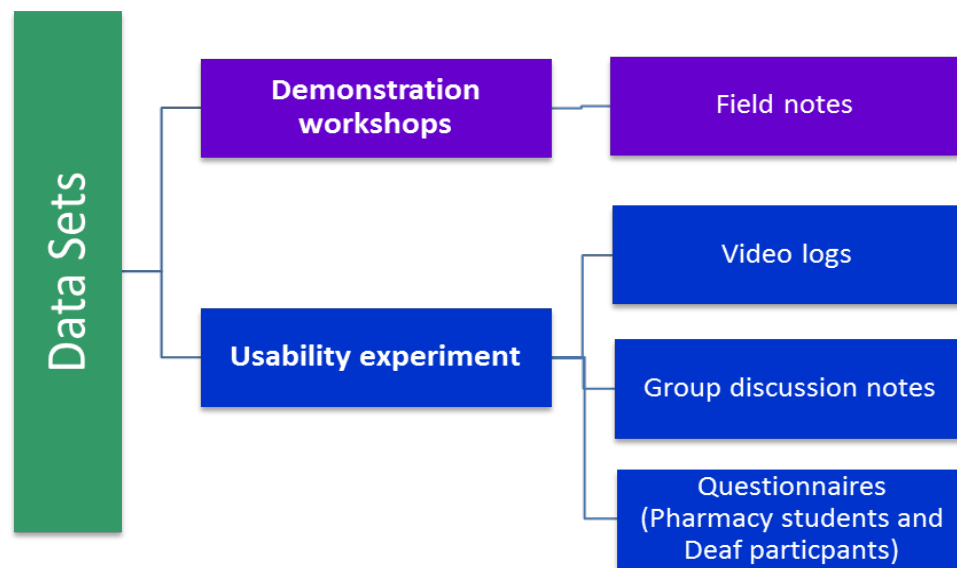
- Step 1: Schedule an experiment day with Deaf persons and pharmacists for 3 hours
- Step 2: Negotiate with pharmacy management to allow one semi-private dispensing area in which to conduct the experiment.
- Step 3: Prepare mock patient identity cards and mock prescriptions and collate medicines corresponding to these prescriptions
- Step 4: On the experiment day, have Deaf participants be seated in the patient waiting area. With them are a SASL interpreter and two research assistants who manage the experiment from the patient waiting area by communicating with the pharmacists in the pharmacy.
- Step 5: Hand each Deaf participant one Samsung® Galaxy phone on which SignSupport is installed and ask them to input their general medical history on the Background information screen.
- Step 6: Ask pharmacists to prepare the mock prescriptions by selecting and preparing the medicines corresponding to the prescriptions.
- Step 7: Once the prescriptions are prepared, direct pharmacists to take their position at the dispensary counter, one at a time, to get ready to dispense the prescription.

- Step 8: The pharmacist calls out the patient name written on the mock prescription.
- Step 9: The SASL interpreter communicates to the Deaf patient whose name was called that their medicine is ready and they can now proceed to the dispensary counter with their phone in hand. When they reach the counter, they hand the phone to the pharmacist.
- Step 10: The pharmacist dispenses the medicines to the Deaf patient using SignSupport.
- Step 11: The Deaf patient is directed by the interpreter to return to his/her seat in the waiting room
- Step 12: Steps 7-11 is repeated with each pharmacist and a different patient.
- Step 13: The entire process is recorded on video by placing video cameras in a position to record participants' hands on the mobile phone to assess how they navigate through SignSupport screens.
- Step 14: Separate group feedback sessions are held with Deaf participants (via a SASL interpreter) and pharmacists to assess their opinions on the dispensing experience and SignSupport. In addition, they are asked to complete a questionnaire on SignSupport.

7.2.6 Data analysis

Data analysis occurred separately for each data set emerging from the demonstration workshops and hospital experiment. The demonstration workshops yielded workshop field notes from the pharmacist's workshop and Deaf participants' workshop, while the hospital experiment yielded three data sets: (i) video logs, (ii) group discussion notes and (iii) usability questionnaires from both pharmacy students and Deaf participants. Figure 1 below illustrates the data sets generated from each research activity.

Figure 28: Data sets generated from hospital study activities



Field notes, video logs and group discussion notes from the demonstration workshop and usability experiment were analysed in terms of Srivasta's (2009) three question framework. The author noted common themes emerging from these data sets. Questionnaire data was input into Microsoft Excel® to obtain frequency scores for responses that indicate positivity, negativity and uncertainty toward SignSupport.

7.2.7 Results

Results are presented separately for data emerging from the demonstration workshop for pharmacists, the demonstration workshop for Deaf participants (both workshops yielded field notes) and for the hospital experiment (which generated video logs, group discussion notes and questionnaires).

7.2.7.1 Demonstration workshops: pharmacists

Pharmacists exhibited an overall positive stance with regards to SignSupport. They felt that the concept was valid and of vital importance to improving communication during their dispensing interactions with the Deaf persons. The presentation which introduced SignSupport was understood and well-received by all the pharmacists.

No confusion or hesitation during the presentation and no questions were asked. All the pharmacists (n=5) were enthusiastic about the application and indicated that they were keen to see how it works. When asked to 'play' with the application and role-play in pairs, all the pharmacist (n=5) found SignSupport easy to use and indicated that it was appropriate for dispensing procedures. All the participants were able to navigate from the start to the end with minimal hesitation. Spelling errors were not encountered and pharmacists (n=4) were pleased that all the medicine names were pre-loaded, indicating that it would save time during dispensing. Difficulty arose at two sections:

1. Omitted medical conditions: The study finding with regard to omitted medical conditions found in the pilot study emerged once again. Pharmacists (n=2) recognized that several medical conditions were excluded from the application even though the list of illnesses/symptoms in the first version of SignSupport was expanded in first iterative modification of the application. When attempting to select a medical condition pertaining to the purpose of medicine therapy, pharmacists encountered a situation in which the medical condition they were attempting to select was not available from the preloaded options. One pharmacist attempted to select the condition 'urinary tract infection,' while another attempted to select the condition 'migraine.' Neither condition was available in the application, because appropriate SASL signs do not exist to precisely articulate these terms. Nonetheless, these particular terms can be replaced in SignSupport with the terms 'bladder infection' and 'pain' respectively, which are programmed in the application.

At this point, I realized that pharmacists could not reasonably be expected to know which medical conditions do and do not have equivalent SASL signs, consequently trying to select an illness/ symptom would be guessing game and a time-consuming exercise. To alleviate the guess-work, the researcher enquired from the pharmacists whether providing them with a list of conditions available on the application would solve this problem. They replied that it would be useful, and that such a list should be kept at the pharmacy. One pharmacist suggested that it would be worthwhile to compile a brief instruction

booklet for SignSupport, since they do not see Deaf patients every day which might cause them to forget how to use the application. It would also assist for pharmacists encountering SignSupport for the first time.

- 2. Photograph screen:** Three of the five pharmacists hesitated at the screen which prompts them to take a photograph of the prescribed medicine. They misinterpreted the screen prompt after the medicine picture was taken and were unsure whether or not the picture had been saved. The same hesitation was encountered during the pilot study, and can be expected since taking a medicine photograph is not a typical feature of the dispensing process. However, the pharmacists were easily able to move along to subsequent screens with only verbal instruction from the researcher with regard to how to proceed after the photograph was taken.

Three days subsequent to the demonstration workshop for pharmacists, a similar workshop was conducted for Deaf participants.



7.2.7.2 Demonstration workshops with Deaf participants

The demonstration workshop for Deaf participants (n=6) was conducted with the assistance of a DeafSA SASL interpreter. During the initial stage of the workshop, all the Deaf participants (n=6) were intrigued by SignSupport and enthusiastic about how it would improve their communication with pharmacists and their understanding of medicine instructions. As the workshop proceeded, Deaf participants navigated the application in a manner that exceeded expectation; they seemed to be more familiar with smart phone technology than the Deaf sample in the pilot experiment. Five of the six participants navigated the screens with no hesitation and were able to input their background medical history without intervention from the researcher. This indicates that the SASL videos which directed them with regard to how to use their medicines are likely to be effective and understandable. The sixth Deaf participant was the only one who experienced problems. The same participant was confused with regard to whether she had to include past illnesses in the background portfolio. The SASL interpreter informed

the researcher that this participant was from a different Deaf community whose SASL was of a different dialect, hence the reason for her problematic experience of SignSupport. One of the reasons the author chose to use a rural-based community was to ascertain whether dialectal differences would impact the usability of SignSupport, thus this was a significant finding. However, for the other five participants, who were of a different dialect to the pilot study group, there seemed to be no difficulty as they were all able to navigate the application with ease.

The demonstration workshop proceeded with asking the participants to play with the application and role-play pharmacy scenarios with a partner. This all continued smoothly and positively except for the same afore-mentioned participant who had dialectal difficulties. In spite of these difficulties, she was able to navigate the application but hesitated at certain points, causing her to ask for assistance. To conclude the workshop, the researcher informed the participants of the imminent hospital experiment and briefed them of the logistical arrangements and of what to expect. One Deaf participant raised her hand and indicated that she had a question. She signed to the interpreter that she has a problem with SignSupport; that: *“it is okay and works fine, but how can it help me when I have to go to the chemist (pharmacy) to go ask for help when my baby is sick?”*

Her question received categorical agreement from all the other Deaf participants and was reminiscent of the dissatisfaction expressed by the Deaf sample after the usability experiment in the pilot study. The pilot study Deaf sample also complained that SignSupport cannot assist them when they approach a community pharmacist with a minor ailment. This is a limitation of SignSupport since the application was primarily designed to provide medicine instructions for prescription medicines. The interaction between the Deaf participants then evolved into a discussion pertaining to their experiences at community pharmacies and of how they frequently left the pharmacy without assistance or incorrect information because the pharmacist could not understand them. As was the case in the pilot study, this finding was not directly related to SignSupport as treatment for minor ailments within the ambit of community pharmacy is not within the scope of the application. It does however, once again allude to the lack of access to health-

related information and primary care services experienced by Deaf people. Two days after the demonstration workshop, I coordinated the usability experiment at Tygerberg hospital.

7.2.7.3 Hospital usability experiment

Data from the hospital usability experiment included video logs of the experiment, group discussion notes and questionnaire data from Deaf participants and pharmacists. Results emerging from each data set are discussed separately below.

Video logs

Video footage revealed that majority of the pharmacists (n=4) seemed confident when dispensing to the Deaf patients using SignSupport were able to navigate the application easily. Hand-to-screen co-ordination with the phones proceeded smoothly and with minimal hesitation for pharmacists and Deaf persons. Facial expression and hand-co-ordination indicated confidence and assurance when navigating SignSupport for all but one pharmacist. The transition from the paper prescription to selecting instructions on SignSupport occurred effortlessly and without indecision for four of the five pharmacists.

One pharmacist was experiencing some difficulty with regard to the patient background screen, on which a pharmacist would be informed whether of the patient's weight, whether the patient is on concomitant medical treatment, experiences allergies, pregnancy status, whether the patient smokes or drinks alcohol and has access to clean water and daily meals. The pharmacist who was having trouble at this screen was unhappy that the information with regard to allergies and concomitant treatment did not specify the exact allergy the patient experiences (it only indicates if a food or medicine allergy is present but not what the patient is allergic to) or the exact medicines the patient was taking concomitantly. The application does however in the event of a positive allergy or concomitant treatment, prompt the pharmacist to check the patient folder; this is a function pharmacist normally do anyway. However, for this pharmacist, it seemed that she did not want to proceed unless that information was available on

SignSupport, which is unrealistic to expect since Deaf people themselves input that information and may not be linguistically able to name their allergy or medicines. The problem this pharmacist had was not with navigating SignSupport, but that she seemed to be unwilling to use SignSupport further without getting the allergy related answers she wanted. The researcher advised her to touch on the forward arrow, which she did, and was then able to effortlessly proceed through the application to the end of the pharmacist interface.

Another pharmacist hesitated briefly when encountering the screen on which she was asked to take a photograph of the medicine, but soon and without intervention realised what she needed to do and proceeded to subsequent screens. Apart from this hesitation and the afore-mentioned discontent with the allergy-specific information, all the pharmacists were able to navigate the entire application form start to finish without intervention. The average dispensing patient-interaction time using SignSupport was 4 minutes 18 seconds. This is expectedly longer than published dispensing time for patient counselling during normal dispensing without SignSupport, which was estimated in South Africa to be 1 minute, 14 seconds (Lubbe and Steyn, 2010). However it is shorter than the dispensing time recorded in the pilot experiment (4 minutes, 30 seconds). All the pharmacists indicated that the time taken to dispense on SignSupport was reasonable and would be appropriate in their daily dispensing activity. Table 18 below depicts the dispensing time per medicine and total prescription dispensing time using SignSupport during the hospital experiment.

Table 18: SignSupport dispensing time per item and per prescription

Pharmacist's code name assigned	Time taken (minutes)		
	1 st item	2 nd item	Total
PhV	01:96	01:02	02:98
PhW	02:00	01:00	03:00
PhX	04:47	01:49	05:96
PhY	02:93	01:78	04:71
PhZ	01:48	01:59	03:07
Average dispensing time			04:18

Four of the five pharmacists appeared enthusiastic with regard to using the application to communicate with Deaf patients and closed the patient counselling session confidently. The Deaf participants and pharmacists handled the application with ease as they were seen to navigate through the application without hesitation. The majority of pharmacists photographed the medicine in a manner that allowed the patient to clearly differentiate between the different medicines. The role-plays progressed smoothly indicating that SignSupport follows a systematic dispensing sequence. The same was also noted in the pilot study. Deaf participants also seemed enthusiastic and appeared to understand the SASL videos on their phones pertaining to instructions for their medicines. This positivity toward SignSupport was also evident in the group discussion during which all participants were given the opportunity to express their opinions of and experience with SignSupport.

Group discussion

Short discussions were held with pharmacists and Deaf participants subsequent to the experiment to glean an overall impression of their experience of the dispensing interaction using SignSupport. All the pharmacists (n=5) reported that the dispensing process using SignSupport was easy; however one pharmacist indicate that she was unhappy that she application did not give her specific details of the patient's allergy. Pharmacists (n=5) commented that the application took very little time to navigate and that it followed a logical dispensing sequence with which they

were familiar. As was the case in the pilot study, all the pharmacists (n=5) commented that the review screen was necessary as it reminded them of all the instructions they had selected on previous screens. Four of the five pharmacists commented that they appreciated that SignSupport allowed them to select warnings and recommendations. All pharmacists agreed that they would rather dispense to Deaf patients with SignSupport than without it.

All Deaf participants (n=6) reported that they understood the instructions on the SASL videos and that the videos would diminish uncertainty with regard to when and how to use medicines. They were optimistic about the application and the study and requested the researcher to return to Paarl as soon as possible to provide feedback on the study results. The session with the Deaf community ended on a positive note, Deaf participants appreciated that they were included in the study despite being from a rural town. Subsequent to the group interview session, pharmacy student participants and Deaf participants were each asked to complete a short usability questionnaire about their opinion of SignSupport.

Questionnaire results

All the participants (pharmacists and Deaf participants) completed usability questionnaires which were based on Likert-scale type closed ended questions which measures positive (yes), negative(no) or uncertain/neutral (unsure) responses to questions about their opinion of SignSupport. The same questionnaires used in the pilot study were administered to the pharmacist group and the Deaf participant group. The questions were structured in a simplistic manner to allow the participants to concisely and confidentially articulate their perception of SignSupport to compensate for the possibility that they may not wanted to have shared this perception in the group discussion. Below, the questionnaire results are presented as a comparative between the pilot study and hospital experiment to highlight the similarity between the findings of the two studies, which were targeted at different pharmacist and Deaf samples and conducted in a different context.

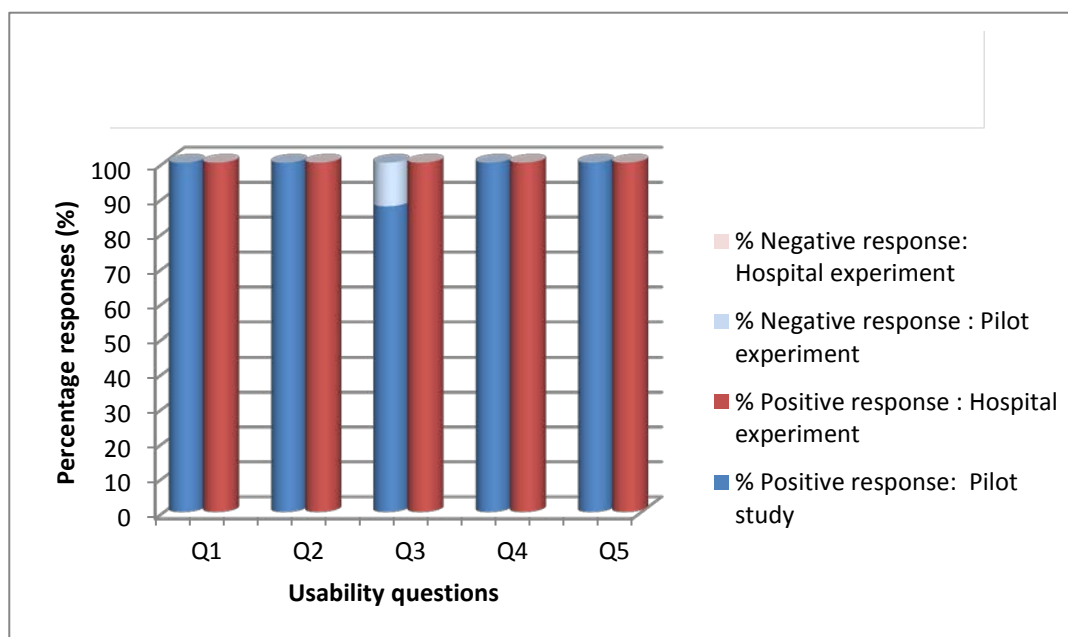
(i) Pharmacist questionnaire responses

The total pharmacist sample (100%, n=5) agreed that SignSupport was a useful intervention in dispensing to Deaf patients, that the application made it easier to assist Deaf patients and is able to facilitate communication with them and that they will recommend the application to their colleagues. The same hundred percent positive response for these questions was found in the pilot study. The only difference between the studies was noted in the question regarding whether the pharmacists felt that SignSupport would improve patient adherence. In the pilot study an 87.5 % positive response was found, with a 12.5 % negative response. In the hospital experiment, a 100% positive response was found, indicating that all the pharmacists are of the opinion that SignSupport will improve patient adherence. Overall, there were no negative responses and no neutral responses across the questions all the questions for all respondents. A hundred percent positivity was found indicating that the pharmacists were optimistic about using SignSupport and would be likely use it in their professional practice in the future. Table 19 below depicts pharmacists' questionnaire results as a comparative between the pilot and hospital usability experiments; this is followed by a graphical presentation illustrating a comparative analysis between positive, negative and neutral questionnaire responses for the two studies.

