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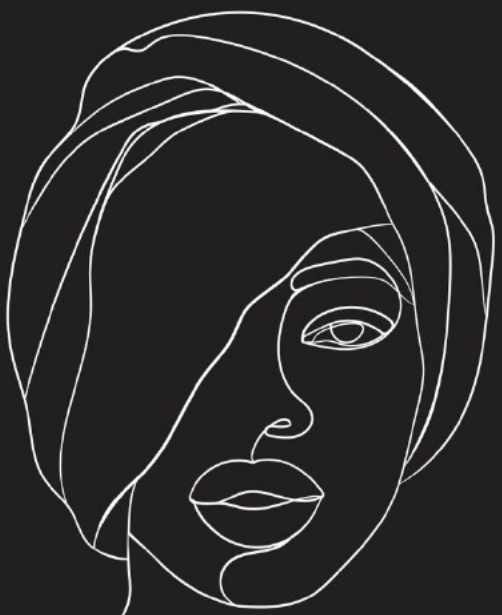
Food security: Complexities in the lives of women living with disabilities

"Those who think they know something do not yet know as they ought to know."
1 Corinthians 8:2



FOOD SECURITY: COMPLEXITIES IN THE LIVES OF WOMEN LIVING WITH DISABILITIES

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD)
in the School of Nursing and Public Health, College of Health Sciences, University of KwaZulu-Natal

November 2022

Supervisor:
Associate Professor (honorary) Mershen Pillay

DEDICATION

This research is dedicated to my husband and daughter,

Bruce and Rachel.

It is done.

Figure 0-1: Looking forward

SUPERVISOR'S PERMISSION TO SUBMIT FOR EXAMINATION

Student: Helga Lister

Student Number: 209541532

Title: Food security: Complexities in the lives of women living with disabilities

As the above candidate's supervisor, I agree to the submission of the thesis in the form of integrative material for examination.

The chapters are written as a set of a research publication and two manuscripts, with an overall introduction and a final summary.

This is to certify that the contents of the thesis are the original research work of Helga Lister.

Supervisor

[redacted]

Associate Professor (honorary) Mershen Pillay

Date: 29 November 2022

DECLARATION

I, Helga Elke Lister, student number 209541532, declare that:

I. The research reported in this thesis, except where otherwise indicated, is my original research.
II. This thesis has not been submitted for any degree or examination at any other university.
III. This thesis does not contain other persons' data, pictures, graphs, or other information, unless specifically acknowledged as being sourced from other persons.
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Signature and name of student

Helga Elke Lister

Date: 30 November 2022

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Permission has been received to publish the images.

ABSTRACT

Background

Food insecurity is a significant public health challenge affecting vulnerable populations globally. Currently, it is not known how health sciences educators train future professionals on the intervention of persons with disabilities who are food insecure. There is also a lack of understanding of food insecurity and disability, where there is additional disadvantage and marginalisation (such as having HIV or being a woman). This study explored how women living with disability in vulnerable contexts experience food security.

Methods

Firstly, an exploratory cross-sectional online survey was conducted in the School of Health Sciences, University of KwaZulu-Natal, South Africa. Through this, a baseline of the knowledge, attitudes and practices of educators regarding teaching of food security and disability in health care sciences was obtained. Secondly, a qualitative life history methodology was used to conduct open-ended interviews with three participants sourced through purposive sampling. Data collection, analysis and interpretation occurred concurrently over a five-year period. This was followed by a process of narrative configuration to produce the stories of the three women. Following this, the paradigmatic mode of analysis was used to describe the findings of three themes in the first two women's narratives relevant to the research question. After this, the third narrative was analysed over the researcher's changing understanding and insights developed within the community oriented primary care (COPC) approach.

Results

Educators from diverse disciplines completed the questionnaire (n=35). They had a partial understanding of the link between food security and disability. Few educators incorporated disability and food security into their training (12% theoretically and 20% practically). They indicated that more should be taught on this topic. Through the qualitative analysis, the three themes which influenced the food security of women living with HIV and disability were resilience; systemic failures; and questions around food security measures. The factors that emerged relevant to COPC engagement in households were the life history interview method for CHWs; improved training in mental health for CHWs and community-based health practitioners; improved care coordination between services; and improved understanding of interrelated HH complexity. This led to the development of the Household Complexity Model (HHCM).

Conclusion

The connection between food insecurity and disability, as experienced by women, must be thoroughly understood in health care. Beyond this, complexity should be addressed directly. Doing so will facilitate an improved understanding of the interrelatedness of household members and thus ensure that intervention can be more sustainable in improving overall wellbeing.

Keywords: food security; women; life history; complex adaptive systems; education; community oriented primary care; Household Complexity Model

OPERATIONAL DEFINITIONS

The following terms will be operationally defined; this will assist in showing the context in which they will be used for the purpose of this study:

Disability	The International Classification of Functioning, Disability and Health (ICF) defines disability as an "umbrella term for impairments, activity limitations or participation restrictions".[1(p3)] Key to the definition is the interaction of the personal factors (for example, gender and age), the environmental factors (for example attitudes of the immediate and extended family; and social support) and the body structures and functions (for example emotional functions, i.e. depression) that collectively influence activities and participation (for example employment).[2] According to the Convention of the Rights of Persons with Disabilities,[2(p1)] disability is "an evolving concept" and "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".
Food Security	In 1996, the Food and Agriculture Organisation stated that "food security exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences in order to lead a healthy and active life".[2(p1)] According to the United States Department of Agriculture, "food insecurity is a complex, multidimensional phenomenon which varies through a continuum of successive stages as the condition becomes more severe".[3(p2)]
Functioning	According to the ICF, functioning is "an umbrella term encompassing all body functions, activities and participation".[4(p3)]
Nyaope	"Nyaope is a street mixture of drugs with the most common substances including heroin and cannabis. Nyaope (heroin part) is sprinkled on cannabis and smoked as a cocktail. On its own it is also injected or 'chased' off foil without cannabis – the active ingredients are mainly heroin and other opioids to give a heroin-like effect. The other substances, such as some small amounts of stimulants are to enhance the initial perception of a high through dopamine activity (which is not primarily linked to heroin use) and as 'bulking' agents. Other examples of street names are whoonga, and unga".[5(p8)]
Occupations	This refers to the everyday human activities that we organize ourselves and that provide meaning. Occupations may be a means to an end, or ends in

	themselves, fulfil roles, be habits and routines, and be constructive or destructive.[6]
Quality of life	This includes all aspects of a person's life, namely their physical wellbeing, emotional wellbeing, social wellbeing, and functional ability.
Resource-constrained contexts	This refers to a community in which the resources required to achieve health and wellbeing are limited, and therefore impact on the functioning of the community. This is associated with vulnerability.
Vulnerable community	Although this term has recently undergone scrutiny, within this thesis it will refer to a group of individuals within a defined area, who are affected disproportionately by poor health and/or experience health inequities.
Wellbeing	Wellbeing is associated with experiencing good health, quality of life and positive functioning. In this study it is viewed in its entirety, namely including mental, physical, social, and spiritual wellbeing.

ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
CHW	Community health worker (also known as community care worker)
COPC	Community-oriented primary care
COSUP	Community-oriented substance use programme
CoT	City of Tshwane
DOH	(South African) Department of Health
FAO	Food and Agriculture Organisation
FHS	Faculty of Health Sciences (University of Pretoria)
FNS	Food and nutrition security
FSN	Food security and nutrition
HH	Household
HIV	Human immunodeficiency virus
ICF	international Classification of Functioning, Disability and Health
KAP	Knowledge, Attitudes and Practices
KZN	KwaZulu-Natal
NGO	Non-governmental organisation
SDGs	Sustainable Developmental Goals
SOHCS	School of Health Care Sciences (University of Pretoria)
PHC	Primary Health Care
PLWH	People living with HIV
UKZN	University of KwaZulu-Natal
UN	United Nations
UP	University of Pretoria
WHO	World Health Organisation
WIL	Work-integrated learning

RESEARCHER STATEMENT

When an artist presents their exhibition or project, it is accompanied by an artist's statement – where they provide a basic overview of what they have produced and why. This can share something important about their work and allows for a deeper insight into their own unique story and to share their world.

So too, with my thesis:

I have used the humanistic approach, namely that the individual needs to be considered as a whole and not a sum of their parts. Therefore, I cannot separate myself (as a human being) from the research process. Nor, can I separate my research, from the day-to-day realities of working in the community. This approach is the position from which I come to describe my (researcher) role, which impacts my (researcher) voice.

Below is an image of myself wearing a head scarf as dressed by one of my research participant's daughters. In traditional Tswana culture, the scarf is tied away from the face and knotted at the back.

Figure 0-1: Image of myself wearing a tuku

RESEARCH OUTPUTS

A. Peer-reviewed publications

- **Lister, HE**, Mostert, K. & Pillay, M. 2021. Teaching about disability and food security in the School of Health Sciences, University of KwaZulu-Natal, South Africa. Afr J Health Professions Educ 2021;13(4):x-x. https://doi.org/10.7196/AJHPE.2021.v13i4.1251

B. Manuscripts intended for journal submission

- **Lister, HE,** Mahlangu, J, Pillay, M. Agenda. Life history: Exploring the lives of women living with HIV and disability in vulnerable contexts regarding their food security. Agenda.
- **Lister, HE,** Janse van Rensburg, MNS, Pillay, M. The Mkhize household complexities – considerations for community oriented primary care (COPC) in the City of Tshwane. Qualitative Health Research.

C. E-Books

- **Lister, HE.** 2022. Anna's Story. Available at: https://www.up.ac.za/media/shared/772/COPC/Storytelling/anna-story-web.zp227429.pdf
- **Lister, HE.** 2022. Boitumelo's Story. Available at: https://www.up.ac.za/media/shared/772/COPC/Storytelling/boitumelo-story-web.zp227815.pdf
- **Lister, HE.** 2022. Dikeledi's Story. Available at: https://www.up.ac.za/media/shared/772/COPC/Storytelling/dikeledi-story-web.zp227816.pdf

(Pseudonyms have been used)

D. 3-D model visualization – the HHCM

- Lister, HE, & Janse van Rensburg, MNS. 2022. The Household Complexity Model (HHCM). Available at: https://youtu.be/VXlyT9Quapc

E. Conferences and webinars where aspects of this PhD were presented

a. International conferences

- **Lister, HE**, Pillay, M & Hunter Adams, J. 2018. Power, difference, connection, belonging: A quest for transformation and finding my voice through my PhD research journey. Poster Presentation. World Federation of Occupational Therapy Conference, Cape Town, South Africa, 21-25 May 2018.

- **Lister, HE** & Pillay, M. 2017. Food security: an exploration of women living with HIV/AIDS and disability in vulnerable contexts. Poster Presentation. 3rd International Conference on Global Food Security, Cape Town, South Africa. 3-6 December 2017.

b. National conferences

- **Lister, HE**. & Pillay, M. 2022. A co-constructed story – a family, a PhD researcher/occupational therapist, lecturer and a social worker employed at a university-managed community. Substance use programme – lives forever changed. Faculty Day. University of Pretoria. 23-24 August, 2022.
- **Lister, HE**, Mostert, K & Pillay, M. Knowledge, attitudes and practices of educators in the School of Health Sciences, University of KwaZulu-Natal (UKZN) on including the topic of disability and food security into the curriculum. Poster Presentation. SAAHE (South African Association of Health Educationalists) Conference, Potchefstroom, South Africa, 6-8 July 2017.
- **Lister, HE** & Pillay, M. Vulnerable women living with HIV and disability: Their food security. Poster Presentation. 8th SA AIDS Conference, Durban, South Africa, 13-15 June 2017.

c. Webinars and panel discussions

- Ana, J, Maeda, Martin, C, Sturmberg, J, **Lister, HE**. Exploring complexity in African primary health care. AfroPHC Workshop 17th Aug 2021. Available at: https://www.youtube.com/watch?v=FPFW-o7Pl3E&t=11s
- **Lister, HE**, Solomon, M., Makwakwa, T., Ncal-Dlamini, B., Masoka, N. 2021. Swallowing and dysphagia society: Relevance of food (in)security for us as healthcare professionals. 27 May 2021.

Figure 0-1: Various conference poster presentations and an advert for a webinar

From top left to bottom right: Webinar for the swallowing and dysphagia society; WFOT 2018; Faculty Day 2022; SAAHE 2017; 3rd International Conference on Global Food Security 2017

F. Community member development and related output

a. Judith Mahlangu

After meeting Judith as a potential research assistant through an occupational therapy colleague and friend, Dr Michelle Janse van Rensburg, this PhD became a crucial part of Judith's journey and development in her career. She was initially a community worker who had unfortunately unsuccessfully tried to complete her studies through UNISA. Together with Dr Michelle Janse van Rensburg, I assisted in applying for assistance for her to publish her story in the SAHR (South African Health Review). We co-wrote the publication. Additionally, I motivated for funding for her registration into a development studies undergraduate degree (through North-West University) and presenting at two conferences (national and international). In 2022, I have thus far been successful in achieving temporary employment for her, first as a community supervisor and currently as a teaching assistant at the University of Pretoria (UP) – where she is fulfilling vital roles as a community liaison with our community projects. She is now also a co-author of one of the manuscripts in this thesis.

b. Peer-reviewed publications

- Mahlangu JN, Lister HE & Janse van Rensburg, MNS. 2019. My experiences in health science education and research: a community worker's auto-ethnographic account. South African Health Review, 193-199.

c. National conference presentation

- Mahlangu, JN & Lister, HE. My personal experience as a community liaison for students and a NGO worker. Poster presentation. Rural Health Conference, Henley on Klip. 21-24 September 2018.

d. International conference presentation

- Mahlangu, J., Janse van Rensburg, M., Lister, HE. Challenges and barriers to participation faced by community development beneficiaries. Virtual world community development conference. Nairobi, Kenya. 21-23 June 2021.
- Mahlangu, J, Lister, HE & Janse van Rensburg, M. 2021. A community worker's experiences in health science education and research. University Social Responsibility (USR) Summit. Pretoria, South Africa. 3-5 February 2021.

Figure 0-2: Community member training

From top left to bottom right: Judith presenting at a workshop in Cape Town; Judith presenting ta the RURESA conference; Judith, Helga and Thobile (community health worker manager) at the USR Summit in 2021; Judith presenting at the USR Summit in 2021

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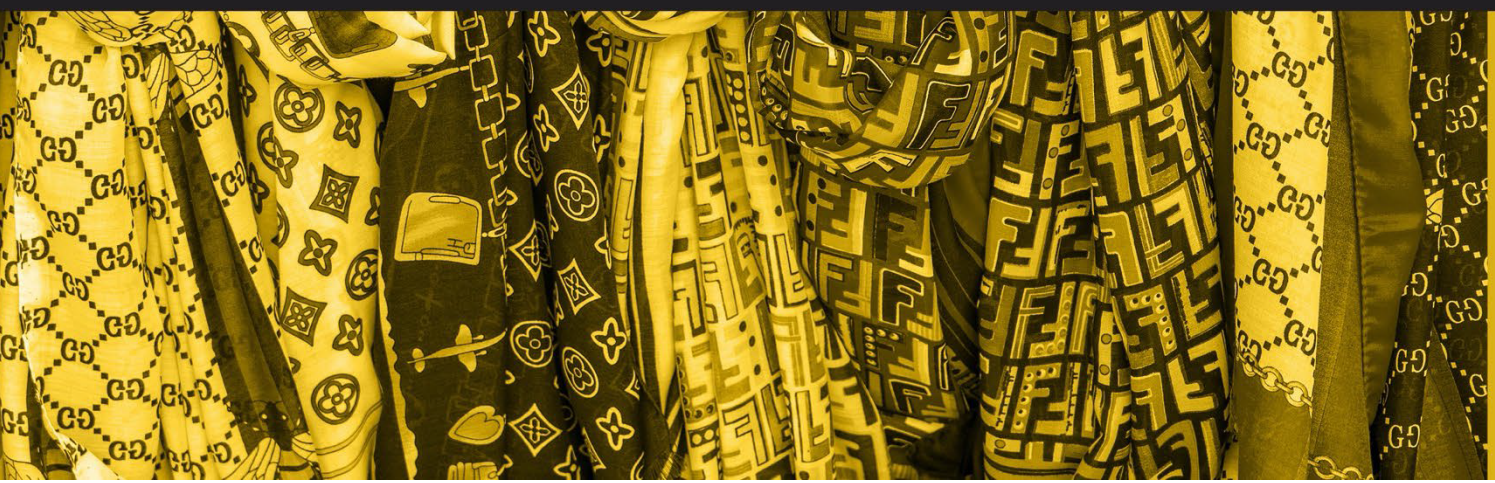
Chapter 1: The tuku

Definition: n. Setswana word meaning head scarf or head wrap. Also known as a doek.



1.1. Prologue

The idea for my research study started when I first met my supervisor, Prof Mershen Pillay, in our occupational therapy department at the University of KwaZulu-Natal (UKZN). He had an engaging way of bringing across fascinating concepts and was making a case for creating awareness around disability and food security. My interest was sparked, and I realised how important this area of research would be. It was something that appeared to have been neglected and would require a deep understanding to be able to really make a difference.

So, I started reading and thinking. From my previous experience and my master's degree in development studies, I had some understanding of our global health challenges. I wondered what would happen when everything was brought together - food insecurity, the spread of HIV/AIDs, continued high levels of poverty, the scope of disability and how women were at a particular disadvantage within this context. The extensive literature searches I had conducted lead me to believe that I needed to understand the intersectionality of these factors: food insecurity, women, HIV/AIDS, disability, and vulnerability – and that by using life history methods, I would come to understand what would constitute a framework on how to address and posit our intervention within public health. I even thought that my research would benefit international organisations, such as the World Food Programme (WFP). I then realised that I needed to understand the practice that was currently occurring in academia in terms of teaching about disability and food security first, to be able to start with a baseline on which I could build once I had understood this subject better.

I submitted a proposal first for the qualitative phase. Then, after reflection, I submitted a second proposal to obtain baseline information through a survey to gather information from academics, and to start building a body of evidence.

After several struggles in finding my research participants for the life history aspect, and once I became embedded within the Mamelodi community, things changed. I had not foreseen that through getting to know three women who fulfilled my pre-determined inclusion criteria, the whole aspiration of my study would transform. Nor had I anticipated how my consequent appointment as a lecturer in the Department of Occupational Therapy at the University of Pretoria (UP), which involved becoming a supervisor of community-situated work integrated learning (WIL) in Mamelodi, in the City of Tshwane (CoT), South Africa (SA) would add to this. I had to search within what had led me to decide on the topic in the first place. It was increasingly difficult to separate my role as researcher, volunteer worker in primary health care and occupational therapist. I would get to know families. People would die. There would be a new co-constructed story. Thus, the lines between my roles as practitioner and researcher, and my innate humanness – with its many faults – would become blurred to such an extent that they could no longer be separated.

Therefore, I invite you into this PhD journey, in what will have to be with an open and willing mind and join me as we learn how to see. Whilst I appreciate that certain pre-determined criteria need to be fulfilled, I will explain and contest my process and thinking to make overt our collective biases. Only through deconstructing these biases, together with a willingness to embrace complexity, can we truly challenge our pre-determined ideas of what contributes to household wellbeing. Furthermore, when we embrace complexity, we have a way forward within our existing frameworks.

1.2. Background

I had always known that I wanted to be a 'teacher'. Becoming an occupational therapist had to initially do with the recommendations I received from others about the future of teaching, together with a deep-seated compulsion to want to 'help people'. However, it was my father's coaxing which centred around "become a teacher of those who influence others", which invariably bought me into academia at a very young age. From the word go, I knew I was fulfilling what I had been called to do. As one of my mentors said, "I know of very few people whose life calling is so closely aligned with the work they do for a living."

I stumbled across an unknown (to me) master's degree halfway through 2019 called development studies. The modules "Poverty and inequality", "South African development, policies and problems", and "Development Management" made my heart skip a beat and instilled the desire to know more. A whole new world opened on the importance of various macro- and micro-economic factors that influenced my profession and community work on a very real level. I researched the factors influencing the transport of persons with disabilities in eThewkini, South Africa. Transport was an occupation in and of itself. It is often an essential requirement to be able to participate in other occupations, such as work and activities of daily living. In other aspects, it is an occupation in itself. As such, you can participate in transport individually or in groups, fulfilling certain roles in our lives.

I can still remember the day I met my future PhD supervisor when he spoke about food insecurity and disability and the desire, he had to establish this as a particular research focus at UKZN. I needed to move on within my studies and had been thinking about topics relating to the concept of hope in occupational therapy on the one side and community engagement initiatives on the other. When I thought about food insecurity, however, I realized how there were similarities with my study on transport. Food security incorporates the activities and occupations of feeding, eating, and meal preparation. These are in themselves important. In the same avenue, eating is a means to an end. I remembered a conference presentation by my aunt (an occupational therapist) on "Hungry children cannot learn". If we cannot eat, we cannot fulfil all the other important occupations, such as social participation, leisure, work, and education. It thus is essential that food insecurity is understood as part of my profession and within health care at large to ensure that holistic intervention will occur. As

I started reading and engaging with other academics, it also became clear that food security was not something other academics and students considered in health care sciences education.

The statistical information is all there - Globally, there are approximately 795 million people undernourished[1] and more than a billion living with some form of disability[2]. Sub-Saharan Africa has seen a persistence of chronic hunger in the 21st century, which is related to our historical context and current socio-economic processes.[3] In Southern Africa, we are especially vulnerable to changes in weather, economy and government policy, which leads to large numbers of our population barely being able to maintain levels above poverty considering the frequency of shocks.[4]

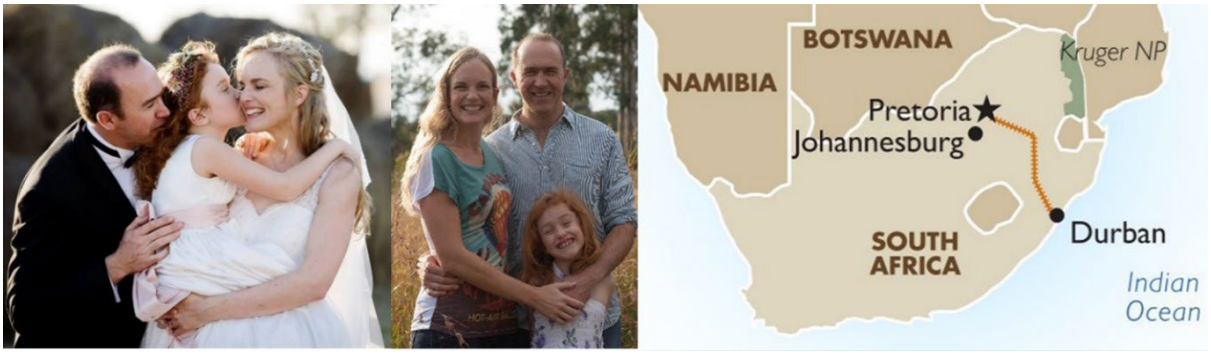


Figure 1-1: My family

From left to right: On our wedding day; an engagement photo shoot, map indicating the move from Durban to Pretoria

If I was entirely honest, choosing this research study topic, all had to do with the current buzzwords, which would invariably yield themselves favourable to funders. I had hoped to receive a grant which would enable me to move to Pretoria and get married, whilst remaining in academia and finding my feet in a new home. I was fortunate to be awarded this grant, and within a few short months, I became a wife and a mother of beautiful 7-year-old. Yet whilst the process of my PhD continued unfolding with proposal development and submission, receiving ethical clearance, and finding my participants, I experienced several difficulties.

As part of goal setting, I worked towards running the Comrades marathon – the iconoclastic South African 91km race between Pietermaritzburg and Durban. Unfortunately, and perhaps symbolically so, somewhere in those gruelling 12 hours and 20 minutes, I developed a stress fracture in my femur.

Figure 1-2: The Comrades Marathon

From left to right: The marathon at the start in Pietermaritzburg; somewhere along the way; at the finish

After finishing without a medal (since I missed the cut-off time), I spent almost four months using a wheelchair in the hope that the stress fracture would heal. It did not. Eventually, I resigned to an ORIF operation. In those months, however, I visited some of my participants and realized, on a very personal level, the impact of multiple disabilities and illnesses on ourselves.

Figure 1-3: The rehabilitation period

From left to right: Visiting participants in Mamelodi in a wheelchair; before the operation with my surgeon; an X-ray of the leg; rehabilitation in hospital

(See video of me walking *in the hospital: https://youtube.com/shorts/TwkHadQygzk?feature=share)*

However, I continued to feel conflicted about my study and what I was investigating. Things were not making sense to me. The situation seemed "bigger".

This changed when I started working full-time at UP in the occupational therapy department and became embedded within the Mamelodi community. The students were running various services and intervention programmes. Through this, I started getting to know the community-oriented primary care (COPC) research unit, specifically the community-oriented substance use programme (COSUP). As a result of the person-centred services, I started focusing not only on the individual women who were participants in my research, but also got to know the others in the household. Over time, my deliberately broad research topic started spiralling, with questions arising regarding the wellbeing of

all the individuals in the household, the collective nature of how they interacted, and how they functioned as a whole.

1.3. Literature review

Considering this background, I herewith present an overview of the literature relevant to this thesis, namely an understanding of food security and disability and how this is addressed in health care science education.

The first aspect of this clarifies food security and its associated terms. It then looks at the international landscape of food insecurity, commenting on the political nature of the organisations dominating the current discourse. After that, it describes the South African situation, followed by the nexus of disability and food insecurity.

1.3.1. Concept clarification

During the 1996 World Food Summit, the Food and Agriculture Organisation (FAO)[5(p1)] stated the following:

> *"Food security exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences in order to lead a healthy and active life."*

In addition to this, the FAO emphasised the multidimensional nature of food security, namely the availability of food, access to food, biological utilization of food, and stability [of the other three dimensions over time].[6] Recently the High-Level Panel of Experts on Food Security and Nutrition (HLPE) Global Narrative report has suggested adding two further dimensions to these: sustainability and agency.[7]

Food security measurement has undergone various changes and developments as organisations and researchers have attempted to work through the different elements of the dimensions and experiences in light of its complexity. Therefore, ideally, food security should be measured using different indicators since these focus on the different dimensions, which can then be combined to produce an overall understanding. There is currently no measurement to assess the entire food insecurity complex. Additionally, food security measurements have political and ideological positions.[8] Table 1-1 summarises various food insecurity assessment measures, categorised according to Pérez-Escamilla et al.[9]

Table 1-1: Food insecurity assessment measures

Categories	Types	Specific measurements
National estimates of FI	Prevalence of Undernourishment (PoU)	
	The Global Hunger Index (GHI)	
	Global Food Security Index (GFSI)	
Household food access	Household Consumption and Expenditure Surveys (HCES)	
	Dietary Intake (DI)	Dietary records
		24-h recall
		Food frequency questionnaire (FFQ)
	Dietary Diversity	Food consumption score (FCS)
		Household dietary diversity score (HDDS)
	Measures Based on Participatory Adaptation (PA)	Coping Strategies Index (CSI)
	Experienced-based food insecurity scales (EBFIS)	US Household Food Security Survey Module (HFSSM)
		Household Food Insecurity Access Scale (HFIAS)
		Household Hunger Scale (HHS)
		Latin American and Caribbean Household Food Security Scale (ELCSA)
		Food Insecurity Experience Scale (FIES)
Food utilization	Anthropometry (ANTHRO)	Anthropometric indicators (height-for-age, weight-for-age, height-for-weight, body mass index) determine nutritional status

As can be seen, these have been divided into scales for national estimates of food insecurity, household food access and food utilization.

Individual or household food insecurity falls on a continuum, moving from being food secure to the other extreme of severe food insecurity or hunger[10]. Table 1-2 contains the eight-item Food Insecurity Experience Scale (FIES), which is currently one of the most common measures to assess food access:[11(p3)]

Table 1-2: English version of the food insecurity experience scale (FIES)

	Short reference	**Question wording**
1	Worried	During the last 12 MONTHS, was there a time when you were worried you would not have enough food to eat because of a lack of money or other resources?
2	Healthy	Still thinking about the last 12 MONTHS, was there a time when you were unable to eat healthy and nutritious food because of a lack of money or other resources?
3	Few Foods	Was there a time when you ate only a few kinds of foods because of a lack of money or other resources?
4	Skipped	Was there a time when you had to skip a meal because there was not enough money or other resources to get food?
5	Ate less	Still thinking about the last 12 MONTHS, was there a time when you ate less than you thought you should because of a lack of money or other resources?
6	Ran out	Was there a time when your household ran out of food because of a lack of money or other resources?
7	Hungry	Was there a time when you were hungry but did not eat because there was not enough money or other resources for food?
8	Whole day	During the last 12 MONTHS, was there a time when you went without eating for a whole day because of a lack of money or other resources?

The questionnaire measures conditions and behaviours that, through a dichotomous ("yes"/"no") response, indicate a severity measurement of food insecurity. Recently, there has been an attempt to develop a global monitoring indicator for food insecurity, using Rasch model-based procedures to enable cross-country comparisons.[10]

Similar, although not the same tool, is the Household Food Insecurity Access Scale (HFIAS).[12] The HFIAS includes a-priori scoring, namely 0 for "never", 1 for "rarely", 2 for "sometimes", and 3 for "often". It also references a 30-day period, as opposed to a 12-month period. Within South Africa, the two national surveys that collect data on hunger, are the General Household Survey (GHS) which is conducted once a year, and the National Income Dynamics Study's Coronavirus Rapid Mobile Survey which was conducted between April 2020 and March 2021 for five of the months.[13-14] The GHS uses

the questions from the HFIAS. The NIDS-CRAM asked questions about household and child hunger and one question on household food insecurity (running out of money to buy food). Specifically, in this survey, if the was an experience of hunger in the household, the period asking if they had skipped a meal or gone hungry was for the past seven days.

As can be seen through the measurement scales, not only is food insecurity complex, but it is also associated with various terms and concepts that are not mutually exclusive. These terms and concepts should not be used interchangeably, considering they each encompass a unique aspect.