Table 19: Hospital experiment questionnaire responses: pharmacists

Questions		Pilot study responses(n=8)				Hospital experiment responses(n=5)			
		YES		NO		YES		NO	
		n	%	n	%	n	%	n	%
1.	Do you find SignSupport useful when dispensing to Deaf patients?	8	100	0	0	5	100	0	0
2.	Do you feel that SignSupport would make it easier when dealing with Deaf patients?	8	100	0	0	5	100	0	0
3.	Do you think that SignSupport would facilitate and improve patient adherence?	7	87.5	1	12.5	5	100	0	0
4.	Is SignSupport works an effective way to facilitate communication between the pharmacist and the Deaf patient?	8	100	0	0	5	100	0	0
5.	Would you recommend SignSupport to colleagues?	8	100	0	0	5	100	0	0

Figure 29: Comparative graphical representation of positive, negative and neutral responses: pharmacist questionnaire



(ii) Deaf participant questionnaire responses

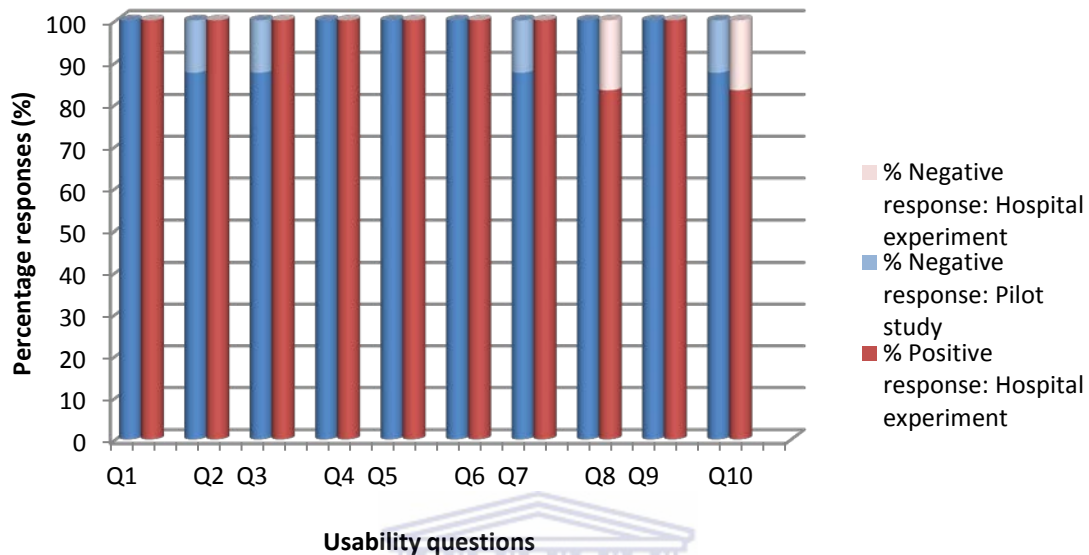
The SASL interpreter translated Deaf patient responses to questionnaire items. In both the pilot and hospital experiments, all Deaf participants (100%) indicated their approval of SignSupport, that the application makes it easy to receive information and understand medicine instructions, that it could assist them to adhere to their medicine regimens and that they enjoy using the application. These results indicate that SignSupport is likely to be used by Deaf people as they approve of its user functionality. The hospital experiment yielded an increase in positive responses for questions relating to whether the participants felt that the application maintains their confidentiality, facilitates ease of understanding medicine usage and whether participants felt that the experimental session was successful, all of which generated a hundred percent positive response.

Across all ten questions posed to 5 participants, only two negative responses were obtained; these include one negative response with regard to whether the participant would tell others about SignSupport, and one negative response with regard to whether the application is useful. This respondent further questioned the usefulness of the application in terms of the context in which SignSupport is intended to be used; the participant expressed that there may be need for an application such as SignSupport in a retail pharmacy setting. Overall, compared to the pilot usability responses, a higher positivity response percentage was found in the hospital experiment, indicating that the iterative modifications completed after the pilot experiment resulted in a positive effect in terms of participant usability. Table 20 below illustrates Deaf participant questionnaire responses for the hospital usability experiment as a comparative to results for the same questionnaire administered in the pilot study. The comparison illustrates the similarities in results obtained across the two studies. This is followed by a graphical illustration which depicts a comparison of the percentage of positive and negative responses.

Table 20: Comparison of Deaf participant responses obtained for pilot study (n=8) and hospital experiment (n=6)

	Questions	Pilot study responses (n=8)				Hospital experiment responses (n=6)			
		YES		NO		YES		NO	
		n	%	n	%	n	%	n	%
1.	Do you like SignSupport?	8	100	0	0	6	100	0	0
2.	Do you feel that your confidentiality is being protected when using SignSupport@?	7	87.5	1	12.5	6	100	0	0
3.	Do you think SignSupport will make it easier for you to understand how to take your medication?	7	87.5	1	12.5	6	100	0	0
4.	Do you feel that SignSupport is easy to understand?	8	100	0	0	6	100	0	0
5.	Will this application help assist you with adhering to your medication?	8	100	0	0	6	100	0	0
6.	Do you feel that it was easier to receive information with the use of SignSupport@?	8	100	0	0	6	100	0	0
7.	Do you feel this session was a success?	7	87.5	1	12.5	6	100	0	0
8.	Will you tell others about SignSupport?	8	100	0	0	5	83	1	17
9.	Did you enjoy this application?	8	100	0	0	6	100	0	0
10.	Did you find SignSupport@ useful?	7	87.5	1	12.5	5	83	1	17

Figure 30: Graphical representation of positive and negative responses: Deaf participant questionnaire



7.2.8 Discussion

The hospital usability evaluation followed the same progression as the pilot study, commencing with separate demonstration workshops targeted at pharmacist participants and Deaf participants, followed by a usability experiment during which the two participant groups merged in a simulation exercise to test SignSupport in a hospital pharmacy.

The demonstration workshop for pharmacists was well received by all participants and provided an overview of and orientation to SignSupport. All the pharmacists were enthusiastic about SignSupport and seemed keen to work with it. Echoing the findings of the pilot study, pharmacists once again recognized that not all symptoms/illnesses were loaded onto SignSupport and commented that it would create a problem in a real-world context if a pharmacist was attempting to use SignSupport but was not able to find the medical condition pertaining to the purpose of the medicines. The same finding occurred in spite of the fact that the additional symptoms and illnesses were added during the first iteration of

SignSupport. It became apparent that the problem being experienced was not that pharmacists were not selecting the correct conditions, but rather that they could not reasonably be expected to predict which medical conditions are and are not loaded in SignSupport as a result of the condition having or not having an equivalent SASL word. Consequently, attempting to select an illness/symptom would be a guessing game. Providing pharmacists with a list of conditions available on the application would assist them to know which conditions are appropriate to select. Furthermore, one pharmacist suggested that it would be useful to have a concisely worded instruction booklet for SignSupport. The demonstration workshop ended positively, with all the pharmacists agreeing to participate in the imminent hospital usability experiment.

The demonstration workshop for Deaf participants was well-received and proceeded as planned without any difficulties. Despite being from a rural town with a different lingual demographic, participants navigated the technology well and were easily able to upload their medical history onto the application. One participant struggled with the SASL videos; the interpreter explained that she was from a different SASL dialect background than the other participants. This indicates that SignSupport may need to be tailored to different communities by incorporating SASL videos which is indigenous to that specific community.

The usability experiment was conducted in a real-world public hospital pharmacy and comprised a simulation exercise during which pharmacists were asked to dispense medicines to Deaf patients who presented a prescription at the pharmacy and were waiting on their name to be called to collect their medicine. The pharmacist was asked to use SignSupport to provide medicine instructions to the patient. In the simulation, the pharmacist would use SignSupport to communicate the medicine instructions to the patient. Video logs and the group discussion notes indicated that pharmacists and Deaf participants experienced a positive dispensing interaction using SignSupport. Video footage revealed that pharmacists navigated the application well and without hesitation. Hand-screen co-ordination occurred seamlessly and the pharmacists generally appeared confident and self-assured that the Deaf patient understood their medicine instructions. One pharmacist indicated

that she was unhappy about the limitation to allergy-specific information that SignSupport provided on the background screen, the other pharmacists indicated this was not a problem as they were able to retrieve such information from a patient file.

All pharmacists were able to take appropriate photographs of the medicine, and navigate the application from start to end with zero or minimal hesitation. In addition, all pharmacists commented that the application was logically organized and found not to be time consuming, hence could easily fit into their regular practice patterns. As was the case in the pilot study, all pharmacists indicated that they would prefer to dispense to a Deaf patient with SignSupport rather than without. There was no mention of the 'awkward silence' or lack of feedback that was reported by pharmacy students in the pilot study, even though neither of these problems was addressed in the previously mentioned iteration. This implies that the pharmaceutical care process and dyadic system of communication may not occur as frequently in the real-world context, possibly due to high workloads, hence the silence or lack of feedback are not as disturbing to practicing pharmacists as they are to the pharmacy students who have been taught to apply pharmaceutical care and establish mutual relationships with patients. This situation highlights a drawback of SignSupport; that the application facilitates one-way medicine instruction but is limited in the provision of pharmaceutical care which is dependent on a two-way communication pattern.

All the Deaf participants indicated that they found SignSupport to be easy to follow, that it facilitated their understanding of how to use their medicines and that it would assist them to adhere to their medicine regimens. One participant had experienced problems related to the SASL dialect on SignSupport. Deaf participants appreciated the sign-language format and did not experience any problems specific to the medicine administration instructions. As was the case in the pilot study, all participants were able to input their medical history questions without difficulty. Additional concerns expressed by Deaf participants were not directly related to SignSupport. These concerns include the lack of access to general healthcare information and restricted access to primary health services as a

result of the communication barriers they face in attempting to seek primary healthcare services. This finding occurred in both the pilot study and hospital experiment.

Results from the questionnaire responses for pharmacist participants and Deaf participants across the pilot study and hospital experiment are remarkably similar, despite having different participants and different study sites. For both studies and both participant groups, the response to SignSupport was overwhelmingly positive. A marginally higher percentage of positive response was achieved in the hospital experiment, indicating that the first iterative modifications were necessary and well-received by participants. The similarity in results between the two studies strengthens the validity of findings and is indicative of procedural quality of measurements.

Generally, pilot user evaluation results indicate that SignSupport is acceptable to pharmacists and Deaf participants and that the application is capable of facilitating the communication of medicine instructions. The application was found to be easy to use, logically sequenced and able to meet the need the user needs of both pharmacists and the Deaf community. Despite its success in this regard, SignSupport is unable to facilitate pharmaceutical care and as it does not allow for a dyadic system of communication. Both the pilot and hospital evaluations unearthed significant problems which Deaf people face with regard to healthcare services. These include the lack of access to healthcare information in a medium that they can understand, and severely limited access to primary healthcare services as result of their inability to communicate and seek healthcare at this level. These problems are not within the scope of SignSupport, but can significantly impact the health status of the Deaf community and must be addressed with urgency.

Apart from its contextual limitation, the Deaf community did not express any functional usability problems with the application. Pharmacists reported one problem; that they were not easily able to find a medical condition, illness or symptom to select as a purpose for medicines. This problem exists because there is a limited number of medical conditions and symptoms for which there is an

equivalent SASL ‘word.’ This problem can be addressed by providing a list of the conditions programmed in SignSupport to the pharmacists, who are then able to match the purpose they wish to select, to one that is available in the application. For example, SignSupport has no option for peptic ulcer, but the pharmacist could select ‘heartburn’ to indicate to the patient the purpose for taking the medicine.

7.2.9 Second design iteration

Findings from the hospital user evaluation generated the following recommendations to the research team for modification to SignSupport:

- On the pharmacist interface, include medicine combination formulations in the list of medicines which can be selected, for example, Rifafour® is combination therapy for tuberculosis. The application currently only allows a pharmacist to select single-ingredient formulations, thereby excluding combination formulations. (this problem was identified by a research assistant)
- There are no iterative recommendations for the Deaf user interface.

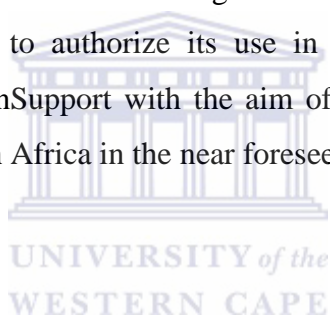
The pharmacist at Tygerberg hospital identified a further recommendation to compile a brief instruction booklet for SignSupport, which incorporates screenshots and a list of the symptoms and illnesses available on the application.

7.2.10 Conclusion

All study objectives articulated for the usability evaluations (pilot and hospital experiment) of SignSupport were achieved. Study procedures were appropriate and experiments progressed as planned. SignSupport was found to be a useful and applicable assistive technology for Deaf people in the context of providing medicine instructions during the dispensing process at public sector institutional pharmacies. The application is able to carry a pharmacist-patient interaction from commencement to conclusion for oral solid dosage forms. While SignSupport can successfully communicate medicine instructions to a Deaf patient in signed language, it does not facilitate dyadic communication necessary to provide pharmaceutical care.

Usability evaluations enabled the researchers to identify problems in the system and effect the necessary iterative modifications to remedy these problems. Usability testing subsequent to the first iteration generated largely positive usability results, with a hundred percent positivity scores achieved for majority of questions posed to both pharmacists and Deaf persons. Success of study endeavors depended heavily on the contribution of SASL interpreters who were the anchors and mediators of the study.

The system in its current form is a fully functional and useful prototype, but is not yet market-ready. Market readiness can be achieved by populating the prototype with all other dosage forms for self-administration and applying usability tests for all additions. Once this has been completed, the device must be subjected to independent quality control evaluations registered with all applicable medicine and technological authorities to authorize its use in South Africa. The researchers continue to work on SignSupport with the aim of availing the application to the Deaf community of South Africa in the near foreseeable future.



CHAPTER EIGHT

DISCUSSION

The three previous chapters (five, six and seven) have presented the outcomes of several conceptual and empirical processes which constitute this dissertation. Each outcome was presented and discussed in the context of its implications for SignSupport development and iteration and imminent research objectives. This penultimate chapter delivers a broader discussion on the themes emerging from the SignSupport project, including a review of the chosen methodology, the strengths and limitations of the study, the ramifications thereof and implications on policy reform and social redress for the Deaf communities. In addition, health information accessibility for Deaf persons and the existing fissures in social competency related to pharmacy curricula and higher education priorities are explored. A related list of recommendations to address these issues closes the chapter.

8. Introduction

This chapter aims to deliver a general discussion of reflections, lessons and implications emerging from this thesis. Divided into four sections, the first section provides a deliberation of the research strategies used to design and evaluate SignSupport. I discuss the dynamics of the multidisciplinary collaboration, the combined employment of qualitative and participatory action methodologies and the strengths and limitations of this study. Furthermore, issues relating to working with the Deaf community and our dependence on signed language interpreters are described.

The second section deals with the difficulties encountered in the provision of equitable and efficient medicine-related health services for Deaf people in South Africa and I highlight the advantages and shortcomings of the choice of a mobile phone intervention to facilitate communication between Deaf patients and pharmacists. The third section explores the specific roles of pharmacists and pharmacy faculty as potential change agents to find resolutions to the medicine-related problems faced by Deaf people and marginalized society groups in general. The fourth and final section outlines future work on SignSupport and continuing initiatives with Deaf communities in the Western Cape.

8.1 RESEARCH METHODS

SignSupport was built on a foundation comprising three fundamental elements: (i) a multidisciplinary collaboration between research partners with vastly different fields of expertise, (ii) an intricate dependence on the Deaf community, pharmacists and signed language interpreters to develop and progress the study and (iii) qualitative, participatory and community-based co-design strategies. The implications of each of these elements for the research progression are described below.