Comparatively to food insecurity, food sovereignty is a concept developed amongst small-scale producers and was presented globally at the United Nations (UN) World Food Summit in 1996 by the transnational movement La Via Campesina (LVC).[15] It was seen as a response from the global South to the dominant neoliberal approach of large-scale industrial farming corporations to solving the food crisis and thus sought to provide an alternate view to the global food system.[16] The seven principles of food sovereignty include the following: protecting natural resources (thus ensuring environmental sustainability); focusing on local food production and thus changing the organisation of food trade; in this, changing the power dynamic currently concentrated in the multinationals; promoting peace; reforming the agricultural systems; increasing the control by local citizens of the food system, and ensuring that food is seen as a basic human right.[16] Similarly, the Nyéléni Synthesis report details the six pillars of food sovereignty, namely[17]:

- Focuses on food for people
- Values food producers
- Localises food systems
- Puts control locally
- Builds knowledge and skills
- Works with nature

This approach, therefore, fosters local food production and control, ensuring that food systems are built on traditional knowledge and skills and respects the work all food providers do.

Recently, Sampson et al.[15] conducted a systematic review on food sovereignty and right-based approaches to strengthen food security and nutrition globally. Herein, food sovereignty is discussed as an approach to food security and nutrition (FSN), different to the approaches of increasing agricultural productivity; or the approaches that focus on food supplementation and other ways of providing undernourished populations with specific micronutrients.[15] As a rights-based approach, this involves social, environmental and political factors of, for example, political conflict oppression in various forms that often underlie the causes of malnutrition and hunger[15].

The other approach often discussed is “the right to food”. In the International Covenant on Economic, Social and Cultural Rights, the UN established this obligation through two articles. These are article 11 “the right to an adequate standard of living, including food, and the right to be free from hunger” and article 12 “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”.[18(p4)] Studies have shown that when a rights to food approach is adopted, FSN outcomes have been strengthened.[15] Conversely, where these rights have been denied, lost or not ensured, there have been negative FSN outcomes.

Food security and nutrition security overlap conceptually in that it is necessary to achieve food security to enable nutrition security.[19] Although food security and nutrition security have sometimes been used interchangeably; nutrition security is actually an expansion of food security. It is defined by the FAO[20(p57)] as

> *“a situation that exists when secure access to an appropriately nutritious diet is coupled with a sanitary environment, adequate health services and care, in order to ensure a healthy and active life for all household members”.*

Undernourishment is an extreme form of food insecurity. It is defined by FAO[21(p57)] as “the state ‘when caloric intake is below the minimum dietary energy requirement”. Hunger is “the uneasy or painful sensation caused by a lack of food… the recurrent and involuntary lack of access to food”, whereas ‘hidden hunger’ refers to micronutrient deficiencies.

In 2003 when the social determinants of health were first considered, ‘food’ was included, as it was well known that an adequate food supply, and a good diet were essential for wellbeing and promoting health.[22] In 2011, during the World Conference on Social Determinants of Health, the Rio Political Declaration on Social Determinants of Health was created. Herein, food and nutritional security was included as one of the current challenges that need to be addressed at all levels and in all sectors.[23] Similarly, this was centre stage in the millennium development goals (MDG1: Eradicate extreme poverty and hunger), and the subsequent sustainable development goals (SDG 2: Zero hunger).

1.3.2. The international landscape of food insecurity

The 2021 “State of food security and nutrition” released by the UN’s FAO focuses on the transformation of food systems.[24] The report details the primary drivers of recent food security and nutrition events, namely conflict (as highlighted in the 2017 edition), climate variability and extremes (discussed in detail in the 2018 edition), and the slowdown and downturn of the economy (2019 edition) and how they interact with each other. It is evident that the underlying causes of poverty and inequality further exacerbate these global drivers. These drivers do not act in isolation but they tend to compound, creating multiple impacts on food systems. Low- and middle-income countries worldwide experience both the greatest impacts on food security and nutrition as a result of these

drivers and are carrying the most considerable burden of the world's population who experience one or more forms of malnutrition, food insecurity and undernourishment.

As much as these drivers are essential to dissect, it is also critical that the driver of corruption, already identified in 2001 at the International Food Policy Research Institute (IFPRI) Symposium on sustainable food security for all by 2020, be considered again internationally[25]. As Uchendu[26(p2)] highlighted, "no initiative, whether on food security or poverty alleviation or anything else for that matter will work in the absence of ethical public behaviour as a result of poor governance culture." This should be seen not only in the national sphere, but also locally and right down to the community level. Research has demonstrated that corruption increases food insecurity and reduces life expectancy[26].

Personal anecdote

To me, it seems that both corruption and cultural influences are often the topics of discussion within South African households. This probably stems from the frustrating influences of corruption evident in the South African economy and political deliveries at the municipal level to the evident rainbow nation, which provides ample opportunity for exploring diversity and difference.

Within South Africa, the feeding scheme in schools has been one of the biggest drivers to improving children's food security. Unfortunately, previously, there was mixed anecdotal evidence of some corrupt teachers keeping most of the food for themselves. Anecdotally, this appears to have since improved. However, recently I was visiting family on a farm, and the neighbour complained that he could not sell his apples to those who had government tenders for providing apples at the schools. According to him, he was told the apples were too large and took up too much space on the pickup (van) truck. Since those carrying out the tenders were being paid per apple and not for the weight of the apples, they preferred purchasing the smaller apples. This meant they could transport more apples per trip, which reduced the overall fuel cost. Unfortunately, even when the farmer was willing to give the apples away for free, the business owners did not want to take them.

I wondered about this and whether it could not have been possible to have another system. What made it difficult on the other end. Could the teachers have cut the larger apples in half and given each child half an apple instead (considering it could have had the potential of a reduced cost). Or would this have been too cumbersome in a school with 1000 children? Is it right that the tender is per apple and not per weight, or do they pay per apple because then at least each child gets one apple, and they can ensure that they have enough?

In addition, Alonso identifies that there remains ample scope for dissecting culture when considering food security policy since available evidence currently concentrates more on high-income countries.[27] In the Eastern Cape, Chakona & Shackleton[28] demonstrated how cultural beliefs increased the nutritional vulnerability of pregnant women. In this study, women reported to avoiding certain foods, for example eggs, butternut, pumkin, beans, fruit, potatoties, fish and meat products, during

pregnancy. Taboos associated with these foods included labour, wanting to avoid a certain body form for their baby and the outcome of their pregnancy. Du Toit et al.[29] also very recently studied the effects of culture on home gardens, which indicated how the constraints of cultural practices, for example, ornamental species and lawns, contributed to a lack of food security. This again underscores the significance and importance of including traditional knowledge systems in any food security policy. Whilst the FAO produced the report, "FAO and traditional knowledge: The linkage with sustainability, food security and climate change impacts", the implementation thereof is not evident.[30]

Personal anecdote

I remember being a supervisor at UKZN (Durban) and working in the communities of KwaDabeka. This was the first time I came across the information from conversations with community members about having gardens in their own yards. According to them, people in the city, or those in peri-urban or township communities, did not want to have food gardens by their homes. To them, food gardens were something that communities in rural areas did and was, therefore an indication of being poor. Not wanting to appear poor to their neighbours meant that this was an unacceptable way of accessing food.

Similarly, when I started data collection in Mamelodi. I would drive through the streets of the RDP[i] housing area where a number of my research participants were and marvel at how each time I returned, there had been an increase in the ownership and beauty of the homes – especially of the gardens. Many households had started constructing and developing beautiful flower beds, interspersed by succulents and rockeries. Yet, amongst perhaps three hundred houses, only one household had planted vegetables in front of their home.

The COVID-19 pandemic resulted in a significant rise in moderate or severe food insecurity – estimated to be the equivalent of the previous five years combined – with 2.37 billion (almost one in three people globally) not having access to adequate food.[24] The rise in food insecurity has resulted from various factors. This includes the social and economic system shocks, the food system disruption, and the gaps in essential health services.[31-32] It was observed that those most affected by food insecurity were young children, adolescents, the elderly and women of reproductive age.[31] Additionally and significantly, job losses, income shortfalls and food shortages have all been part of these burdens.[31]

These alarming statistics have created increased awareness of this violation of human rights, triggering international response efforts to try and mitigate hunger extremes.[33-34] There is a greater understanding that the food system cannot be addressed independently, but requires a combination of various systems (including health and social protection to interact with each other to offer win-win

[i] This refers to a Reconstruction and Development Programme (RDP) house. RDP houses are provided free of charge by the government to beneficiaries.

solutions.[34] Within South Africa, significant investments were made in social protection. But despite this, hunger and food insecurity remain obstinately high.[13]

It is acknowledged that even before the COVID-19 pandemic, the world was not on track to achieve the sustainable development goal (SDG 2) of ending world hunger and malnutrition in all its forms by 2030.[35] The FAO report indicates current predictions to confirm this unless "bold actions are taken to accelerate progress, especially actions to address inequality in access to food".[24(pxii)]

Two SDG targets in which the world has specifically not been progressing are the following:

- SDG Target 2.1 Ensuring access to safe, nutritious, and sufficient food for all people all year round, and
- SDG Target 2.2 Eradicating all forms of malnutrition.

UN member states are required to provide their citizens with food aid if their citizens cannot realize this right – and together with this, should facilitate the ability to become self-reliant in the future and achieve food security. Notably, the UN specifies in the General Comment No. 12, that "food aid should, as far as possible, be provided in ways which do not adversely affect local producers and local markets and should be organized in ways that facilitate the return to food self-reliance of the beneficiaries. Such aid should be based on the needs of the intended beneficiaries. Products included in international food trade or aid programmes must be safe and culturally acceptable to the recipient population".[36(p8)]

Additionally, "the international financial institutions, notably the International Monetary Fund (IMF) and the World Bank, should pay greater attention to the protection of the right to food in their lending policies and credit agreements and in international measures to deal with the debt crisis. Care should be taken, in line with the Committee's general comment No. 2, paragraph 9, in any structural adjustment programme to ensure that the right to food is protected".[36(p9)]

1.3.3. The food insecurity and disability nexus (including the influence of gender and HIV/AIDS)

Since the onset of this study, there has been an increase in the available literature regarding food security and disability, although mostly from developed nations.[37-39] This creates a bias in understanding of this nexus, as well as recommendations and policy implications. Literature that is available from middle- and low-income countries often forefronts children.[40-44] Yet, these is also an awareness of the absence of information regarding children with disabilities in severe malnutrition protocols (only 4% of the 71 guidelines reviewed).[45]

Within the South African landscape, the scoping review by Moore et al.[46], from the University of Pretoria regarding food and nutrition security (FNS) and disability did not find any research articles from South Africa. In a different scoping review examining the relationship between disability, food

access and insecurity, one study from South Africa (in Mpumalanga province) was included.[47] This study shared an insider perspective of living on a disability grant and determined that often, there was not enough food for the entire month.[48] This was exacerbated when the disability grant was the only source of income for the household.

Households that include a working-age adult with a disability and no household members in the labour force, have been shown in America to have the highest rate of very low food security.[49] Households that have adults or children with any form of disability have an increased prevalence of food insecurity compared to those households which do not include anyone with a disability.[50-51] This occurs even in countries that offer social protection for people with disabilities.

Increased food insecurity is also seen in episodic disability, which is characterised by unpredictable periods of wellness and illness. O'Brien et al.[52] highlighted that episodic disability resulted in anxiety and inability to plan for the future.

Numerous studies have highlighted how people living with HIV/AIDS (PLWH) are at increased risk of various episodic and permanent disabilities.[53] These functional limitations also occur with people on antiretroviral therapy.[54] Examples include musculoskeletal impairments, neuro-cognitive disorders, mental disorders and mental health problems, sensory disabilities (blindness and hearing impairments), respiratory impairments, and fatigue.[54-60] Different impairments are interacting with the environment, causing discrimination, stigma, and barriers to participation.[61] People with disabilities are also at a higher risk for exposure to HIV. This is due to the exclusion from education and information; poverty and sexual abuse; HIV risk factors; and the lack of access to health services.[62] Yoshida et al.[63] shared the narrative of a woman with disability, who had increased exposure to HIV as she engaged in transactional sex so that her children could eat. Women with post-traumatic stress disorder have also been shown to experience a higher risk of HIV, since their decision-making was affected.[64]

Food insecurity and hunger are prevalent amongst PLWH since, amongst others, HIV has an impact on income due to individuals falling ill and having reduced ability to work.[65-69] Although once individuals start with ART their functioning rapidly increases, their ability to sustain their livelihoods may have already decreased significantly. Households are even more significantly effected when a productive member of the household dies due to AIDS.[65]

Food insecurity also causes numerous health problems in PLWH. Anema et al.[69] highlighted that for those individuals receiving antiretrovirals, food insecurity reduces the efficacy of the ARVs and is associated with a lower baseline CD4 cell count, incomplete virologic suppression, and decreased ART adherence, which all contribute to a lower survival rate. Also, PWLH experience difficulties coping with disability and poverty, obtaining nutritious and sufficient food required for treatment.[61]

In both resource-rich and resource-poor settings, food insecurity creates a barrier to accessing health care.[69] There is a bi-directional relationship between disability and food insecurity. Research has demonstrated the association between numerous illnesses and various health problems with food insecurity. These include anxiety, asthma, birth defects, depression, and anaemia.[70-72] Also included are social problems, for example, children and youth with food insecurity experience higher rates of bullying or being bullied than those where families are not food insecure.[73]

In a household where the head is a woman and has a disability, the risk for food insecurity is especially high.[38] Women generally are at a higher risk of food insecurity than men.[74] It has long been recognised that women are the significant, if not dominant, role players in addressing the pillars of food security, namely food availability, economic access to food and nutritional security.[74-75] However, they are discriminated against far more regarding social, cultural and economic factors. In terms of food availability, women mainly produce the food consumed, work in processing food crops and providing household water and fuelwood and conduct the work required for food storage and transportation from the farm to the village, do the hoeing and weeding, and the work of harvesting and marketing.[75-76] The Stats SA Labour Force Survey indicated that 61% of those involved in subsistence activities are women (in order to achieve an additional source of food).[77] In rural contexts, when women experience ill health or care for those who are sick, there is a profound impact on the household's overall wellbeing, since the household's agricultural production, food and livelihood security is reduced.[78] Women are also known to skip meals so that their children can eat.[79]

Women with disabilities are also at increased risk of exposure to HIV.[80] Women with HIV are associated with a greater risk of psychiatric disabilities than men.[55,81] Women with HIV, and disability have inadequate support systems since they are often abandoned by family members or partners after disclosing their disability or HIV status.[82]

Women should be supported to ensure improved food security of the household. Quisumbing et al.[75] recommended that women's physical and human capital should be improved by facilitating access to resources, technology and information. This would increase women's ability to generate an income with appropriate strategies, increasing their paid work and domestic production. Women's health and nutritional status needs to be ensured, by appropriate safety net or development programs so that they can fulfil their productive and reproductive roles. In a food security intervention project in Bangladesh, women with disabilities were included. These women were, as a result, able to earn their own income and improve the household's ability to obtain food.[83] This literature is elaborated on in article one and manuscript one.

1.3.4. Health care and food insecurity – a curricula issue

In 2019, the WHO released its report on 'Nutrition in universal health coverage', calling for integrating essential nutrition actions in the health system.[84] At the Tokyo Nutrition for Growth (N4G) Summit in

2021, it was recognised that one of the ways in which this commitment can be followed is through the proper training of health workers.[85] There are now multiple resources available through the USAID Advancing Nutrition Platform, which, amongst others, include resources focussed on capacity strengthening.[86] Whilst these resources include multi-sectoral tools designed to facilitate intersectoral coordination for nutrition, they are still in their infancy stages in terms of implementation.[87] Additionally, there is as yet no evidence of their use within South Africa, nor any evidence of the training of health workers and health professionals in their use.

Internationally, there is limited information regarding incorporating food insecurity into health sciences curricula, beyond nutritionist, dietician or nursing training.[88-89] Even when this training occurs within these two disciplines, it is limited in practical activities, decision-making, leadership and management.[88] Also, research indicated that there should be a stronger link between theory and practice, and including social sciences and humanities into curricula by sharing people's lived realities. This will provide insights into cultural differences, and the social and political landscape.[88] It has been recommended that a public health nutrition (PHN) workforce be trained in i) the functions of needs assessment, monitoring and evaluation (namely analytical), ii) capacity building, which includes building partnerships, developing organisational capacity and growing leadership, and finally iii) intervention management. All of this should be done through strong advocacy at all levels.[90]

Following a thorough review of the literature, there is no updated information regarding incorporating food security into the training of all health care professionals. In the United States, recommendations have been made to include information about food insecurity, specifically around assessment and other related screening tools, into all areas of the education of nurses. This includes ensuring that the evaluation of nurses (in this instance, the National Council Licensure Examination) incorporates questions around food insecurity assessment within the examination.[89]

1.4. Problem statement

Food insecurity for persons with disabilities is a significant concern internationally. However, it is not known to what extent health care professionals understand the nexus between disability and food insecurity so as to address this within practice. Since educators train health care professionals, it is essential to determine whether the educators are informed and whether they include this in their teaching practice.

To be able to inform educators, food insecurity for persons with disabilities needs to be understood in its entirety. This includes how multiple vulnerabilities influence an individual's food security. However, the problem was that the intersection of these multiple vulnerabilities had not yet been explored. To delve deeper into multiple vulnerabilities, it was necessary to choose specific aspects which would allow for an in-depth understanding. Since women are a particularly vulnerable group, having HIV/AIDs exacerbates a person's vulnerability and living in a vulnerable context further

contributes to this, these multiple factors should be incorporated. Once this complexity is understood, it can again inform educators in the teaching of health care professionals.

1.5. Research questions

- What are the knowledge, attitudes and practice of instruction regarding food insecurity and the nexus between food insecurity and disability among educators at the School of Health Sciences at UKZN?
- How do women living with HIV and disability in vulnerable contexts experience food security?

Creswell already noted that sometimes in the middle of the study, the research question changes – and qualitative research allows for this change – since we need to be able to understand the research problem.[91]

- What lessons can be learnt from exploring the complexities evident in a household as well as engagement with the household related to community-oriented primary care (COPC) implementation?

1.6. Overview of the study methodology and location

1.6.1. Methods

The study was conducted in three phases using two different methodologies.

The first phase answered the first research question through an exploratory cross-sectional online survey using closed- and open-ended questions. It followed the knowledge, attitudes and practice (KAP) survey model.[92] This is described as a quantitative method, that gives access to quantitative and qualitative information. The open-ended questions are analysed thematically and reported as such. This approach has been used extensively to determine a baseline in an area where little information is known or understood.[92]

The second phase of this research answered my second research question, where I explored how women living with HIV and disability in vulnerable contexts experience food security. Ribar and Hamrick[93] note that since food insecurity is usually transient, quantitative studies have noted the limitation on the lack of measurement of a temporal problem. A qualitative methodology was utilized to obtain the necessary information to achieve the aim of the study. According to Yin[94(p7-8)] qualitative research involves "studying the meaning of people's lives, under real-world conditions"; representing "the views and perspectives of the participants in a study"; covering the "contextual conditions" within which people live; developing insights into "existing or emerging concepts"; and striving to "collect, integrate, and present data from a variety of sources of evidence". Bjarnason[95(p21)] notes that qualitative inquiry involving people in vulnerable situations "can be a way of giving the participants a voice in matters concerning their own lives, furthering the understanding of difference… and

informing policymakers, professionals and the general public on matters involving diversity, social justice and lived experiences of people labelled as the other". Qualitative researchers "stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry".[96(p14)]

Since I wanted to remain as close to the data as possible, to give as much credibility to the voices heard, I utilised a narrative approach, namely life history research, as a method of qualitative enquiry.[97] We all lead storied lives. Stories "are one means by which human beings attempt to make sense of that complex human condition: to create some order out of the chaos of competing and contradictory experiences; to bring into dialogue the world of the real and the world of the imagination. To stand Janus-headed, looking backwards and forward into past life experiences and anticipating the future".[98(p3)] The purpose of using life history research within this study, is that stories constructed from detailed studies of the women's lives, could "function as political responses, broadcasting 'voices' that are excluded from or neglected within dominant political structures and processes".[99(p20)] Therefore the women who experienced multiple marginalisation, could express their own 'truths' as they experienced the social systems and institutions.[99]

As I became embedded within the lives of the women, I started getting to know the household. I also realised that I had resources (which included airtime, connections, transport, and persistence). On a human and an ethical level, it was impossible to be so deeply embedded in the lives of these women without also having to intervene. Therefore, my spontaneous and necessary role as a community worker influenced the research process, as a new co-constructed narrative emerged (because of the intervention which occurred).

I reflected on my engagement with the community throughout the PhD process. I used reflexivity to understand the lives I was researching, our interactions and what was happening inside of me. I needed to wrestle with what I was hearing, seeing and learning. These thoughts, feelings and perceptions were described in observations, voice recordings and written reflexive notes throughout the data-gathering and analysis process to aid in reflexivity.[100]

In the third phase of my study, I developed and answered a third research question. Here, I used the life history methodology from phase two and an additional layer of reflexivity on the research process (as encouraged in qualitative research). This analysis of narratives allowed me to interrogate the data and present a new household complexity model (HHCM) in which the household is described as a complex adaptive system (CAS).

Knowledge Attitudes and Practices (KAP) studies

KAP studies are useful in public health research to determine people's knowledge, attitudes, and practices regarding a particular topic.[101] They are easy to design and execute and have been shown to be of considerable use in areas of unfamiliar research.[92] Of particular value is that they collect both

qualitative and quantitative data.[102-103] The results of KAP studies have been known to be used as a baseline for designing effective interventions and increasing awareness.[92,104]

Life history research

Life history is "essentially a collaborative and reciprocal process of developing understanding".[99(p25)] The aim is to "reach the internal array of an Other's experience, bounded always by our (the researcher's) shared participation in a matrix of signification".[105(p317)] Therefore, the life stories become co-constructed between the researcher and the participants. The relationship between the two, "brings about reciprocal learning by both the researcher and the researched, about their experiences of the social world, and how the different social dynamics and cultural elements interact resulting in their individual and collective experience as such".[99(p25)] There is of course the question of power within a co-constructed narrative. This is further discussed under the section "power" in section 5.4.2 (chapter 5).

"Attention to human suffering means attention to stories, for the ill and their healers have many stories to tell. Serious illness takes people from ordinary to extraordinary".[106(p1)] People with disabilities need to share their stories as part of their experience, even though they live on the margins. As in the case of HIV/AIDS, where the individuals may feel that "death is never far away", this "physical and mental suffering… seems to demand a narrative shape".[106(p1)] Therefore, there can be healing power in telling and creating your story. It can also be a way of problem-solving – showing how participants perceive their practical problems and, in the storytelling, trying to make practical decisions.

There are various definitions and understandings of life history research. Additionally, the terminology around life history and narrative research can sometimes be blurred and confusing. Different authors and researchers have attempted to explain their understanding of the research methodology. My understanding gleaned from a review of the literature, notes life history research as the following:

Goodson and Gill[99(pxi)] underline narrative as "pedagogy from the point of view that it invokes a 'third voice', which is the voice of the collaboration between the people involved in the narrative encounter". They focus on four major concerns, discussed herewith. Firstly, the challenge of the sense of self, which can be 'decentred', 'multiple', 'shifting' and 'fragmented', depends on how the individual makes sense of their past and present, which changes how they act in the future. Secondly, they note that the individual telling their life story cannot be separated from the relationship with the researcher since the conversations develop into a closeness between the two, and ultimately the researcher's interest, what is important biographically to them as well, their reflexivity, as their personal involvement influence the knowledge that is generated. This aspect should be embraced and addressed within the research process. Thirdly, they acknowledge that life history interviews can be a

substantial form of intervention. Fourth, individuals can, through the process, learn to develop and change.

Ojermark[107(p4)] provides a summary of terminology in narrative and life history research, from which the following three definitions are taken:

- Narrative: "A story, having a plot and existence separate from life of the teller. Narrative is linked with time as a fundamental aspect of social action. Narratives provide the organisation for our actions and experiences, since we experience life through conceptions of the past, present and future."
- Life history: "Account of a life based on interviews and conversation. The life history is based on the collection of a written or transcribed oral account requested by a researcher. The life story is subsequently edited, interpreted and presented in one of a number of ways, often in conjunction with other sources. Life histories may be topical, focusing on only one segmented portion of a life, or complete, attempting to tell the full details of a life as it is recollected."
- Narrative inquiry: "Similar to 'biographical research', or 'life history research', this term is a loose frame of reference for a subset of qualitative research that uses personal narratives as the basis of research. 'Narrative' refers to a discourse form in which events and happenings are configured into a personal unity by means of a plot."

Let me explore narratives in greater detail. As seen above, narratives have a temporal nature narrative theorists "study how stories help people make sense of the world, while also studying how people make sense of stories".[108(para1)] Narrative theory implores that people will produce an account of themselves that is in a storied nature; they link the past to the present; and there is a narrative form that is produced during the interview. Narrative research has originated and emerged in various disciplines, including cultural studies, ethnography, anthropology, and linguistics. Each discipline thus has a different take on narrative research in terms of its nature and form.

In narrative research, the researcher pursues the structure in the story's discourse, looking for the way the interviewee tells the life events as well as the temporality of the plot.[99] As this unfolds, a collaboration between the two occurs, and the researcher attempts to delineate "meaning and understanding of events as narrated".[99(p23)]

In life history work, it is important to understand the historical and social context in which the individual's life is lived. Hendriks[109] notes that in order for effective targeting of interventions, it is necessary to understand the complexity of the multiple dimensions, namely the experiences, causes and consequences of food insecurity, and how these compound and reinforce the problem.

In narrative research, the interview method of data collection is highly empathetic. I prepared myself and had also been trained in interviewing during my master's study, and during my Occupational Therapy undergraduate degree. The skills that were practiced whist working as an occupational therapist and during my interviews in the data collection of my various research projects, enabled me to gain confidence and ensure I had the necessary skills to conduct this research. I prepared myself for the first interviews, by asking the individual to tell their life story chronologically. I ensured that I listened closely, and made notes where required to be able to ask questions at a later stage.[110] I tried as much as possible not to interrupt the storytelling. I prepared for the follow-up interviews, after listening and transcribing the recordings, to ensure that I was able to clarify where I had questions. I had to be sensitive to the linguistics and culture.[110] Translated narratives are a complex interplay between the researcher, the research assistant and the participant. It involves making some difficult interpretive decisions. Some difficulties that arise are that the translator can be "in the shadows", for which the researcher can include the translator "as [an] active participant in knowledge production".[111(p49)] Additionally, the researcher cannot interrogate certain words and phrases because a word's meaning may not be the same in different languages. By interviewing in another language, it was difficult to fully interrogate certain phrases' deeper meanings fully. I consulted and discussed with Judith to ensure that when I was concerned about an aspect of the conversation, she clarified and explained afterwards what had occurred.

1.6.2. Ethical clearance

Ethical approval was obtained from the UKZN Humanities and Social Sciences Research Ethics Committee - no. HSS/1740/016 for study's first phase, answering the first research question (see appendix A). The same committee also approved the second phase (and second research question) – no. HSS/1064/106D, which arose to the third phase and answered the third research question (see appendix B). Gatekeeper permission from the UKZN registrar was received to conduct research with the educators in the School of Health Sciences (see appendix C). Permission was also received from the Tshwane Research Committee, NHRD reference number GB_201708_007 for conducting research in the city of Tshwane (see appendix D). As an initial result of poor response rate from emails, an ethics amendment was requested for research question one to include telephonic recruitment of participants in addition to emails; and approval was received (see appendix E). Additional ethical approval was provided for both recertification requests, necessary due to the ongoing data collection for questions two and three (see appendix F and G). Additional ethical considerations are discussed in section 1.9 (in this chapter), and in section 5.3.3 (chapter five).

1.6.3. Research setting

The first phase of the research study took place at UKZN, in eThewkini, KwaZulu-Natal, South Africa where I worked since 2008 in the occupational therapy department and was working at the time of this portion of the study. UKZN is a historically black university which currently is seen as one of the

leading research institutions in the country.[112] Students have argued for decolonial education at UKZN, to ensure that the curriculum responds to the lived experiences of African people.[113] UKZN is in the eThekwini Metropolitan Municipality, created in 2000, and includes the city of Durban and surrounding towns. It spans an area of approximately 2297km^2 with a population of 3.5 million people.[114]

UKZN has five campuses with four colleges, one of which is the College of Health Sciences. The School of Health Sciences is in this college, and consists of eight disciplines, namely audiology, speech-language therapy, dentistry, physiotherapy, occupational therapy, pharmaceutical sciences, and biokinetics, exercise and leisure sciences (BELS). At the time of the study, BELS was called sports science. Additionally, because of the limited inclusion of pharmaceutical sciences into the health care sciences disciplines internationally, I decided not to include this discipline. UKZN describes the aim of the programmes in the Health Sciences, namely to "train Health Science professionals to play preventative, promotive, supportive, curative and rehabilitative roles in the public and private sectors".[115]

While writing my research proposal for the second research question and knowing that I wanted to move to Pretoria, where my future husband and daughter were living, I planned to locate my participants in Mamelodi. This was intentionally chosen, since I was hoping to continue my academic career at the University of Pretoria, and I knew that one of their community sites for community-situated WIL was in this peri-urban community. Furthermore, I wanted to get to know the community on a deep and intimate level, where I was hoping to be working professionally.

Mamelodi was established in 1953 due to spatial segregation laws and was originally called Clakfontein Bantu Location.[116] During planning, Mamelodi was designed into ethnic neighbourhoods.[117] It grew at a rapid speed and was known to embody the 'struggle for liberation' during the apartheid years, especially in the 1980s.[116] Currently, it is the seventh largest township in South Africa, with a population of 334 577 living in 110 703 households.[118,] It is densely populated and located within the City of Tshwane Metropolitan Municipality (CTMM). The last available statistics from the 2011 census indicate that female-headed households comprise a third of the households, 61% of the population live within formal dwellings, and 40% of the population live on less than R20 000 a year.[119] Although the census noted that 42.5% of residents speak Sepedi as their first language;[119] further literature and anecdotal evidence suggests, however that most individuals speak "Sepitori/S'pitori" or "Kasi Lingo"[116]:

Heita – Hello

Ke Zola Zozo – I need Food

Ke zoze'kile – I am hungry

Six-Nine – toilet

Splasha – taking a bath

Sepitori originated in Pretoria and is a mixed language, combining mostly Setswana, Sepedi, English and Afrikaans.[120] It is not a formally recognized language in South Africa, although it has been suggested that it is over 100 years old.[121] It serves to facilitate communication between those from different linguistic and ethnicities, thus bringing people together.[121]

Figure 1-4: Various images in Mamelodi (credit Kirstin Niebuhr)

Nighty-eight point eight per cent of the population of Mamelodi are black African.[119] However, with the rapid urbanisation of this peri-urban community, one can assume that the population statistics are now far higher, with increased informal dwellings, as visibly observable within the community. It is a community rich in cultural diversity, experiences and activities – for example music festivals, vegetable gardens, social clubs, and church activities.[117] It also experiences high levels of unemployment, poverty, food insecurity and crime challenges. This site was selected for the study's relevance, as well as contacts through my professional network. I also considered safety for myself, and that of my research assistants by establishing good rapport with the organisations and community leadership within Mamelodi. Although at the beginning of data collection, my cellphone was stolen whilst I was asking for directions, this was a good learning experience to ensure I remained vigilant in case of opportunistic crime.