8.1.1 Multi-disciplinary collaboration

Combination of skills

The collaborative effort of researchers who hold pharmacy, computer programming and industrial design expertise was essential to building SignSupport. Their collective knowledge and skills were interwoven and employed at each stage of development and evaluation. Moreover, the interdependence of the triad research partnership encouraged learning across our respective professional boundaries with regard to the requisites of an assistive mobile phone application to facilitate patient counselling for Deaf persons. For example, as the pharmacist partner, I was the last member to join the team and prior to my involvement; the blueprint for SignSupport consisted only of very basic medicine directions that were intended to form the entire application (e.g. Take 1 tablet three times per day). Neither the computer programmer nor the industrial design engineer were aware of the importance of communicating background medical information, warnings and recommendations or the many permutations and additional instructions of medicine information. Similarly, neither the pharmacist nor the computer programmer possessed the skills to design SignSupport's screens and icons using pictures and colors in a manner that could cognitively be understood for members of the Deaf community. In addition, neither the pharmacist nor the industrial design engineer was able to program SignSupport onto computer software in order for it to become a tangible and functional application. Thus each member of the collaborative team depended immensely on the remaining two members to work synergistically to achieve our collective goal of creating SignSupport.

Healthy conflict

While there was some conflict between the three partners, such conflict was always a result of the desire of each partner to optimize our own specific professional perspectives. It was inevitable that working in a team consisting of diverse skills and backgrounds, that difference in approach and opinions would lead to conflict situations during the investigative process. The resolution of our conflicts came with the realization that our collaborative effort would require each of us to be open

to negotiation and that it was not always in the interest of the Deaf community to be rigid in our perspectives. At the first conflict situation, the pharmacist (I) was at the verge of concluding my involvement in the project unless the application contained all the pharmacy-specific information that I deemed necessary. At the same time, the computer programmer was of the opinion that it was unrealistic and not feasible to include patient greetings and other ‘unnecessary’ courtesies due to the coding complexities and storage limitations of the phones. By combining our professional knowledge and perspectives, we were able to attain flexibility by working through the conflict to find a solution that was suitable for both partners. If the computer programmer was not part of the collaboration, the pharmacist may have designed an all-inclusive application which was not operationally practical in terms of coding and the mobile phone storage capacity. On the other hand, without the pharmacist, SignSupport would likely only have contained basic medicine instructions, without medical history, warnings and recommendations or a review screen.

In the greater scheme of things, the conflict which we experienced and the resolution thereof led to reflection that inter-professional collaborations should form a core component in pharmacy training, focusing on contextualized learning where professional flexibility, embracing differences and negotiating skills could be developed in order to equip pharmacy graduates with the skill sets to enter into collaborative projects.

Team support

Perhaps the most valuable aspect of the collaboration was that, for each partner, there were always two other partners who could motivate the researcher who was stumbling across a hurdle. Inevitably each partner was required to reassess their professional contribution relative to the common overarching goal of an assistive communication device for the Deaf community.

This project was highly sensitive: once I became immersed in the Deaf community culture and understood their daily struggle and frustration in all spheres of life and

particularly at health facilities, I was angered and frustrated that society, the government, health authorities and academia were not doing enough to alleviate their plight. In such moments of aggravation and despair, my co-dependence on the research partners to share in my frustration and understand what we were collectively working towards was an immense comfort enabled us to find solace in sharing our frustration and creating an impetus that paved the way for successive accomplishment of each phase of the project.

The multidisciplinary collaboration approach offered an opportunity to combine different skills and areas of knowledge. It also allowed me access to human resources in areas where my proficiency in digital technology and industrial design was limited. In addition, it allowed me to glean motivation and inspiration from team members and the emotional support and stimulus to navigate through a highly complex and exhaustive research process. Yet another advantage to the collaboration was that it rendered me accountable to the two other members of the team if I did not meet research deadlines.

In pursuing research, many masters and doctoral thesis candidates do not complete their projects. In a team situation, one does not have the option of delaying or extending project deadlines because the timelines and funding commitments of respective team members are at stake. In this way, the collaboration ensured that I met all research deadlines in the stipulated time and did not defer from my own timeline or the project timeline in any way. I have no doubt that the multidisciplinary collaboration strengthened the project and provided the necessary resources to see the project through to completion.

Academic silos

In spite of the many advantages of collaborative projects, they are often not fully supported by academic infrastructure. During several encounters in this research journey, I was questioned about the appropriateness and ethics of submitting a collaborative project as a doctoral thesis. My response that I was only submitting the ‘pharmacy perspectives’ of the project and work that I did, seemed to carry

little weight as a counter-argument. Even in submitting this dissertation, I, as all other doctoral candidates, was requested to submit a signed declaration that the work submitted is mine only. Frankly, this did not sit well with me, because even though all the work I reported on was led and conducted by myself (assisted by research assistants, team members, Deaf community partners and pharmacist partners), it would not have reached fruition without the valuable and essential input of the computer programmer or the industrial designer. It is unfortunate that, contrary to collaborative efforts, the typical nature of academic and empirical projects is to work in a silo so as to ensure ownership of data. Perhaps such a stance could only discourage academics from working collaboratively and to the jeopardy of society at large who can benefit from collaborative efforts.

A project of this nature which aims at social change is very difficult, if not impossible, to achieve without the contribution of multi-disciplinary partners. Inclusive research involves people who may otherwise be seen as subjects for the research, become equal partners in the process of inquiry (Johnson, 2009). In this regard, the Deaf community partners actively shaped the requisites for developing a digital technology prototype. The involvement of multiple researchers is encouraged to engage in technological assessment (Shah, 2007). In my experience, professionals often prefer to practice in their own areas of expertise with strong reluctance to venture into other fields of practice.

The isolating nature of academic work has received substantial attention. Linton (2009) describes a “silo effect”, which speaks to the isolation of academics in their own areas of focus, with minimal interaction with the “academic neighbourhood” and even less with the outside world to which they should be more responsive. This can be accounted for by the pressures faced by academics in class preparation, grading and research and publication, among others. Even more so, academic silos are encouraged by faculty infrastructure, as the majority of institutions of higher learning “place little value on teamwork among faculty members (Linton, 2009).” In appraisals and concerns of tenure, little attention is given to collaborative work to engage on issues of social justice. Instead, publications and peer recognition carry the most weight, while making a significant impact in social change is “seen

as a distraction” (Manning, 2014; Riaz, 2013). Moreover, Surowiecki (2004) warns that this “silo effect” is damaging to the academic project because people are not as productive when working alone as they may be when collaborating with others. While doing what one has been trained to do and fulfilling professional norms should not be negated, society perhaps loses out on very powerful solutions and interventions which could result from multiple professional’s groups collaborating to address social quandaries.

Are professional silos of practice creating a barrier to addressing social problems? Literature suggests the affirmative. In light of the known immensity of social injustices facing humanity, urgent attention must be given to re-integrate the academic project as mechanism of social transformation.

8.1.2 Combining qualitative and participatory action research methods

During the very early stages of this research, I intended to undertake a quantitative study with Deaf people to gain statistically significant data that would inform the pharmacy design features of SignSupport. However, in reviewing the literature of similar studies with Deaf people, I found that published studies were largely anecdotal and qualitative in nature. This was due to a number of reasons. Firstly, Deaf people belong to small, marginalized communities and have very specific preferences. Their small and scattered numbers renders statistically based studies impractical. Secondly, Deaf people often exhibit limited levels of literacy and can neither fill out a questionnaire nor provide a verbal response as is normally the case with statistically based studies with human subjects. Instead, every piece of data from the Deaf community is obtained via a signed language interpreter. This makes the data collection process much more time consuming and much slower than is normally the case. To expect thousands of surveys answered out by Deaf people as would be a requisite for an inference-based study is simply unrealistic.

Thirdly, Deafness is uncontestedly heterogeneous. Deaf people differ in their degree of Deafness, levels of literacy and cognitive capability. Furthermore, one Deaf community may differ vastly to the next in terms of signed language dialect

and cultural values and societal norms. A statistically based study with such largely different individuals and communities may not yield statistically significant data sets.

Lastly, the type of information I was hoping to glean from the Deaf community was about their opinions, experiences and daily behavioral patterns. Quantitative inquiry produces objective data. We required in-depth insights into the experiences of Deaf people and natural behaviour patterns of pharmacists to influence SignSupport user features. Research into experiences and behavioural patterns require subjective, rather than objective data generated through quantitative study. Qualitative strategies allowed me to create simulation exercises in which overt and covert observations and in-depth interviews were adequate to glean the data I required to inform SignSupport. Much of the empirical activities of this thesis used simulation in the form of role-plays to obtain user needs and usability data on SignSupport. I described the organisation of such role-plays in a series of stepwise processes throughout the thesis. While role-plays are logistically cumbersome to set up and require participation from several partners, it allowed the research team a front-seat view into how pharmacists and Deaf persons behave in real-world situations. Possible alternative methods to obtain the same information include surveys of interviews which question the participants with regard to how they would behave in a dispensing situation. These methods however would not provide the depth of insight that I was able to glean by watching video footage of the body language, hand-screen co-ordination and general attitude toward the study proceedings.

Qualitative methods provided insight into the belief systems and behaviors of the Deaf community. However, we were not able to achieve such data without immersing ourselves within the community and becoming members of their social circle. Deaf people exhibit a strong sense of identity and cultural connectedness. Tending to interact in a closed social group with other Deaf people who communicate in signed language, they do not easily share their beliefs and opinions with 'outsiders'. In order to break these social barriers and gain the necessary buy-in from the Deaf community, I chose a participatory action approach of which

participation is central element. Earlier in this thesis, I quoted the slogan of South Africa's disability movement: *"Nothing about us, without us."* In actively involving Deaf people at every stage of this research, not only as participants, but as co-designers of SignSupport, the research team adopted the same slogan as our motto. It inspired us to include the Deaf community in every decision and seek their approval for every aspect of SignSupport's development.

A high level of participation was achieved throughout this study. At each stage, from conceptualization to implementation, the input of Deaf persons and/or pharmacy students/pharmacists was incorporated into research and design processes. The very idea for SignSupport was sketched out by the Deaf community, whilst all pharmaceutical elements were contributed through research with pharmacy students and pharmacists. The prototype was evaluated by Deaf participants, pharmacy students and practicing pharmacists and their feedback was incorporated into the first iteration, resulting in SignSupport version 2. The process was repeated, again with both participant groups to inform the second iteration. In combinations with qualitative techniques, participatory action research methods were employed in the framework of community based co-design, a design strategy in which both the researchers and users of a device collaborate as the design team.

The successful usability results reported in the previous chapter is attributed to the rigorous input and involvement of both Deaf participants and pharmacists. I am doubtful that such positive outcomes would have been achieved without their input. An alternative to designing the application without input from the users may have resulted in very different usability results. Furthermore, active user participation ensured high levels of receptiveness and acceptability of the prototype.

This complex study employed several different methods including interviews, observations, simulations, participatory design and questionnaires. While questionnaires are typically a quantitative method, I integrated it in a qualitative approach, allowing the participants an additional opportunity to express their opinions via a confidential route and concise manner. The questionnaires not only served this purpose well, but allowed me to compare usability findings from the

pilot study to the hospital experiment. Interestingly, questionnaire results across the two studies, which involved different participants and sites and was done two years apart (pilot study in 2013 and hospital experiment in 2015) were remarkably similar, adding validity to findings and implying that usability testing achieved saturation of data. The employment of multiple methods proved useful in allowing the research team to assess SignSupport from various standpoints.

Strengths and limitations of this study

A significant strength of the research process was the contribution and combined skills of the multi-disciplinary partners. Not only did it allow us to brainstorm the most appropriate design strategies for SignSupport and its evaluation methods, but it also provided the necessary support and motivation to see the study through to completion. Another strength was the high level of and rigorous participation from study participants (Deaf people and pharmacists). This enabled us to truly find design solutions and research strategies that were acceptable to our participant groups, thereby ensuring their buy-in and goodwill throughout study proceedings. Through the application of multiple sampling techniques to ensure representation from urban and rural Deaf communities, and prospective pharmacists with little experience and practicing pharmacists with high levels of experience, this study was able to detect independent usability results for SignSupport. Additionally, the accuracy of study findings was supported through the strong similarities in results between the two groups. Finally, the exhaustive list of strategies to ensure validity and reliability of study findings helped to enhance the strength and quality of deductions made from research outcomes.

There are a number of limitations to the study. Although this is a primarily qualitative study and participant numbers were within the norms of those employed in usability testing, the low participation rate remains a weakness. Due the small and scattered numbers of Deaf people, the study could be implemented on a national level (not even provincial or municipal); this however would mean that modified versions of SignSupport need to be created to suit all the possible different dialects of SignSupport in the country. This highlights another study limitation in that the application was only evaluated in the Western Cape region,

and thus was only tested for provincially common SASL dialects. Furthermore, SignSupport was only evaluated in a public sector tertiary hospital pharmacy. This was done because the Deaf community indicated that they mostly frequent such facilities to collect their medicine. Further studies should evaluate the applicability of Sign support in other institutional pharmacy settings.

Finally, the unique psychosocial and socioeconomic footprint of South African marginalized communities, rendered by apartheid policies to be of a lower income group and poor educational status as described in the preliminary chapters of this dissertation, may have influenced the acceptability and usability findings of SignSupport to some extent as very different usability results may be attained with Deaf communities abroad. As such, the findings generated from this research may have limited extrapolative clout for universal pharmacy contexts.

8.1.3 Conducting research with the Deaf community

The research team unanimously agreed that we would not attempt to design SignSupport without rigorous input and feedback from the Deaf community. However, not any of the researchers were fluent in signed language; consequently communication with the Deaf community was achieved through the interpretive services of SASL interpreters. The prospect of doing so was met with reluctance.

Sign language interpretation in data collection

Not only was I hesitant due to the ethical and confidentiality implications of conducting research via a third party, but the logistical inconvenience and expense of hiring interpreters and the fear that these interpreters would not ‘fit in’ and be accepted by our participant group magnified my resistance. The dearth in published research with Deaf communities may be owing to similar reluctance by researchers to conduct studies via signed language interpreters. In reality however, the SASL interpreters were not only essential to the study progression, but they also provided a buffer to ease the tensions that exist between speaking and non-speaking groups. For example, the researchers were reluctant to talk to one another during the study processes, so as to avoid causing the Deaf community to feel

excluded an as if we were speaking about them (deafness paranoia). With their presence however, the SASL interpreters could interpret whatever we were saying, even loose conversation that did not involve the research, and often the Deaf community responded via the interpreter. I also observed that all the interpreters became SASL interpreters due to having family members who are Deaf. As a result, they are able to understand the nuances of the Deaf community and were an indispensable information resource and a guide for the researchers throughout the study.

Ethical issues were curtailed by having the sign language interpreters sign non-disclosure agreements and the same participant information and consent documents as the participants. This study could not have progressed without the services of SASL interpreters unfortunately they are a scarce resource worldwide and concerted efforts should be made to train and employ interpreters not only in health facilities but also in academic endeavors with Deaf communities.

Deaf community context

Apart from undertaking all research-related endeavors via a third party (SASL interpreters), the specific cultural behaviors of Deaf people was another obstacle to surmount. Several psychosocial barriers were encountered in our study with the Deaf community. These included the strong sense of cultural connectedness within Deaf communities (which causes them to display reluctance in interacting with 'outsiders'); their diminished literacy capabilities; their impartiality to lip-reading and accommodation of their socio-economic circumstances.

These factors had significant ramifications for study processes. To overcome the reluctance among Deaf participants to engage in meaningful interactions with researchers, we had to invest significant amounts of time and effort in immersing ourselves in their community, building trust and familiarity until we were able to intuitively sense that they had become open to participation in the project and interaction with us. While this initially delayed study proceedings, the time invested was well worth it as the research process ensued smoothly and without incident. In addition, it empowered the researchers with the skills and capability to

continue their work with the Deaf community well beyond the perimeters of this thesis. As researchers, our way of engaging with the Deaf community led to us unpacking the experiences of an isolated community relative to our own world view. By recognizing differences in our social, cultural and professional practices, we could contribute to a dialogical process that acknowledges the co-existence of different rationalities.

Diminished literacy capability meant that we did not use typical methods of data collection. At no point did we rely on written or spoken means to obtain data. All responses from the Deaf community were given in signed language and translated for us as data by SASL interpreters. In a world where Deaf people are frequently forced to communicate in a language with which they are unfamiliar, this consideration was well appreciated by our Deaf participants who were notably relieved that they were not required to speak, lip-read or write anything. Even informed consent was taken by video recording a show of hands that they agreed to participate in the study.

The Deaf communities, with whom we conducted research, were typically of a low socio-economic stature. In the initial stages of the research, many of them indicated concern with regard to whether they could afford the taxi or train fare to reach the research destination. They were pleased by an offer from the research team to take care of all transport and meal costs. While this may be seen as an unethical incentive, it was crucial to ensuring study participation and creating a harmonious platform for meaningful engagement.

8.2 PROVISION OF HEALTHCARE SERVICES FOR DEAF COMMUNITIES

This section delves into difficulties encountered in the delivery of efficient and equitable healthcare services for Deaf people in South Africa. I explore the choice of mobile phone technology to alleviate some of these problems and suggest additional solutions to ensure acceptable levels of healthcare service delivery.

8.2.1 Disparities in healthcare services for Deaf people

Findings from the literature and from this thesis suggest that the health care system in South Africa is failing to deliver equal and efficient healthcare services to Deaf people. Not only is the healthcare system inadequate to cater for the specialized needs of Deaf people, but society at large and academia too are failing to connect with Deaf communities to resolve their frustration and helplessness. One such example is that of waiting areas in public sector healthcare facilities. Not during the study, or in any prior experience did I observe any signed or pictorial information or instructions of how to proceed within the facilities. Literature about the frustration and struggles of Deaf people in waiting rooms is immense and unambiguous, with a plethora of reports of Deaf patrons waiting all day long only to not receive any services at all (Reeves et al., 2002; Iezzoni et al., 2004; Ubido et al., 2002, Kritzinger et al., 2014, Valios and Vale, 2004). Similar situations occur in postal offices, banks and other situations where Deaf people are required to queue. Yet, with sophisticated technology at our disposal, this continues to be a problem for Deaf communities. When healthcare services are not available in a language that can be understood by patrons, it is clearly obvious that the plethora of health policy advocating for 'equal rights' and 'equitable services' for all citizens are clearly failing at an implementation level.

8.2.2 Medicine-related problems faced by Deaf people

In this thesis I have reported on at least three cases in which Deaf people did not use their medicines because they did not know the purpose thereof. Similarly, I quoted an author who reported on a case of a rape victim who received prophylactic therapy for HIV/ AIDS which she did not use because she had no idea of why she had to take the medicine. Subsequently, she was diagnosed as being HIV positive. These scenarios illustrate how the health-seeking behavior of Deaf people is negatively affected by the inability of healthcare staff to communicate with them in sign language. In addition, Deaf people often use medicines incorrectly and are more reliant on their own misconstrued instructions of using medicine than they are reliant on medicine instructions relayed to them by

pharmacists. As a result, they have many misconceptions with regard to how to use medicines, consequently taking medicines incorrectly and compromising their therapeutic outcomes (Ferguson & Liu, 2015; Haricharan et al., 2010; Reeves et al., 2002). Once again, the right to healthcare is negated.

8.2.3 Lack of access to healthcare information

Perhaps the most significant observation of this thesis is the lack of access to general healthcare information faced by Deaf people. In a world where mainstream society relies heavily on media including television, radio, internet and printed media to glean general information on healthcare such as healthy lifestyles, eating habits, sexual behaviours etc., the Deaf community are wholly excluded. They cannot hear, therefore radio and television do not serve as sources of information, and their limited literacy prevents them from gleaning such information from the internet or printed media. From my observations throughout the research process, Deaf people really are 'in the dark' with regard to healthcare information.

Even the risks of pregnancy and sexually transmitted disease associated with sexual habits are unknown to many Deaf people. During both usability evaluations of SignSupport, Deaf participants indicated their approval of the application but desperately wanted a resource where they could find answers with regard to their healthcare questions for themselves and their family members. In modern times, we tend to do a web search on any question which we may ponder about. For most Deaf people, these resources are unusable due to their literacy deficits. And even when they are forced to seek healthcare services because they have no other option to find answers, healthcare professionals are unable to communicate with them. This lack of access to healthcare information is a critical issue that needs to be addressed with urgency. Pharmacists, along with other healthcare professionals would be failing in their professional obligation in not addressing the health care information needs of Deaf patients.

8.2.4 Lack of Deaf awareness among health care providers

The problems that plague Deaf people are immense and may need a concerted and joint effort from the government, the healthcare sector and academia to combine skills and resources to address these issues. The first step toward ensuring equal services is to eradicate the lack of Deaf awareness exhibited by healthcare professionals. Both from the reviewed literature (Huntington et al., 1995; Lomas, 1998; Moola, 2010) and in the findings from this dissertation, a common theme is that Deafness is not recognized nor understood by healthcare professionals. Being an ‘invisible disability,’ people often do not recognize that a person is in fact Deaf. Even when such recognition does occur, healthcare workers often have no idea that many Deaf people cannot lip-read and are unable to understand written instructions due to their literacy deficits. In the context of a healthcare facility, it is no wonder that Deaf people wait all day without being seen to and receive suboptimal services that do not cater for their special needs.

Personally, I too as a junior pharmacist working at a public hospital was unaware of the specific issues faced by Deaf people. When I interacted with a Deaf person, I attempted to speak as slowly as possible because I assumed they could lip-read. I also typed exhaustively long instruction labels for the medicines I was dispensing in the hope that they would face no ambiguity in understanding the instructions. I was wholly unaware that many Deaf people have reading difficulties. Deaf awareness must be entrenched among healthcare workers. This can occur through inclusion of Deaf awareness in healthcare curricula, educational campaigns and symposia. Only when a healthcare worker is aware of what Deafness means will they have the motivation and knowledge to implement practical solutions to alleviate the difficulties faced by Deaf people at healthcare facilities.

8.2.5 Policy implementation-an imperative for disability service delivery

In addition to creating Deaf awareness, there must be an effort to implement human rights and disability policy. South Africa in particular has respectable policy in place to support all disabled people but such policy fails at an implementation

level. With regard to the Deaf community, legislation does not mandate signed language interpretive services at hospitals; neither does it specify any other disability specific services. Dialogues must be entered with authorities to ensure government adheres to and implement their policies and are held accountable should they fail to do so. Some suggestions to implement their policy for Deaf people are to mandate accessibility to sign-language interpretive services at all healthcare facilities. In addition, investing resources into infrastructure specific for Deaf people should be prioritized; this may include systems similar to those seen at fast-food outlets, where patrons are given a disk which vibrates accompanied with flickering lights to indicate that their order is ready to be collected. Similar disks should be provided to Deaf people at the reception and handed in at waiting rooms to indicate to staff and Deaf patients that it is their turn to either consult with the doctor or to collect their medicine. Another plausible suggestion is to include television screens in the waiting areas which run videos of sign language interpreters providing health-related information. This would mean that while waiting to be seen, Deaf people will be able to glean such information in their own language and may consequently learn the ambient healthcare information provided on mainstream television, radio and internet to which they are not normally privy. The availability of sign language interpreters, vibrating disks in waiting rooms and television screens broadcasting information in sign-language can potentially immensely improve the healthcare experience of Deaf people and perhaps even re-integrate them into the healthcare system in a way that they feel like part of the system instead of as an outsider that nobody seems to see or hear. Perhaps such measures may alter their health seeking behaviors and even desegregate them from mainstream society.

8.3 A MOBILE PHONE INTERVENTION AS AN OPTION TO FACILITATE COMMUNICATION BETWEEN DEAF PATIENTS AND PHARMACISTS

SignSupport is a mobile phone application crafted to assist Deaf people in their interaction with pharmacists, with the overarching goal of positively impacting

their medicine-related health outcomes. This dissertation is centered on the design and evaluation of SignSupport in this regard.

8.3.1 SignSupport usability evaluation

Both a pilot study and real-world experimentation of SignSupport yielded overwhelmingly positive results. Pharmacists reported that the application was easy to navigate and that it would easily fit into their regular practice activities. They were confident that it has the capability to accurately translate medicine instructions into signed language, but requested that they be provided with a short instruction manual should they have any practical problems with the application. Dispensing time using SignSupport does not differ greatly compared to regular dispensing. In a resource constrained, high workload environment this is crucial to ensure the acceptability of the application. Deaf participants also indicated their approval of the application. In particular they appreciated the sign language format and that they were not at all required to use spoken or written language when using SignSupport. In addition, they expressed appreciation for the autonomy and independence they were afforded by using the application.

8.3.2 Mobile phone technology

The choice of mobile phone technology as a medium to achieve these goals was found to be appropriate and had many advantages. All participants (pharmacists and Deaf community) were familiar with smart phone technology and were easily able to use the application. Majority of the Deaf participants own their own smartphones and would be able to download the application if it were available in their play store. Being on mobile phones, the application is in a compact package that is easily portable for Deaf people; this feature is essential for the daily reminders to take medicines that are input into the phones by pharmacists. Lastly, all the phones were able to play the SASL videos clearly and with no delay, indicating that the technology is compatible with that of mid-range commercially available smart phones.

8.3.3 SignSupport limitations

In spite of these positive findings, evaluation of SignSupport highlighted a number of limitations. The first limitation is that SignSupport is context specific for hospital pharmacy, and while it can be easily adapted to accommodate a prescription scenario in a retail pharmacy, it is not suited to a situation in which a patient seeks health advice and treatment for a minor ailment. Such a service entails primary health care which is integral to the health system in South Africa, where resources or capacity to treat people at a tertiary care level is severely limited. Moreover, Deaf community members are desperate to have somebody to be able to assist them at the primary care level, which often does not happen due to the existing communication barriers. SignSupport cannot be adapted to accommodate such services; the prototype would fail for reasons similar to the faults of the Looijestein-Mutemwa doctor-Deaf patient prototype; the domain of possible interactions between a pharmacist and a patient seeking ambulatory care is simply too large to be contained in SignSupport. Just as SignSupport was designed to bridge the communication gaps existing in the dispensing of prescription medicines, alternative methods should be explored to facilitate the provision of over-the-counter medicines for minor ailments.

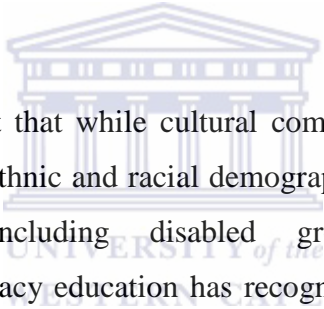
Secondly, the application is not able to achieve a dyadic interaction between a pharmacist and Deaf patient. This implies that SignSupport is unable to achieve a two-way system of communication, incorporating receiver (Deaf person) feedback, response and questions to the message (medicine instructions) given by the sender (pharmacist). With regard to pharmacists' professional practice philosophy, this means that pharmaceutical care, which depends on mutual engagement between pharmacist and patient, cannot truly be achieved. Instead, SignSupport is able to accomplish only an aspect of pharmaceutical care: the communication of medicine instructions. While this is a significant accomplishment and a core duty of pharmacist which is very difficult to fulfil without SignSupport, cognizance must be taken of the fact that we must continue to strive for pharmaceutical care provision and equitable and efficient service delivery for Deaf people.

8.4 LOOKING FORWARD: PHARMACISTS AND PHARMACY FACULTY AS CHANGE AGENTS TO SEEK SOLUTIONS TO THE MEDICINE-RELATED PROBLEMS FACED BY DEAF COMMUNITIES

This dissertation aimed to craft a solution for the linguistic barrier that is evident between pharmacists and Deaf patients. During our investigation, we were confronted with the reality that the barriers that exist are not only linguistic, but also sociological and psychological. One of the main barriers that exist is from the pharmacists and other health care practitioners is the lack of Deaf awareness. Healthcare personnel are not able to meet the needs of patient if they are unaware of what those needs are. This can be illustrated in the waiting room scenario and in the patient counselling situation. In waiting rooms Deaf people wait all day without being seen to. Deafness is not visible, personnel do not recognize that the person sitting there all day is Deaf and unable to hear their name being called or query how much longer their prescription will take to be processed. During their consultation at the healthcare facilities and pharmacies, doctors and nurses and pharmacists may not understand the complexities of Deafness. Such complexities include literacy and cognitive deficits, inability or unwillingness to lip-read and the nuances of Deaf culture. Furthermore, the heterogeneity of Deafness means that Deaf people cannot all be treated in the same manner, negating a one-size fits all solution. The reviewed literature and findings from this thesis have indicated this lack of Deaf awareness. Consequently, healthcare professionals do not respond appropriately to Deaf people. They talk more slowly in the hopes that the Deaf person can lip-read, and provide spoken written treatment consent form and healthcare instructions as though the Deaf person is able to hear and read proficiently. The importance of experiential and service-oriented curricula that target patrons with disabilities should be prioritized in institutions of higher learning.

8.4.1 Experiential and service-oriented curricula

The solution to the problems faced by Deaf communities in relation to health care may plausibly lie in the reform of the academic curricula of healthcare professionals, including pharmacists. In the mandatory undergraduate curriculum and embedded in social accountability of pharmacy schools, Deaf awareness must be prioritized thereby empowering graduates with the knowledge and skills to appropriately provide medicine-related care to Deaf people. It is enormous injustice that healthcare workers are not specifically trained in handling the needs and complexities associated with disabled groups. Pharmacy schools in particular should aspire to become socially accountable. Research, education and service activities of pharmacy schools should be aligned with social accountability criteria and principles of equity, quality, relevance and cost-effectiveness (Boelen et al., 2012).



Smith et al (2010) report that while cultural competency has been adopted as a focus area in education, ethnic and racial demographics are called attention to and alternative cultures, including disabled groups have typically been underrepresented. Pharmacy education has recognized the importance of cultural competency training as a means of diminishing health disparities. This is evident in initiatives by various colleges and schools of pharmacy to include such training in their curricula. However, few institutions identify disability as a culture (Smith et al., 2010), with even fewer providing disability-specific education. Moreover, even if disability-specific training is incorporated into curricula, such training must not comprise wholly of didactic, classroom type teaching. To truly understand the nuances of disabled culture such as the Deaf community, learning must be experiential in nature. This may include service-learning, community-based learning or inter-professional service experiences which are combined with other healthcare students. The diversity of cultural competency training methods that are already embedded in many schools of pharmacy worldwide indicates that the specific cultural issues which affect the medicine-related needs of the Deaf community can be addressed in the professional curriculum. In doing so, pharmacy students can learn about the needs of Deaf people and may be trained to adopt

constructive approaches in an attempt to ease their experience at health care facilities.

In my experience working with Deaf communities over the past few years, I believe that even minor practice change by pharmacists, such as realizing that the person in the waiting room is Deaf and will probably not hear their name being called, or recognizing that the Deaf person cannot understand written instructions well and using alternative methods of instruction, can have potentially positive impact on patient health seeking behavior and even quality of life.

This dissertation has demonstrated that glaring gaps and inequalities exist in the provision of healthcare services for Deaf people. Healthcare professionals are failing to provide the services so desperately needed by this community. In the broader perspective, Frenk et al., 2010 indicate that this failure to provide services appropriate to communities is a global and widespread phenomenon. Causal to this trend is the failure of professional education to keep pace with changing and escalating health challenges, not localized to any one group or community (Frenk et al., 2010). This calls for global reform by way of a universal social movement to adapt core competencies of graduating healthcare professionals with competency based-curricula that is responsive to changing health needs, rather than curricula that is dominated by static and outdated course-work (Frenk et al., 2010). With increasing technological advances, pharmacists have the potential to become agents of change in provision of pharmaceutical care for people with disability.

8.4.2 Pharmacists as change agents

In modern day society, medicines are an important commodity upon which society relies for their health and wellbeing as it enables the treatment of acute and chronic medical conditions. Accordingly, pharmacists play significant roles in society not only as the custodians of medicines but also a convenient and accessible resource for health-related information and advice. Often situated within communities, they serve as the first port-of-call for people requiring health-related attention and are typically respected and trusted members of society with strong connections to the

communities they serve. This renders pharmacists well placed to affect social change with regard to health-related quandaries, both for mainstream society and marginalized groups. For the Deaf community, the prospect for change is even better when pharmacists have been trained about the characteristics of Deafness and the nuances of Deaf culture.

This dissertation has created a strong case for social transformation with regard to the healthcare of Deaf people. Such change must be effected both within the Deaf community themselves and with the practice behaviors of health care professionals. With regard to the Deaf community, pharmacists are required to interact more closely to breakdown the misconceptions they have about using medicines. More specifically, pharmacists are pivotal in providing the health-related information which Deaf community so desperately requires. Such an initiative could inform and motivate Deaf people towards positive health outcomes. The barriers faced by Deaf people in healthcare are not only lingual; it is also psychological and psychosocial. As a dependable and trustworthy information resource for the Deaf community, pharmacists can encourage Deaf people to interact more readily with hearing society and so too, encourage the hearing members of the community to learn about Deafness and create awareness for the plight of Deaf people.

8.4.3 The role of higher education in social redress

Universities are globally recognized as institutions of higher learning and knowledge production and transfer. They are lesser known for another important role; that of being centers for social transformation. The academic project is not only about intellectual effort, but also about critical engagement, connectedness with society, inclusiveness and about using the knowledge that is produced for the betterment of people's lives. Yet, universities are dichotomously polarized institutions. One the one hand, the focus is the 'pure science.' It is about generating new knowledge, about maximizing publications as a source of revenue and about networking with international societies and partners securing large-scale funding for research. On the other hand is the ethical project, which includes engaging with communities, creating a culture of connectedness and social accountability in order

to dismantle the inequalities and injustices that exist in society. This is especially important in South Africa, which, twenty years into its democracy, remains one of the most inequitable and socio-economically divided countries the world over. This inequality suggests that universities are failing at fulfilling their dual roles, that the intellectual project is prioritized over the ethical project. If this were not indeed the case, a community would not suffer the plight and remain an ignored and unheard voice as the Deaf communities have been for the past decades.

The unfortunate reality in South Africa is that, like the Deaf community many minority groups and marginalized societies suffer social, educational, economic, linguistic injustices. This dissertation has only examined the quandaries of the Deaf community. As a multidisciplinary group, we have used the resources of the university and tapped into the skill sets of various individuals at institution of higher learning and within the community itself to find solutions. Our team continues to engage with Deaf communities in the Western Cape to seek resolutions for the issues that SignSupport could not solve. Such efforts require rigorous and continued efforts in the field, engaging with communities to create tangible solutions aimed at social redress. Universities battle to acknowledge such efforts in a manner that is equivalent to the acknowledgment afforded to the production and dissemination of new 'scientific' knowledge. This is regrettable, and if universities are to fulfil their fundamental role of societal transformation they must prioritize work aimed at social redress and work which applies their institutional knowledge and skill for benefit of marginalized communities.