Of relevance to this study is the distinction between UKZN and UP, where I am currently employed. The Faculty of Health Sciences (FHS) includes the School of Health Care Sciences (SOHCS), which consists of five professions: occupational therapy, physiotherapy, radiography, nursing science and human nutrition. Speech-language pathology and audiology are a part of the Faculty of Humanities, although they participate in the interprofessional education modules.

1.6.4. Study participants, selection of sample and sample size

The study population for the first research question were all the educators that were employed at UKZN in the professions of audiology, occupational therapy, optometry, physiotherapy, speech-language pathology and sports science whose email addresses had been received from the heads of departments of these professions (n=70 in January 2017). Consecutive sampling occurred and is described in further detail in chapter two.

For the second research question, sampling occurred. In qualitative research, sampling "is to acquire information that is useful for understanding the complexity, depth, variation, or context surrounding a phenomenon, rather than to represent populations as in quantitative research".[122(p1782)] Since this study required intense interviews over some time, a smaller number of participants were required. Baker[123(p18)] notes that "life story research… is like to entail a much smaller sample size because of the fine-grained analysis that is often involved" and "that it was not sample size per se that mattered nor even that the distribution of numbers of persons within a group that was so critical but rather the inclusion of a particular case". The time taken to establish rapport with the participants, understand their lived experiences and obtain the data required for the in-depth understanding of the topic thus required a limited sample size. Additionally, great care was taken to select the appropriate participants who could yield information-rich data. Thus the sample size included three women living with HIV and disability in vulnerable contexts. The reason for selecting a limited number of participants for this aspect of data collection was so that the researcher could "spend more time with each household to collected detailed information".[124(p57)] Inclusion criteria were women who had a self-reported positive HIV status; disability across the spectrum (incorporating persons with physical, sensory, cognitive and psychological impairments); self-reported food insecurity; and who were living in a vulnerable context. Women who were severely impaired and unable to nominate a proxy would have been excluded. Data collection and analysis is described in more detail in chapters three (manuscript one) and four (manuscript two).

For the second (and third) research question, the method of inquiry was qualitative and, therefore, not meant to be a representative sample of the population. I set out to select participants using purposive and snowball sampling. Purposive sampling calls for "experts in a particular field to be the subjects of the purposive sampling".[125(p3)] This type of sampling has been described as applicable when there is at present a "lack of observational evidence" and when "investigating new areas of research".[125(p3)] Since this is novel research, the women living with HIV and disability in vulnerable

contexts are seen as experts of their own lives and thus the necessary persons to collect data from for the research. Patton in Gentles et al.[122(p1778)] describes purposeful sampling as follows: "The logic and power of purposeful sampling lie in selecting information-rich cases for in-depth study. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry… Studying information-rich cases yields insights and in-depth understanding".

Goodson[110] notes that it is usually vital to have a spectrum of interviewees. Therefore, the participants chosen were based on their richness of information provided across the spectrum of disability and thus potential experience.

The process of finding participants became more difficult than expected.

Initially, the research assistant was employed at a community organisation with a resident social worker. This social worker referred her to a community worker who was working with persons who have HIV/AIDS. I had explained to the research assistant in detail the inclusion criteria required; however from the list of first potential participants received; it became clear that there had been a miscommunication and the focus had only been on HIV/AIDS, not on disability. I had to thus explain to the research assistant different examples of clients that I would be looking for. Examples that were used, were for example women who had an existing disability, for example Cerebral Palsy, and then contracted HIV through being abused by someone; a woman with the occupation of prostitution, who contracted HIV and then had a stroke; a person with a communication disorder who had HIV, a person with a mental illness because of AIDS. All these individuals would have to be food insecure and be willing to participate in the interview process. Even though I did not want to lead the research assistant in this process, the examples were necessary to ensure that the sample fulfilled the inclusion criteria.

Additionally, it was suggested that she contacts various organisations that were available within the Mamelodi context, and not work through only one person. The research assistant returned to the community worker, who provided her with another list of potential participants. These appeared to fulfil the inclusion criteria and meetings were set up on which to have the initial interview. However, on the day these meetings were to occur, there was a strike in the community, and it was deemed unsafe to go. The meetings were postponed, and the following week the potential participants notified the research assistant that they were only willing to participate in the study if they were financially compensated. The research assistant noted that it appeared the potential participants had been colluding with each other, and all three were maintaining the same position. My understanding at the time was that payment could yield to biased results and creating expectations that could not be met. In the proposal for which I have received ethical clearance, I had not indicated that I would pay the caregivers to assist me in the study either. However, I have interrogated this within the final chapter, and in the future, will include compensation in my research studies. At the time of recruitment however, I decided to try other approaches.

The research assistant contacted a nurse in Mamelodi who referred her to one of the clinics[ii] to conduct the research. Since this is a department of health institution, ethical clearance was requested from the Tshwane Research Ethics Committee. The clinic manager agreed to the clinic being used to provide access to participants for the research, however after permission was obtained from the Tshwane Research Ethics Committee, he withdrew his consent, stating that they were not allowed to give out names of people who have HIV. Following this, the clinic manager for the community health centre was approached. Ethical clearance was again sought from the Tshwane Research Ethics committee for the change in location. This was approved, and permission provided to work with the Ward Based Outreach Team (WBOT) managing the community health workers (CHWs). In addition, the occupational therapy department and the dietician were consulted to request the names of potential participants. Initially, the Occupational Therapy Department manager was very concerned about the research. She was asking how one could conduct research on food insecure people, without offering intervention for the said situation. This is discussed in a later section under ethical considerations.

Further, the Occupational Therapy Department referred me to the Disability Organisation chairperson. The organisation was consulted and they shared a list of names with us. The research assistant contacted these individuals; however, they were unwilling to disclose their status and therefore were unable to be approached to see whether they fulfilled the inclusion criteria. Three CHWs provided a list of potential participants and these persons were visited. An initial interview was conducted in which consent was obtained to participate in the study if they fulfilled the inclusion criteria. This process can be compared to Goodson[110] suggesting an initial survey as to include diverse cases and themes to research. He also proposes an alternative strategy of having a series of "pilot" (initial) interviews with the available participants. Out of these, only one person fulfilled the inclusion criteria. It was arranged to meet her again for a follow-up interview, however on this day I was attacked in the community and my cellphone was stolen. We were unable to visit her. After this, she moved away to an unknown location. The CHWs attempted to find her. She was finally found but then moved again because the place she was staying was inaccessible. Her cellphone was constantly switched off, and therefore the CHWs attempted to find her through her networks.

During this time, attempted communication continued to occur with the chairperson of the disability organisation, whose cellphone was not working for three weeks and after contacting her again, she seemed to have misunderstood the criteria and stating that there were available persons who fulfilled the inclusion criteria, however, she would need to approach them personally to describe the anonymity of the research process so that they may be more willing to participate.

[ii] The name of the specific clinics have been removed to protect the identity of the participants.

At the same time, I approached the organisation where research assistant had originally spoken with the social worker to see whether they could help. The director referred me to the social worker, who had a list of 2000 households they had data on, that could be reviewed for potential participants. At this time, I found out that there had been disagreements between my research assistant and the NGO directors, creating difficulty with potentially working with the organisation. My research assistant still had a relationship with the social worker, and she phoned her to say that she did not mind being involved in the data collection if participants were found because I had a discussion with the director. She had been fearful otherwise, that it would influence her employment.

Through the initial interviews which had already been conducted, it became clear that there would need to be an adjustment of the criteria for inclusion into the study.

I used the General Household Survey (GHS), to determine the food security status of my potential participants.[126] As much as this provided me with a measure to work from, through the process of using it I learnt that it was very difficult to determine accurately the extent of food insecurity, since the participants had difficulties quantifying the answers to the questions. Additionally, the CHWs had assured of their food insecurity, however, when asking the questions, they appeared not to give a holistic answer to the questions. In order to make sense of what I had observed, I interrogated the measure in more detail.

The GHS has expanded its questions on food security since 2002, to include a battery of questions adapted from the Household Food Insecurity (Access) Scale (HFIAS).[126] This includes the quantitative element, in that there are four incidence questions, followed by four frequency questions. Specifically, the questions aim at assessing whether households have experience problems with accessing food in the last 30 days and whether the household has changed their food consumption patterns or diet because of having limited resources to acquire food. Therefore the questions are more in line with food access and food utilization, than including the complete dimensions of food security/insecurity.[126] They also look at self-reported experiences of hunger. There are no universally accepted cut-off points to determine exactly when a household is food secure or food insecure. The GHS notes the following procedure for scoring: “zero was attributed if the event described by the question never occurred; 1 point if it occurred; and another point if it occurred five or more days during the past 30 days. For each household, the score corresponds to the sum of these points and could range from 0 to 8. The results are presented as categorical designations, namely: Adequate access to food (score 0-1); inadequate access to food (score 2-5); and severely inadequate access to food (score 6-8)”.[126(p4)] However the limitations of this kind of questionnaire is that it does not look at individual food security, which can be dependent on the intra-household distribution of food. Furthermore, it does not identify why households are food insecure, which is why qualitative research is so important. Although I initially set out to use the GHS battery of questions to fulfil the inclusion

criteria for my participants, it soon became very clear that relying on this would not give me an adequate indication of whether the individual was or had been food insecure.

Objective measures are used as indicators of food security, including daily calorie intake and anthropometric measures. Minimum energy requirements have been developed by the FAO and the United States Department of Agriculture (USDA), which are based on gender and age distributions of individual countries.[126] Internationally, it is recognised that no "perfect single measure that captures all aspects of food insecurity" exists.[127(p1205S)] Also, food insecurity is not homogenous and thus cannot be easily measured in energy availability, economic, or anthropometric terms.[127] Hendriks[128(p145)] notes that "food insecurity is not a single experience but a sequence of experiences reflecting increasing deprivation of basic food needs, accompanied by process of decision making and behaviour in response to increasingly constrained household resources". Thus it is a continuum, which ranges from starvation to complete food security, where all criteria for food security are met, and at the same time, there is no concern over the future of the individual's availability, supply and affordability to meet these criteria.[128] Another important aspect to note is that food (in)security status is dynamic, and thus a once-off measurement would not consider seasonality.[128]. I realised that valuable information would be lost if I only concentrated on individuals that were at that point of the initial interview food insecure than looking at individuals who had been food insecure at some point in the past. This would indicate what kind of adaptations they had put in place to improve their food security and whether their food insecurity was transient.

The different international assessments of food insecurity "do not all measure the same thing; rather, each focuses on one or more of the four key elements – availability, access, utilization or nutrition, and stability".[128(p143)] During my first interviews with the potential long-term participants for the study, I considered information-rich cases to include persons with different disabilities (physical, cognitive and psychiatric), persons with and without access to social grants and women who are the head of the household or not. I also considered household size in my selection of participants.

Pseudonyms have been used throughout the study. Two of the participants knew each other, since they were recruited through similar procedures and attended the same disability organisations and rehabilitation services. Additionally, the area where two of the participants lived, was in the RDP housing area, where numerous people with disabilities had received government housing. Therefore, the network amongst the people with disabilities in this part of Mamelodi was small.

1.6.5. Data collection and analysis

The process of data collection has been described in detail within the article and manuscripts, as well as in the associated e-books.

1.6.6. Quality criteria

For the first phase of the study, it was essential to establish the validity of the data collection instrument.[129] The survey was designed using information that emerged from a thorough review of the literature. Since I could not find any similar studies that had previously been conducted, I had to merge my understanding of the integration of disability and food security within curricula. In addition to this, I received input from a research expert, an expert in food security and a statistician. Secondly, content validity was established by ensuring the data collection tool appropriately addressed all the relevant themes and components of what was being investigated.[130-131] A panel of five experts reviewed the questionnaire, and reviewed if the questions were easy to answer and understandable. Feedback received allowed for the opportunity to revise and improve the instrument.[132] This ensured that the instrument was sensitive enough to measure what it needed to measure, thus establishing face validity. As a final measure of quality, the questionnaire was piloted with three health science educators who were, at that time, employed at another institution. Their feedback also improved the content and clarity of the instrument.

For the second and third phases, trustworthiness was obtained through credibility, dependability, transferability and confirmability. Regarding credibility, prolonged engagement is evident in the four years of being connected to the participants and the frequency of visits and involvement.[133] The interpretation of the stories occurred during the data collection process, where I would ask the participants follow-up questions based on what they had previously said, clarify their positions and engage in challenging their perceptions.[133] Thirdly, as can be seen from the original data sources (the e-books), thick descriptions and thick interpretations are used.[134] Dependability is obtained through credibility as described and by documenting the changes as they occurred throughout the research process. Transferability is possible in that I have herewith provided the rich background and context to the study thereby enabling a greater understanding of where the study is situated, as well as how and why certain questions have been asked and answered in the way that they have been. This provides evidence that the study's findings could be applicable to other populations, contexts and situations.[133] I have carefully considered my research participants' motivations and intentions and also observed the social system within which they are living through persistent observation.[135] Data transparency is achieved by making the original data sources used in these phases available.[136] Finally, confirmability is achieved through documentation of data collection and data analysis.

The methodological descriptions shared, which I will also go into more detail again in the synthesis, will hopefully encourage more researchers to adopt similar methods – and embed themselves within the community, as I have been able to do. This ensures dependability. Credibility was ensured since life history is a well-recognised research methodology. Additionally, I was able to become familiar with Mamelodi's culture, since I was a supervisor for occupational therapy students in this community. Through this, I was able to establish rapport with the community members. I quote one of the peer

supporters in the COSUP programme whom I work with, recently wrote a recommendation letter for me as part of a community engagement award nomination. He wrote:

> *"Ms Helga Lister, it has been a pleasure and an honour working with you and the OT students. I am so inspired on how committed and involved in helping the community of Mamelodi, you even know places that I have never been to in Mamelodi and yet I am the one staying in Mamelodi and which showed me how committed you are with what you do and it has also inspired me to reach out and help where I can and with your help and your OT students whom are always smiling and have done a good job in uplifting our clients with skills. What made me happy the most is that you and the OT students were able to analyse the need in our community … Please keep up the exceptional work you and the students have been doing in our community like it's you own community. May the Lord bless and keep you as the community of Mamelodi still needs you, I need you. The exposure that you have given me and been invited to places which I have never dreamt of even setting my foot there, but because of you I have Doctors on my contact list, I even forgot that am also a recovering substance user but part of a bigger team to help my community with substance use and other social ills. Am looking forward to working with you again, and may Lord bless you and give you strength as me and the community of Mamelodi still needs you. Thank you, Ms Helga Lister."*

Member-checking is also important in qualitative research. Unfortunately, since one of the participants passed away, it was not possible to go through the final manuscript with her. However, this has been completed with Boitumelo for manuscript one, and Anna for manuscript two. They both had the opportunity to indicate whether the findings and themes determined were indicative and accurate regarding their experiences. This, therefore, ensured greater authenticity of the results.[137-138]

Finally, Lincoln and Guba argue that authenticity is crucial in qualitative research to move away from positivist criteria.[139] The intervention carried out can be seen as catalytic authenticity since the issues the participants raised during the discussions needed deliberate actions to deal with them.[140] This is even more pertinent in extremely vulnerable situations like those that will be described here. For me, the most critical trustworthiness of the study, is the trust the participants placed in Judith and me, as we were doing life ***with*** them.

Figure 1-5: Working in Mamelodi

From top left to bottom: Presenting to a forum of primary school teachers regarding substance use prevention; playing games at COSUP; social participation at Mamelodi Old Age Home; group session on building trust at COSUP; warm-up to discuss aspects regarding the building of the gazebo at COSUP

1.7. Conceptions of the self and the other

I attended an exhibition titled "Mostert na die Maal" (mustard after the meal) in White River, Mpumalanga, from the 14th to the 15th of July 2018. The curator of the exhibition, Dana MacFarlane described the exhibition as the following,[141]

"This exhibition explores the nuances of mealtimes, the sharing of meals, and the emotions that we attach to these occasions. Food remains a means of sustenance and nourishment, however underlying the basic physical need to eat, mealtimes contain undertones of happiness, loneliness, abundance, scarcity, and generosity. The act of eating alone or sharing a meal allows us to view the preparation and presentation of meals in different ways. To each of us, the utensils used for meals may have significance in history, or memory attached to pieces passed down through generations. To some utensils are entirely functional. Kitchen and dining rooms, tables and chairs may be steeped in family tradition, or devoid of any

significant attachment. Family rituals, the act of saying grace, human posturing around meals is explored in this group exhibition through various media."

Below is a piece titled "food for thought", that was produced by one of the artists, Erica Schoeman.

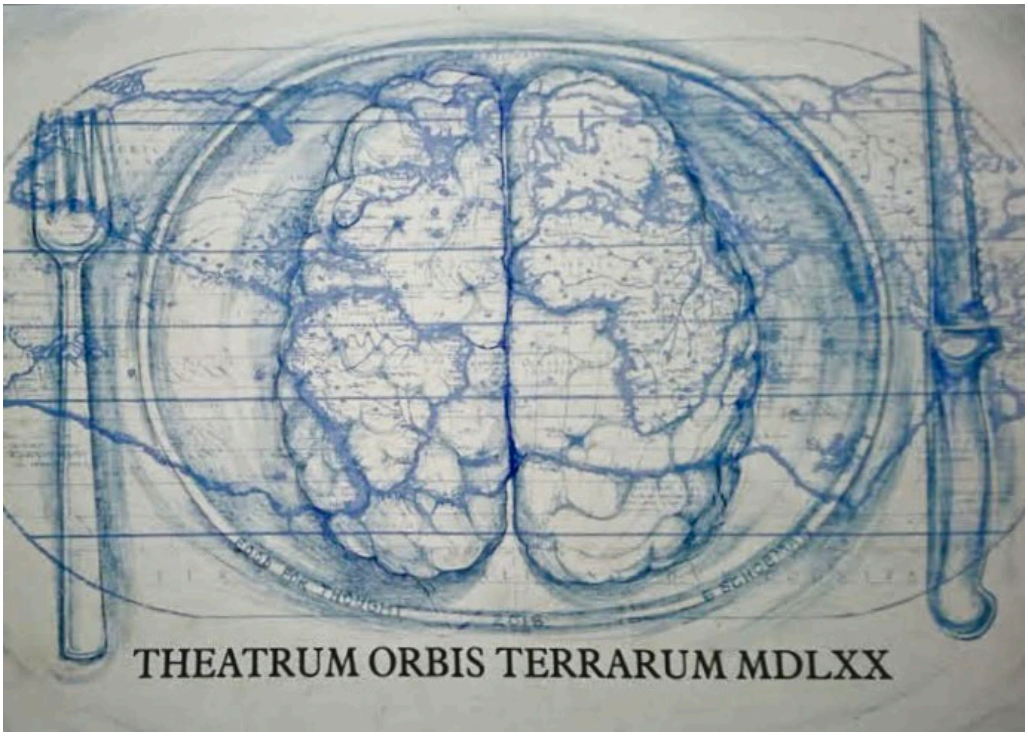


Figure 1-6: Food for thought by Erica Schoeman

This piece was an inspiration in my thesis for the critical thinking that I needed to do, especially considering how I was embedded within the research project.

Creswell et al[91] describe the importance of understanding the self and others at the outset of the research process. They note that this begins in phase one, where we can declare what we will bring to the research study – which includes aspects of our personal history, the view that we have of ourselves and others, as well as our political and ethical stances.

For me, I must declare that I was brought up in the apartheid regime and that for most of my childhood, I saw (then referred to) "black people" as very different from myself. During 1994, when the elections took place, I remember analysing our entire house (we lived on a farm), and deciding that the safest place to be, would be the small toilet. I wanted us all to congregate within this toilet, because it had a key so we could lock ourselves in. In addition, it had a small window, through which we could escape if need be.

I was very afraid, thinking we would all be shot. For three days I did not want to leave the house. On the final day, my mother suggested we go and source some nuts from the trees in the garden. I thought

she was mad, since I imagined that the farm workers were waiting with their guns in the houses above our home, ready to shoot us.

For many years this fear continued, as numerous farm murders occurred in our small community of Wartburg. I still remember writing down, somewhere, “The question isn’t anymore who will be next, but when will it be me.”

It is incredible when I reflect upon this, the change that has occurred since, in my life. I started realising the passion I had for working in resource-constrained communities and environments whilst studying occupational therapy. In my fourth year, I undertook to plan and host a large disability awareness day in Hammanskraal, inviting the entire community, organisations for people with disabilities, speakers and the like, together with a stage sponsored by Coca-Cola, food and t-shirts.

I completed my community service year in Vryheid. Although the usual practice at the time was being at clinics two days a week, I ended up being in the community almost four days a week. This is how I met Osborn Nkosi, who became one of my best friends, my confidant, and my mentor. He had a double-amputation and lived in Bhekuzulu. In the mornings I would fetch him from his home, and together we would drive to various clinics in the yellow government Condor.

My mother would still call, “Are you safe? Please let me know when you are at home, so I know you are okay.” She meant well. It was a world she was not used to, and a world she perceived as being hostile towards “white people”, which lead to a world of fear.

This is partially the reason why one of my life-long goals is to work towards addressing the divides that exist within our communities and establishing friendships. Through this, I hope that we can create bridges of collaboration, understanding, and support – mutual learning, a celebration of diversity, and an understanding of where we all come from – and why we behave and think the way that we do.

I recently arranged an outreach programme between a private secondary school in Pretoria and four community sites. The learners in the private school, described by some as “living in a bubble”, were given the opportunity to work with the occupational therapy students, in the community. It was important to see, how the learners, having never encountered some of these situations before, received renewed insights which is not otherwise gained in the classroom. Therefore, I believe I can and need to create these spaces of learning and transformation.

Another aspect of who I am, is that I hope to uphold the Christian values and ethics I have been raised with. One of these has plagued me, namely,

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“If anyone, then, knows the good they ought to do and doesn't do it, it is sin for them.” (James 4:17 (NIV)

When working in a resource-constrained community, there always seems to be so much good that needs to be done. Perhaps there is guidance in another translation, which indicates,

> *"So, whoever knows the right thing to do and fails to do it, for him it is sin." James 4:17 (ESV)*

I definitely do not always know what the right thing is to do. In fact, whilst I was working in my community service, there were so many programmes that I tried to start without considering the principles of sustainability. When I left, so many of these fell apart (in fact, I think all of them were discontinued). This left deep scars in that afterwards, when I started working in the Valley of 1000 Hills outside of Durban, as well as in KwaDabeka, I used to discourage students from starting any project unless they were assured that it would be sustainable (which itself, is impossible to guarantee).

Reflexive practice is essential to this study. Berger[142] refers to three different types of researcher positions, where I identify most with moving from the position of an outsider to becoming an insider whilst the study is taking place. This would resonate with my experience of coming into Mamelodi initially blind of how the community worked, to starting to work as a lecturer and supervisor of students embedded within COPC. I however maintain that the value in coming in first as an outsider has provided a unique insight I would otherwise not have had. I have reflected upon this in the final manuscript as part of the lessons learnt for working with CHWs.

Finlay[100(p531)] so beautifully notes that in reflexivity, "the researcher engages in an explicit, self-aware meta-analysis of the research process. Through reflexivity, subjectivity in research can be transformed from a problem to an opportunity." Even though reflexivity has been critiqued to overemphasise the self at the expense of looking at the research participants, I believe it has been very necessary in this study. It is through the reflexive process of continually looking at the responses of the participants, the dynamics between the participants as well as the research process that I have been able to develop the insights required for these particular messages to be shared.[100] This study demonstrates contradictions and complexities, and through reflexivity, a depth of analysis was achieved, not otherwise possible.

1.8. Considerations

1.8.1. Philosophical considerations

I cannot talk about philosophical considerations without sharing my spirituality. For a long time I thought it was important to separate the two. But it is like trying to remove your stomach lining and think you can still digest food. Together with my supervisor, I have instead, learnt that this should be embraced. When others understand where you are coming from, they will be able to make sense of your worldview and how you have come to believe what you do and how you understand.

I was baptised in the Lutheran church when I was ten days old. Throughout my school life, I had a very strong, although at times also legalistic relationships with God. Looking back now, I constantly thought I had to be obedient for obedience's sake. Even though I purported to understand grace and was grateful for it. When I was confirmed, the pastor shared 1 Timothy 2, v7 with me, "For God gave us a spirit not of fear but of power and love and self-control." At the time, I did not understand it. But throughout my life, this has become a guiding verse. Later in life I realised that the commandments of scripture are not there to earn our way into heaven, but rather to protect us. If we live within these, we can play, have fun, revel in the beauty of the Lord. It is when we step outside of them, that so often it leads to hurt, to destruction and to pain. I have found within my vocation, my calling. The work that I do in my daily life, so deeply resonates with me, as the saying goes, "Ek werk nie vir my werkgewer nie, ek werk vir God" (I do not work for my employer, instead I work for God). That is why I sometimes carry what almost seems like a burden – the weight of the social ills I witness in the communities I visit. The evil that is decimating the lives of so many. The families that are being destroyed. How things go against the order as it was designed – so that we may have life and have it in abundance (John 10:10).

1.8.2. Paradigmatic considerations

Throughout this work, I have embedded the philosophical nature of both pragmatism and interpretivism. The pragmatic paradigm originated in the work of John Dewey in the late 1800s and early 1900s. Importantly in his work was the move from abstract concerns to concentrating on human experiences.[143] He was aware of how necessary it is to conduct thoughtful reflection (visible through my reflexivity), as one brings together beliefs and actions (which occurred both through the literature, the data collection as well as the active community volunteer work and reflections thereon), in order to answer the research question. Fundamentally, pragmatism wants to find solutions to existing problems and facilitates this through human problem-solving.[144] The first phase of the research had a question it sought to answer. As this research question was answered, it brought up other questions, which were answered in the second phase. Even whilst these were being answered, a final question arose again, which was answered in the third phase. Therefore, attention is focused on social injustices, which is evident in food insecurity.[143] Additionally, pragmatic research occurs within political, historical, social and other contexts.[91]

Interpretivism also considers socio-cultural issues, situational factors, the relationship between the participant and the researcher. Importantly, situations are fluid and changing, and therefore not static.[145] The interpretive analysis that occurred in the narratives' constructions included detailed explanations. Due to the prolonged engagement with the participants, I was able to clarify meanings which enriched the narrative. Within interpretive methodology, knowledge is jointly constructed between participants; the context and socio-cultural aspects influence reality, and it aims to

understand multiple truths. Within this domain, the researcher is critical in disclosing opinions and biases and playing an active role in the research process.

I have seen how students in the occupational therapy programme grow and learn in their understanding of the world as they experience things in the community and interpret these experiences.[146] I clearly remember a fourth-year occupational student discussing her concerns with me prior to working in Mamelodi during their community-situated work integrated learning (WIL), particularly on engaging with clients in the community-oriented substance use (COSUP) programme. "How will I talk to them? I am scared I will not know how to act," were some of her initial fears and biases. I remember answering that she should just talk to the clients as if they were people she encountered during social situations, or family members. It was particularly rewarding the same student was teary when six weeks at having to leave the community; having formed friendships in the short time there. This always motivates me to advocate for the continuous numbers of students from diverse disciplines and professions to have the same experiences. Only in these experiences of discovering each person's humanity, will we be able to change things in South Africa – and overcome our inherent fears and biases. Therefore, interpretivism permeates from my practice through my research.

Ontologically, I embrace that there are multiple realities that individuals experience. However, this does not contradict the nature of truth and thus an absolute truth from a spiritual perspective. Epistemologically, I advocate for the importance of prolonged engagement with participants and conducting the research in the field, as opposed to from a distance. Even though it was not possible for me to live in Mamelodi, my research assistant moved to the Mamelodi community during our most intense data collection; and thus provided an additional unique perspective.

1.9. Ethical Considerations

The Declaration of Helsinki was adhered to by the researcher. General ethical considerations will be summarized below first:

1.9.1. Right to privacy and confidentiality

The researcher protected the participants' right to privacy and confidentiality by not disclosing any personal information obtained in the study. The personal records were kept private and confidential. This was done by ensuring that the electronic data was password protected and hard copies of information were under lock and key. The information obtained was shared only between the researcher and the supervisors (and transcribers where required). As noted under data management, the information will be kept for five years before it is appropriately terminated.

1.9.2. Informed consent

For the first research question, participants received an information document via email detailing the study outline (see appendix H). Informed consent was obtained by agreeing to participate in the study electronically upon commencement of answering the questionnaire. For the second and third research questions, I prepared a "sourcing participants interview guide" (see appendix I), which contained all the relevant information and questions that I needed to determine before knowing whether the participants met the inclusion criteria of the study. If the participants qualified for the study, then I prepared an additional detailed information letter and consent form (see appendix J), which was translated beforehand into both Sepedi (see appendix K) and Setswana (see appendix L). This was to ensure that it was available in Mamelodi's two most spoken languages. Participants in all aspects of the study were informed that they had the right to refuse to participate or answer any question or to withdraw from the study at any point. Although participants had at various stages provided consent for their photos to be shared, and in one case, a participant had initially provided consent for her name to be disclosed, I reviewed this and decided it was important to anonymise all of them. This is discussed in more detail in section 5.3.4.

1.9.3. Beneficence

I aim for the study to benefit educators in the health sciences professions, to develop relevant material for curricula regarding food security and disability, as well as the complexity of the household. This in turn, will hopefully benefit vulnerable populations, specifically when health care professionals and CHWs work in households. Please see section 5.3 (significance for public health) for additional aspects. I had initially prepared to offer the participants some remuneration (not monetary) for their participation in the study by asking what I could possibly assist them with. However, when I discussed this with Judith, she strongly suggested this be removed since it would influence the study. I have interrogated this again in the synthesis, section 5.3.3. The participants were informed that they would not benefit directly by participating in the study, however, their stories would benefit the health care system and those working in it, to understand better and thus improve their intervention when working with women who are food insecure and have disabilities.

1.9.4. Non-maleficence

For the first research question, there were no identified risks for the participants involved, and potential participants were not subjected to any harm. If answering the questionnaire caused the educators any concern, they were able to contact myself, and I would have intervened appropriately.

For the qualitative research, there was the potential for psychological risks. This risk is associated with all research involving humans; and as such it was relevant to remember, that to be human is to be vulnerable. However, some people may be more vulnerable than others.[147] The women interviewed experienced multiple vulnerabilities based on their context, food insecurity, HIV/AIDS status, disability

and the socio-cultural consequences of being a woman. According to Judith (my research assistant), life history methodology is a very unfamiliar research method in communities such as Mamelodi. Therefore, it was important to ensure that the women who also had disabilities understood what it would involve. This included the women allowing me accessing into their lives, activities, minds, and emotions. Therefore, the participants needed to know from the beginning, why they should allow me to intrude to such an extent. I considered this carefully when planning the information sheet and informed consent document to ensure that the explanation or account of the proposed research was vigilant.[148]

The participants were interviewed in their personal environment, thus ensuring that they were comfortable. The interviews were held in a conversational manner, thereby creating a non-threatening and friendly environment. Participants were not probed where they did not want to answer certain questions. They were not subjected to any discrimination, danger or harm due to participating in the study. When researching people in vulnerable situations, the researcher must be aware that errors made can "irrevocably harm the lives of (the) research participants, people often already vulnerable, disempowered and socially excluded".[95(p23)]

Although counselling for aspects related to the research was not necessary with the participants, I had to refer two participants for psychiatric intervention due to their psychological illnesses. These aspects are discussed in more detail in chapters three and four, as well as in the e-books.

1.9.5. Working with a research assistant

Although I had initially planned for Judith to only fulfil the role of research assistant and translator, she became a co-researcher during the data collection process. Before commencing data collection, I had carefully considered the importance of a research assistant. For me, it was vital that this person would be someone who understood the research process, the cultural nuances of the community, could form a good rapport with both the participants and myself, someone whom I could trust and who would be committed to the entire process. Further suggestions from the Researchers in Development PhD Network[149] included someone with experience, who is friendly, displays resourcefulness, has excellent language and facilitation skills and is flexible.

Dr Michelle Janse van Rensburg recommended Judith Mahlangu to me. She was a female from the Ndebele culture who had been involved in various research endeavours and was working in a peri-urban community at the time. She also had existing links within the Mamelodi community, was very interested in the research topic and committed to learning throughout the process. She had prior training in translating and being a research assistant and came well recommended. Even though she did not have a professional degree (she had however completed various modules in development studies through the University of South Africa) I elected to ask whether she would be willing to work with me, based on the ability that she had to form relationships quickly with the community. In

addition, she would be relatable to my participants, being a woman, and would aid in the formation of a trusting relationship in the research process.

That is how an incredible relationship began with Judith. Naufel and Beike[150] note that research assistants can experience unique social, psychological and physical risks when conducting their duties. Research assistants may participate in the process to improve their curricula vitae, which was one of the reasons that my research assistant wanted to be a part of the study. Therefore, I discussed her rights as being part of the research with her (see table 1 below).

Table 1-3: The rights of a research assistant

Article	**Summary**
Article 1. Right to safety	Research assistants' risks of harm from participants, environments, and apparati should be minimized.
Article 2. Right to informed consent	Research assistants have the right to informed consent with regard to their involvement in the research. The informed consent should document the potential risks and benefits associated with the study, unless withholding the purpose of the study is essential for the study's validity.
Article 3. Right to refuse to participate in data collection activities that one finds objectionable	Research assistants can refuse to conduct research or engage in other activities that they find objectionable. If a research assistant does find such an activity objectionable, an alternative assignment should be offered.
Article 4. Right to withdraw	Research assistants have the right to withdraw during a session or study that they have begun, without penalty.
Article 5. Right to counselling and notification of incident if harm occurs	Research assistants have the right to have an incident reported to the appropriate body (for example the research supervisor's superior or a body that typically handles research integrity) if they experience harm. Research assistants also have the right to counselling.
Article 6. Right to proper training	Research assistants should be trained before being entrusted with research duties.
Article 7. Right to feedback	Research assistants should receive feedback about their performance. Students and supervisees should be evaluated on the basis of their actual performance on relevant and established program requirements.

Article 8. Right to debriefing	Research assistants have the right to know the outcome of studies to which they contributed.
Article 9. Right to receive benefits for the work performed	Research assistants should receive benefits for the amount of work that they have completed, but they do not have to receive benefits for work from which they have withdrawn.
Article 10. Right to choose confidentiality in public acknowledgements	Research assistants have the right to keep their name un-associated with their role in the experiment in published reports or presentations of the research.

These rights were based on the Research Assistant's Bill of Rights, which was constructed by Naufel and Beike[150(p10-11)] using the ethical principles and code of conduct of the American Psychological Association (2002), the Tri-Council Policy Statement on Research Ethics (CIHR, NSERC, & SSHRC, 2010), the American Educational Research Association's (AERA) Ethical Standards (1992), and the Nuremberg (or Nuernberg) Code ("Trials," 1946-1949).

In addition, an information sheet (see appendix M), informed consent form (see appendix N) confidentiality agreement (see appendix O) was developed. The confidentiality agreement was based on the Augsburg College Research Assistant Confidentiality Agreement.[151] Since the conversations between Judith and myself were of empirical value to the self-reflexivity and understanding of cultural and linguistic nuances, this consent included the recording of discussions held between us.

Prior to the commencement of the data collection, I trained Judith. This was based on suggestions from the Researchers in Development PhD Network (RiDNet)[149] and included the following: A clear understanding of the research topic, thoroughly going over the interview schedule (and in this case, the importance of following the life history interview process), clarifying words or concepts which may be difficult to understand, especially regarding the sensitive areas or topics (in this case food security and HIV/AIDS); ensuring that she understood the significance of each question and the reason for asking them; and reinforcing the importance of translating verbatim, especially to not summarize what the respondent has said. Translation techniques also included ensuring that the participants fully understood what was being said, and what they were given consent to. Additionally, she needed to understand the ethical issues of conducting research; why our relationship would be significant; and the difficulties that may arise. I thus asked her to discuss any problems with me as soon as something arose.

Judith became essential in selecting participants, ensuring community entry, translating the interviews, and aiding in the co-construction of the narratives. She also offered valuable support,

helped share the difficulties that were faced and assisted in the formation of a trusting relationship with the participants.

1.9.6. Obtaining a good researcher-participant rapport

A good relationship needed to be formed between myself and the participants to enable trust. I did this by listening to the participants "so that they feel that their experiences and opinions (were) valued".[152(p9)] I had learnt that a good researcher-participant relationship will help the interviewees "find their voice" and would help them "gain empowerment and validation in new ways".[152(p9-10)] The participants were at all times be treated with respect and dignity and their voices honoured. Dawson[153] advocates for the participants experiencing care from the researcher for their wellbeing, and that the research will not only be about gaining information but rather getting an understanding of their perceptions and situations. However, I also needed to find a balance between establishing a close rapport with the participants through immersing or submerging myself whilst "at the same time maintaining a professional distance to avoid skewed data".[154(p1727)] Yin[94(p22)] warned that by emphasising that in situations where a relationship of trust has been formed between the participant and researcher, the researcher has to increase their "awareness of ethical dilemmas and possible pitfalls, and… [show] vigilant anticipation of these as the fieldwork unravels".

1.9.7. Considerations for narrative research with vulnerable persons

Goodson and Gill[99] note that there is too little regard for the diverse ethical concerns that are embedded within a narrative research approach. Therefore, I would like to discuss in more detail, specifically the second (and then the third) research question. I purposefully explored and interrogated this prior to the start of the data collection to ensure what became a mind field was addressed with the sincerity and sensitivity it required.

Following a review of the literature, the following are key concerns that were highlighted and which I addressed in specific ways.

To ensure that I recruited the appropriate participants for the study, it was necessary to visit various organisations and institutions within different communities, outlining the aims of my research and generating discussions to purposefully sample those participants who would enable a rich data gathering process. Accordingly, I visited the Mamelodi disability organisation and shared my research, visited the community health centre and worked through the CHW district manager of Mamelodi, Eesterust and Nellmapius.

I needed to anticipate difficulties that could arise when entering the field, especially concerning "recruiting participants and building rapport, power relations, reciprocity and friendship".[155(p73)] For this reason, I worked with Judith, my research assistant, who assisted with community entry. We also went on the first home visit with the CHW, or the head of the disability organisation (Reneliwe), to

ensure that the correct community principles were followed. Literature also suggests additional ways of addressing vulnerability, which include being reflective throughout the process, about the researcher's actions and decisions that were taken; being aware of power differentials and relationships and paying close attention to how the communication occurs – namely looking at language and understanding.[147] Both Judith and I had to be sensitive towards observing whether the participants had understood the information or whether there were signs of potential misunderstanding. Often, Judith translated what I had said to ensure there were no language problems. Jargon was avoided as much as possible, and the participants were frequently asked whether they had understood or were given the opportunity to ask questions.

I needed to find a balance between establishing a close rapport with the participants through immersing or submerging myself whilst "at the same time maintaining a professional distance to avoid skewed data".[154(p1727)] This aspect, however, was challenged, since by being so deeply embedded within the lives of the participants, it became very difficult to maintain a professional difference. Therefore, when Dikeledi passed away, I cried with her daughter. Likewise, when Anna experienced significant concern regarding her son, I acted upon this.

Emotional engagement is a necessary component for the completion and quality of the project, allowing a "sense of connectedness between the researcher and fieldwork".[154(p1728),156] Being connected emotionally with the participants enabled a deeper level of understanding.[156] This has been reflected upon extensively within the e-books.

I needed to ensure that participants knew ahead of time what my plans were for where I would be going after the research process. I had prepared to stay in touch with the research participants, as was appropriate, which I have done with the three families in this study.[148]

1.10 Outline of the journey

This hybrid thesis is submitted in the format of five chapters, of which chapters two, three and four include an article or manuscript each. The article and manuscripts are aligned through the overarching aspect of food security: complexities in the lives of women with disabilities.

In summary, the chapters in this thesis have been arranged as follows:

Chapter 1: As you have seen, this chapter described the overall research study. It provided an introduction and crucial background to understanding the development of the research. In this, it reviewed existing literature and the problem statement. Out of this grew the research questions. These were answered using specific methods, which have been described in detail. Additionally, academic quality has been explained. Ethics and data management are also referred to. This chapter is the foundation of the one article and two manuscripts, leading to chapter five – the synthesis of the study.

Chapter 2, 3, and 4: These chapters consist of the one article and two manuscripts based on the study's findings. They build on each other – each time, highlighting the following question and how it is being answered.

The first article (chapter 2) provides a baseline of information regarding the knowledge, attitudes and practices of health care professionals regarding the teaching of food security and disability in the curriculum. From this study, it was already revealed that the nexus is a complicated one, as the educators revealed limited understanding, which impacted their practice.

The first manuscript (chapter 3), therefore, aimed to provide some of this understanding by exploring the complexity in the lives of women living with HIV and disability in vulnerable contexts and their food security. Through the richness in the stories, policymakers, community members, researchers, academics and health care professionals can gain a greater sense of understanding regarding food security and disability, as well as how to consider this complex dynamic. However, this manuscript also asked the question about how one can approach complexity and in which way complexity could be understood.

The second manuscript (chapter 4) answers this question and provides additional information regarding working in COPC. COPC is the chosen approach since this is used within Mamelodi (and the City of Tshwane). It provides practical recommendations for including life history interviewing into the work of CHWs, increasing their understanding of mental health through additional training, improving care coordination and addressing complexity. As such, this is descriptive of pragmatism, in that it is solution focused, through collective problem-solving of social injustices (as previously described).

Please see 1.3 below for an overview of the one article and the two manuscripts: as well as the contribution of each.

Table 1-4: Overview of the article/manuscripts

Phase and chapter Number	**Title of article / manuscript**	**Research question**	**Aim of the article / manuscript**	**Research approach**	**Contribution of paper**
Phase 1, Chapter 2	Teaching about disability and food security in the School	What are the knowledge, attitudes and practice of instruction regarding	To discover the knowledge, attitudes and practices associated	Exploratory cross-sectional online survey using closed- and open-ended questions.	Whilst educators in the health care professions should have knowledge of the relationship between disability and food security, this study determined that at one specific institution, it was limited.

Phase and chapter Number	Title of article / manuscript	Research question	Aim of the article / manuscript	Research approach	Contribution of paper
	of Health Sciences, University of KwaZulu-Natal, South Africa	food insecurity and the nexus between food insecurity and disability among educators at the School of Health Sciences at UKZN?	with including food security and disability into curricula in the School of Health Sciences at the University of KwaZulu-Natal (UKZN).	Quantitative data were analysed using descriptive statistics and qualitative data were analysed thematically using Nvivo 11 software. Themes were established through three-level coding.	Both the literature reviewed, as well as the results of the study indicated a lack of understanding regarding both the assessment and intervention that would be required. This demonstrated the need to provide further evidence regarding the complexity evident between food (in)security and disability in vulnerable contexts.
Phase 2, Chapter 3	Life history: Exploring the lives of women living with HIV and disability in vulnerable contexts regarding their food security	How do women living with HIV and disability in vulnerable contexts experience food security?	To explore the lives of women living with HIV and disability regarding their food security.	Life history methodology using open-ended interviews over a period of prolonged engagement. Data was compiled through narrative configuration. It was then analysed through paradigmatic mode of analysis (also referred to as analysis of narratives). Initially inductive,	This study demonstrated that women in vulnerable contexts with disabilities can display resilience contributing to their food security. However, the systemic failures in the health, education and social departments limit food access and compound food insecurity. Additionally, the study highlighted that traditional food and nutrition security measures do not necessarily provide a true understanding of the household, nor does it lead to knowing which interventions for the household may be most beneficial in improving their food security. The study also demonstrated that addressing food insecurity may not

Phase and chapter Number	Title of article / manuscript	Research question	Aim of the article / manuscript	Research approach	Contribution of paper
				and then deductive reasoning determined the themes.	improve wellbeing. The manuscript thus raised the question of how to obtain an improved understanding of the household, so that collective problem-solving can lead to overall improved functioning.
Phase 2 and 3, Chapter 4	The Mkhize household complexities – considerations for community oriented primary care (COPC) in the City of Tshwane	What lessons can be learnt, from exploring the complexities evident in a household as well as engagement with the household, related to COPC implementation?	To explore the complexities evident in a household as well as engagement with the household, to describe three relevant factors related to COPC implementation	Life history methodology using open-ended interviews over a period of prolonged engagement. Data was compiled through narrative configuration. Deductive paradigmatic mode of analysis (also referred to as analysis of narratives) of both the Mkhize household narrative and the research process of engagement experienced, layered over my changing understanding and insights	This manuscript proposed four important contributions that the study has elicited, which will facilitate COPC implementation in the city of Tshwane and lead to more effective health, wellbeing and functioning. Using life history during interviews with the household, will facilitate insights in the CHWs and the household members regarding themselves. CHW will benefit from receiving additional training in mental health, using relevant examples in their communities. Care coordination should improve, especially between the CHWs and the facilities. Finally, there needs to be a means of complexity management since each household is unique and the interrelatedness between the household members is unique. A model was therefore developed to demonstrate the household as a complex adaptive system (CAS). This is called the household complexity model or HHCM. This

Phase and chapter Number	Title of article / manuscript	Research question	Aim of the article / manuscript	Research approach	Contribution of paper
				developed over a period of time working in the community of Mamelodi.	household is a part of the community which is also a CAS. Understanding these systems by both CHWs and the household can lead to collective problem-solving to address the demands and disruptions that arise in daily life. This will hopefully lead to overall improved household and community function. Finally, if implemented, these resources and understandings can improve the teaching of health care professionals, as identified as a concern in phase one.

Chapter 5: This synthesis interrogates all that has been shared and summarises the main findings of the entire research study. It also considers its significance for public health and shares thoughts about transformative ethical research. It then critically looks at the critique of the study, the strengths and considerations, provides recommendations and ends with a take-home message.

After the references and appendices, I close the thesis with a postlude in which all my acknowledgements are shared.

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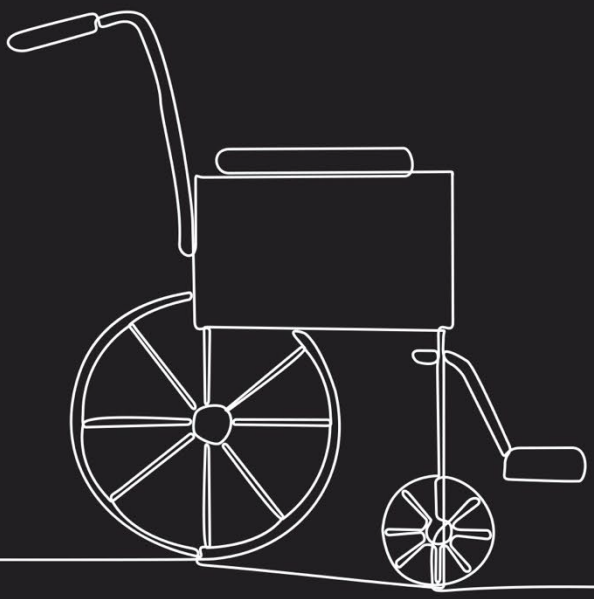
Chapter 2: Teaching about disability and food security

"We are all students of the world; frail embodied consciousnesses struggling to understand, and be a meaningful part of this great, mysterious gift of life."

Bryant McGill



2.1. Prologue

Food security is an important public health agenda. As such, it should be understood in the various disciplines and professions, that are facilitating public health. Amongst these are the health care sciences professions. These professions also have a unique understanding of disability, as well as the functional implications of having a disability. Since the connection between food security and disability has been established, it should be translated into the training of future health care professionals. To be able to do this, the educators themselves need to have an understanding first.

The literature reviewed indicated that a baseline study amongst health care professionals had not yet been conducted regarding their understanding and practices related to the teaching of disability and food security. Knowledge, attitudes and practices (KAP) questionnaires are favoured by researchers when needing to determine a baseline from which further studies and developments can emerge.

The published article, which follows, presents and discusses the first research question, its methods and results. The intention of this article was not to generalize findings, nor to capture a sample from the workforce. Instead, the value of the article provides the impetus for thinking about training of health care professionals training and food security.

2.2. Publication details

Table 2-1: Article one publication details

Title	Teaching about disability and food security in the School of Health Sciences, University of KwaZulu-Natal, South Africa
Authors	Lister, HE, Mostert, K, & Pillay, M.
Journal	African Journal of Health Professions Education (AJHPE)
Year	2021
Volume	Dec. 13, No. 4
Pages	265-269
DOI number	https://doi.org/10.7196/AJHPE.2021.v13i4.1251

2.3. Journal details

African Journal of Health Professions Education (AJHPE) is a peer-reviewed Department of Higher Education and Training (DHET) approved, open-access journal. It publishes editions quarterly and covers matters relevant to education for health professionals. It currently has an impact factor of 0.5. I wanted to publish in an African journal to ensure that the journal is contextually relevant; and to build on indigenous scholarship contribution.

2.4. Publication timeline

The first draft of this article was submitted to AJHPE on the 20th of September 2019. Following the peer-review process, it was accepted on the 29th of October 2020. The delay arose since the editors wanted to publish the study as a short report, however as authors, we requested to keep the original research submission, for the following reasons:

- This research is a novel study within health professions education by addressing food security within health sciences curricula. Food security remains a significant challenge in Africa, is one of the sustainable development goals, and thus requires interprofessional solutions. This journal was the ideal platform to highlight the need for cross-sectoral collaboration, especially starting in the education of health care professionals.
- Although it is a single-institution study, the population comprised of educators from all the professions in the School of Health Sciences at the institution, all of whom were invited to participate.
- It includes both quantitative and qualitative findings, which have shown that health professionals are not aware of what food security comprises, but they acknowledge the link between food insecurity and disability. This provides the impetus for further studies to be done in the field.
- Importantly, shortening the manuscript will limit the information that we can share about this fundamental human right.

The submission was then approved and published in the December edition in 2021. Unfortunately, almost two years had lapsed since the initial submission before publication. The journal indicated that they had significant delays in publication due to the number of articles requiring publication.

2.5. Contribution details

All authors conceptualised the study. HL completed the data collection, KM and HL analysed the data, and MP reviewed the data analysis. HL wrote the first article draft, and KM and MP contributed to the integration and refinement of information for the article. MP provided the conceptual base for connecting food security and disability.

2.6. Article one

Research

Teaching about disability and food security in the School of Health Sciences, University of KwaZulu-Natal, South Africa

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Background. Food security is a significant challenge in South Africa, especially for persons with disabilities. This topic is therefore important for educators in the health sciences. Nevertheless, little is known about educators' awareness of the relationship between food security and people with disabilities, or to what extent the topic is included in their curricula or what their attitudes are regarding this topic.

Objectives. We explored the knowledge and attitudes of educators pertaining to food security and people with disabilities. We assessed the current teaching practice associated with the food security of people with disabilities in the School of Health Sciences, University of KwaZulu-Natal.

Methods. Thirty-five participants completed a cross-sectional online survey. The participants represented diverse disciplines including audiology, occupational therapy, optometry, physiotherapy, speech-language pathology and sports science. Quantitative data were analysed using descriptive statistics and qualitative data were analysed thematically.

Results. The participants had limited self-reported knowledge about the definition of food security. Fewer than 60% of the participants reported a relationship between three of the dimensions of food security and disability, and 80% for one of the dimensions (food utilisation). Of the participants, 88% did not teach food security and disability theoretically, and 80% did not teach it practically. According to the participants, students were not equipped to assess if their clients with disability had food security problems, and were unsure of appropriate interventions.

Conclusion. Despite a lack of knowledge, participants had positive attitudes towards including food security into their teaching, although limited teaching existed at the time of the study.

Afr J Health Professions Educ 2021;13(4):264-269. https://doi.org/10.7196/AJHPE.2021.v13i4.1251

Food security remains a significant challenge in South Africa (SA), as in other economically developing countries, with persons with disabilities specifically being at risk of inadequate nutrition.[1] In SA, according to the General Household Survey of 2016, 22.3% of households had inadequate or severely inadequate access to food, 11.8% households experienced hunger and 13.4% individuals experienced hunger.[2] Based on the same survey, 4.7% of South Africans aged 5 years and older were classified as disabled.[2] Persons with disabilities are vulnerable to food insecurity, because they are often economically marginalised and therefore chronically poor.[3] The relationships between poverty, food security and disability are bi-directional as one can cause the other.[4-6] For example, poverty results in limited purchasing power for food and limited intake, rendering the individual unable to work, further reducing available income. Malnutrition arising from food insecurity may drive disability in individuals with chronic illnesses, such as HIV/AIDS, further limiting their ability to access, prepare and consume food. Disability may therefore cause poverty and vice versa, especially if there is limited access to healthcare services[7] and inadequate community support.

Baro and Deubel[8] argue that community involvement, new technologies and support from both international and national governments and non-governmental organisations (NGOs) are vital to food security responses in Africa. Drimie and McLachlan[9] agree that solving the complex food security challenge requires an explicit transdisciplinary approach, including input from health sciences professionals. Health sciences professionals work with individuals on a one-on-one basis and multidisciplinary teams are often in contact with persons with disabilities. Community healthcare workers should also be aware of and able to assess the nutritional status of persons with disabilities, and be able to identify appropriate interventions to promote food security (Table 1) in these individuals.

Many healthcare professionals work with persons with disabilities, and healthcare students should be trained to assess and work with affected persons. The extent to which the relationship between food security and persons with disabilities is covered in health sciences curricula is unknown, both internationally and in SA. We found no literature on the attitudes of educators towards teaching this subject, even though the subject is societally important. We aimed to discover the knowledge, attitudes and practices associated with including food security and disability into curricula in the School of Health Sciences at the University of KwaZulu-Natal (UKZN).

Methods

We conducted an explorative cross-sectional online survey using closed- and open-ended questions. We structured the questionnaire into three sections,

Table 1. The four dimensions of food security

Food availability	The supply side of food security, namely the availability of sufficient quantities of quality food coming from imports and domestic agriculture production. In other words, the level of food production, stock levels and net trade.[10,11]
Food access	The income, expenditure and buying capacity of individuals or households.[11] Therefore it takes into consideration whether the individual has enough resources to be able to acquire the appropriate quantity of quality, nutritious foods.
Food utilisation	How individuals utilise food through adequate diet, sanitation and healthcare, so that they can reach a state of nutritional well-being;[12] therefore, how much food, and what and how individuals eat.[11] Other components include food preparation, water, healthcare practices and intra-household food distribution.
Food stability	The continuation of the other three dimensions over time, namely stability of availability, accessibility and proper utilisation conditions.[11] Food stability may be affected by numerous conditions, e.g political instability, adverse weather conditions and economic factors, e.g. unemployment and rising food prices.[10]

based on a literature review, and input from a statistician, a research expert and an expert in food security. We established content validity by sending the questionnaire to five experts for review.[13] This panel determined whether the questions were understandable, easy to answer and appropriate for what the researcher was wanting to determine. The questionnaire was then piloted with three health sciences professionals not currently employed at UKZN, improving the clarity and content of the instrument.

The population comprised all educators whose email addresses were received from the heads of departments within the professions of audiology, occupational therapy, optometry, physiotherapy, speech language pathology and sports science (n=70 in January 2017). A link to the survey, together with the information document and informed consent form, was emailed to all educators. Thirty-five staff responded (response rate of 50%). Table 2 depicts the demographics of the participants.

Quantitative data were analysed using descriptive statistics and qualitative data were analysed thematically using Nvivo 11 software. Themes were established through three-level coding. Data were coded in Nvivo, using the exact words in the text, and descriptively, where the text was described and interpreted by the researcher. The study was approved by the Humanities and Social Sciences Research Ethics Committee at UKZN (ref. no. HSS/1740/016). Gatekeeper permission was also obtained from the registrar of UKZN.

Results

Knowledge of food security and disability

We asked the participants if they understood the different dimensions of food security (Table 1). Participants either answered 'no', 'somewhat' or 'yes', and if they answered 'yes' or 'somewhat', we asked them to elaborate. Table 3 indicates the participants' self-reported understanding of the different dimensions of food security.

Upon further elaboration, the participants understood food availability as having sufficient quantities of food; food that is available (locally and internationally); that there is food being produced; the 'percentage of fats, carbohydrates etc. (that are) contained in food'; or having access to good food for all in a group of people.

Participants understood food access as the ability to 'get' food, through finding the means, being in close proximity, affordability, ease of obtaining, or physical and economic access to nutritious food; all people having access to food; 'the percentage of fats, carbohydrates etc. (that are) contained in the food'; or having 'reliable and trusted access to food'.

Participants understood food utilisation as using food, either how they use it, or 'how the body uses food', how much food is eaten, for what purpose and 'how much of a specific food group' is used; using the 'available channels to access food'; one's ability to eat food that is available; the 'correct consumption patterns of food'; the 'ability of an individual to prepare regular meals using food'; or the ability of a person to choose what food is 'good'.

In addition, participants understood food stability as having sustained and sufficient food in terms of supply, over a period of time, at a given time, consistently and regularly; the shelf-life of food; 'all the variables of food production and supply'; or 'having food and being able to get food and eat food that is available.

The final questions within this section gauged participants' opinions regarding the relationship between the different dimensions of food security and disability. The dimensions were further explained within the question so that the participants had a clear understanding of the dimensions. Refer to Table 4 for findings.

Five themes, as seen in Table 5, emerged from the data. The categories are represented under the four dimensions of food security.

Attitude about including food security and disability in the curriculum

We provided the participants with 15 items that could possibly be included

Table 2. Demographics of participants

Discipline	n (%)	Educational level	n (%)	Employment level	n (%)	Employment type	n (%)
Audiology	3 (9)	Bachelor's degree	4 (12)	Senior tutor	8 (25)	Part-time	6 (18)
Occupational therapy	11 (32)	Master's degree	22 (65)	Junior lecturer	18 (56)	Practical supervision only	1 (3)
Optometry	5 (15)	Doctoral degree	8 (24)	Senior lecturer	5 (16)	Full-time	26 (79)
Physiotherapy	6 (18)			Associate professor	1 (3)		
Speech language pathology	5 (15)			Professor	0		
Sports science	4 (12)						

Table 3. The self-reported understanding of the different dimensions of food security of participating educators*

Dimension	No, %	Somewhat, %	Yes, %
Food availability	46	46	9
Food access	46	46	9
Food utilisation	57	34	9
Food stability	60	34	6

*Percentages have been rounded off, hence this dimension does not add up to 100%.

Table 4. Educators' opinions on the relationship between the different dimensions of food security and disability

Is there a relationship between this dimension of food security and disability?	No, %	Yes, %	Do not know, %
Food availability	12	47	41
Food access	3	80	17
Food utilisation	9	54	37
Food stability	3	54	43

in the curriculum. We asked participants to rank the items on a scale of 1 to 5, with 1 being 'definitely exclude from teaching' and 5 being 'essential to include in teaching'. Of the 15 items, 10 items were ranked by 80% of participants as either 'important to include in teaching' or 'essential to include in teaching'. These were:

- the definition of food security
- the influence of the social context on food security
- the influence of the environmental context on food security
- the influence of the economic context on food security
- the risk factors of food insecurity
- the consequences of food insecurity
- the macro factors influencing the food security of persons with disabilities
- the micro factors influencing the food security of persons with disabilities
- how to incorporate food security into the assessment of persons with disabilities
- how to incorporate food security into the treatment of persons with disabilities.

Current practice of teaching about the relationship between food security and disability

In the final section of the survey questionnaire, participants were asked, 'Do you currently teach anything about the relationship between disability and food security in clinical settings' practically and theoretically, and 'Do you think students are currently equipped to treat and advise persons with disabilities who have food insecurity problems?'