8.5 FUTURE WORK and CONTINUING INVOLVEMENT WITH DEAF COMMUNITY PARTNERS

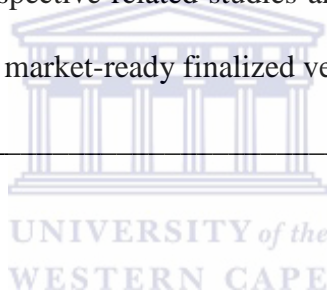
While this dissertation is approaching its conclusion, several initiatives continue to run with the SignSupport project and with Deaf communities in the Western Cape. Below I briefly outline these initiatives and future endeavors which are in the pipeline:

- Work with Deaf communities in the Western Cape continues. Members of the research team have established relationships with additional rural-based Deaf communities outside of Cape Town. We also continue our affiliations with the DCCT and DeafSA Paarl, who have eagerly requested to know the outcomes of this study. Symposia to disseminate the study findings to these Deaf communities are scheduled for January 2016.
- As a result of the finding from this thesis that Deaf people experience marked limitations in access to healthcare information, SignSupport is being modified to include videos on healthcare information topics including diabetes, healthy sexual behaviours, HIV/AIDS and sexually transmitted diseases, chronic illnesses, asthma etc.
- Randomised control trials are planned in which Deaf people take actual medicines as per SignSupport-assisted instructions with a view to have the application registered by the relevant medical and health authorities in South Africa. This would enable the application to become market-ready and commercially available.
- While SignSupport is the main thrust of this thesis, major findings which are not related to SignSupport have emerged. These include the difficulties experienced by Deaf people at health care facilities, the lack of Deaf awareness by health care providers, and the lack of access to healthcare information experienced by Deaf people. I plan to disseminate these findings at conferences targeted at healthcare professionals including pharmacists, and at pharmacy academia. I also hope to disseminate such findings to the nursing community and the medical community.
- Being an academic staff member at UWC School of Pharmacy, I intend to embed Deaf awareness training within the school's experiential learning program. Outcomes from these initiatives will be shared with other schools of pharmacy in the country in the hope that they entrench similar programs in their curricula.

CHAPTER NINE

CONCLUSION AND RECOMMENDATIONS

The purpose of this closing chapter is to reconcile the findings of this dissertation with the primary research objectives. In addition, I deliver a list of recommendations for prospective related studies and a proposed follow-up plan to advance SignSupport to a market-ready finalized version.



9.1 Distillation of findings

The evidence demonstrated in this thesis has shown that glaring inequities exist in the provision of medicine-related care services to people in Deaf communities. Deaf people experience numerous challenges including attitudinal barriers of healthcare personnel, a lack of Deaf awareness and suboptimal service delivery, all of which impact their health-seeking behavior and the attainment of positive therapeutic outcomes. Poor pharmaceutical service delivery, amongst other challenges such as general lack of literacy, has translated to Deaf patients taking medicines incorrectly or not at all, misconceptions with regard to the use of medicines and non-adherence to treatment.

To address these issues, a multi-disciplinary effort was undertaken to design and evaluate a mobile phone intervention to facilitate communication between pharmacists and Deaf people. From these efforts, we were able to successfully extract a dialogue pattern typically exhibited by pharmacists during dispensing interactions to build a communication structure for the mobile phone intervention. Thereafter, I undertook the conceptual processes of elucidating a medicines database and a symptoms/illnesses database to program into our intervention. The next step was to verify SASL videos which translate the communication structure and illness/ symptoms names into sign language for the information of Deaf patients. The collation of the afore-mentioned dialogue pattern, medicines database, symptoms/illnesses database and verified videos culminated in the first functional version of our intervention, called SignSupport.

Iterative usability tests of SignSupport in a simulated dispensary and a real-world hospital pharmacy revealed positive and remarkably similar results. Both pharmacists and Deaf people indicated their approval of the application and indicated that they would most likely use it in the future. While evaluation of SignSupport was found to be effective in the purpose for which it was designed, study findings highlighted its limitations in interaction between a pharmacist and patient. Such limitations include that it does not allow for a dyadic mode of communication and as such is not able to facilitate the provision of

pharmaceutical care. Although not within the scope of SignSupport, Deaf participants were disappointed that the application is not able to provide generalized healthcare information. This was identified as a completing study finding; Deaf people are desperate for access to healthcare information in a medium and language that they can understand.

This thesis and the literature have indicated that attention must be called to healthcare service provision to Deaf people. I have discussed policy implementation and the role of pharmacists and pharmacy faculty in addressing the health disparities for Deaf people. The literature has demonstrated that involving practicing professionals and institutions of higher learning bodes well for initiatives geared toward social transformation.

9.2 Recommendations for SignSupport

With a view to advance SignSupport to a market-ready version appropriate for implementation and use by Deaf people, the following recommendations are proposed:

- a) Populate SignSupport programming infrastructure with additional dosage forms, in the same way that we incorporated tablets and capsules.
- b) Add combination dosage forms to the program.
- c) After accomplishing (a) and (b), subject the application to usability experimentation to detect any problems with the system.
- d) Once completed, present the application and usability results thereof to the relevant statutory authority which may deem it necessary to register as a medical device. Even if this is not the case, obtain the necessary regulatory permission to make SignSupport commercially available as an application that can be downloaded on commercially available phones.
- e) Continue to evaluate SignSupport by users and have a system in place to maintain and upgrade the application as necessary.

9.3 Recommendations beyond SignSupport

Findings from this study have brought to light a several issues faced by the Deaf community which are beyond the scope of SignSupport and warrant further research and continued interactions with the Deaf community to address these issues. As such, the following recommendations are proposed:

a.) Establish sign-language interpreter roles in healthcare facilities

Findings in the literature and from this thesis create a substantial case for the inclusion of sign-language interpreters at healthcare facilities. Deaf people uncontestably prefer to interact with healthcare professionals with the assistance of sign-language interpreters and the many medicine and health-related problems they encounter presents a strong case for this. The South African government needs to be made aware of this, and also that they are failing to implement their policies with respect to the specific needs of the Deaf community. Alternatively, authorities should look toward up-skilling healthcare staff to learn sign-language and assess the feasibility and practicality thereof.

b.) Undergraduate pharmacy training

Pharmacists possess generic skills to provide patient counselling. They however lack the awareness of Deafness to recognize that they must adapt these skills to suite the specific characteristics of the Deaf community which results in poor application of their skills in interactions with Deaf patients. To gain such awareness, they must be afforded opportunities to engage meaningfully and critically to recognize their own skills deficits and identify the struggles faced by the Deaf community. This can occur through experiential and service-orientated initiatives which afford students the opportunity to immerse themselves in the Deaf community.

c.) Establish meaningful connections between pharmacists and Deaf communities

As custodians of medicine and trusted members of society, pharmacists are conveniently and ideally placed to provide healthcare services and information to

Deaf people. Through continued professional development which is mandatory for pharmacists in South Africa, they can develop the skills and solutions they require to interact more readily with Deaf people. The Deaf community is desperate for access to health-related information since they are unable to glean such information from the means typically used by the hearing society (radio, television, printed media, internet etc.). In this regard, pharmacists are an untapped resource and their potential for meaningful engagement with Deaf people as providers of such information is plausibly significant.

d.) Embed inclusive research in institutions of higher learning as vehicles for social change

This dissertation has merely presented a case of one marginalized community who urgently require the attention of efforts of professionals, society and academia to alleviate the enormous health disparities they face on a daily basis. Universities have the resources and multiple skill levels to address such problems, not only for Deaf people but for many other forgotten communities who can benefit from the varied skills and services of such institutions. Social accountability must be embedded as a core activity of universities and such endeavors must be given equal acknowledgement as knowledge production and publication of research. Attempts at social redress can be greatly improved by the active and continued involvement of institutions of higher learning through research, education and service. Furthermore, dismantling academic silos has the potential to enrich and improve not only the lives of the societies we serve, but also challenge the status quo of academia.

9.4 Concluding remarks

In the early chapters of this thesis I presented comparison of a hearing baby and a Deaf baby, painting a picture of the numerous and varied social, psychological, socio-economic, developmental and emotional struggles of Deaf people throughout their lifespan. SignSupport was successfully developed as a novel intervention capable of communicating medicine instructions to Deaf people in a manner acceptable to the Deaf community and pharmacists in the Western Cape Province

of South Africa. Through SignSupport, this thesis has merely presented one potential avenue of support; the truth of the matter is far more can be done for the Deaf community not only to improve their health status, but also to re-integrate them into society as equally important members. The future health and wellbeing of the Deaf community hinges on human efforts to alleviate their struggles. However, this will remain a mere ideology unless pharmacists, other healthcare professionals and pharmacy faculty mobilize their efforts behind this strategy.



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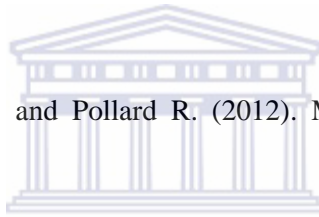
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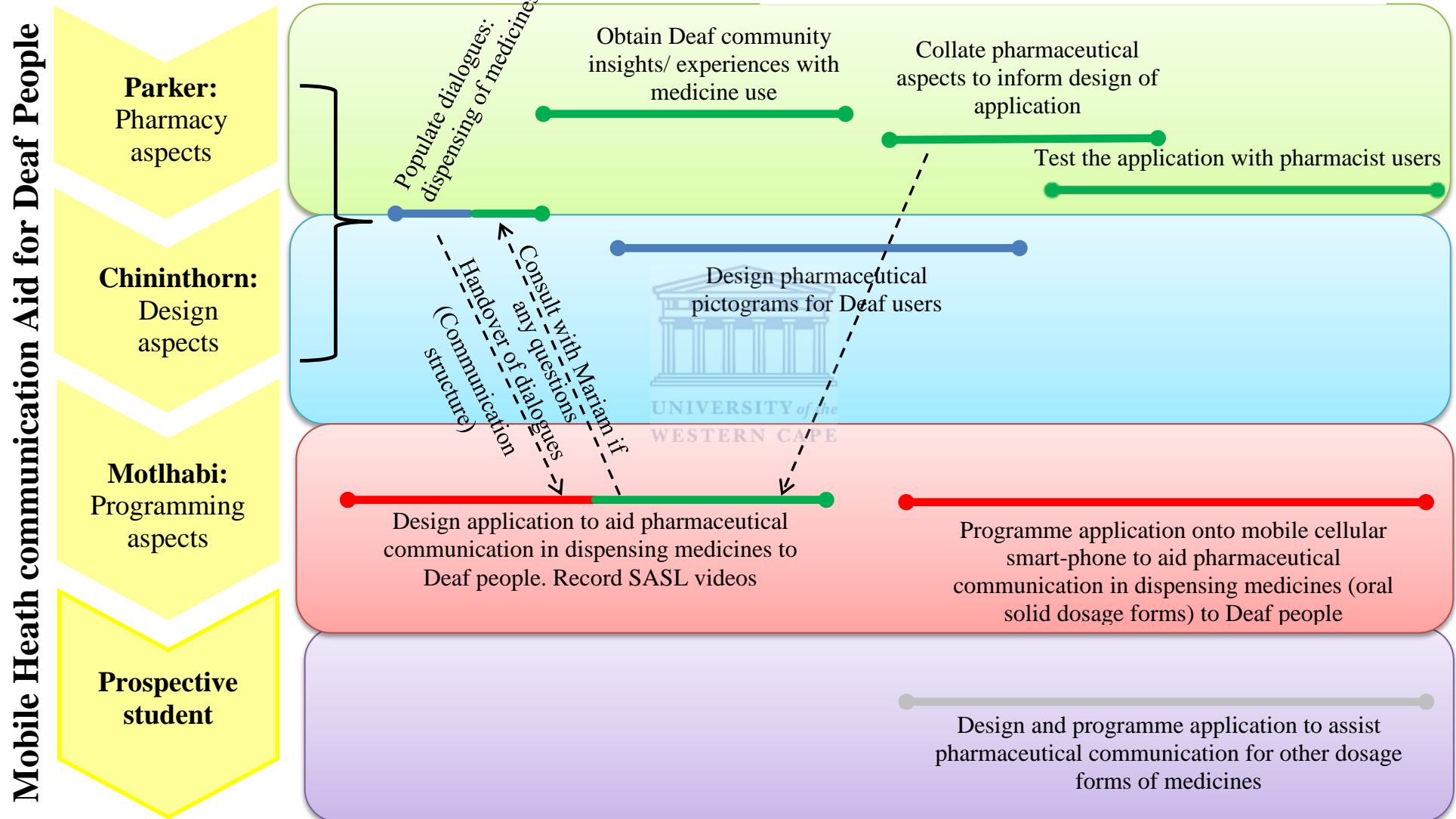
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APPENDIX A: ROLES, AFFILIATIONS AND PARTNERS

	Role	Affiliation	Supervisor	Co-researchers
Mariam Parker	Pharmacist Member	UWC School of Pharmacy	Angeni Bheeki William Tucker	Assistant researchers: Golden. T Gusha.S Higgins.K, Mack. L Made. S Mnguni. N Ahmed. N Chen. ST De Kock. K Potelwa.A Sehume B Arendse. T Julius.E Mashaba. C Mohammed. M Moola, M Smith, N
Michael Mothlabi	Computer programmer	UWC Computer Science	Meryl Glaser William Tucker	N/A
Prang Chininthorn	Industrial design member	Delft University of Technology (Netherlands)	William Tucker Adinda Freudenthal	N/A
DCCT	Input in design and preliminary testing	DEAFSA	Meryl Glaser	N/A
Paarl DEAFSA	Hospital testing	DEAFSA	N/A	N/A

APPENDIX B: SCOPE OF WORK

Scope of Work



APPENDIX C: PARTICIPANT INFORMATION SHEET (Baseline study)



Investigating medicine use in the Deaf community: toward informing a mobile cellular phone pharmaceutical application for Deaf users and pharmacists

Background:

You are invited to partake in a research study Medicine use in the deaf community. Before deciding to participate in this study, it is important that you understand why the research is being done and what it will involve. Please take your time to read the following information carefully. Please ask the researcher to clarify any unclear information.

Purpose of the Research:

This research study is designed to obtain information that may possibly inform a mobile application on Android media to enable communication between a pharmacist and a deaf patient. The data from this research will be used to explore medicine use by obtaining information from the deaf patients, to highlight the possible challenges faced by deaf patients regarding access to health care information, to possibly improve adherence to medicine use in deaf patients, to highlight possible successful mechanisms regarding medicine use in deaf patients

Study Procedure:

Your expected time commitment for this study is: time (1 hour 30 minutes)

The study will be conducted in the form of a focus group interview/ key informant interview/ simulated dispensing role-play format.

Risks:

There are no risks of participating in this study. Everything you say to us will be kept confidential. Interviews will be tape recorded and responses will also be recorded in writing but no names will be used in transcription of the data thereby ensuring confidentiality, you may decline to answer any or all questions and you may terminate your involvement at any time if you choose. The same applies for the simulated role-plays which will be video recorded.

There will be no direct benefit to you for your participation in this study. However, we hope that the information obtained from this study may help the health pharmacists and health care workers to improve service deliveries to the facilities.

Confidentiality:

We assure you that every effort will be made by the researcher to maintain your confidentiality including the following:

- Assigning code names/numbers for participants that will be used on all researcher notes and documents.

- Notes, interview transcriptions, video recordings and transcribed notes and any other identifying participant information will be kept in a locked file cabinet in the personal possession of the researcher. When no longer necessary for research, all materials will be destroyed.
- The researcher and the members of the researcher's committee will review the researcher's collected data. Information from this research will be used solely for the purpose of this study and any publications that may result from this study. Any final publication will contain the names of the organizations and researchers that have consented to participate in this study (unless they have requested anonymity): all other participants involved in this study will not be identified and their anonymity will be maintained

Each participant has the opportunity to obtain a transcribed copy of their interview. Participants should request a copy of the interview if desired.

Person to Contact:

Should you have any questions about the research or any related matters, please contact the researcher at the details below.

Voluntary Participation:

Your participation in this study is voluntary; it is up to you to decide whether or not to take part in this study. If you do decide to take part in this study, you will be asked to sign a consent form. If you take part in this study, you are still free to withdraw at any time without reason. You are free to not answer any question or questions if you choose. This will not affect the relationship you have with the researcher.

Unforeseeable Risks:

There may be risks that are not anticipated. However every effort will be made to minimize any risks.

Costs to Subject:

There are no costs to you for your participation in this study

Compensation:

There is no monetary compensation to you for your participation in this study.

Principal Investigator: Ms M. B. Parker

Department: Pharmacy Practice

E-mail: mbparker@uwc.ac.za

Signature: _____

Date: _____

APPENDIX D: CONSENT FORM (Baseline study)



Title: **Investigating medicine use in the Deaf community: toward informing a mobile cellular phone pharmaceutical application for Deaf users and pharmacists**

Declaration by participant:

By signing below, I agree to take part in a research study entitled: Investigating medicine use in the Deaf community: toward informing a cellular phone mobile pharmaceutical application for Deaf users and pharmacists



I declare that:

- I fully understand the consent form and it is signed a language with which I am fluent and comfortable.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I understand that I will be given a copy of this consent form upon request
- I voluntarily agree to take part in this study (Investigating medicine use in the Deaf community: toward informing a cellular phone mobile pharmaceutical application for Deaf users and pharmacists)

Signed at (place)on (date)..... 2012

.....
Signature of participant

.....
Signature of witness

APPENDIX E: DECLARATION OF PARTICIPANT INFORMATION BY INTERPRETER (Baseline study)



Title: **Investigating medicine use in the Deaf community: toward informing a cellular phone mobile pharmaceutical application for Deaf users and pharmacists**

I (name) declare that:

- I assisted the investigator (name) to explain the information in this document to (name of participant) using the language medium of South African Sign Language.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her questions satisfactorily answered.
- I shall keep all information conveyed to me by the participants confidential.

Signed at (place).....on (date).....2012

.....
Signature of interpreter

.....
Signature of witness

APPENDIX F: FOCUS GROUP GUIDELINE (Baseline study)



Title: Investigating medicine use in the Deaf community: toward informing a mobile cellular phonepharmaceutical application for Deaf users and pharmacists

Background questions:

1. Where do you live?
2. What is your age?
3. How long have you been Deaf?
4. What is your level of schooling? Primary, secondary or tertiary?
5. Do you make use of the public or private health sector?