Theoretical teaching about the relationship between disability and food security

Of the participants, only 11.8% reported that they included something in their teaching about the relationship between disability and food security theoretically and 88.2% said that they did not. Where it was taught, it was done in the study themes 'accessibility issues on disability issues'; incorporating the social and economic context into assessment; within intervention required for visual problems (e.g. glasses) so that the individual with visual problems can see the food; and in referrals to a dietician.

Practical teaching about the relationship between disability and food security

Twenty percent of participants included teaching something about the relationship between disability and food security practically, while 80% did not include anything. The practical teaching occurred within assessment, intervention, and on a case-by-case basis. Regarding assessment, if 'the patient was found to have poor nutrition/low socio-economic status and disability then emphasis is placed on the vulnerability of the patient to this kind of crisis'; it is addressed if there is poor volition of the client to attend therapy and why this may be so; and in incorporating the social and economic context into assessment. Regarding intervention, it was included for those who have visual problems, and referral to the dietician.

Educators' opinion on whether students are equipped to treat and advise persons with disabilities who have food insecurity problems

Regarding the perception of participants on whether students are equipped to treat and advise persons with disabilities who have food insecurity problems, 37.1% stated that they felt students were somewhat prepared and 62.9% felt that students were unprepared. Participants further explained that this situation was a curriculum problem (on why it was not included), that it may be covered in some places, should be included, or even that it should not be included as there was already an overload of teaching. Participants felt that students learn incidentally and should be encouraged to think and treat holistically, and that they should make use of allied team members. In this way, food security is addressed within individualised healthcare, as opposed to only on a larger scale.

These factors are integral to the realisation that it is essential to address disability and food security holistically within health sciences professions.

Discussion

We assessed the knowledge, attitude about inclusion in teaching and the current teaching practice of educators regarding food security and disability in the School of Health Sciences at UKZN. Educators had little theoretical understanding of the different dimensions of food security but once the dimensions were explained, they acknowledged the importance of the relationship between disability and food availability and that it should be included more extensively in the curriculum.

Knowledge: What the educators understood about the relationship between disability and food security

Despite not understanding the different dimensions of food security, health sciences educators showed a general appreciation for the relationship between food security and disability. More than 40% of participants (this study) stated that they did not understand the food security dimension. However, less than 12% of participants did not acknowledge the relationship between the different food security dimensions and disability. We were unable to find literature that specifically links the dimensions of food security to disability. We were, however, able to find examples of how food insecurity drives disability and vice versa. Studies have shown, that food insecurity is associated with reduced physical and mental health status.[4-6] Persons with disabilities experience high levels of poverty and unemployment.[14] This increases food insecurity of the individual and of the household.[5] Food insecurity is also a barrier to accessing health care.[15] The SA Department of Agriculture[16] notes in its 'Integrated Food Security Strategy for South Africa' that access to food may be affected because of disability. Additionally,

Table 5. Themes and categories displaying the relationship between the different dimensions of food security and disability

Theme	Food availability	Food access	Food utilisation	Food stability
The relationship between disability and food insecurity is bi-directional	Lack of food can cause and influence disability	Disability leads to food being inaccessible and conversely, poor access to food can lead to disability	Food insecurity can create or worsen the disability, yet food security improves health	Lack of food can lead to a disability
Disability, poverty and food insecurity are interlinked	The food insecurity of persons with disabilities 'is one of the contributors to poverty'	Poverty leads to lack of food which leads to a disability. Disability results in unemployment which results in less access to food	Disability leads to poverty which leads to lower quantity, less nutrition, less variety of food and inappropriate food choice	Lack of food stability leads to poverty and conversely poverty leads to lack of food stability
Disability influences food production, food preparation and feeding	Persons with disabilities are unable to contribute to food production		Disability affects the ability to grow food. Disability affects the ability to prepare food. Disability leads to poorer feeding, for example, in having a cleft lip or palate	Disability limits access to and preparation of food
Economic and social factors influence food security	When there is greater availability of food fostered by a strong economy, this creates cheaper, more accessible and greater variety of food for persons with disabilities. However, 'if the production and import is low or not sufficient, (and people rely on subsistence farming) people with disabilities suffer the most as they cannot produce food' on their own'	Economic and social factors affect the quality and frequency of food. The disability grant limits access to food (since it may not be sufficient for nutritious food, or is being used by the family)		
Food security positively influences disability		'Access (to food) fosters wellness'		'If food is constantly available, this can positively impact the disability' Persons with disability who rely on their families are dependent on others to buy and prepare food, as well as feed them
Dietary requirements and food choice are influenced by disability		Persons with disability 'have specific dietary requirements, hence food may be available but not necessarily accessible'	Disability leads to poorer food choice as individuals may not be in control of choosing their food as they have to rely on what is handed to others. Persons with disability may not have the cognitive capacity to be aware of what constitutes nutritious food	

malnutrition, considered under 'food utilisation', is a cause of disability.[17-19] Malnutrition can be caused by the inability to feed. Feeding can be impaired through different types of disabilities, e.g. cerebral palsy, which is characterised by low muscle tone that can cause difficulties in swallowing.[20,21]

Attitude: Educator's attitudes to providing instruction about disability and food security

We were unable to find any direct guidelines on what the curriculum content for the various professions within health sciences should be, as well as what

is needed in order to intervene appropriately with affected persons. When presented with relevant items to be included in the curriculum, participants placed much importance on these various themes. In SA, especially KwaZulu-Natal Province, almost half of the people live in rural areas. Rural areas are usually low-resource areas, where most of the population relies on subsistence farming, comprise single-income households and have inadequate access to resources. In this milieu, the relationship between food security and disability is vitally important and community health workers need to know how to approach the problem.

Practice: What educators already included in the curriculum about the relationship between disability and food security

We were unable to find any information about what health sciences educators at other institutions teach about the relationship between disability and food security. In this study, we ascertained that, when included, this topic is not taught in a structured, explicit way, but rather as the need arises and as a part of the so-called hidden curriculum. The ad hoc way in which the topic is included also leads to the limited presentation of themes related to food security. For example, one participant teaches about intervention for persons with visual impairments, so that they can see the food (e.g. with glasses); however, visual impairments encompass a much broader range of consequences for food security. These individuals may experience difficulties in shopping, and accessing environments, as well as being able to prepare food and have a variety of food to eat (because of inaccessibility to materials).[22] Food security should be addressed in individualised healthcare, to ensure that the intervention is person-specific, as opposed to being a generic solution. Generic solutions do not cater for individuals who have specific needs. For example, having a food kitchen will not necessarily ensure that a person who requires a wheelchair will be able to access meals.

Study limitations

This study was only conducted at one university. The study did not specify the results of the questionnaire in accordance with the various professions. The implications of including food security and disability into the curriculum may be different according to each profession's scope of practice. We propose that the theory of food security should be included as a generic subject at first- or second-year level, with the theme adapting as students in different disciplines progress.

Recommendations

One of the possible reasons for the lack of content in the curriculum is that the food security of people with disabilities living in rural areas is not currently being studied in SA. The prioritisation of research in this field would promote inclusion into the curriculum.

Further studies should be conducted among the health sciences professions at other universities in SA and cover how to include food security and disability into the curriculum. The health science professions should review how they can intervene with persons with disabilities who are food insecure. These issues should also be discussed with the Health Professions Councils, including a review of the scope of practice, as well as the curriculum of the various disciplines with specific exit-level competencies being identified.

Conclusion

According to the present study, educators had a limited subjective knowledge of food security at a specific School of Health Sciences. Educators had a somewhat good understanding of the link between the different dimensions of food security and disability and they felt that more should be taught about disability and food security in the School of Health Sciences professions. Including this content should enable students and graduates who deal with persons with disabilities who are at risk of food insecurity. If students learn about this link, they should have the necessary awareness to address food security to be able to intervene with their clients and patients holistically. For example, if someone with a swallowing disability does not have access to appropriate food, teaching them how to eat will not ensure that they receive appropriate nourishment. Therefore, as food security is a baseline challenge which impacts all areas of functioning, rehabilitation can either remain incomplete or be unsuccessful if this basic need is not addressed.

The study raised awareness among participants about the importance of food security and disability. The findings will be used to inform participants of gaps within their curricula, and ensure that this pertinent aspect of disability is addressed in student education. These aspects should be foregrounded by important discussions with the Health Professions Council of South Africa (HPCSA) to address the different disciplines' scope of practice.

Declaration. None.

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Author contributions. All authors conceptualised the study. HL completed the data collection, KM and HL analysed the data, and MP reviewed the data analysis. HL wrote the first article draft, and KM and MP contributed to the integration and refinement of information for the article. MP provided the conceptual base for connecting food security and disability.

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2.7. Epilogue

As can be seen in the manuscript, from both the literature reviewed and the research conducted, there is a lack of understanding and training in the curricula at this South African institution regarding the assessment and intervention that would be required when engaging with persons who are affected by food insecurity and disability.

As stated, one of the potential reasons for this is that qualitative contextual research, illuminating the complexities and personal realities, has not been conducted.

Therefore, whilst educators appreciate that it would be important and that more information is required, they themselves cannot provide the guidance to students. Therefore, when working in the field, professionals will consequently experience difficulties understanding and finding solutions.

The study identified that it should be a priority to conduct research in this field to promote inclusion of the nexus of food security and disability into the curriculum. This, therefore, prepared the ground for the second research question in this PhD.

Chapter 3:Life history: Exploring the lives of women living with HIV and disability in vulnerable contexts regarding their food security

"I have felt that it is important, in trying to understand other persons' positions in life or description of themselves and their relations to others, to let their voices be heard, to let them speak for and about themselves first. If we want to know the unique experience and perspective of an individual, there is no better way to get this than in the person's own voice."

Robert Atkinson

3.1. Prologue

The previous chapter described the curriculum study conducted in the School of Health Sciences at UKZN. From the results of the questionnaire, it was determined that the knowledge of the relationship between disability and food security amongst the educators was limited. Whilst there was a positive attitude towards including this in the curriculum, educators seemed not to, themselves, understand how intervention would occur. This is potentially from a lack of research available regarding the context-specific realities of people with disabilities who are food insecure.

It is thus necessary to demonstrate and provide evidence regarding food security and disability. With this evidence, educators, and also policy makers, students, NGO workers, and others advocating for public health, can gain insight into the complexity evident between food (in)security and disability in vulnerable contexts.

Although public health programmes intervene nationally and locally in food insecurity, people with disabilities are still significantly affected by food insecurity. Food insecurity is a complex phenomenon and therefore needs to be addressed in a person-specific way in primary health care. An example provided in the previous study, is that a person with a physical impairment who requires the use of a wheelchair, may not necessarily be able to obtain food access through a community food kitchen, if they are unable to propel themselves to the site, or if the path to the site is inaccessible. Similarly, creating an urban garden may not be a viable solution for the same person.

This, therefore, highlights the need for an in-depth understanding of the lives of people with disabilities and their food security. Life history research is one methodology that can be used to determine a detailed picture of a complex situation.

Since women are most commonly associated with the occupation of food preparation and dissemination (providers of care), this is an additional dimension to consider in a thorough analysis. Similarly, literature has demonstrated the significance of food security in people living with HIV, since food insecurity can be both consequential to having HIV and a driver of HIV transmission. Both these vulnerabilities have been highlighted in literature and described in the introduction.

Therefore, the manuscript which follows answers the second question in this research study, namely, “How do women living with HIV and disability in vulnerable contexts experience food security?”

3.2. Details of manuscript intention to submit

Table 3-1: Manuscript one intention to submit details

Title	Life history: Exploring the lives of women living with HIV and disability in vulnerable contexts regarding their food security
Authors	Lister, HE, Mahlangu, J, & Pillay, M.

Journal	Agenda
Year	Intention to submit following feedback on my thesis from the examiners.
Volume	
Pages	
DOI number	

3.3. Journal details

Agenda is a journal that originated in South Africa in 1987 through a volunteer project. The journal aims to challenge and question what is currently understood and practised in gender relations. One of the main reasons this journal was chosen is that it focuses on wanting to develop women and their capacity to take ownership and reflect on their experiences. Judith, a co-author of the paper, experienced this development as a research assistant in this study. Agenda is on the IBSS list of accredited journals (thus also DHeT) published by Taylor & Francis Ltd. It has an impact factor of 0.4.

3.4. Contribution details

HEL and MP conceptualised the study. HEL and JM completed the data collection. HEL analysed the data, and JM reviewed the data analysis. HEL wrote the first manuscript draft, and JM and BN reviewed the manuscript. MP provided guidance for the manuscript composition, completed the final review and provided the conceptual base for connecting food security and disability.

3.5. Manuscript one

Title: Life history: Exploring the lives of women living with HIV and disability in vulnerable contexts regarding their food security

Abstract

Multiple disadvantages can heighten the risk of food insecurity for people compared to those without these confounding factors. Unfortunately, when we do not interrogate these cycles that arise, they remain poorly understood – and thus inadequately addressed. In this article, we investigated the lives of two women living with HIV and disability regarding their food security. We chose a life history methodology in order to obtain a deeper understanding. The researcher was intermittently embedded within the community over four years and experienced many key events with the households. During this time, the lives of these women changed significantly. The changes occurred both because of the voluntary community intervention provided and the shocks and stressors that impacted their lives. Three important themes emerged in the analysis. Firstly, the women displayed resilience which contributed to their food security. Notably, both women did not view their disabilities as disabling. Secondly, systemic failures not only limited food access but also compounded these women's food insecurity. Thirdly, the international measures taken to derive population statistics of food and

nutrition security (FNS) can be wholly inadequate or incorrect. This can lead to traditional food security programmes not providing a sustainable solution. Therefore, statistical information needs to be supplemented by lived realities to ensure that the community and policy response can make a meaningful difference.

Key Words: Food security, women, disability, life history, multiple disadvantage, HIV

Introduction

People with disabilities are more prone to food insecurity than those without disabilities.[1-3] Generally, women are at a greater risk of food insecurity.[4] Being a woman and having a disability or disabilities further increases this risk.[5-6] When additional comorbidities and illnesses (for example, HIV) are experienced together with confounding factors (for example living in a vulnerable context and being the head of a household), these aspects further exacerbate food insecurity.[2] Whilst various studies have investigated multiple disadvantages and marginalisations in an attempt to understand the extent of the problem,[2,7-9] only a few studies have looked at these particular factors highlighted here. Muderedzi et al. explored the relationship between gender roles, food insecurity and HIV/AIDS in Zimbabwe. By interviewing the carers of children with disabilities, the interrelationship between these three aspects created a cycle of heightening vulnerability, with their effects being amplified.[10]

Various factors contribute to food insecurity among women with comorbidities, disabilities, and illnesses. Derose et al[11] found that women living with HIV in the Dominican Republic experienced economic instability, contributing the most to their food insecurity. Their situation worsened through stigma they experienced in both applying for work and within their social spheres. One scoping review that has recently been completed by Schwartz et al[12], explored the relationship between disability and food insecurity. They described individual, social, organisational and institutional, as well as environmental factors impacting the food security of persons with disabilities. Within this study, being a woman who is disabled increased the risk of food insecurity. Also noted is that there remains a dearth of literature on food insecurity and disability from developing countries, especially studies examining younger adults and families with children. Additionally, disability is rarely considered critically beyond the biomedical model which focuses on the physical conditions and limitations. If the social model of disability were used, this would include restrictions created by the interaction of people living with impairments and their inaccessible environments,[13] however its continued omission demonstrates a lack of undertaking to address the complexity of issues pertaining to food security.

In critique, the scoping review does not mention multiple disabilities (especially the connection between mental illness and physical disability). Similarly, a scoping review by Moore et al.[1], which aimed to describe the focus, extent and nature of the available literature addressing food and nutrition security (FNS) and disability, viewed disability in terms of the biomedical model. The most frequent

disabilities in the studies included were stroke, cerebral palsy and autism spectrum disorder. There were no available studies from South Africa.

Although numerous household food insecurity measurement scales exist[14], only one study included in these reviews used a household disability scale to measure food insecurity. This Korean study[2] compares families with and without members with disabilities and their household food insecurity. The following factors purported a moderate or severe household food insecurity status: where the head was a female; those living without spouses and in one-person households, single-parent households, households with an unemployed head, households without economically active members and households in metropolitan cities. All households with people with disabilities were more food insecure than those without disabilities. The risk for food insecurity was especially high for households where the head is a female and has a disability and where households have members with mental disabilities. Again, disability was not examined through the social model. Therefore, in this research, our aim was to explore the factors that influence the food security of women living with HIV and disability in vulnerable contexts.

Methodology

The findings elucidated in this article are drawn from a larger PhD study. Data was collected using life history methodology. Goodson[15] describes life history as a reciprocal collaborative process where understanding is developed. Life history research aims to develop and understand the collective experiences that 'the other' has whilst at the same time being bound together in the researcher's shared participation in the development of signification.[15] Therefore, life history research develops stories and personal narratives through interviews between the researcher and the researched.[16] This occurred over a period of four years necessitated by the complexity evident in the households, the changing nature of their lived reality, and the ongoing primary health care intervention provided by us as community workers during the process. Purposive and snowball sampling techniques were used to select the participants. The stories of two out of the three participants in the study have been selected, for analysis here. The sample size remains small because of the information-rich data, the fin-grained analysis required, the time taken to collect the data and the in-depth understanding of the topic required.

We as the researchers and the participants shared commonalities and differences. JM shared geographical residence, ethnicity, language and gender traits with the participants, whilst HEL had experience of working in the participants' community and being a mother. All of us did not separate our spirituality and faith in Christ from the research process, which enabled a deep connection between us.

Open-ended interviews occurred in the participants' homes, or the community as required. This alternated between being in the participants' home language (Sepedi), Afrikaans or English.

Collectively, these interviews were audio-recorded, translated (either real-time by JM or afterwards by a transcriber) and transcribed verbatim. In addition, reflexive notes were written to reflect upon and include ad-hoc discussions which were held with the participants, their family members, community members or professionals (for example, a psychologist). This information was used to supplement the life history of the women. We also conducted participant observations, took photographs and videos, obtained assessment reports and hospital records, and discussed and interpreted our experiences retrospectively during the data collection process. The data collection and interpretation occurred concurrently.

Methodological considerations

Although we had anticipated the need for reciprocity with vulnerable populations in the research design, we had not anticipated that we would become voluntary community workers during the process. We had to provide intervention, which at times was considered disaster-response. This intervention significantly impacted the life trajectory of the individuals concerned and thus altered their stories. In 2019, I (HEL) started working as a lecturer and supervisor of occupational therapy students in the community of Mamelodi. During this process, I developed a greater understanding of the available networks that could be accessed for the healthcare needs of the participants.

Narrative research is regularly argued to represent the reality of the storyteller and often the co-construction of the narrative as it is told to the listener. Therefore, typically, the researcher would listen to the story being reflected upon that has been lived.[17] Our research experience was different in that we were embedded within the story as it was unfolding. Whilst at times, the research participants would share something that had previously occurred, other times we were actively there whilst life was unfolding and a genuine part of the co-construction of the story. In fact, their stories changed because of the work we were doing as community workers.

Data Analysis

The two women in this article present significantly different lives lived. We combined the previously described forms of data to compile the story of both Dikeledi and Boitumelo[3]. The narratives include many of the participants' own words from the transcriptions. However, aspects of the transcriptions that were not crucial elements of the stories were removed, words and sentences were joined wherever appropriate, questions posed were rephrased, and my (HEL's) personal narrative was intertwined in between. Their stories already include the first layer of interpretations, aided by our current understanding derived from various community-engaged work. This insight we have used as an updated layer on the reflexive notes. This entire process is referred to as "narrative configuration" by Polkinghorne[18] to produce the coherent narrative presented within this article. The whole

[3] All names used in this article are pseudonyms

narratives are available to read in the community oriented primary care (COPC) storytelling library at https://www.up.ac.za/media/shared/772/COPC/Storytelling/dikeledi-story-web.zp227816.pdf (Dikeledi's story) and https://www.up.ac.za/media/shared/772/COPC/Storytelling/boitumelo-story-web.zp227815.pdf (Anna's story).

Data collection, analysis and interpretation did not occur in sequence but simultaneously throughout the research process. Additionally, the life history was not shared in a single event. Instead, we were embedded within the women's lives and present during significant life events that occurred. Therefore, I (HEL) was conducting a narrative mode of analysis continuously during the data collection process and the writing up of the original coherent story of each of the participants (shared e-books).[18] Following this, I used the paradigmatic mode of analysis (also referred to as analysis of narratives) to describe the findings of the life histories according to common themes across both stories and within the stories.[18-19] The three themes presented here, were determined through a process of reflexive-inspirational interpretation and are relevant to the particular research question being answered in this article.[20] I (JM), participated in member-checking of the compiled e-books and themes derived. Finally, one of the participants (Boitumelo) reviewed the summarized narrative shared in this article. Throughout this process, we tried to remain true to the messiness and complexity evident in each of their lives since tensions, challenges, and conflicting realities remained. We provide significant details of the lives of Boitumelo and Dikeledi in the following synopses.

Ethical considerations

Ethics for the research study was obtained through UKZN's research ethics committee (HSS/1064/106D) and from the city of Tshwane research ethics board (NHRD reference number GB_201708_007). The participants provided informed consent. Important to note is that, sadly, Dikeledi passed away during the data collection process. However, her narrative continued through the reflections we provide in our ongoing engagements with the family. Community ethics was considered in that we went to her family in the rural village, obtaining consent from the household leaders (uncle and aunts of Dikeledi's children) to continue sharing the story anonymously. Boitumelo reviewed the synopsis shared in this article. No financial incentives were given to the participants or their families.

Dikeledi's story: A synopsis

At the first interview in December 2017, Dikeledi was 34 years old. She was the mother of two children, Lerato (14) and Naledi (8). She was a woman who did not let her circumstances control her. Instead, she always maintained her agency and would make a plan in whichever way she had to, especially when it came to being there for her children. She had multiple partners, most of whom had ill-treated her. She contracted HIV and in 2012, was diagnosed with Spinal tuberculosis, and remained in hospital for a year. Although she received some exercise therapy, she was discharged without full rehabilitation, without a wheelchair or bladder management training, thus requiring adult diapers. After escaping one of the abusive relationships, she moved into a shack[4], without flooring when flooding occurred in Mamelodi. The image below was taken during the flooding.[21(p15)]

Figure 3-1: Dikeledi and Lerato in their shack during the flooding in Mamelodi

We assisted her in staying in a hall during this time and then facilitated the process of her receiving her RDP house (which she had been on a waiting list for, for twenty-two years). Lerato was in a prevocational school since she had a learning disability. Naledi was also having difficulties with her schooling. Dikeledi experienced numerous health challenges which required hospitalisation. Among others, from having unprotected sex and acquiring an STD and bladder infection. In December 2018, Dikeledi was taken to the hospital by ambulance and died. Dikeledi's family came from the rural village and assisted in the house. Naledi moved to Maganeng, whilst Lerato stayed in Mamelodi. She had no means to support herself. I (HEL) had not heard that any of this had happened, and by the time I met her, Lerato had dropped out of her prevocational school. Although we tried to ensure her return to education, she became pregnant with her partner, Mpho. He has hearing loss and cerebral palsy and receives a disability grant. Lerato returned to the rural village her mother was from when she had her

[4] This is a colloquial term in South Africa for an informal dwelling built mostly from corrugated iron sheets and often attached to a basic wooden frame

child. She was reunited with her sister and is being looked after by the extended family since. She would like to return to Mamelodi and live with Mpho and her daughter in her mother's house.

Boitumelo's story: A synopsis

Boitumelo was born in Mamelodi. She and her siblings (an older brother and older sister, and two younger brothers and one younger sister) grew up with their grandmother. She was abused as a young child. Her mother was divorced. She remarried another man and with him had two of her siblings. She failed grades 10 and 11 and did not complete her matric. She then worked at the Spar for three years. There were problems with her salary, which is why she left in 2007. Her father died in 2008, although he had no part of her upbringing. She contracted HIV in 2008 whilst living with her boyfriend at the time. In 2010 she got meningitis and lost her vision. She is totally blind in her left eye and partially blind in her right. She defaulted on her ARVs and meningitis medication in 2015 and became very sick. She was admitted to the hospital and diagnosed with severe anaemia. At a similar time, she also started having auditory hallucinations. She experienced anger and had difficulties sleeping. Her voices said, "Why don't you kill yourself?" The anger influenced her relationship with her boyfriend at the time because she would fight with him, and one day she took a knife and stabbed him. She then went to see a psychiatrist. The psychiatrist was unclear on the exact cause of the psychosis, since it could have been caused by the HIV, ARVs or secondary to depression.

In 2018, she met Peter through the disability organisation at the Christmas party; he is completely blind. They started a relationship, even though Boitumelo knew he was also in a relationship with another woman and proposed to the other woman. Although Boitumelo did not want to be in a polygamous relationship, she did miss him and would see him again infrequently. It became apparent that he was controlling and manipulative, for example, using his networks to support Boitumelo with food parcels. Boitumelo's emotional wellbeing continued to fluctuate. She indicated that the psychiatrist had said she should discontinue her medication for the depression and hallucinations. We facilitated discussions with her and her family regarding her illness to improve her support networks. Additionally, we worked together to enrol her into a college for the blind, where she could be accommodated whilst receiving training in computer skills and business management. After several months and various courses, she returned to Mamelodi. She did not secure employment; however, she entered a relationship with Sipho to whom she is currently engaged. She has been receiving private healthcare through his medical insurance. Her psychiatric illness has continued to fluctuate.

Below is an image of Boitumelo in her home.[22(p11)]

Figure 3-2: Boitumelo in her RDP house in Mamelodi, cooking food on the gas two-plate stove

Results and discussion

Three themes emerged: resilience; the failure of the system; and the unreliability of food insecurity assessment measures, titled 'to be food secure or not to be, is that the question?'.

Resilience

Within these two lives, the women demonstrated agency and resilience throughout, which contributed to their food security. Resilience can be described as an individual's capacity to effectively cope with and adapt to challenges, allowing them to flourish and recover from adversities or disruptive events.[23] This was shown in three ways.

First, it was shown in their functional independence despite their disability, demonstrating self-ownership and in being cautious of whom they would trust. Boitumelo[22(p8)] stated, "I'm independent in the community… I'm used to the area, and I just take my walking stick." They both were cautious regarding the funds that they had and the potential for being taken advantage of as receiving a disability grant. Dikeledi[21(p46)] stated,

> *"I'm not worried that a man might want to be in a relationship because of my disability grant. Most of them don't know that. They think I still need to register to get it. Like the previous*

boyfriend, he thought I was still in the process of registering for a grant. I did not tell him, because my heart just said I shouldn't."

Secondly, they were both incredibly resourceful. Dikeledi used social networks and strategic thinking. She had a friend who would provide her children with food if they did not have enough. She explained her needs to the community worker, who initially was part of an NGO, and arranged for food and diapers to be delivered to her. She would realise her rights if she felt she had been taken advantage of. When she moved into the RDP housing, she started a spaza shop from her house where she sold cigarettes, chips and sweets.

Thirdly, they were grounded in their spirituality. Both had wrestled with God regarding their circumstances. When Dikeledi received the house, she wrote a poem for God in gratitude for both Judith and myself for assisting her in the process:[21(p53-4)]

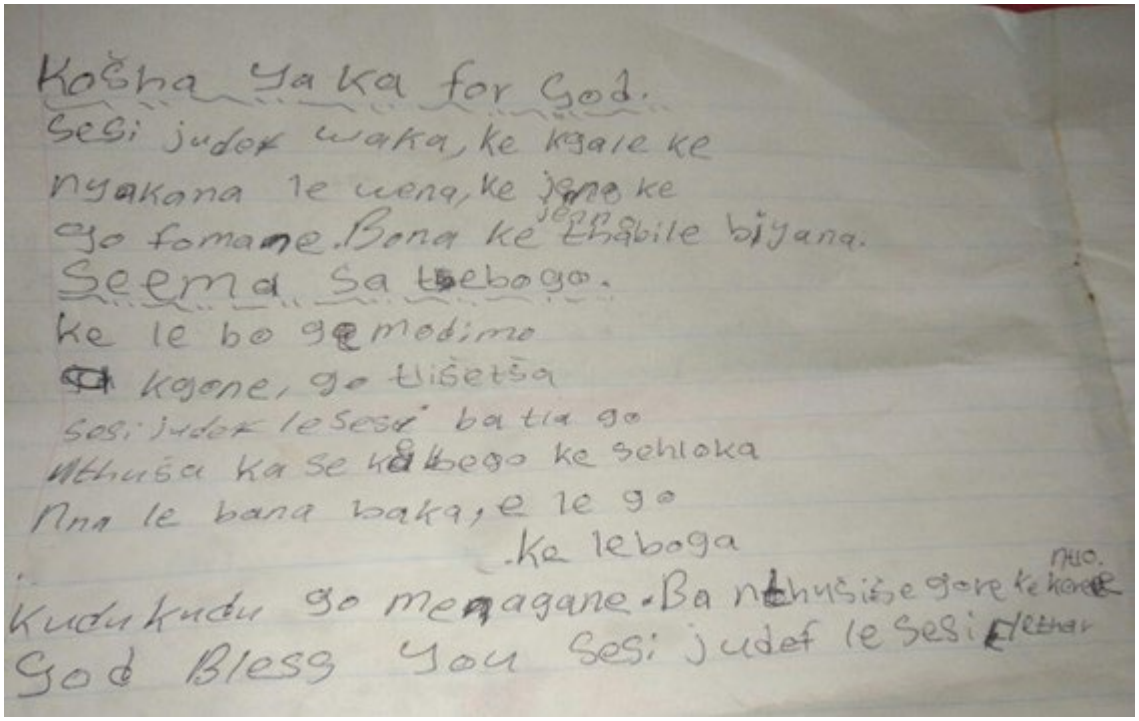

Figure 3-3: The poem of thanksgiving that Dikeledi wrote

My song for God

My sister Judif (Judith, is been long I have looking for you, today I found you. Look how happy am I today.

Song of thanks giving

I thank God who brought sister Judef (Judith) and other sister by coming to help me with what I was in need of. Me and my kids Lerato and Naledi. I so much thankful. They helped me to get a house. God bless you sister Judef (Judith) and sister Nethar (Helga)

Resilience here is explored through the lens of recent literature trends as dynamic and not a characteristic that one is born with.[24] As much as they both had numerous challenges that arose throughout their lives, limited protective factors and reduced access to proper health care, social services or positive role models, Dikeledi appeared to experience coherence through meaningfulness and Boitumelo through manageability.[24] Dikeledi wanted to work at adapting her situation for her children. Boitumelo described the access she had to resources (for example, her neighbour and friend from which she could receive food). Both viewed themselves as independent and had an attitude of "I get on with it". Although their limitations were there in light of their disability, they were aware that it was not due to their own effort or lack of adaptability. Investigating the profiles of psychological resilience in college students with disabilities, highly resilient individuals were found to, amongst others, be adaptable, to see themselves as being capable of managing difficult situations, and of exercising a degree of personal control over their environment.[25] This personal control can be seen in Dikeledi's creativity that she employed as an entrepreneur. Dikeledi and Boitumelo's agency also extended to whom they trusted. Whilst it may seem questionable that they would be in sexual relationships with those whom they could not fully trust, research has also demonstrated that women receiving a disability grant can be open to abuse of this grant by their male partners.[26] Being aware of available resources and accessing these is also a trait of resilience seen in families of children with disabilities, who are considered to be more resilient when they access resources and support in both formal use of services and informal social support.[27]. Both women had created and sustained relationships that offered resources and held a certain 'image' in the community of who they are. They also used the opportunity of the research experience and agreed to be participants, to obtain resources. Finally, faith is considered an important factor contributing to resilience, which has been demonstrated elsewhere[28], including in the context of household food insecurity.[29]

Systemic failures

The second theme demonstrates how not only can systemic failures limit food access, but the effects can also actually compound food insecurity. Although both women's disabilities allowed for them to be recipients of the disability grant, their overall ability to sustain their livelihoods was limited due to unnecessary costs that they were being exposed to (for example the ongoing cost of diapers for Dikeledi, since she had received inadequate rehabilitation) and lack of vocational pursuits (for example Boitumelo not being referred for vocational training when she became blind). We asked Dikeledi about her priorities, in terms of what she would purchase if she had money. Dikeledi[21(p2)] answered, that she would buy diapers above food, "The diapers are very expensive. I sometimes spend my money on nappies [diapers] and then there is no money to buy food."

Additionally, it can be argued that a poor holistic understanding of the functional implications of their physical and psychiatric illnesses and their context and a lack of trauma counselling and support for the abuse they experienced further impacted their food insecurity. Even when considering both of their situations from the social model of disability, their historical background is not integrated. This includes being raped as a child, being abused, or having family members abused (physically and/or sexually), to being a woman finding connection with and dependence on men – who, in various circumstances, ended up taking advantage of them. This is despite trying to prevent this from recurring.

As Boitumelo[22(p15-6)] says,

> *"The one, my boyfriend, my ex-boyfriend, I don't know what to call him, he just call[ed] me... He told me that there are food-parcel people. So, he's in this Disability Forum support group… So, he put my name there when they wanted the blind people, they want to support them with groceries, and he asked for me. He asked, "People, could you also please add Boitumelo?" And they said, "No, Boitumelo she's not in, she's not with us, she's not in our organisation, there's no way we can take Boitumelo." And he insisted. We are going to Joburg, they're organising transport, the taxi. The taxi will take us here. It's me, him, and the other blind people. At their organisation. When he calls, I feel satisfied."*

Potentially, if this support and these resources had been offered to her through the system, she would not have been drawn to him. She continued, "Another thing that made me to love him even more is that he considered me in that organisation, that thing of theirs. But it [loving him] might be for other reasons."[22(p16)]

The lack of holistic understanding may also be attributed to fragmented service provision. For example, Boitumelo receives her psychiatric medication from one clinic and her ARVs from another clinic. Additionally, her psychiatric history from the public hospital was not shared with the private hospital, limiting the service providers from understanding her entire situation.

Dikeledi, at times, also displayed the effects of depression and shared that she had suicidal thoughts. Research focusing on only one type of disability does not acknowledge the culminating effect of disabilities, illnesses and limitations, both of transient and permanent nature. In Moore et al.'s[1] scoping review of 76 studies FNS in people with disabilities, none of the articles investigated multiple disabilities in one person.

Finally, the systemic lack of support was evident when Dikeledi passed away and Lerato, having an intellectual disability, lived in the house on her own. Since she had difficulties processing her mother's death, she left the school. The school did not follow up on her and did not attempt to assist her in receiving support and return. Even though the CHWs happened to be present when Lerato had to tell Naledi their mother had died (they were conducting home visits in the area), they did not continue

following up with Lerato, nor did they refer her to a social worker for intervention (for example food support, or to facilitate her needs concerning that of the family in the rural homestead). This requires improved care-coordination with the interprofessional team, the family as well as the extended family. Care-coordination has been shown to be a valuable approach to ensure that patients identified as being stuck in the system are connected to their families and the necessary resources (services and professionals) within their communities. As such, it thus extends from the hospital and specialist service back to the community.[30] Lerato's story has demonstrated the importance of adopting a similar approach for situations when someone dies in the hospital – that the organisations in the community support the family members affected by the death, and there is follow-through on what the effects of the death may mean for the household. This is especially important in single-parent households, where the children depend on their mother or father. Lerato continues to have difficulties processing these life events, impacting her in her functioning.

To be food secure or not to be, is that the question?

The third theme considers the unreliability of food insecurity assessment measures. This is expressed in the tensions we experienced to establish to what extent Boitumelo and Dikeledi experienced food insecurity. They can be resolved through Nichols's insights on navigating the messiness of narrative data[17] and binding together perceived contradictions in truth and fact. These seeming conflicts can instead call for deeper discernment.

One of the lessons that I (HEL) have learnt in conducting research with people about food security is that it is challenging to seek participants with specific inclusion criteria without there being an expectation of the provision of food through the study's resources. I remember battling with the questions I had planned to determine my study's inclusion criteria. The food security questions from the General Household Survey at the time as used.[31] Questions included, for example, if participants had run out of food more than five times in the last month or not, thereby determining the severity of food insecurity.

Boitumelo was very quick in answering the food security questionnaire. She indicated with each question, "yes", which classified her as severely food insecure on the scale. She also stated that Kelebogile, who had referred her to us as a potential research participant, said we would be able to provide her with food. We realised six months into the study that Boitumelo still hoped we would provide her with food. Her responses were also incongruent with the food we observed her having available in her house.

Dikeledi, on the other hand, in response to these and other questions, had much difficulty articulating transient food insecurity without appearing to lose her credibility as a mother and provider. This was evident considering the authority with which she thought we came and the vulnerability this would leave her if she was required to defend herself. Her daughters gave her life meaning, and she

resolutely tried to provide for them. Some of the different avenues she used to access food included the schools' feeding schemes, asking a friendly neighbour, and through one of her boyfriends (even though he was later abusive). This research did not include nutritional intake, which should have been noted. Both Dikeledi's children were actively growing and at risk for malnutrition and Dikeledi had various nutritional requirements that needed to be met whilst taking ARVs and maintaining healthy bladder and bowel management. We observed her children eating rice and tomato sauce during the flooding in the shack. Therefore, even though (according to the questionnaire) she may have answered that she had not gone hungry in the last month (due to having a staple of maize), it was inadequate in terms of variety.

Dikeledi[21(p2)] says,

> *"It happens often, that I would like to eat something different or a variety of foods but circumstances do not allow me to afford them or access them. For example, pap[5], meat and vegetables, but because of financial constraints, I can't afford them."*

Beyond this, even when variety was present (through food that Dikeledi received from the home-based care workers), it was expired (although it may have still been adequate nutritionally).

Also demonstrating the difficulty of food security measurement scales are the various community resources that became available during shocks. These may be either positive or potentially negative. For Dikeledi, when she had to escape the abusive relationship, she received food from a friend. Her daughter, similarly, also received food from a neighbour after her mother died. Lerato was eventually food and nutrition secure when she went to live in Maganeng. Boitumelo, rather, who returned to the man who was engaged to another woman because of his perceived kindness and being able to offer food for her, may be seen as receiving dependent support. Regardless, it is the connections and networks that enable access to food.

Another consideration in this theme are cultural factors and their impact on access to food and the type of solutions that are an option for someone who is food insecure or has perceived food insecurity.

Boitumelo[22(p19)] stated,

> *"I cannot start a vegetable garden; I don't have the rich soil. I think that at my back, there is something – cement thing, concrete. I'm afraid to plant my vegetables here in front. It won't look nice. I'm thinking to do them there at my back. But there is a dog there. That dog there, they don't watch it."*

A programme offering the facilitation of developing your own vegetable garden to offer more nutritious food may not be a sustainable solution for someone like Boitumelo. Where the culture and

[5] A South African dish of white maize meal

tradition of a community dictate the environmental aspects of the community, this transcends the need for food. Du Toit et al.[32] have recently investigated why urban gardens fail to enhance food security and observed an increase in European colonial gardens (including ornamental plants) over food and medicinal plants. In 2014, this trend amongst peri-urban spaces had already been noted by Mosina.[33] However, this study adds to the body of literature in that someone who is blind would prefer to have an ornamental garden than the option of a garden to provide for dietary diversity.

The factors in this theme highlight the complex nature of food insecurity for women with disabilities and the difficulty with which their situation is measured. This could contribute to difficulty in planning an intervention with them.

Conclusion

This article has raised questions about the measures that are considered when people do not have adequate access to food; and looks at the various dimensions of food security. While food security measurements are important to ensure policy response, we need to critically evaluate how we interpret statistical data regarding food security questionnaires and measures.

Additionally, it is essential to understand the household participants' complex lived and ever-changing realities for the long-term sustainability of any kind of intervention. If systemic challenges are addressed early in the illness, the rehabilitation of persons with disabilities can contribute to greater food security. This will mitigate the impact that shocks have on them and lessen the burden and resource requirements on the health and social services sector. Also, there must be ongoing care-coordination after the death of someone in a vulnerable household to ensure that the remaining household members are cared for.

This article has also highlighted that one cannot overlook the personal factors which demonstrate significant resilience in situations of adversity. When these are pursued beyond the immediate limitations (in Dikeledi's case, her motivation to care for her daughters), they provide creative solutions for the individual and the household to demonstrate agency. This includes, amongst others, the resourcefulness of the community. Whilst Hart[34] has highlighted this within rural homesteads, as far as the authors are aware, this study is the first to highlight the extended resourcefulness amongst women with disabilities in a peri-urban setting.

These stories have foregrounded the complexity of multiple disabilities, household experiences, varying experiences of food (in)security, and a changing narrative through the research experience. We hope that through these examples, food security will continuously be explored as a complex issue, requiring multiple levels of understanding and intervention responses. Solutions should be sought with the women themselves since they demonstrate remarkable resilience, helping them to overcome. Additionally, the fundamental systemic governance failures should be recognized and addressed, to ensure that the country's most vulnerable citizens are protected.

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Author biographies

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Judith Mahlangu has been a community development practitioner since early 2000s, doing community development, stakeholder engagement, and research. She worked as student supervisor for occupational therapy undergraduate students, University of Pretoria. She contributes to interprofessional education and collaborative practice for Community Based Inclusive Development, (Department of Health and Rehabilitation Sciences), University of Cape Town. Judith contributed to academic research by being a fieldworker, research assistant, and author of academic work (including autoethnographic publication in the South African Health Review). She holds Bachelor of Social Science with Development Studies. She's currently studying postgraduate Diploma in Disability Studies at University of Cape Town.

Mershen Pillay, professor, is the Programme Coordinator at Massey University, New Zealand. He is an audiologist and Speech Therapist. He has held numerous academic positions, including at Stellenbosch University, University of KwaZulu-Natal and honorary positions at the University of Cape Town and at Manchester Metropolitan University (England). Mershen has, in three decades, worked mostly as a clinical practitioner in England, the United Arab Emirates and South Africa. He is passionate about theoretically and practically repositioning the way in which health care professionals work with people who have disabilities.

3.6. Epilogue

The second research objective of the PhD study has demonstrated that food security is a complex issue. It is, therefore, not going to be addressed adequately for persons with disabilities by only providing food parcels. As can be seen, through the sharing of the life histories of the two women, an awareness is required of the interplay between the various factors on many levels and how these factors are interacting with each other. Firstly, the systemic failures that exist reduce the functioning of the women. This was seen in the various examples used, for example, Dikeledi's inadequate rehabilitation.

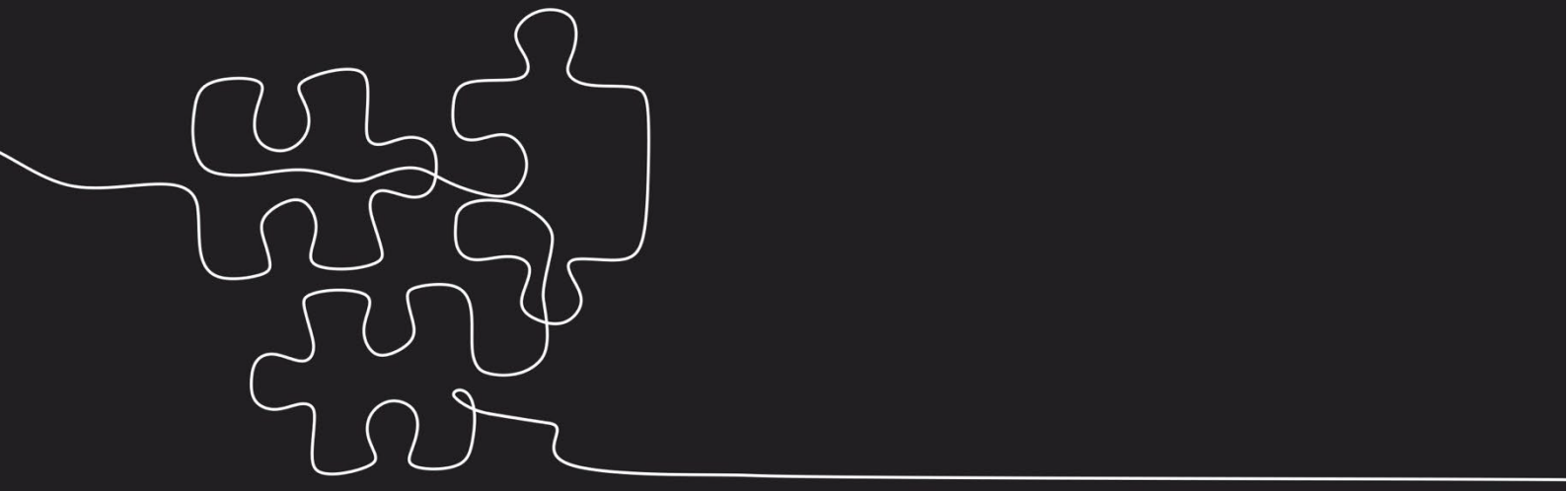
Secondly, interpersonal factors can either be a facilitator or a barrier to functioning. The dependence on men and the potential toxic relationships became barriers to functioning. On the other hand, the friendships that existed, as well as access to various NGOs, were facilitators in their functioning. Thirdly, the women displayed resilience. This was an enabler in the face of adversity. What has also been clearly demonstrated through Dikeledi's story is that food security is a household issue. Therefore, even for persons with disabilities, it cannot be analysed and addressed in isolation.

However, the question raised now is, how do we better understand the household? How does this information translate into public health, and how should we address systemic barriers which limit the household's functioning? How do we enable facilitators to, among others, facilitate connections and resilience?

Chapter 4: The Mkhize household complexities – considerations for community oriented primary care (COPC) in the City of Tshwane

Abandon the urge to simplify everything, to look for formulas and easy answers, and to begin to think multidimensionally, to glory in the mystery and paradoxes of life, not to be dismayed by the multitude of causes and consequences that are inherent in each experience -- to appreciate the fact that life is complex.

M. Scott Peck



4.1. Prologue

The previous chapter asked some important questions that arose from the research study. As was described in the introduction, qualitative research allows for this interrogation, to bring forth additional research questions. Thus, in summary, the PhD culminated in this third research question: "What lessons can be learnt from exploring the complexities evident in a household, as well as engagement with the household, related to community oriented primary care (COPC) implementation?"

This question is relevant; since it has been forefronted that food security is complex. Additionally, it may be that food security cannot be addressed directly; and may not even be the overriding burden in the household. Therefore, one should not focus only on one aspect, be it food security, disability, HIV or the vulnerability arising from being a women, or even the multiple disadvantage from these various intersections. Instead, we need to find a way to see the various and multi-faceted challenges, whichever they may be, to work together with the household and enable improved functioning and overall wellbeing.

Therefore, this third research question is situated within the approach that the city of Tshwane forefronts for delivering household services, namely COPC. The community health workers (CHWs) are at the frontline of the response team at the household level. Since Judith and I had started responding to the needs of the participants as voluntary community workers, which is similar to the function the CHWs serve, it is appropriate that the lessons we learnt whilst engaging with the household should be aimed at the service delivery offered by CHWs.

This was the point at which the PhD shifted its focus on food security to the overall care provided through the COPC approach in the household.

4.2. Details of manuscript intention to submit

Table 4-1: Manuscript two intention to submit details

Title	The Mkhize household complexities – considerations for community oriented primary care (COPC) in the City of Tshwane.
Authors	Lister, HE, Janse van Rensburg, MNS, Pillay, M
Journal	Qualitative Health Research
Year	Intention to submit following feedback on my thesis from the examiners.
Volume	
Pages	
DOI number	

4.3. Journal Details

Qualitative Health Research is a peer-reviewed Department of Higher Education and Training (DHET) approved, open-access journal. It provides an international and interdisciplinary forum through sharing qualitative research enhancing health care understanding. It is aimed at an audience of not just researchers or individuals in health but also administrators and others in social service professions. As such, it is the ideal platform to describe how, through a qualitative study, I have designed a model to use within COPC called the Household Complexity Model (HHCM). I hope that this will influence health care policy, the experience of CHWs and the sociocultural organisation of health care.

4.4. Contribution Details

HEL conceptualised the study. HEL completed the data collection, analysed the data and conteptualised the adaptations on the HHCM. MNSJvR participated in the model refinement. HEL wrote the first draft of the manuscript. MNSJvR participated in refining the manuscript. MP reviewed the manuscript.

4.5. Manuscript two

The Mkhize household complexities – Considerations for community oriented primary care in Tshwane, South Africa

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Abstract

The Community Oriented Primary Care (COPC) approach has guided the implementation of primary health care re-engineering in the city of Tshwane, South Africa, since 2011. It focuses on delivering household (HH) health promotion services by community health workers. Despite primary health care (PHC) improving population health outcomes, overwhelming challenges are evident in HHs of the city.

Additionally, there is a dearth of literature on understanding HH complexities, how HH members influence each other's wellbeing and how this contributes to overall functioning. This article explores engagement with a HH and the complexities evident in the HH through complex adaptive systems (CAS) theory to describe four relevant factors related to COPC: the value of the life history interview method for CHWs; improved training in mental health for CHWs; improved care coordination between services; and improved understanding of interrelated HH complexity. This would facilitate improved overall HH functioning. As health care systems are being redesigned to move towards Universal Health Coverage (UHC), a strategic priority of the World Health Organisation (WHO), this provides a unique opportunity to reimagine an improved understanding of the HH narrative, which should facilitate greater wellbeing in communities.

Keywords

Household wellbeing; community oriented primary care; qualitative research; life history research; complexity; South Africa; City of Tshwane; community health workers

Introduction

Primary health care re-engineering (rPHC) has been prioritised in South Africa since 2011.[1] While strides were made since the establishment of democracy in 1994 in refocussing the health system towards primary health care (PHC), there has been a need to improve health and wellbeing, particularly in households (HHs) facing socio-economic challenges.

The Community Oriented Primary Care (COPC) approach has informed the implementation of rPHC in South Africa.[2] As defined by Abramson[3], it is "a continuous process by which primary health care is provided to a defined community based on its assessed health needs, by the planned integration of primary care practice and public health". The principles of COPC are 1) local health and institutional analysis, 2) comprehensive care, 3) equity, 4) practice with science, and 5) service integration around users.[4-5] The application of these principles guides community-oriented PHC to be contextual, comprehensive, integrated, continuous, person-centred, based on human rights, evidence-based and sustainable.[6] Fundamental to COPC is that the social environment determines people's health, and it focuses on the importance of the HH and the community in addressing the health needs of individuals.

In South Africa, rPHC focused on establishing ward-based primary health care outreach teams (WBPHCOTs), consisting of around 10 community health workers (CHWs) who are each allocated 250-300 HHs in a particular municipal ward.[7] WBPHCOTs are led by nurse practitioners (professional- or enrolled nurse), who report to sub-district coordinators within each district in a province.

The World Health Organisation (WHO) has provided a universal language in health care through the International Classification of Functioning, Disability and Health (ICF)[8]. It provides a known lens through which person-centred health care can be understood. The ICF highlights that the person

(personal factors and any impairments in body functions and body structures), their activities (or limitations thereof) and participation in life (or restrictions to participation), and the facilitators and barriers in their environment (both physical and social) all influence function.[9]

Other health care models have also been useful in advocating and describing person-centred care. The Meikirch Model was developed to ensure an all-encompassing approach that provides an improvement in healthcare delivery.[10] In the Meikirch model, the social- and environmental determinants of health have been distinguished, along with the individual determinants (biologically given- and personally acquired potential) and the demands of life. Between them are complex interactions.[10] The model has been applied within PHC and offers contributions in alignment with existing COPC literature.

However, applying these models does not necessarily forefront the HH, and there may be a limited emphasis on interactions within the HH. Within COPC, the unit of analysis starts at the HH to provide practical intervention. Note: it is not the family since family members can live in various HHs (sometimes across provinces) to accommodate vocational and educational needs. A HH-approach is required to provide services through the CHWs in a defined area.

Internationally, various authors have recognised that PHC necessitates a complex adaptive systems (CAS) approach.[11-14] Complexity science contrasts the traditional narrative of linearity and instead proposes that the complex system is unpredictable and non-linear. Some important features include that the system has history and memory; there are numerous interactions between the various components of the system, and from these, behaviours and roles emerge; these interactions are dynamic and often cannot be anticipated or predicted; and perturbations are brought upon by internal and external events.[13] Although these disturbances can be messy and haphazard, patterns develop, leading to a form of equilibrium.[13] It has been recommended to study a complex system by examining its properties and characteristics, instead of taking the system apart.

Recently, CAS thinking has been applied to PHC in Africa to achieve universal health coverage (UHC).[15] Moosa[15] describes the concept of complexity as a way of thinking about how system structures within the CAS are interconnected. There are non-linear, multi-directional interactions that occur as the system evolves. Well-functioning CAS have a clear purpose, values and principles, for example if person-centeredness is a core value of PHC, then quality interaction between the healthcare provider and the person is the purpose.[15] The interaction between the health system and the HH, and the HH as a CAS, require exploration and analysis. Thus far, we are unaware of this being done.

Aim

The aim of this article is to explore engagement with a peri-urban HH and the complexities evident in that HH as considerations for COPC.

Method

The lessons compiled are taken from a larger narrative study investigating the lives of women living with human immunodeficiency virus (HIV) and disability in vulnerable contexts regarding their food security. Hence, various examples used, forefront the dynamics of food insecurity.

Life history narratives have been shown to provide a detailed perspective on a small group (in this case, a HH) that is more holistic than what can be achieved by using quantitative methods such as surveys or through observation.[16] The life history approach has numerous benefits, such as linking micro- and macro processes, capturing change, and understanding relationships.[16] Being narrative in nature, it is linked to oral histories and storytelling, which are important and powerful cultural components of many African traditions.[17]

Life history methodology[18] was used to obtain a rich co-constructed narrative of a HH over time through the lens of the primary informant (Anna)[6], myself (Helga) as a researcher, and my research assistant (Judith), who became a co-researcher in the process. A CHW in Mamelodi introduced us to Anna Mkhize. Anna has HIV and a disability. She had been injured in a hit-and-run accident, and her leg had been affected. Due to hospitalisation after the accident, she could not maintain her employment, and finding other employment was difficult due to the resulting disability. The loss of income led to her living off a childcare grant for which she was eligible for as a result of her school-going daughter.

Very soon into the first interview, I realised that I would have to use my knowledge as an occupational therapist to provide intervention. Judith and I became voluntary community workers, navigating the system as we understood it, but not having worked professionally in that community before. Judith also moved to Mamelodi and became a community member, thus able to provide a contextual experience.

I conducted interviews over four years and reflected upon my engagements throughout. Multiple sources have been used to augment Anna's story, including research reflections, participant observations, and photographs. Numerous questions arose regarding COPC, and the emergence of the HH as a CAS was organically derived.

Although narrative research traditionally represents the story from the storyteller's perspective, our research experience was unique in that both Judith and I were actively present in the participants' lives whilst they were living them. Polkinghorne[19] refers to data constructions completed in this way as narrative configuration. A deductive paradigmatic narrative mode of analysis, also referred to analysis of narratives, was conducted of the co-constructed narrative, the documented reflections, as well as the research process.[19] Anna's whole narrative is available for reading in the (COPC online

[6] All participant names have been changed to pseudonyms

storytelling library) titled Anna's story: https://www.up.ac.za/media/shared/772/COPC/Storytelling/anna-story-web.zp227429.pdf

Lincoln and Guba's[20] criteria of trustworthiness (credibility, transferability, dependability and confirmability) were adhered to through prolonged engagement in the setting, sustained engagement, and reflective processes. Ethical approval for the research study was obtained through the University of Kwa-Zulu Natal's (UKZN) Research Ethics Committee (HSS/1064/106D) and from the City of Tshwane's Research Ethics Board (GB_201708_007). The summarised narrative, shared in this article, has been read through with Anna and her daughter, and their permission was received to share it in this final form. They both selected their pseudonyms and those of the other HH members.

The Mkhize HH – key moments in its life

When I was first introduced to the Mkhize HH in 2018, it consisted of five members, namely Anna (the HH head), her three sons (David, Andries, and Bule) and her daughter, Precious. The CHWs told me Anna was always crying, which I observed on the first visit. As a result, we administered the Depression and Anxiety Scale[21], in which she scored 12/15, and I arranged for an urgent intervention with the psychiatrist at the local CHC.

Anna was never married; her three boys had the same father, while her daughter had another father. The oldest son, David, had been living on a rubbish dump for three years, trying to source food items. Andries, Bule and Precious were living in the house. When I met Anna, Precious was still in school, but her three sons had all dropped out of school as they were all using illicit substances (nyaope[7]).

Some years prior, David and a group of boys from the area were given a 'piece' job[8] by one of the community leaders to remove all the illegal electricity connections in the nearby informal settlement. The mothers in the area had complained to the community leader (a wealthy tavern owner) that they did not have sustained electricity due to the high load on the system. Even though their connections were also illegal, the community leader arranged for dismantling the electricity connections in the informal settlement, amounting to five vans full of copper wires. The boys (all in secondary school at that time) were paid ZAR500[9] each for their work. Not knowing what to do with the money, they went to the local tavern and after experimenting with alcohol, some started experimenting with smoking nyaope. Andries observed that when David smoked, he was not hungry but rather slept, so he decided to try it too. One by one, the boys dropped out of high school. According to Andries, many of the boys who originally removed the illegal electricity connections are dead – killed by community mob justice[10]

[7] A street drug concoction containing heroin

[8] Piece jobs, as they are commonly referred to in the community of Mamelodi, is a specific unit or action of work that is paid for and agreed on prior to commencing the unit (for example cleaning the yard or washing a car)

[9] This is the equivalent of approximately ZAR1500 in current monetary value

[10] A form of community assault where a person who is suspected of criminal activity is beaten up (and often killed) by a group of people from the same community.

(after they started stealing to sustain their substance use). Precious also eventually left school halfway through her grade 11 year because the childcare grant (her mother's only sustained income) had come to an end when she turned 18. She thought it better to leave schooling to find work, which she, unfortunately, was unable to do.

On one of my visits, when I arrived at the HH, Andries was not well. He had been admitted to the nearby regional hospital the previous week but left because of the withdrawals he was experiencing. He had returned home but was not well. He had acute pain in his stomach and heart, shortness of breath, and an increased heart rate. Seeing that he was in a bad condition, I took him to the emergency unit of a tertiary academic hospital. Here, he received three units of blood, it was determined that he had stomach ulcers and the distress to his heart was caused by vomiting a lot of blood (following his visit to a traditional healer). A few months later, David went to the outside toilet, and when he did not return, his mother went to look for him. She found him dead, the cause of which is still unknown.

Anna had been obtaining infrequent payment in different forms (for example looking after someone's young child) and had converted her outside rooms into rental rooms, which two people from Mozambique occupied. To obtain greater financial security, Anna entered an agreement with the local recycling bosses to establish a recycling point in her yard for extra income. Having the recycling point in her yard caused significant challenges with safety, because many of the persons accessing the property would come to drop off recycling and purchase drugs from nearby drug dealers.

At a point, Anna started using alcohol and would drink continuously throughout the day. She said this was to numb herself, so she was never fully sober. Her daughter, deterred by the situation in the yard, would sometimes not come home. Many of the HHs in the street put up fences for safety because of the increased crime that had come to this area. Anna would not leave the HH because she had been in another hit-and-run accident and had high levels of pain and could not get to the clinic. Furthermore, she was afraid that if she left the house, her sons would steal the remainder of what was in her home to purchase substances. She had lapsed on her appointments with the physiotherapist, further investigations at the hospital and stopped taking all her medication.

When Judith and I saw her dire situation, we spent a long time sitting with her on her outside stoep[11] (she did not want us to enter the house since, as according to her, it was too dirty). We discussed how she could take small steps to make changes. These included washing herself, ensuring she went to get her medication and sweeping the inside of her house. When we visited her three months later, Anna had significantly changed her life. She had insisted that the persons renting, as well as the recycling point, leave the yard. She had returned to the clinic and was taking her medication again. Her daughter had come home, and Anna had stopped drinking alcohol. When we asked her what happened, she

[11] Side steps outside the house, where people can sit

said,[22(p37)] "That day you came, you told me, if I don't take my medication, I am going to die. So, I decided to change. I did not want to die."

Findings and discussion

Through analysing Anna's narrative and the researcher's reflections, four pertinent factors emerged relevant to COPC engagement in HHs. These are the value of the life history interview method for CHWs, improved training in mental health for CHWs and community-based health practitioners, improved care coordination between services, and improved understanding of interrelated HH complexity.

Value of the life history interview method for CHWs

Even though this engagement initially commenced as a research study, it became clear that the life history interview method allowed for an improved overall understanding of the HH, and key moments that had impacted them. The intervention required could be more clearly articulated, having understood the multiple factors impacting each area of concern, for example Anna's depression and anxiety due to the impact of her sons' substance use.