Focus group guidelines:

1. How often do you interact with a health care provider with respect to receiving medication?
2. How often do you go to the pharmacy and speak to the pharmacist?
3. Describe your experience when going to the pharmacy?
4. Are you on any medication?
5. What type of medication are you on? (chronic/acute)?
6. Do you know what your medication is for?
7. How do you take your medication?
8. When do you take your medication?
9. Do you take them regularly and on time as instructed?
10. Who told you how to take your medication?
11. Is it difficult to take your medication?
12. What are the difficulties? Why?
13. How can a pharmacist make it easier for you to take your medication?
14. Which communication style do you prefer: signing or lip-reading? Why?
15. Do you prefer the use of pictograms?

APPENDIX G: KEY INFORMANT INTERVIEW GUIDELINE (Baseline study)



Title: **Investigating medicine use in the Deaf community: toward informing a mobile cellular phone pharmaceutical application for Deaf users and pharmacists**

1. Do you think Deaf people use medicines correctly?
2. Who instructs them on how to use medicines?
3. Are there any misconceptions of the Deaf regarding medicine use?
4. Are there any challenges of the Deaf with regard to medicine use?
5. What do they know about their medication?
6. Which communication method do you feel is most effective when you communicate with the Deaf, lip reading, signing?
7. Do you think that pictograms are effective when communicating with the Deaf?
8. What do you think plays a role in having a positive outcome when using medicine?
9. How are they able to use their medication correctly?
10. Do you think that there is or should be a relationship between the Deaf patient and a pharmacist?
11. What do you think the relationship is like between a Deaf patient and a pharmacist?
12. What do you think the relationship should be like between a Deaf patient and a pharmacist should be like?
13. What do you think can be done by pharmacists to improve the quality of life of Deaf individuals?

APPENDIX H: OSCE CHECKLIST FOR DIALOGUE PATTERN (Baseline study)

OSCE (Modified) Points

STEP A:

1. Greeting
2. Confirm identification
3. Clarification of the problem

STEP B: General history

4. Age
5. Physiological status (weight etc.)
6. Allergies and Reactions to drugs
7. Previous and Current illness
8. Medicines were taken in the last 6 months
9. Current medication

STEP C: Social professional information

10. Access to water and meals
11. History of Illnesses in the family
12. Smoking/exposure to smoking and alcohol use
13. Diet (in relation to specific disease)

STEP D: Clinical reasoning

14. Explanation of current problems
 15. Reassure patient
 16. Relevant Drug and non-drug treatment
 17. Directions for use
 18. Warning and recommendations
 19. Test recall
 20. Follow-up (if necessary)
-

APPENDIX I: PARTICIPANT INFORMATION SHEET FOR PHARMACY STUDENTS/PHARMACISTS



Title: Testing and modification of SignSupport®: a mobile phone application prototype for Deaf users and pharmacists

Background:

You are invited to partake in a research study on SignSupport use in a pharmacy environment. Before deciding to participate in this study, it is important that you understand why the research is being done and what it will involve. Please take your time to read the following information carefully. Please ask the researcher to clarify any unclear information.

Purpose of the Research

This research study is designed to obtain information that would determine usability and improve the mobile application, SignSupport, on Android media to enable communication between a pharmacist and a deaf patient. The data from this research will be used to explore SignSupport use by obtaining information from pharmacy students/pharmacists and to highlight the possible challenges faced by the students regarding the dispensing of medication to Deaf participants whilst using the mobile application on site in a simulated/ real world hospital dispensary, simulating the dispensing of fictitious prescriptions to a Deaf person.

Study Procedure:

Your expected time commitment for this study is:

The study will be conducted in the form of a role-play in which you (the pharmacy student/pharmacist) will be dispensing medication to a deaf patient in a simulated/ real world dispensary while using the mobile application. The entire role-play will be recorded.

Risks:

There are no foreseeable risks associated with participation in this study. Everything you do will be kept confidential and will be video recorded and no names will be used in transcription of the data thereby ensuring confidentiality. You may terminate your involvement at any time, provided that you have notified the research members 24 hours in advance of your intent to terminate your participation.

Confidentiality:

We assure you that every effort will be made by the researcher to maintain your confidentiality including the following:

Assigning code names/numbers for participants that will be used on all researcher notes and documents.

Notes, interview transcriptions, transcribed notes and any other identifying participant information will be kept in a locked file cabinet in the personal possession of the researcher. When no longer necessary for research, all materials will be destroyed through shredding.

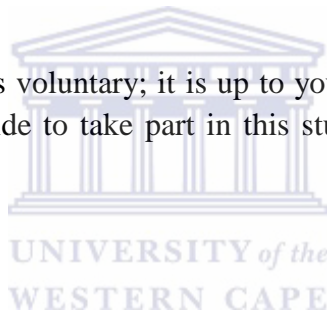
The researcher and the members of the researcher's committee will review the researcher's collected data. Information from this research will be used solely for the purpose of this study and any publications that may result from this study. Any final publication will contain the names of the organizations/researchers that have consented to participate in this study (unless requested anonymity): all other participants involved in this study will not be identified and their anonymity will be maintained.

Person to Contact:

Should you have any questions about the research or any related matters, please contact the researcher at the details below.

Voluntary Participation:

Your participation in this study is voluntary; it is up to you to decide whether or not to take part in this study. If you do decide to take part in this study, you will be asked to sign an informed consent form.



Unforeseeable Risks:

There may be risks that are not anticipated. However every effort will be made to minimize any risks pertaining to or arising from this study.

Costs to Subject: There are no costs to you for your participation in this study.

Compensation:

There is no monetary compensation to you for your participation in this study. A certificate of acknowledgement will be given at the end of the research study to acknowledge your participation.

Principal Investigator: Ms M. B. Parker
Department: Pharmacy Practice
E-mail: mbparker@uwc.ac.za
Contact number: 083 650 1644

Signature: _____

APPENDIX J: INFORMED CONSENT DOCUMENT FOR PHARMACY STUDENTS/PHARMACISTS



Date: _____

Title: Trial testing and modification of SignSupport®: a mobile phone application prototype for Deaf users and pharmacists

DECLARATION BY PARTICIPANT

By signing below, I (full name) agree to take part in a research study entitled: Trial testing and modification of SignSupport®: a mobile phone application prototype for Deaf users and pharmacists

I declare that:

- I fully understand the consent form and it is signed in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time given that I notify the researcher 24 hours in advance and will not be penalised or prejudiced in any way.
- I understand that I will be given a copy of this consent form.
- I voluntarily agree to take part in this study: Trial testing and modification of SignSupport®: a mobile phone application prototype for Deaf users and pharmacists

Signed at (place)on (date)..... 2015

.....
Signature of participant

.....
Signature of witness

APPENDIX K: DECLARATION BY INTERPRETER



Title: Trial testing and modification of SignSupport®: a mobile phone application prototype for Deaf users and pharmacists

I (full names) declare that:

- I assisted the investigator (name) to explain the Information in this document to (name of participant).....using the language medium of South African Sign Language.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her questions satisfactorily answered.
- I shall keep all information conveyed to me by the participants and investigators confidential.

Signed at (place)on (date).....2015.



.....

Signature of participant

.....

Signature of witness

APPENDIX L: PARTICIPANT INFORMATION SHEET AND INFORMED CONSENT DOCUMENT FOR DEAF COMMUNITY



School of
PHARMACY

Title: Trial testing and modification of SignSupport®: a mobile phone application prototype for Deaf users and pharmacists

Background:

You are invited to partake in a research study on SignSupport® use in pharmacy environment: The experiences, challenges, and triumphs. Before deciding to participate in this study, it is important that you understand why the research is being conducted and what it will involve. Please take your time to read the following information carefully. Please ask the researcher to clarify any unclear information.

Purpose of the Research

This research study is designed to obtain information that would determine usability and improve the mobile application, SignSupport®, on Android media to enable communication between a pharmacist and a deaf participant. The data from this research will be used to explore SignSupport® use by obtaining information from the pharmacists and to highlight the possible challenges faced by the students regarding the dispensing of medication to Deaf participants whilst using the mobile application on site in a virtual dispensary.

Study Procedure:

Your expected time commitment for this study is:

The study will be conducted in the form of a role-play whereby the pharmacy student will be dispensing medication to a deaf patient in a virtual dispensary while using the mobile application. The entire role-play will be recorded.

Risks:

There are no risks of participating in this study. Everything you do will be kept confidential and will be video recorded and no names will be used in transcription of the data thereby ensuring confidentiality. You may terminate your involvement at any time, provided that you have notified the research members 24 hours in advance to the termination of participation.

Confidentiality:

We assure you that every effort will be made by the researcher to maintain your confidentiality including the following:

Assigning code names/numbers for participants that will be used on all researcher notes and documents.

Notes, interview transcriptions, transcribed notes and any other identifying participant information will be kept in a locked file cabinet in the personal possession of the researcher. When no longer necessary for research, all materials will be destroyed.

The researcher and the members of the researcher's committee will review the researcher's collected data. Information from this research will be used solely for the purpose of this study and any publications that may result from this study. Any final publication will contain the names of the public figures that have consented to participate in this study (unless a public figure participant has requested anonymity): all other participants involved in this study will not be identified and their anonymity will be maintained

Person to Contact:

Should you have any questions about the research or any related matters, please contact the researcher at the details below

Voluntary Participation:

Your participation in this study is voluntary; it is up to you to decide whether or not to take part in this study. If you do decide to take part in this study, you will be asked to sign a consent form.

Unforeseeable Risks:

There may be risks that are not anticipated. However every effort will be made to minimize any risks.

Costs to Subject: There are no costs to you for your participation in this study

Compensation:

There is no monetary compensation to you for your participation in this study.

Principal Investigator: Ms M. B. Parker

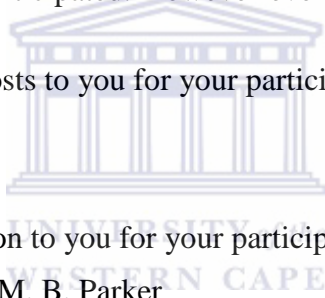
Department: Pharmacy Practice

E-mail: mbparker@uwc.ac.za

Contact number: 083 650 1644

Signature: _____

Date: _____



**APPENDIX M: QUESTIONNAIRE FOR PHARMACY STUDENTS/
PHARMACISTS (Post-intervention study)**



Title: Trial testing and modification of SignSupport[®]: a mobile phone application prototype for Deaf users and pharmacists

	YES	NO	MAYBE
1. Do you find SignSupport [®] useful to you as the pharmacist when dispensing to Deaf patients?			
2. Do you feel that SignSupport [®] would make it easier when dealing with Deaf patients in the future?			
3. Do you think that SignSupport [®] would facilitate and improve patient adherence?			
4. Would you say that the way which SignSupport [®] works is an effective way to facilitate communication between the pharmacist and Deaf patient?			
5. Would you recommend SignSupport [®] to your colleagues?			

1. How did you experience helping a Deaf patient while using SignSupport[®]?

2. While dispensing to Deaf patients using SignSupport[®], was there any challenges that you faced? If so, please explain.

3. In future encounters with Deaf patients, would you communicate with Deaf patients with/without SignSupport[®] and why?

4. Using SignSupport[®], how would you rate your service as a pharmacist to Deaf patients?

5. Other comments that you would like to add concerning SignSupport®.



APPENDIX N: QUESTIONNAIRE FOR DEAF PARTICIPANTS (Post-intervention study)

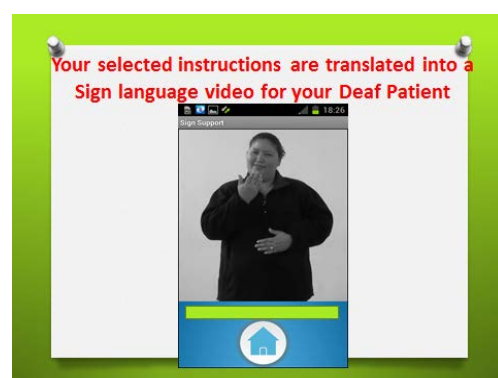
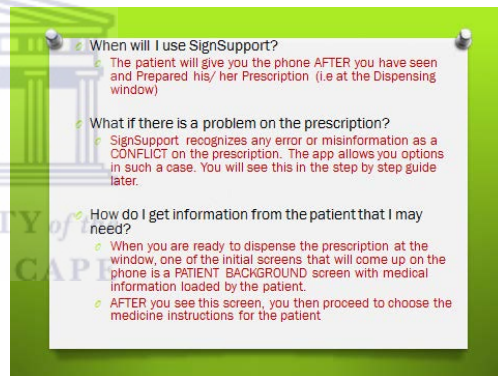
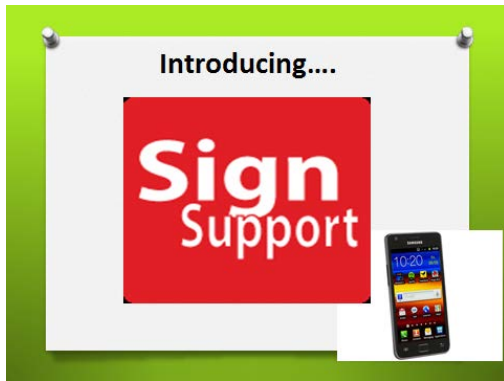