Life histories try to determine an individual's life story.[23] The life history interview method has been identified as relevant for physicians in cancer intervention[24]. Related to this is the concept of narrative medicine. In Brazil, narrative medicine was tested in CHW prevention- and care services.[25] In various studies, narrative medicine has value in discovering the meaning of the character of illness[26]. However, narrative medicine would be considered too narrow in its implementation for COPC, as it does not include life history beyond the illness. A life history beyond illness, moving to overall HH wellbeing is more aligned with health promotion, disease prevention, and optimal functioning and flourishing.

Narrative medicine provides guidelines that will enable engagement (including compassion, humility, and the building of trust).[27] Trust can further be developed through the CHW sharing personal narratives, too, thereby developing connection and even friendship. As trust continues to build, the narrative changes, elucidating a deeper level of understanding not otherwise possible.

COPC forefronts an understanding of the HH to provide HH intervention. CHWs are trained to consider individuals within the HH, and interviews with the various HH members are done to complete a HH registration form. Amongst others, questions are asked about socio-economic factors (including food insecurity). Although the analysis may provide details regarding these various factors (abuse, death, etc.), it does not describe *how* these factors have occurred and their interrelatedness. If CHWs can form a HH narrative from the information, and if the assessment could include factors of HH interrelatedness, this could facilitate problem-solving with the HH to address their needs.

The combined HH narratives can lead CHWs to understand the community narrative and how the various dynamics within the community have influenced its overall functioning. For example, how

adolescent boys within a defined community all started using substances at a similar time. Similarly, the change in the Mkhize HH to becoming a recycling point changed the narrative of the street, in that everyone put up fences because of increased crime in this street.

Whilst this will initially require an investment of time, within an already high workload, this approach will allow more effective understanding and investment of all persons, and therefore hopefully reduce the time spent on healthcare overall. These benefits will only be seen through longitudinal studies.

Increased training of CHWs in mental health

Although mental health training has been increasingly offered to CHWs, the Mkhize HH demonstrates the lack of knowledge some CHWs have regarding mental health conditions (in this case, depression and substance use disorder), as well as the referral process for further intervention. This is evident in both Anna's lack of referral for psychiatric and psychosocial intervention, as well as the lack of referral of her sons to COSUP (Community Oriented Substance Use Programme) – a community-based harm reduction programme in Tshwane.

When I met Anna for the first time, her continuous crying, suicidal thoughts and lack of motivation were significant concerns. Unfortunately, the CHWs only commented that Anna cries whenever they are there. Their intervention had been to listen to her, and although this had immense value, it had not led to her accessing professional intervention.

I learnt about the COSUP program through the CHWs, but they had not referred the three brothers to COSUP. The CHWs were, at that time, unable to advocate for the harm reduction approach (likely due to misunderstanding it). Although, more recently, additional support has been offered through COSUP to the community's HH members (especially support groups for parents), at the start of the research study, this was not yet visible. HH members who are unable to attend support programs would benefit from CHWs explaining harm reduction to them. When I explained in detail to Anna the ongoing provision of clean needles and Judith provided suggestions on how she and her daughter could support the brothers to engage in self-care, they both demonstrated that they had not understood this before.

I also experienced some social workers indicating that unless the person using substances wants to change, they cannot do anything about it. However, considering that Anna would drink alcohol continuously during the day and the effects of her depression and anxiety on her motivation, it would be very difficult for Anna to commence self-motivated change. Unfortunately, the perspective that accessing health services requires the person to decide to take ownership of their health care minimises the complexity of why people may not choose to or be able to do so.

Improved care coordination

It is evident from the Mkhize HH narrative that there is fragmented service delivery and a lack of care coordination. This includes communication from the HH to the facility and from the facility back to the

HH, which remains disjunct at best and fatal at worst. Examples include when Andries was admitted into the local regional hospital, the hospital staff were not informed by himself, the HH, or the CHWs that he had a substance use disorder. Further, when he discharged himself due to unbearable withdrawals, there was no follow through to the CHWs to determine how he was doing or a referral to COSUP.

When I took Andries to the tertiary academic hospital a week later, I actively informed the emergency staff that he had a known substance use disorder and required withdrawal management. But, when I arrived the following day to check on him, this information had not been noted on his file, nor had he received any medication. It was only through my insistence to the specialist doctor, together with my personal connections to the local COSUP social worker, that the referral letter to COSUP was written when Andries was discharged. Had the social worker not taken personal responsibility for follow-up, the brothers may never have commenced the harm reduction program.

Another example is when Anna did not return for her follow up treatments after relapsing on her psychiatric medication. There was no indication that CHWs were requested to follow-up on why she was not returning. Similarly, with the death of David, there was no follow-up to the HH to see why he had died nor how the HH was coping with the loss.

A care pathway is defined as a "complex care strategy for decision-making and the organisation of processes" to provide care for complex health needs of individuals, thus avoiding the fragmentation of care.[28(p1)] Care pathways have been examined through care coordination of patients in public health facilities in Tshwane and were shown to reduce healthcare costs and improve patient outcomes.[29] How much more can care pathways be facilitated if the HH wellbeing could be determined and if the various pathways between services were established and regularly oiled?

Improved understanding of interrelated HH complexity

In addition to establishing and maintaining care pathways, it is important to understand the reasons for the lack of follow-through of the HH members to certain required medical interventions. For example, the reasons Anna was no longer attending the clinic to receive her medication could be as a result of her not wanting to leave the HH, considering the sons may steal from her while she is gone; or as a result of her having been in an accident and no longer able to walk to the clinic because of pain; or continuously drinking alcohol to be able to cope with the death of her son and the other stressors she was facing. As was the complexity in Anna's life, it was likely a combination of all of these.

Several significant and interrelated factors affected the Mkhize HH's wellbeing. These include illicit substance use, food insecurity, HIV, stigma, lack of safety, family breakdowns, illiteracy and incomplete schooling, unemployment, and death. Although the HH approach is highlighted within COPC, often, health-focused services do not engage with the complexity of how the factors of the HH influence each other. For example, identifying that Anna is food insecure, and sourcing a food security programme

that would provide her with a monthly basket of food may not be a sustainable solution if her sons sell the food to purchase substances.

Proposing the Household Complexity Model (HHCM)

Literature recognises the healthcare system as a CAS, but up until now the HH interactions have mostly been considered under the individual's social determinants of health. Whilst this remains true, it limits awareness of the complexity evident in the HH. Understanding the HH as a CAS requires an awareness that there are "multiple levels, multiple stakeholders, and usually encompasses simple, complicated, complex, and even chaotic behaviour".[30(p1)] What follows is a proposal that describes the HH as a CAS within the functioning of the community as a CAS. Integrated into this model are both the Meikirch model and the ICF.

The White Paper on Analysing Complexity with its associated characteristics, and being applied to health care, has formed the basis of describing the Household Complexity Model (HHCM).[13] Additionally, CAS – as the name suggests – forefronts its adaptiveness. Here, we draw insights from the Theory of Occupational Adaptation, an intervention framework that focuses on improving adaptiveness.[31] Although the theory describes the person, we draw inferences from it to describe a function-dysfunction continuum that is applied to the HH. We postulate that the adaptive response of the HH indicates its internal response to demands and disruptions.[32] Dysfunction can occur when the HH is unable to generate an appropriate adaptive response from either personal or environmental factors. Dysfunction can occur when the demands and disruptions exceed the capacity of the HH to adapt. The more adaptive the HH, the more functional the HH will be.[31] This capacity is, in addition to internal processes, also influenced by the community and governance processes[33] through for example policy and procedures. In health[34], these governance processes have also been described as a CAS.

Within the HHCM, the HH is demonstrated as a sphere consisting of different interlinking circular bands representing the HH members. The visual model of a sphere, best observed as a video (please see: https://www.youtube.com/watch?v=VXlyT9Quapc), will be explained below. Note: even though the Mkhize HH consisted of five members, only three bands are presented, as five bands were too difficult to incorporate graphically. Ideally, all five bands should be represented. As much as we have attempted to describe the HHCM in different steps, please do not mistake this for simplicity. As this is the first description of the HHCM, we welcome further input, critique, and development.

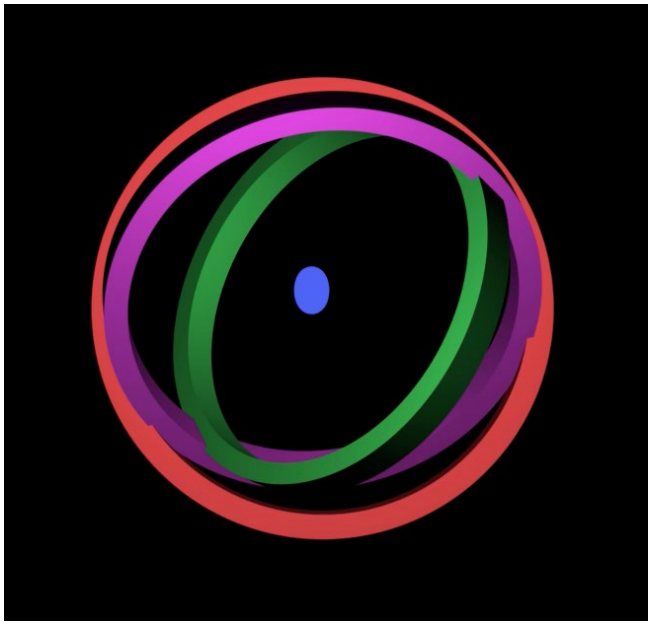

Figure 4-1: A diagrammatic representation of the HH

Each band is made up of unique properties. Each HH member potentially processes information/inputs or situations/disruptions differently, with various responses. The Meikirch model would refer to this as biologically given- and personally acquired potential. The ICF considers this to be body functions and structures, and personal factors. The fact that these bands are complex and unpredictable means that their responses to demands, sourced both internally and externally, will be unique[13] and significantly impact overall health, wellbeing and functioning.

Each of the HH members' bands varies in thickness, demonstrating the hierarchical nature of HH members, which may arise from age, gender or disability. These hierarchies may be traditional, for example in many African cultures, the father is seen as the head of the HH. The mother will be the HH head where there is no father. The thickness of these bands can change. As Anna ages, her role in the HH changes as other members of the HH take up various responsibilities. If Anna can no longer exert the same influence she previously had, her band diminishes; this occurs at the same time her daughter grows older, and her band increases in thickness. See figures 4-2 and 4-3.

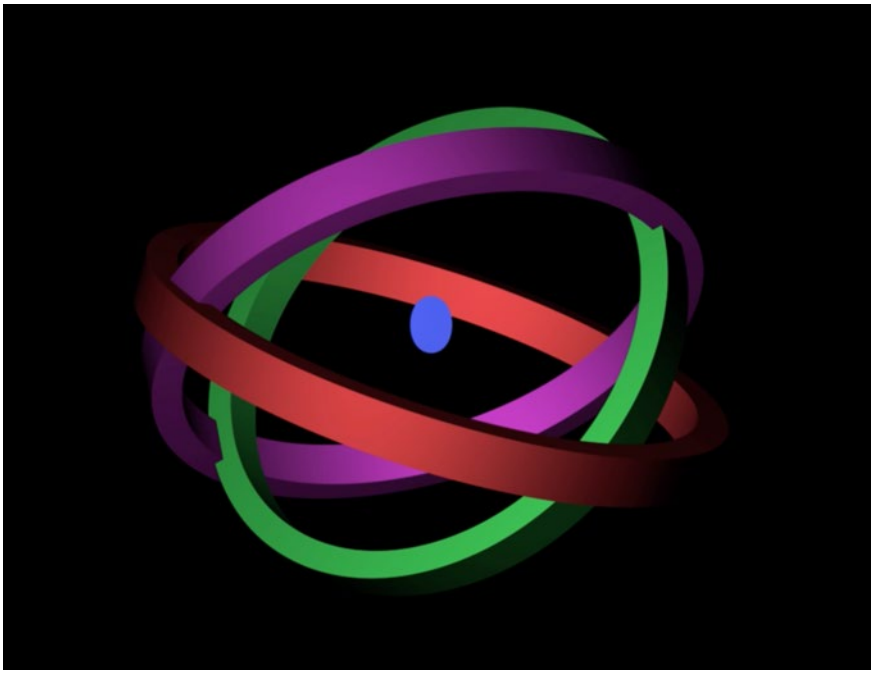

Figure 4-2: The red band refers to Anna's role in the HH (which is the thickest)

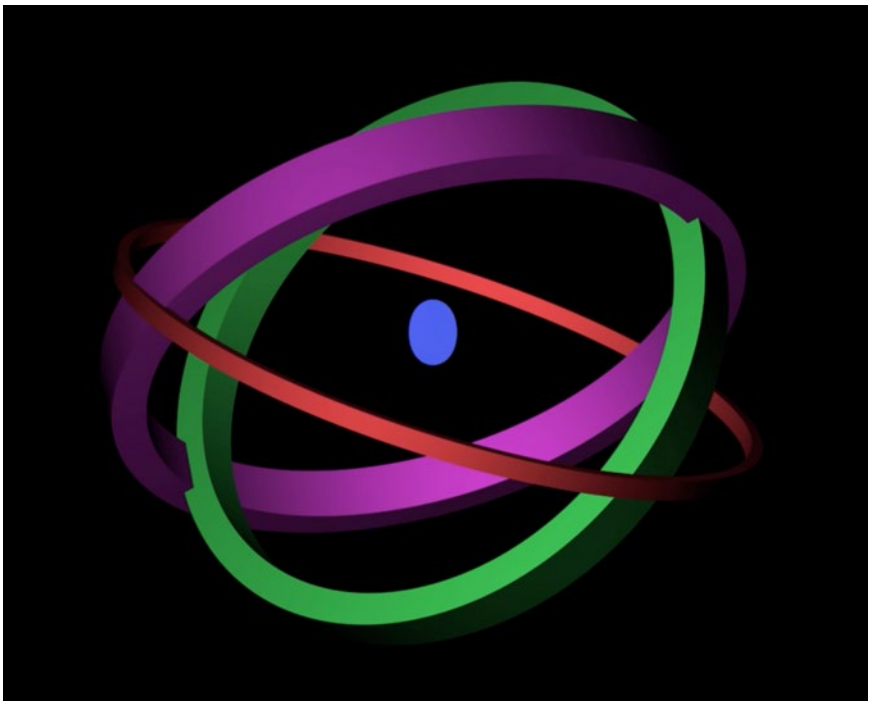

Figure 4-3: The red band decreases in thickness, demonstrating her decreased hierarchical influence

Those HH members who relate to each other in a levelled way (for example siblings) are represented with the same thickness bands. Again, this may not be that simple, considering a person with a disability may exert significant influence in the HH.

Demands and disruptions in the HH may arise internally or externally, initially influence an individual from where the other HH members are influenced, or may influence the entire HH simultaneously. The adaptive response may occur in a variety of ways. As the bands absorb demands and disruptions, their properties change (observed through a change in shape, colour or both). For example, the disruption Anna being injured in an accident caused body structures and functions to change (the pain in her leg). As an adaptive response, the band may need to stretch, or it may bend (into for example a star or an oval). These responses affect how the individual and the HH engage in activities and participate in life. For example, Anna had to find new ways of doing HH chores to compensate for her pain. See figures 4-4 and 4-5.

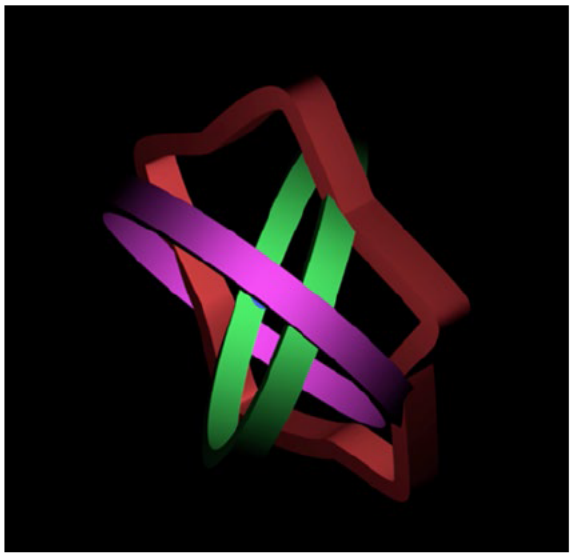

Figure 4-4: As the shock occurs to the red band (Anna), it starts changing shape

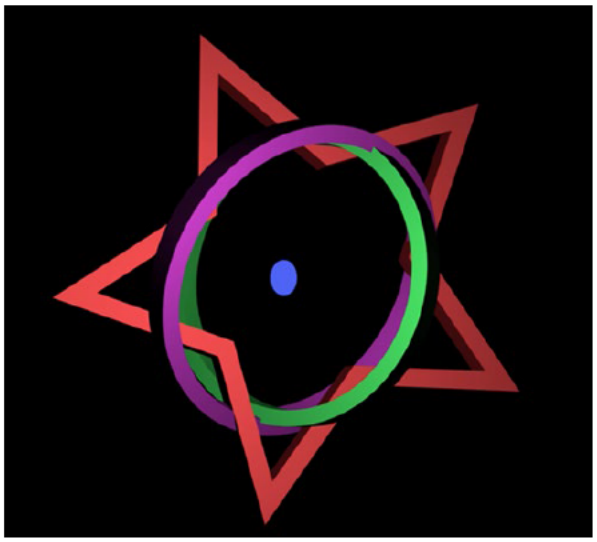

Figure 4-5: As Anna develops skills and learns to adapt, the formation of her new shape takes place

With this change, the other HH members also need to adapt (adaptive response) since the change in one band causes the other bands to stretch or bend. For example, Precious had to start going to the store to buy groceries because her mother could not. Thus, the way she engages in activities and participation changed. As Anna's band changes shape, so Precious's band also changes shape, as seen in figure 4-6.

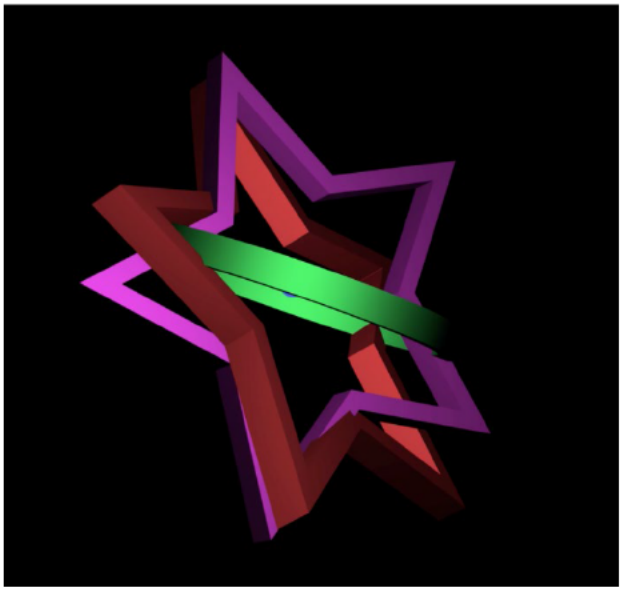

Figure 4-6: When one HH member's band changes, the other members' bands change too

The adaptation could take an extended period of time, or the HH members do not fully adapt. This could be observed in the three sons using substances to cope with being hungry, but also resulted in them leaving school, not finding work, and not participating in self-care. This is visualised in figure 4-7.

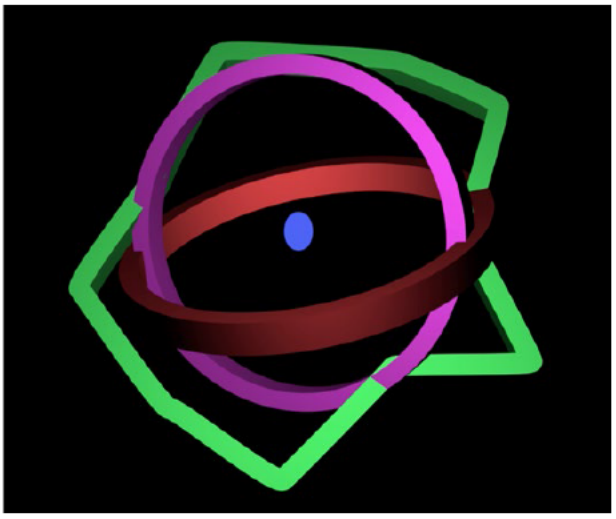

Figure 4-7: Whilst the shape is attempting to change, it is not able to do so in an equilibrium state, leading to reduced functioning.

Even though the initial adaptive response is sub-optimal or unpredictable, a kind of equilibrium ensues, visible in figure 4-8.

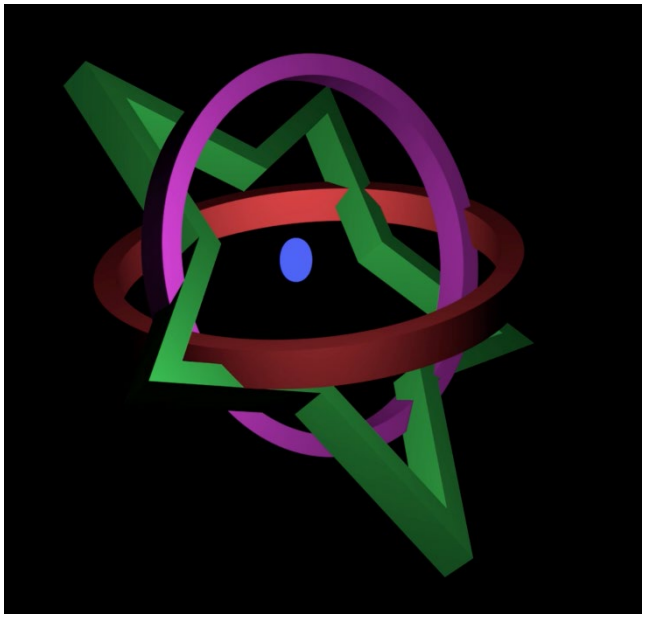

Figure 4-8 A state of equilibrium, although it may not be fully functional

This can be seen in Andries and Bule fulfilling a routine by finding piece jobs or selling recyclable materials so that they can purchase their substances. The way in which substance use influences the HH may be unpredictable, and the extent to which it creates dysfunction in the HH can vary. Since substance use is an adaption (often a coping mechanism) to various forms of stress, substance use results in a change in shape, reaching a new equilibrium. Suppose the person using substances starts stealing from other members in the HH in order to purchase drugs. In that case, the response creates a significantly different effect in activities of the other HH members (for example Anna not being able to leave the house) and the properties of the HH members (for example distrust), than if the HH member using substances does not steal.

Disruptions can be of various forms. Apart from changing shape, the bands could change colour. When Anna's depression developed, there were functional effects such as poor appetite, low energy for HH chores, and strained relationships with her children. The porous nature of the bands means that the property change in one band also affects the property of the other bands (observed in all bands changing colour to varying degrees). Anna's children may have also experienced depressed mood and reduced motivation. This could also lead to role reversal in a HH, where younger children may need to bear responsibilities of the home instead of effective functioning of the parent. This was evident when Precious needed to cook before or after going to school, or leaving school altogether to seek employment. See figures 4-9 to 4-12.

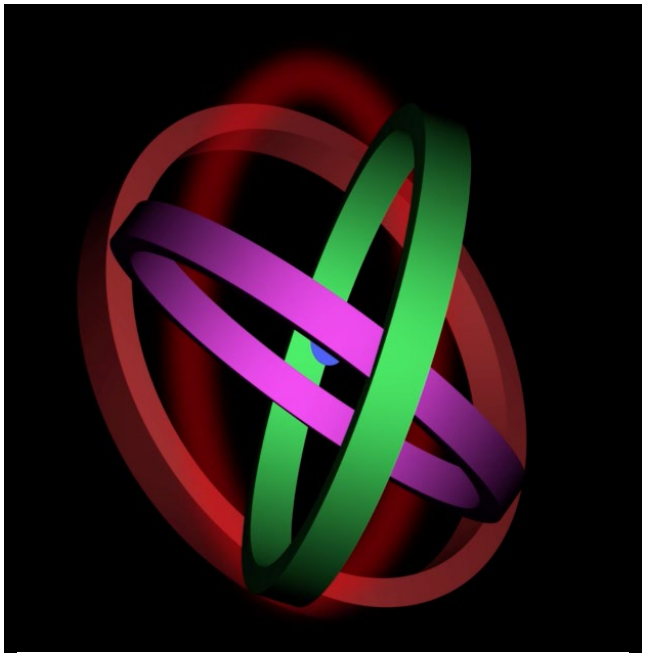

Figure 4-9: The disruption observed in the form of a shock wave (red wave) occurs in the HH, resulting in the red band starting to change colour

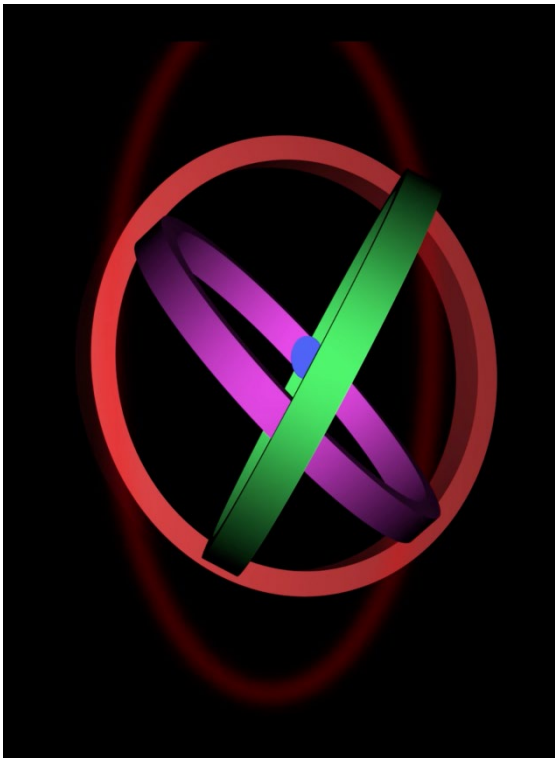

Figure 4-10: As the shock waves extend, the red band further changes colour (bright red visible)

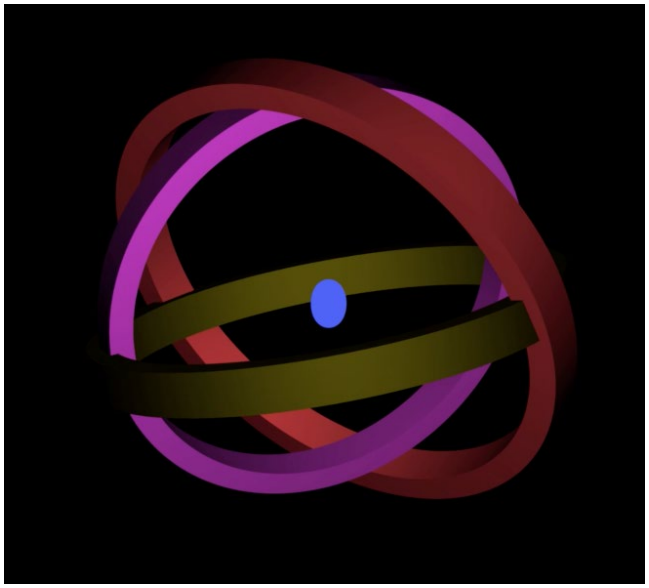

Figure 4-11: Through the porous nature of the bands, the green band starts changing colour too (observed here as dark green)

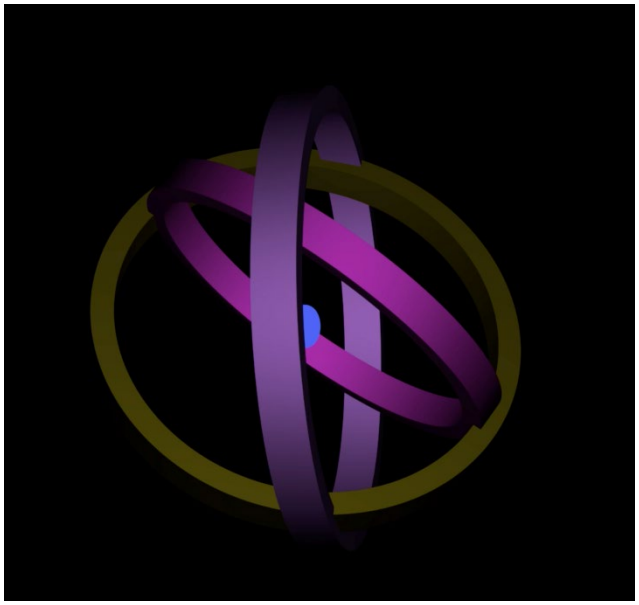

Figure 4-12: The purple band also starts to change colour as the red band continues to change colour (dark purple)

Demands and disruptions may be from external sources. For example, the HH experiencing food insecurity (a demand over a period of time) or Andries being hospitalised (a single event). Something that is experienced by all HH members simultaneously creates an adaptive response that is visible in how the various bands stretch and bend, change colour, how the HH moves (visible in how the entire HH rotates around the axis). See figures 4-13 to 4-15.