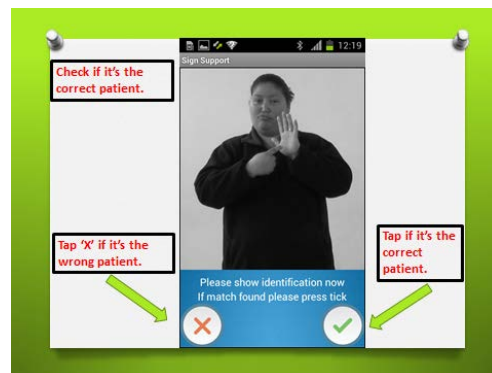
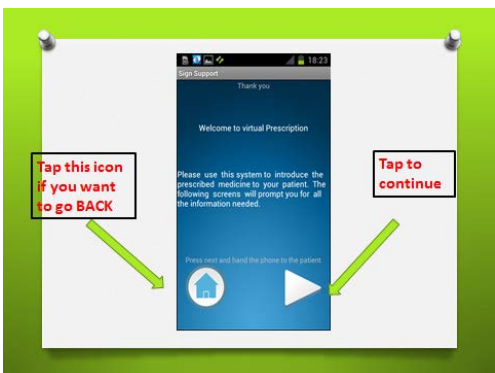
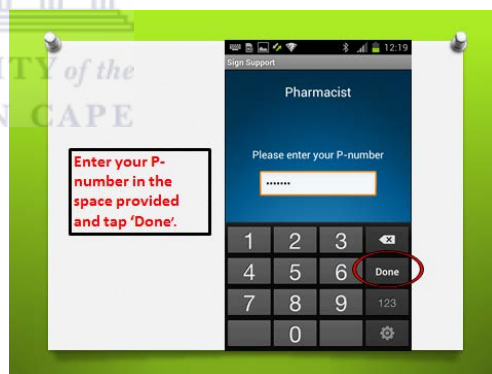
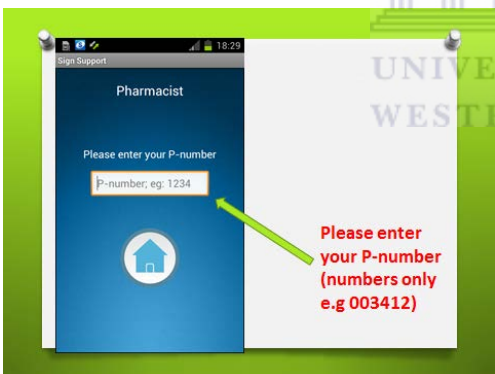
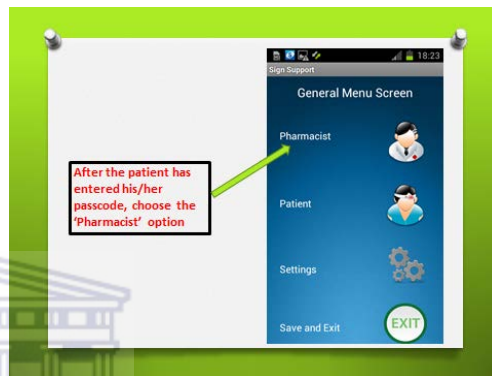
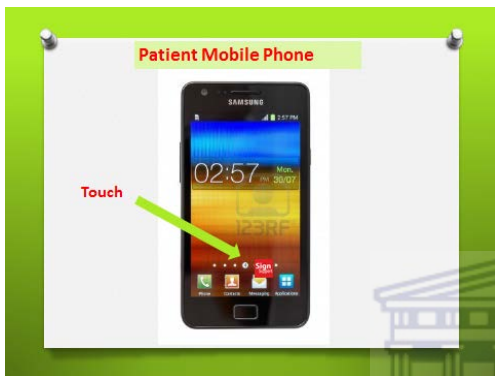
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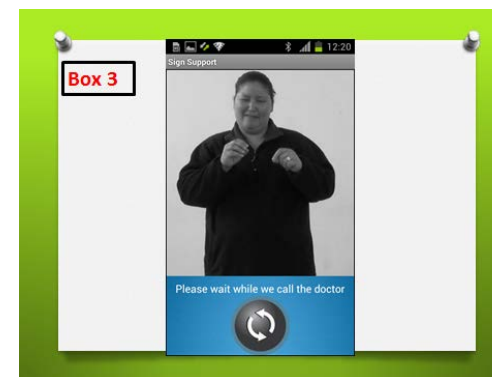
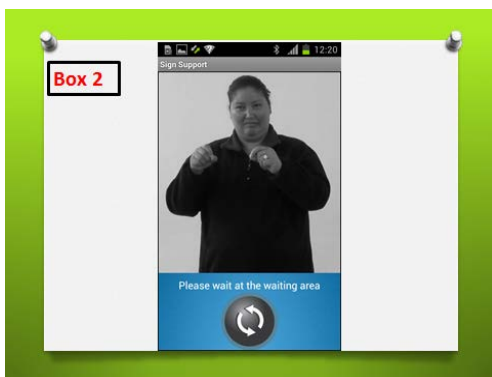
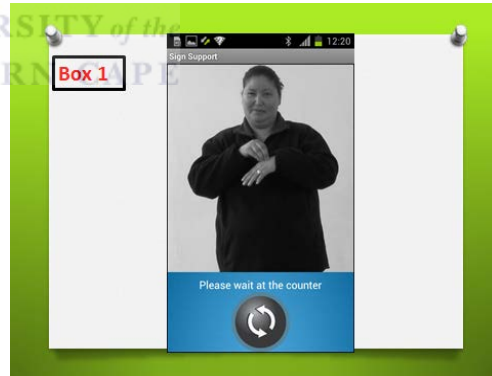
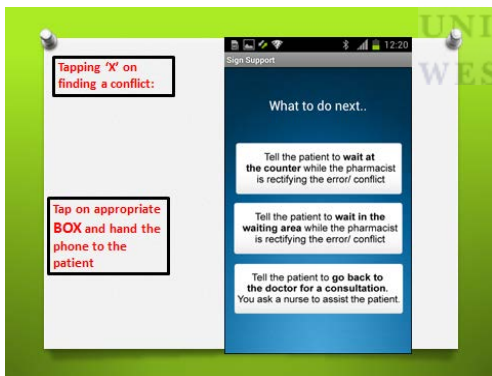
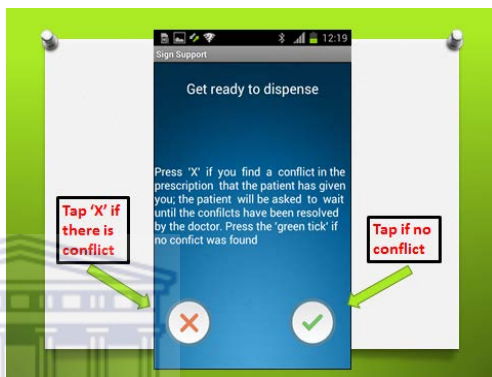
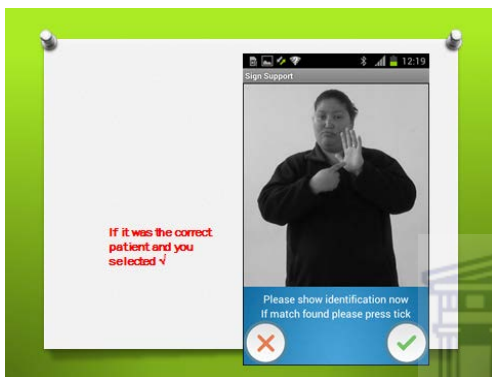
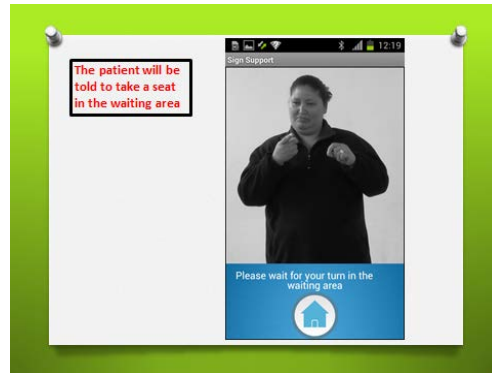
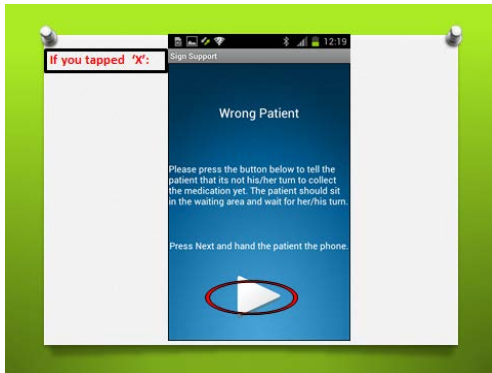
Mark the appropriate answer with an X

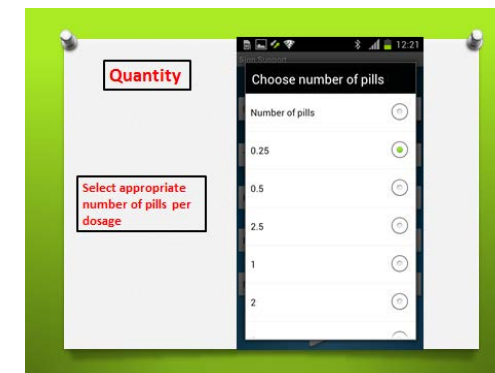
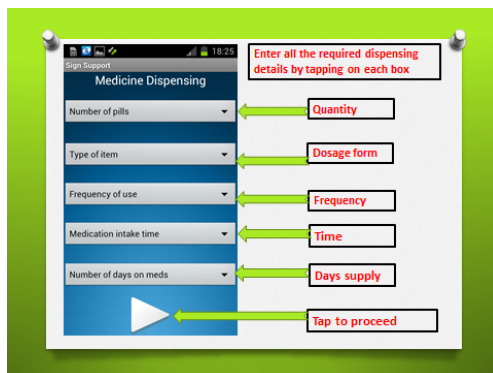
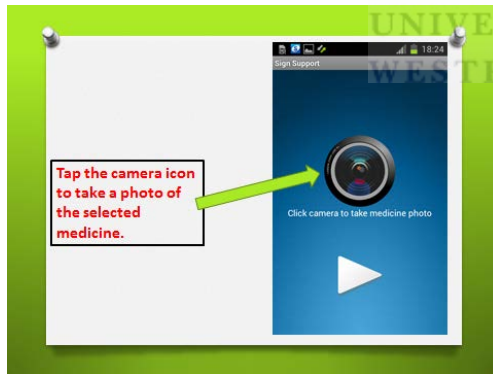
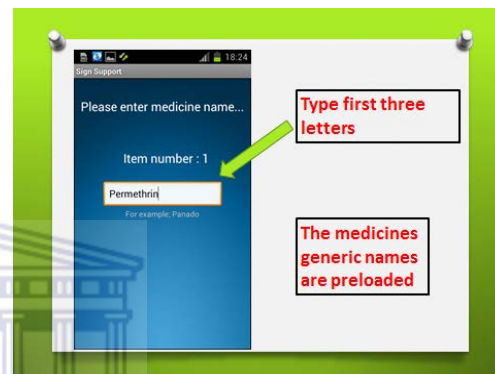
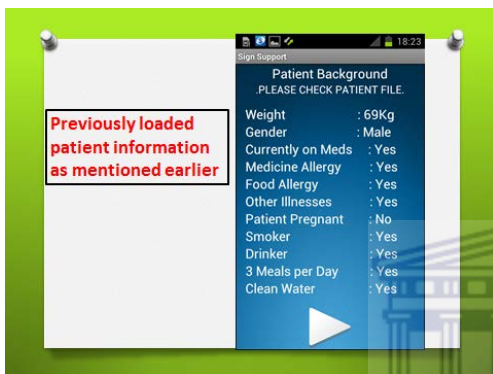
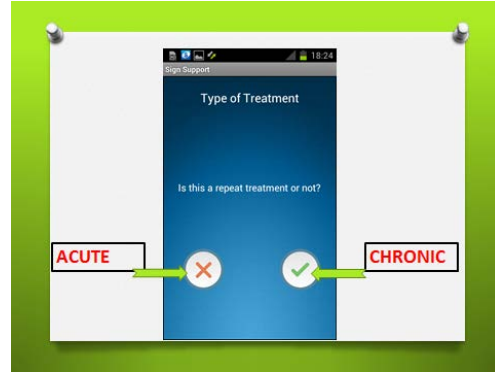
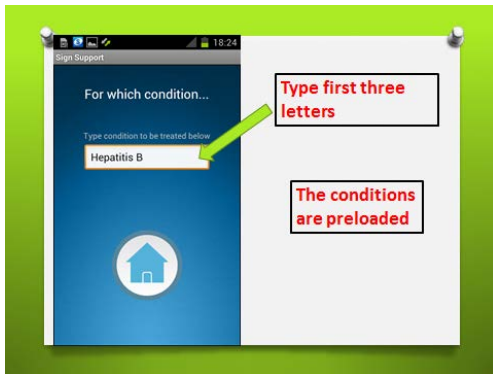
	YES	NO	MAYBE
1. Do you like SignSupport?			
2. Do you feel that your confidentiality is being protected when using SignSupport®?			
3. Do you think SignSupport will make it easier for you to understand how to take your medication?			
4. Do you feel that the application was easy to understand?			
5. Will this application help assist you with adhering to your medication?			
6. Do you feel that it was easier receiving information with the use of SignSupport®?			
7. Do you feel that this session was a success?			
8. Will you tell others about this application and research study?			
9. Did you enjoy this experience?			
10. Did you find SignSupport® useful?			

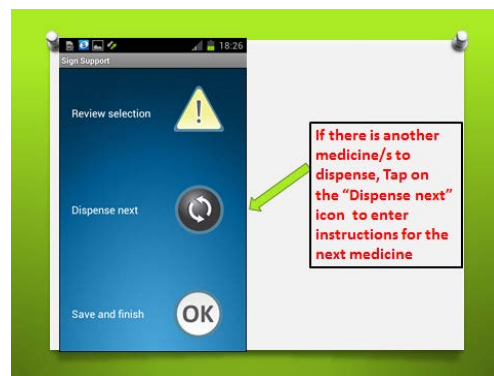
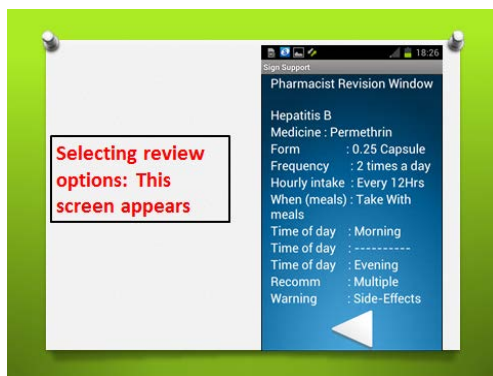
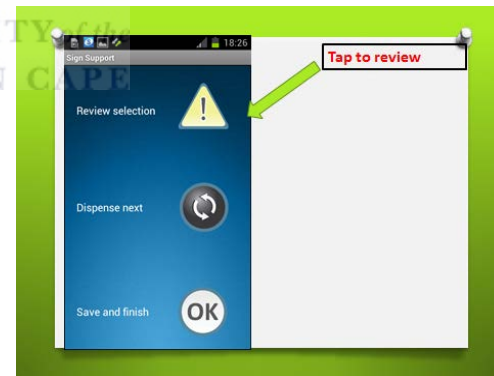
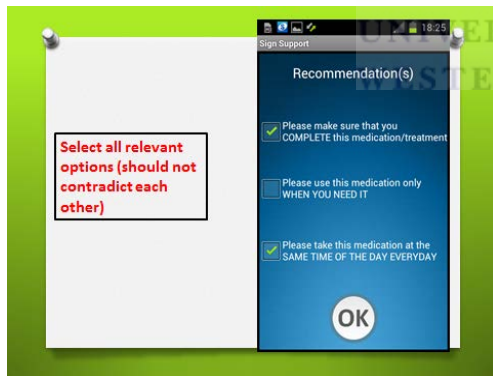
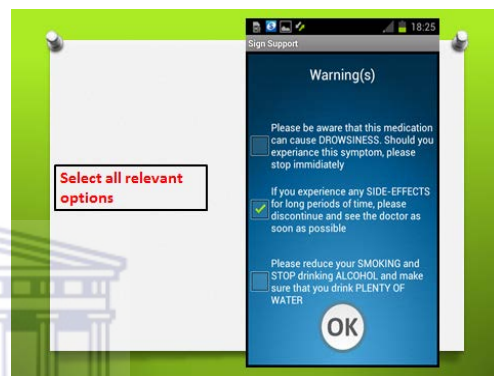
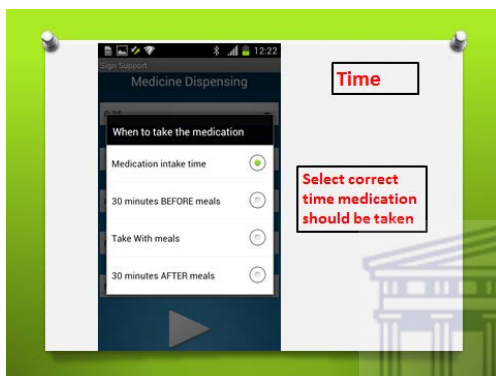
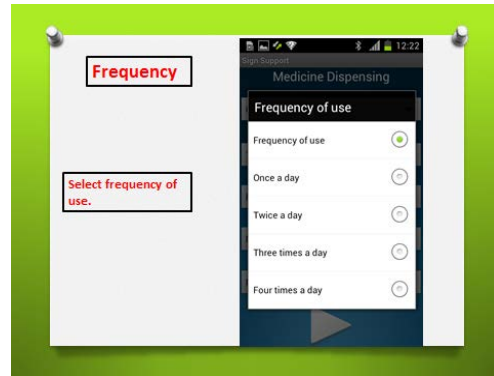
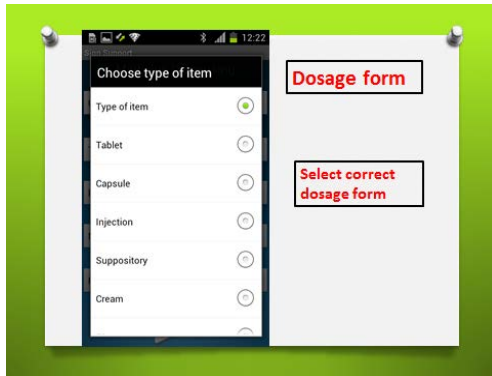
APPENDIX O: DEMONSTRATION WORKSHOP PRESENTATION FOR PHARMACY STUDENTS/PHARMACISTS (Post-intervention study)

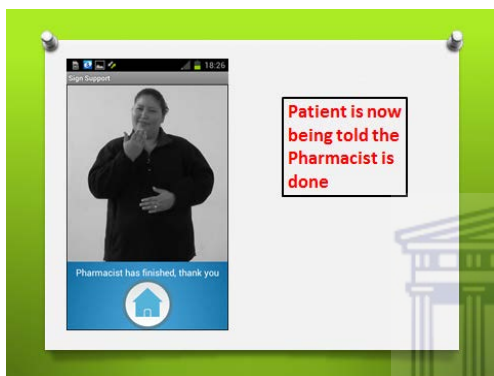
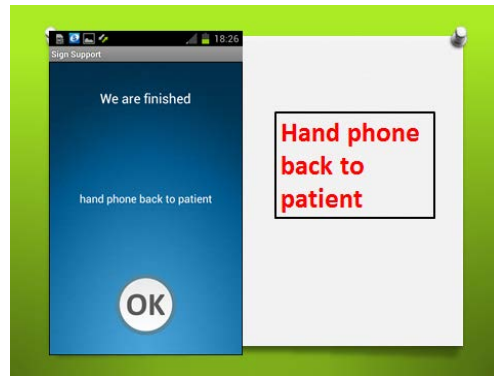
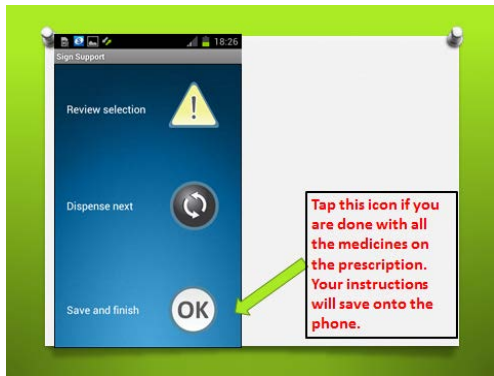












APPENDIX P: VIDEO OBSERVATION NOTES (INCLUDING TRANSCRIPTS): DEMONSTRATION WORKSHOP PRESENTATION FOR /PHARMACISTS (Post-intervention study)

Date: 6 August 2015
Time started: 8h00
Duration: 1 hour and 30 minutes
Time ended: 9h30

Brief description: The video observation notes below describe the first exposure of the pharmacists to the mobile phone application SignSupport®. These video observation notes consists of a description of five videos in which pharmacists (n=5), research assistants as well the principal researcher (pharmacist) are all present during this exposure. During the exposure session, pharmacists were introduced to SignSupport® and asked to navigate the application on Huawei® and Samsung® smart phones. The purpose of this observation was bi-fold:

- (i) To introduce the application to pharmacists and
- (ii) To observe pharmacists using and navigating the application in a workshop-type setting, where they are able to ask the researchers questions or for assistance should they encounter problems.

The workshop was recorded by video and notes taken.

Pharmacist n=5	Code Name Assigned
1	V
2	W
3	X
4	Y
5	Z

Fourth year pharmacy students (research assistants; RA)	Code Name Assigned
Tamsin Arendse	RA1
Elana Julius	RA2
Cebile Mashaba	RA3
Mohseen Mohammed	RA4
Maryam Moola	RA5
Nerissa Smith	RA6

Video 1:

Summary

Researchers welcomed and introduced themselves to the pharmacists; pharmacists were given background to the study, information sheets, and consent was obtained for participation in the study.

The principal researcher (pharmacist) welcomed and introduced herself to the pharmacists, stated her position in the study as the principal researcher (pharmacist) from the School of Pharmacy of the University of the Western Cape. The principal researcher (pharmacist) then introduced the research assistants as fellow researchers of the SignSupport® application. She then handed over to RA6 who did a brief presentation on the SignSupport® mobile phone application SignSupport, followed by a brief overview of the study and what was the pharmacists could expect during the training workshop and on the experiment day.

The research assistants (RA's) led the rest of the workshop by firstly informing the pharmacists about the background of SignSupport® and the objectives of the current study. RA5 then explained the information sheet, which informed the pharmacists of their involvement in the study. It was also mentioned that no foreseeable risks or costs were identified. The pharmacists were informed that they may withdraw from the study at any time they wish to do so, giving 24hrs notice to the researchers. The consent form was also explained and subsequently signed by all the pharmacists.

The consent form explained to the pharmacists stated the following:

- Their participation was completely voluntary,
- They were not forced to partake in the study.
- All information was to be kept confidential and known only by the researchers.

Thereafter the pharmacists were given the platform to clarify and uncertainties and ask any questions. They were then asked to sign their consent on the consent form.

Video 2:

Summary

All pharmacists (n=5) were given phones with SignSupport® and asked to navigate through the mobile phone application. One pharmacist raised an issue, thereafter the principal researcher (pharmacist) dealt with any issues that arose.

All phones were shown at the same time

- All pharmacists were receptive to the application
- All pharmacists using the mobile phone application navigated through the screens on the mobile phone application swiftly and without hesitation.
- The screen which prompted a photo to be taken, elicited a common issue amongst the pharmacists. There was confusion and hesitation on how to proceed after taking the photo.
- The screen which required the medicine dispensing instructions was followed properly and swiftly.
- The recommendation and warning screens were navigated accurately and swiftly.

Camera focuses in on one particular pharmacist

Pharmacist “W” was confused as a result of misinterpreting the “return” button as a way to review the selection made.

Camera zooms out, and all phones were shown at the same time

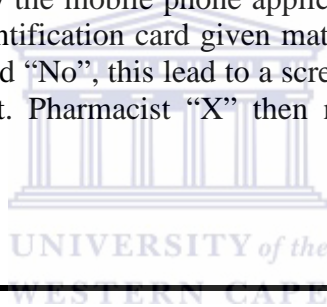
- All Pharmacists were able to save and finish.
- The principal researcher clarified that a “meal time” was used to indicate the time of use of a particular medication as well as an alarm system linked to the specific Deaf patient’s medication time.
- She explained that exact specification on when the meal was to be taken (Morning, Afternoon, and Night) was not practical due to the space limitations on the mobile application. Therefore the patients are able to set an alarm for medication taken in the night, afternoon, or morning.

Video 3:

Summary

Camera focuses on one particular pharmacist; the pharmacist incurs an error by mistakenly selecting an incorrect icon.

Pharmacist “X” was prompted by the mobile phone application regarding the validity of the script and whether or not the identification card given matched the identification number on the script. Pharmacist “X” selected “No”, this lead to a screen with three options which could be relayed to a Deaf participant. Pharmacist “X” then navigated back to the patient ID validity screen and selected “yes”



Video 4:

Summary

Camera focuses on one particular pharmacist, the pharmacist enquired about the list of conditions available loaded on the mobile phone application.

Pharmacist “V” was looking for a particular condition and could not find the condition she was searching for on the mobile phone application. The principal researcher explained to pharmacist “V” that the conditions must be in layman’s terms which may be interpreted into sign language. (E.g. hypertension stored as heart disease) and therefore had to be named accordingly.

Pharmacist “V” then asked for a list of conditions that are on the mobile phone application and how they are named, to be made available to the pharmacist. Other than that pharmacist “V” navigated through the application from start to finish swiftly and without hesitation.

Video 5:

Summary

Four pharmacists were generally able to navigate SignSupport®, three issues were raised.

Camera focuses on each pharmacist:

Pharmacist “W” navigated through the mobile phone application SignSupport® swiftly and without hesitation.

Pharmacist “Y” came late thus missed out on the introductory session. When she came to the condition screen she searched for the word ‘hypertension’, which the application saved as the condition ‘heart disease’. Overall pharmacist “Y” experienced slight hesitation whilst navigating through the application.

Pharmacist “V” asked why conditions are not listed per system, and the principal researcher explained about the different dialects existing within Sign Language.

Pharmacist “X” navigated through the application swiftly and without hesitation. When pharmacist “X” came to the camera screen, pharmacist “X” pressed the forward icon instead of the camera icon to take a picture of the medication.



APPENDIX Q: VIDEO OBSERVATION NOTES (INCLUDING TRANSCRIPTS): DEMONSTRATION WORKSHOP PRESENTATION FOR DEAF COMMUNITY : Post-intervention study

Date: 11 August 2015
Time started: 10h30
Duration: 2 hours and 30 minutes
Time ended: 13h00

Brief description: The video observation notes below describe the first exposure of the Deaf participants to the mobile phone application SignSupport®. These video observation notes consists of a description of three videos in which Deaf participants (n=6), research assistants as well the principal researcher (pharmacist) are all present during this exposure whereby the Deaf are trained on how to use the mobile phone application as well as what the experiment will entail:

Deaf n=6	Code Name Assigned
Participant 1	A
Participant 2	B
Participant 3	C
Participant 4	D
Participant 5	E
Participant 6	F
Interpreter	IF

Fourth year pharmacy students (research assistants; RA)	Code Name Assigned
Tamsin Arendse	RA1
Elana Julius	RA2
Cebile Mashaba	RA3
Mohseen Mohammed	RA4
Maryam Moola	RA5
Nerissa Smith	RA6

Video 1:

Summary

Researchers welcomed and introduced themselves to the Deaf participants; Deaf participants were given background to the study, information sheets and consent was obtained for participation in the study. Deaf participants were then allowed to navigate through the SignSupport® application.

Via an interpreter, the principal researcher (pharmacist) welcomed and introduced herself as a pharmacist and PhD student at the University of the Western Cape. The principal researcher (pharmacist) also mentioned that she is currently working on a mobile phone application that allows pharmacists to communicate medicine instruction with Deaf patients in a way that they will understand how to take their medication once they have left the pharmacy. The principal researcher (pharmacist) stressed the importance of taking their medication properly, she then asked whether they understood and the participants responded by nodding their heads.

The principal researcher (pharmacist) introduced the research group as fourth year pharmacy students and then explained that each pharmacy student will sit with one participant and that they will assist the Deaf participant, where needed, to navigate through the SignSupport® application on the mobile phone.

RA1 explained the purpose of the visit by the researchers; which was to provide training, inform participants of the aim of the mobile phone application SignSupport and the aim of the experiment; which is to test the usability and functionality of the application for future use in a pharmacy. RA2 explained what their involvement would be and mentioned that there would be no foreseeable risks and no cost involved. The Deaf participants were also made aware that they have the right to withdraw their participation at any time if they wish to do so. They respond by nodding their heads.

The principal researcher (pharmacist) then explained the consent form and stated the following:

- That their participation is completely voluntary and that no one is forcing them to partake in the study.
- That all their information will be kept confidential and only known by the researchers; after which she then asked them if they are willing to partake in the study. They were required to raise their hands to show that they agree to partake in the study.
- They all then raised their hands and kept it in the air for the camera to record it.

Consent forms were then filled in and signed by the Deaf participants and the research assistants as witnesses. The researcher assistants also ticked off the consent forms to show that consent was given.

The Deaf participants navigated through the screens of the mobile phone application with a pharmacy student. It was mentioned that once they understood the application they can say whether, in their opinion, they feel that such an application would help them with communication in a pharmacy.

The Deaf participants navigated through the screens of the mobile phone application swiftly without hesitation. When clarity was needed, the Deaf participant would sign to the interpreter. They would get attention by waving or raising their hands or tapping on each

other's shoulder. Participant "D" had difficulty with understanding the video as participant "D" is of a different dialect than the interpreter on the SignSupport® application.

Participant "A" wanted to know whether all the participants would know the end result of the experiment.

Video 2:

Summary

Burning issues were raised and discussed.

The Deaf participants were asked to navigate through the phone and identify problems (burning issues) that they may have experienced.

Burning issues:

- How would they know the milligrams of the tablets to take and how would they know if the medicine is dangerous or not.
- Whether they would be able to see the expiry date of the medicine.
- Participant "D" was confused about whether cancer was a past illness that she should maybe mention in her patient details; she was unsure about the past illness being checked in the patient file.
- Participant "D" had difficulty understanding the SASL dialect displayed and she needed the interpreter to translate the sign language video she had viewed on the SignSupport® application.
- Participant "E" wanted to know whether they could smoke 24 hours after taking the medication. It was then explained by the principal researcher (pharmacist) that the pharmacist dispensing the medication to the Deaf will enter recommendations and warnings regarding their medication instruction and in this way the Deaf user/patient would know whether they are allowed or not allowed to smoke.
-

The principal researcher (pharmacist) then explained to the participants that the mobile phone application will indicate how many tablets should to be taken; the dispensing pharmacist will also take a picture of each medication dispensed, its packet as well as enter warnings and recommendations for the Deaf to view.

The Deaf participants were then given refreshments before continuing with the exposure workshop, where each participant was allowed to familiarize themselves with the SignSupport application.

Video 3:

Summary

Deaf participants were informed regarding experiment day.

The participants were then allowed to navigate through the phone once more, after which the participants taught the research assistant how to sign their names and certain phrases such as "thank you", "nice to meet you".

RA1 then provided in-depth information regarding the hospital experiment:

- The time the participants would be picked up from DeafSA and the time the participants should be at Tygerberg Hospital
- The participants would go straight to the waiting room of the hospital until their names were called by the dispensing pharmacist.
- After the pharmacist calls each Deaf participant, the participant would go up to the dispensing window and hand the phone to the pharmacist followed by their mock patient ID card.
- The medicine instructions regarding the dispensed medication would be loaded onto the phone and handed back to the Deaf participant.
- The expected time that the participants would be dropped off at DeafSA after the experiment
- Lunch would be provided to them after the experiment.

All the participants agreed that they would participate in the experiment. The principal researcher (pharmacist) then thanked them.



APPENDIX R: VIDEO OBSERVATION NOTES (INCLUDING TRANSCRIPTS): HOSPITAL STUDY EXPERIMENT FOR PHARMACISTS AND DEAF PARTICIPANTS

Date: 13 August 2015
Time started: 09h00
Duration: 2 hours and 30 minutes
Time ended: 11h30

Brief description: The video observation notes below describe the experiment at Tygerberg Hospital pharmacy from the pharmacist’s point of view. After experimental set up was completed, all pharmacists were briefed, thereafter the experiment commenced. This involved the pharmacist dispensing medication to the Deaf participants via the SignSupport mobile phone application relaying the medicine instructions. These video observation notes consists of a description of four videos in which Deaf participants (n=6) and pharmacists (n=5) are all present during this experiment.

Pharmacists n=5	Code Name Assigned
Pharmacist 1	V
Pharmacist 2	W
Pharmacist 3	X
Pharmacist 4	Y
Pharmacist 5	Z

Video	Participants involved
1	W and A
	V and B
	X and C
2	Y and D
3	Z and E
4	W and F

Pharmacist's code name assigned	Time taken (minutes)		
	1 st item	2 nd item	Total
V	01:96	01:02	02:98
W	02:00	01:00	03:00
X	04:47	01:49	05:96
Y	02:93	01:78	04:71
Z	01:48	01:59	03:07

Video 1:

Summary

Camera focuses on 3 pharmacists, of whom two pharmacists navigated through the screens of the mobile phone application without hesitation, whereas one pharmacist was observed to have experienced difficulties.

Pharmacist “W” navigated through the screens of the mobile phone application swiftly and without hesitation. Pharmacist “W” followed the application instructions and no hesitation was observed throughout the dispensing of the medicine. Pharmacist “W” took the picture of the medicine in a manner that the patient could clearly differentiate between two or more medicines and knew when to hand over the phone to the Deaf participant in time to view the signed video loaded on the mobile phone application.

Pharmacist “V” navigated through the screens of the mobile phone application thoroughly and without hesitation. Pharmacist “V” followed the application instructions and no hesitation was observed throughout the dispensing of the medicine. Pharmacist “V” took the picture of the medicine in a manner that the patient could clearly differentiate between two or more medicines and knew when to hand over the phone to the Deaf participant in time to view the signed video loaded on the mobile phone application.

Pharmacist “X” hesitated from the beginning, difficulty was observed in the process of operating the mobile phone application to get to the “Get ready to dispense” screen. The following occurred:

- Hesitated at the “Get ready to dispense” screen, selected the X icon instead of the tick. Thereafter the first paragraph was selected, indicating that the patient should wait at the counter while the pharmacists checked the patient file. The pharmacist placed the phone on the desk and walked away.
- The pharmacist enquired about allergy prompt, whereby the application indicated that the patient had an allergy but no further details were given as to what type of allergy. Participant was then advised by the research team that an indication of a patient allergy should just prompt one to look at the patient’s hospital folder, where more details will be specified. Pharmacist returned and continued with the dispensing process.
- Had difficulty in deciding how to take the picture of the medicine.

Pharmacist “X” took the picture of the medicine in a manner in which the patient could clearly differentiate between two or more medicines. The second time around pharmacist “X”

knew when to hand over the phone to the Deaf participant in time to view the signed video loaded on the mobile phone application.

Video 2:

Summary

Camera focuses on one pharmacist experiencing difficulties with the “Type of treatment”, “Camera” and “Medicine instruction” screens.

Pharmacist “Y” hesitated on the “welcome screen” and delayed showing the patient the video on time. After commencing the dispensing process of the first item, pharmacist “Y” hesitated at the following screens:

- Type of treatment screen
- Camera screen, pharmacist did not know how to proceed after taking the first picture and therefore took another picture.
- Medicine instruction screen, when dispensing the second item, pharmacist “Y” hesitated at the camera screen once more and took two pictures of the medication. However it was observed that Pharmacist “Y” was faster with medicine instructions.

Video 3:

Summary

Camera focuses on one pharmacist and is observed to have navigated through the screens of the mobile phone application without hesitation.

Pharmacist “Z” navigated through the screens of the mobile phone application without hesitation. Pharmacist “Z” followed the application instructions and no hesitation was observed throughout the dispensing of the medicine. Pharmacist “Z” took the picture of the medicine in a manner that the patient could clearly differentiate between two or more medicines and knew when to hand over the phone to the Deaf participant in time to view the signed video loaded on the mobile phone application.

Video 4:

Summary

Camera focuses on one pharmacist and is observed to have navigated through the screens of the mobile phone application swiftly and without hesitation.

Pharmacist “W” navigated through the screens of the mobile phone application swiftly and without hesitation. Pharmacist “W” followed the application instructions and no hesitation was observed throughout the dispensing of the medicine. Pharmacist “W” took the picture of the medicine in a manner that the patient could clearly differentiate between two or more medicines and knew when to hand over the phone to the Deaf participant in time to view the signed video loaded on the mobile phone application.

APPENDIX S

Video Observation Notes (Including transcripts): Deaf Experiment day

Date: 13 August 2015
Time started: 09h00
Duration: 2 hours and 30 minutes
Time ended: 11h30

Brief description: The video observation notes below describe the experiment at Tygerberg Hospital pharmacy from the Deaf participant's view. This involved the pharmacist dispensing medication to the Deaf participants via the SignSupport mobile phone application relaying the medicine instructions. These video observation notes consists of a description of four videos in which Deaf participants (n=6) and pharmacists (n=5) are all present during this experiment.

Deaf participants	Code Name Assigned
Participant 1	A
Participant 2	B
Participant 3	C
Participant 4	D
Participant 5	E
Participant 6	F

Video 1:

Summary

Three Deaf participants navigated through the screens of the mobile phone application. One Deaf participant encountered some issues and two Deaf participants navigated through the screens swiftly and easily.

Participant "A" navigated through the screens of the mobile phone application without hesitation. "A" watched each video and was able to progress to next screen.

Participant "B" navigated through the screens of the mobile phone application without hesitation. "B" watched each video and was able to progress to next screen.

Participant "C" did not hesitate whilst navigating through the screens of the mobile phone application but did not follow the sign language videos, however did the following:

- Viewed the introduction video, which the pharmacist was supposed to do
- Proceeded with the screens on the mobile application after viewing introduction video of which the pharmacist was supposed to do so.

The pharmacist was then not able to view the patient history and had to go back to view the patient history screen. Initially participant "C" viewed the prescription review with the

pharmacist help but thereafter navigated through the screens of the mobile application without hesitation.

Video 2:

Summary

Camera focused on one Deaf participant navigating through the mobile phone application.

Participant “D” navigated through the screens of the mobile phone application without hesitation.

Video 3:

Summary

Camera focuses on one Deaf participant whereby some issues were identified.

Participant “E” did not hesitate with navigating through the screens of the mobile phone application but hesitation was observed due to the following:

- Reviewed the first item of the script three times.
- Was thorough in viewing the prescription review after the third attempt but navigated through without viewing the videos.
- Selected patient background icon to re-enter his personal information.

Video 4:

Summary

Camera focused on one Deaf participant and no problems were observed.

Participant “F” navigated through the screens of the mobile application through without hesitation. Participant “F” watched each video and was able to progress to the next screen.



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