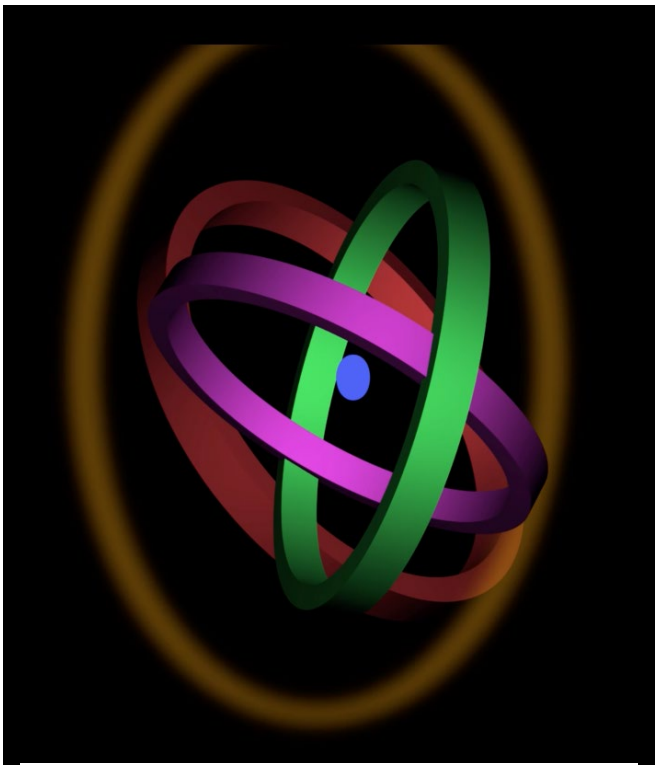

Figure 4-13: The external event is visible in the brown outside wave

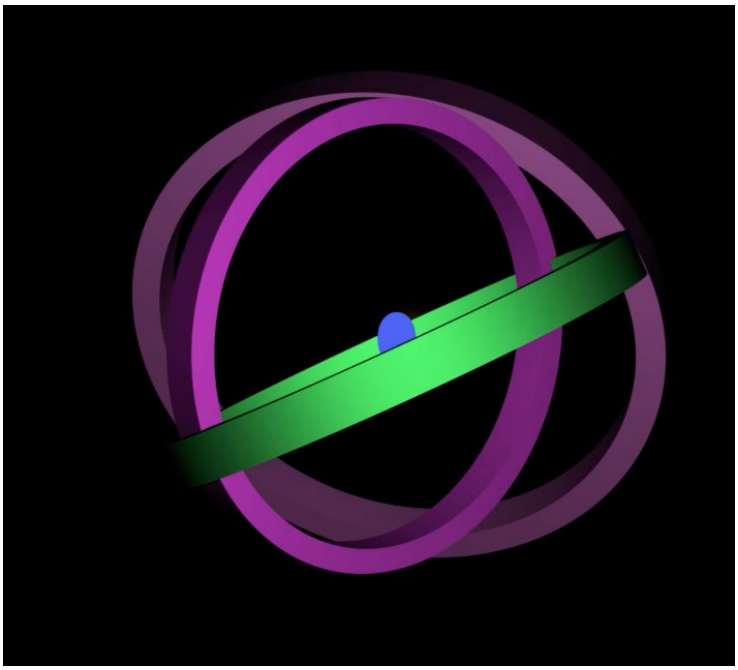

Figure 4-14: The bands concurrently change colour and shape, also changing each other and the entire sphere

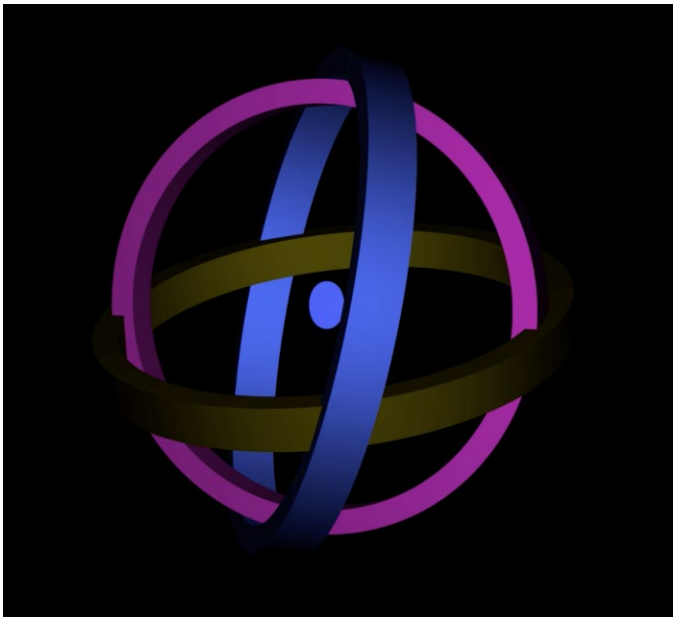

Figure 4-15: The bands continue to change shape and colour, and move in different ways as they adapt

A CAS is never this simple since the connections between the HH members are not at two points only. Instead, the connections are multifaceted and interact concurrently with each other, causing various unpredictable movements. This is observed when the bands (HH members) are displayed from a different view. Here, the images show the constant movement, flow and multiple influences occurring simultaneously. See figures 4-16 to 4-18.

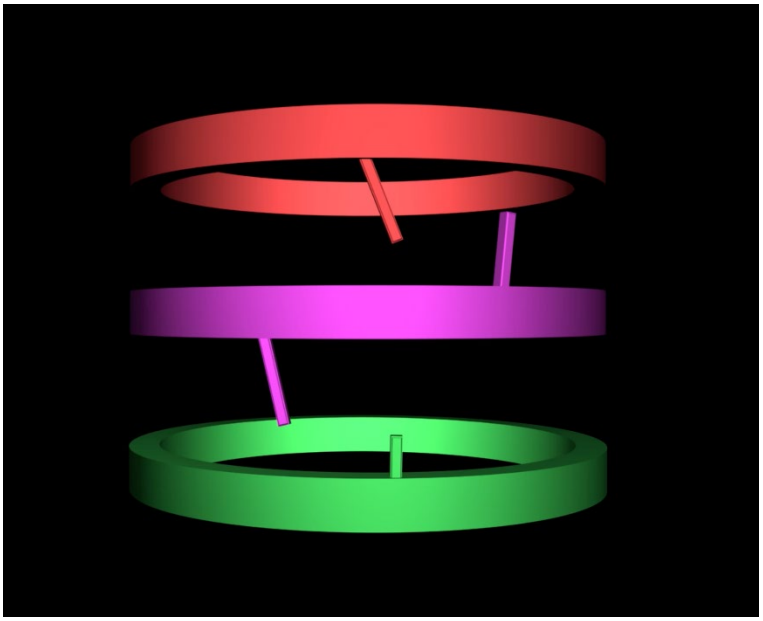

Figure 4-16: The HH members and connections are constantly influencing each other

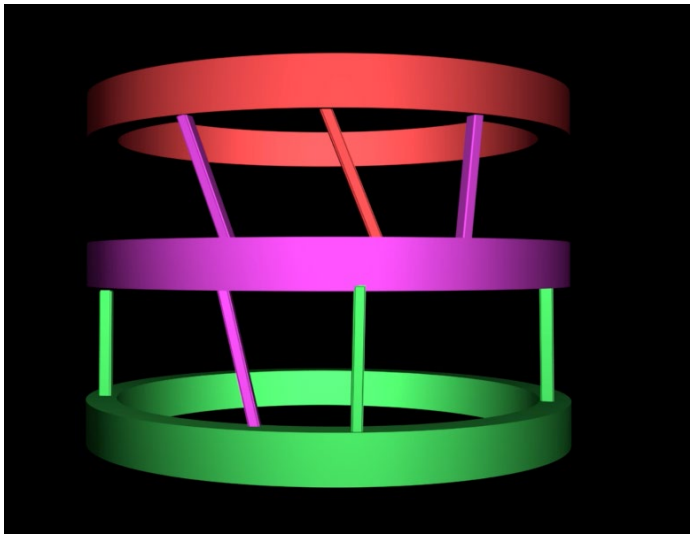

Figure 4-17: There are multiple strings that interconnect the various bands

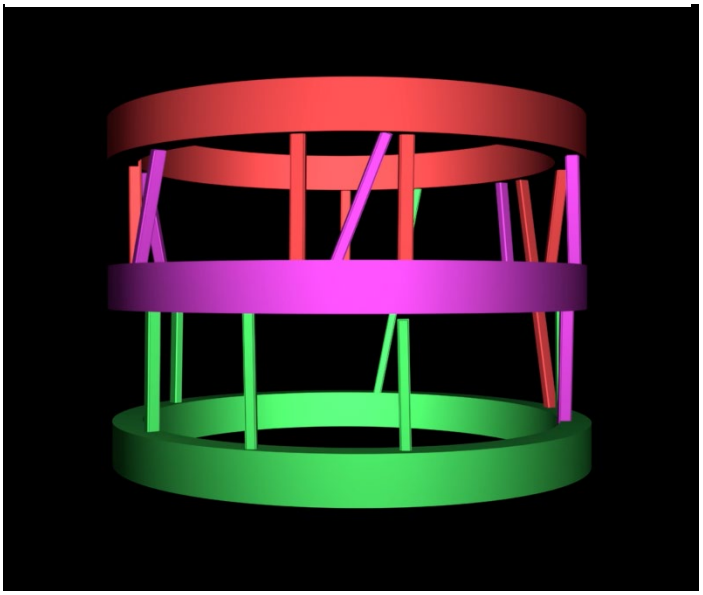

Figure 4-18: The influences occur in multiple ways, just as the HH members constantly influence each other in different ways

We can observe the HH moving on the functioning-dysfunction continuum due to various reasons. The most obvious may be when one band dissolves due to death, and the entire HH sphere changes. This was observed when David passed away. As the band dissolves, this can cause significant difficulties in the HH's functioning. This is seen in figures 4-19 to 4-21.

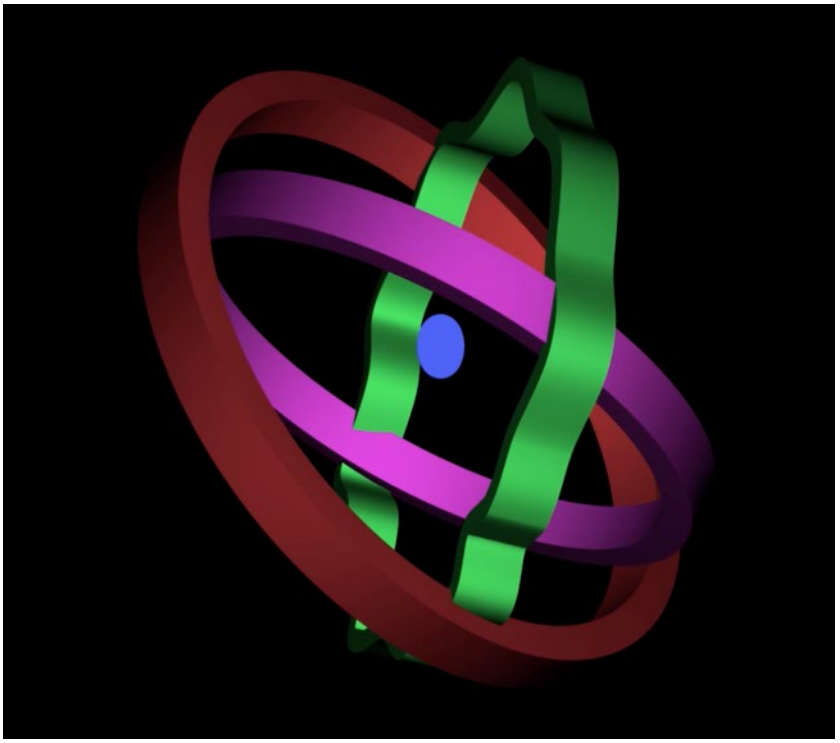

Figure 4-19: The green band starts dissolving

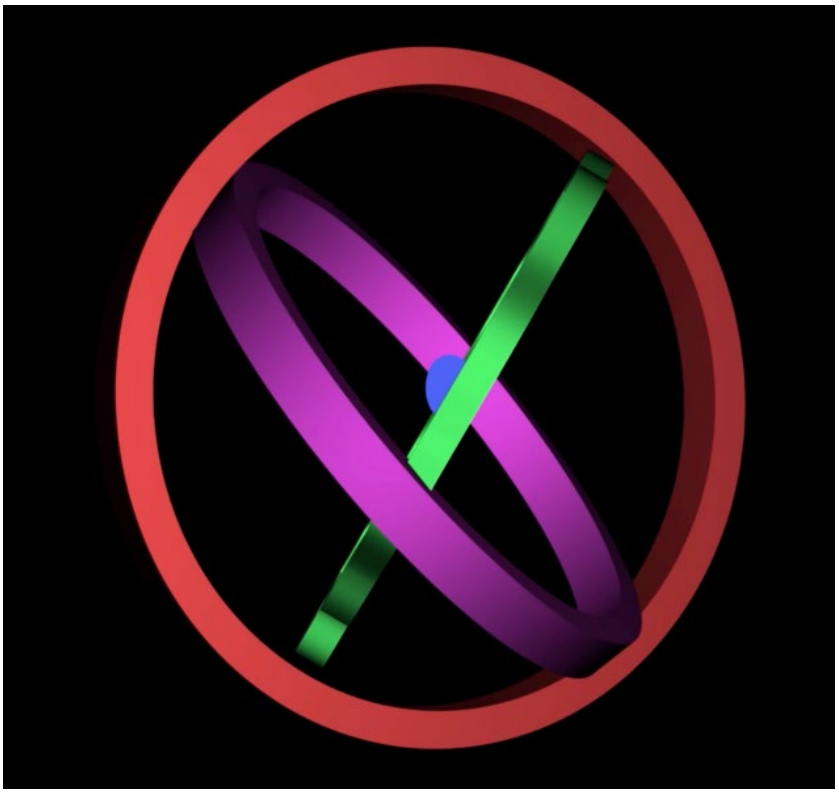

Figure 4-20: Demonstrating the effects of a HH member passing away through the green band

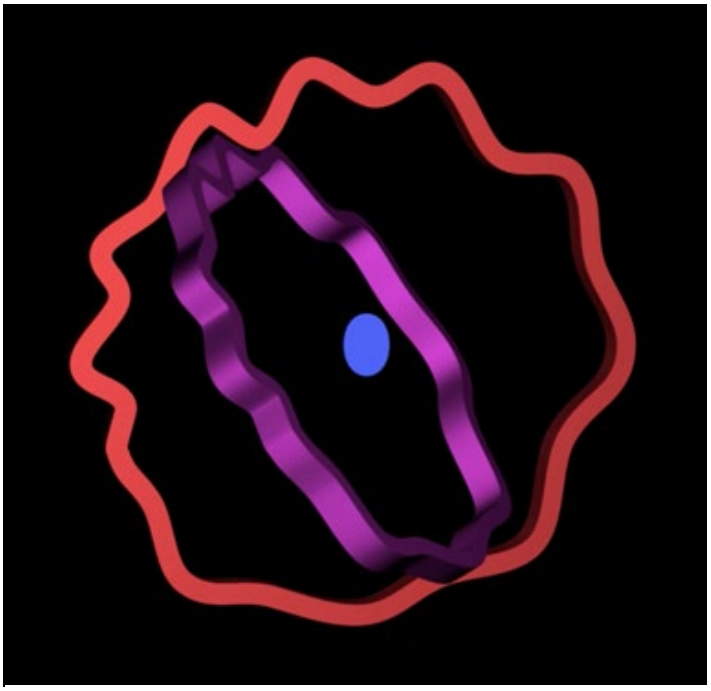

Figure 4-21: The remaining HH members are impacted

Although each HH member and the entire HH would have experienced the death differently, a positive adaptive response for Anna would have been for her to seek counselling and, with the assistance of the psychiatrist, review her medication to support her in processing her trauma. Instead, she resorted to the use of alcohol, which eventually led to the deterioration of personal health management, home management and overall self-care. This also dampened Anna's ambitions of starting a small home business to earn an income to assist with food security in the home.

The second example of potential dysfunction can be seen through Precious' (the purple band) confusion in her influence in the HH (as her band increased and decreased in size), symbolising her role and her changing hierarchical nature. This occurred as she attempted to assist at home, but also did not want to be there because of the recycling point. The dysfunction of the HH may result in certain members, or the whole HH, behaving in different ways. See figures 4-22 to 4-24.

Figure 4-22: A disfunction is visible here in the hierarchical nature, where the band is having difficulties adapting

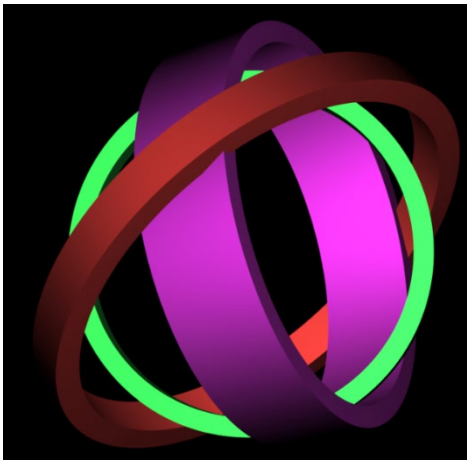

Figure 4-23: And therefore, continuously changes in thickness in a pulsating rhythm

Figure 4-24: Which also influences the other HH members

Numerous other minor or major events may move the entire HH out of balance. For example, when we initially met Anna, she was constantly angry with her sons for using substances and stealing from her, and there was no engagement between them. As a result, the HH was not able to move in synchronisation, and the HH members instead each focussed on themselves.

The complex nature of the HH is highlighted when we observe various demands and disruptions occurring simultaneously or in quick succession, both from internal and external sources, affecting various HH members in sequences or all at once. This will be seen in a HH that experiences one member being unemployed, one member dropping out of school, one being injured during a hit-and-run, and another developing substance use disorder. The interconnections themselves can potentially create significant barriers for the CAS to apply to itself, and the adaptations may be suboptimal with ever-increasing dysfunction. In addition to what has already been described, dysfunction can also occur in the rhythm of the HH (observed as stop-start jerkiness), in the activities and participation (observed in the shape and form of the band), and in the interpersonal relationships (observed at the connections of the bands).

One way we can observe a dysfunctional HH is when the various bands have started moving outside the sphere. The bands have essentially ceased to rotate, and the overall rotation of the HH around an axis has stopped. This was most evident when the recycling point was in Anna's yard, and she was drinking alcohol continuously, her daughter did not want to be at home, and her sons were using substances. See figures 4-25 to 4-26.

Figure 4-25: The rhythm, movement, and interactions of the HH have reduced in their functioning

Figure 4-26: observed by the bands moving out of sync and drawing away from a sphere

The HH then creates an influence on other HHs in the community. This is observed in the HHs orbiting in a functional state around a central point. Since the HHs exert forces, this explains how when one HH moves out of orbit, it can pull the other HHs out of orbit too. See figures 4-27 to 4-29.

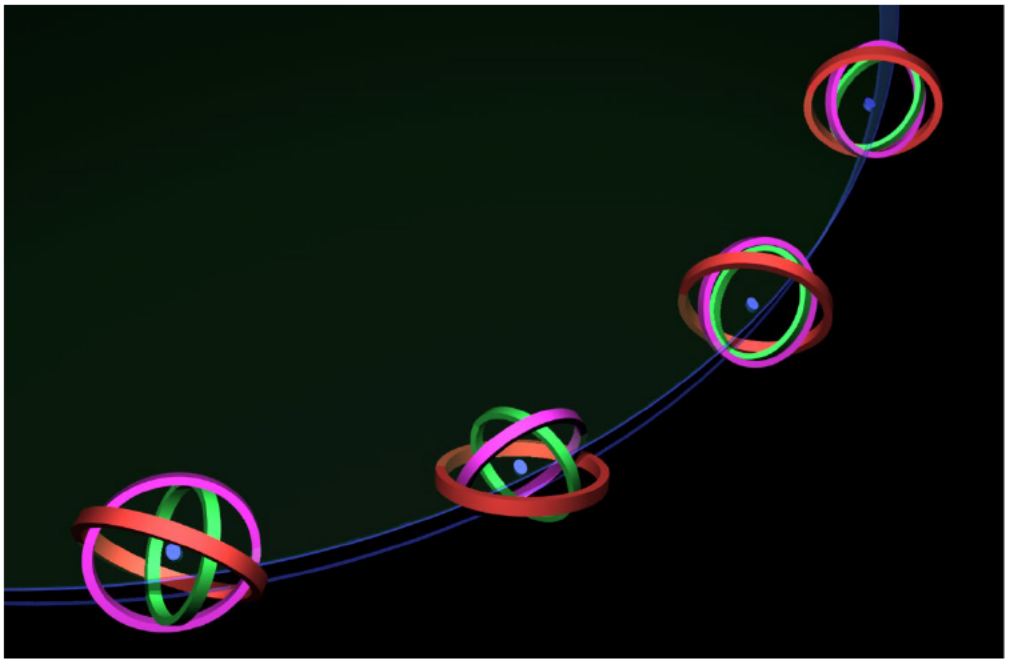

Figure 4-27: The HHs all moving in an orbit (shown here by a segment of the orbit)

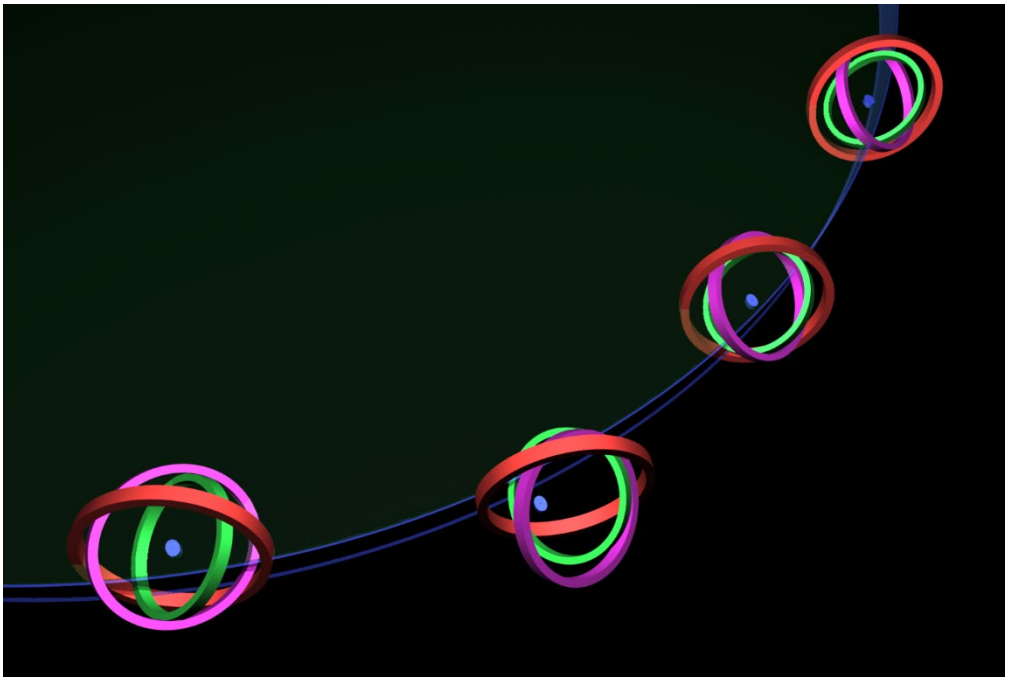

Figure 4-28: One of the HH starts moving out of the orbit

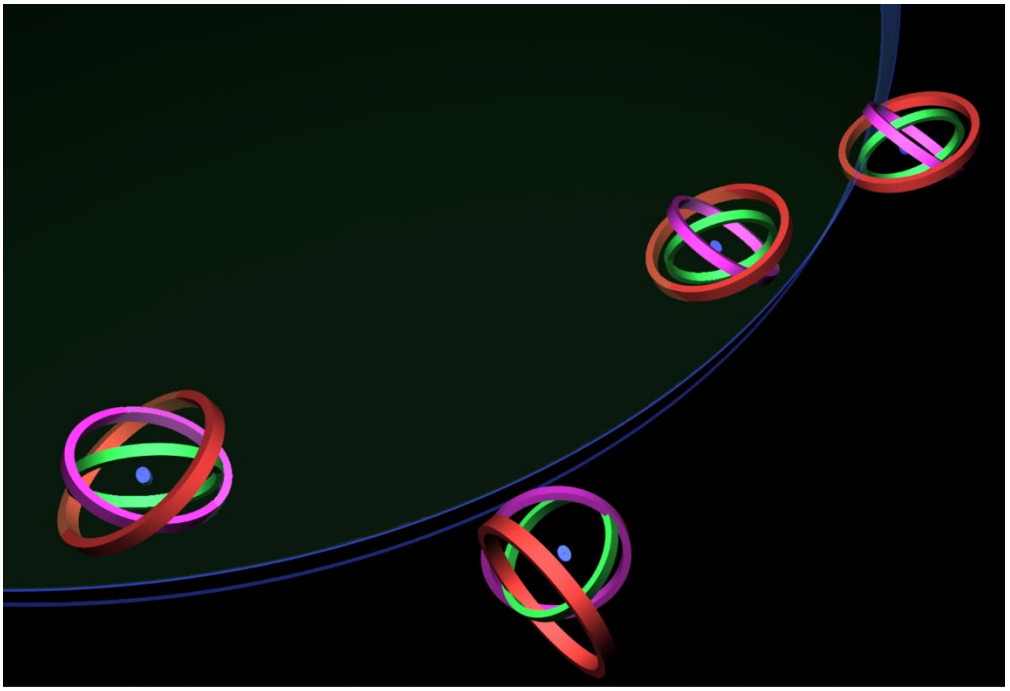

Figure 4-29 Which results in the other HHs also moving out of orbit

In Anna's example, the recycling point in their yard significantly influenced the other HHs in their street. The other HHs put up fences and increased their safety mechanisms to adapt to the increased crime. See figure 4-30 of Anna at her home.

Figure 4-30: Anna standing in front of the area where the recycling point used to be

Finally, all the HHs in a defined community function within the environment or context. See figure 4-31.

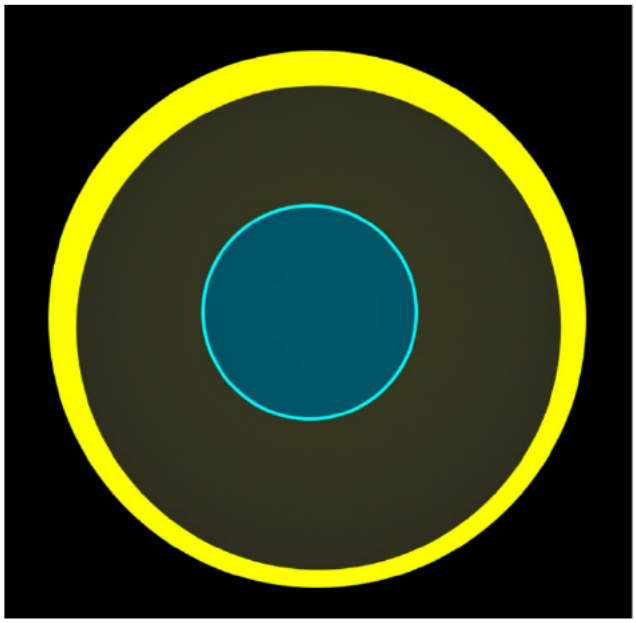

Figure 4-31: The HHs (inside blue sphere) within the environment (outside yellow sphere)

The yellow orbit demonstrates the environmental (or contextual) level (of the ICF) or a combination of the social and environmental determinants of health (as defined by the Meikirch model). In Mamelodi, various challenges exist at this level. This includes high youth unemployment, limited infrastructure such as poor-quality roads or a broken drainage system and mob justice (which resulted in several of David's friends being murdered). All of these may create pressure at the environmental level on how HHs function (observed by the thickness of the changing sphere, creating restrictions in the movement of the HHs. See figure 4-32.

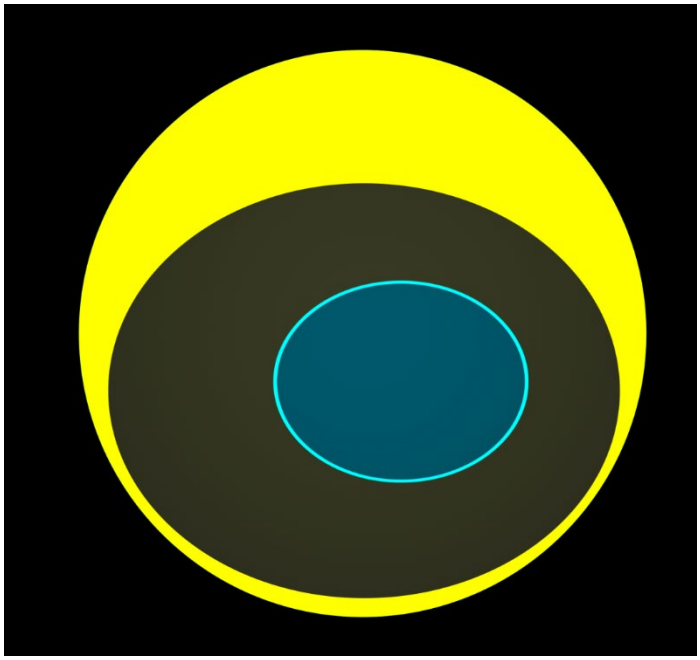

Figure 4-32: The increasing pressure from the environment sphere creates pressure and changes the shape of the orbit of the HHs (circle to oval)

Contextual pressures may also arise from sudden events or shocks. The HHs, however, display the ability to adapt and push back against the shocks. This is visible in figures 4-33 and 4-34.

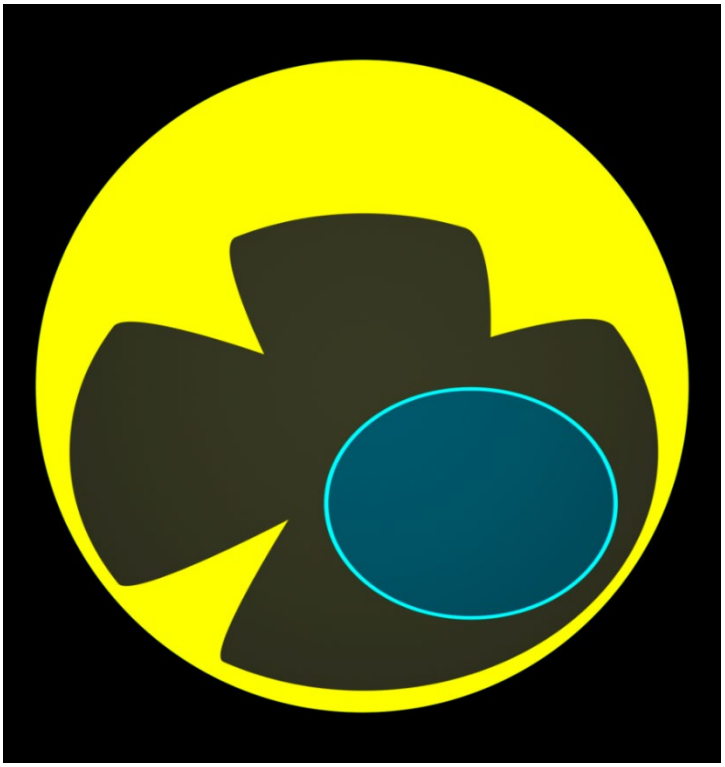

Figure 4-33: The shocks observed as sharp 'daggers' entering the movement sphere of the HHs

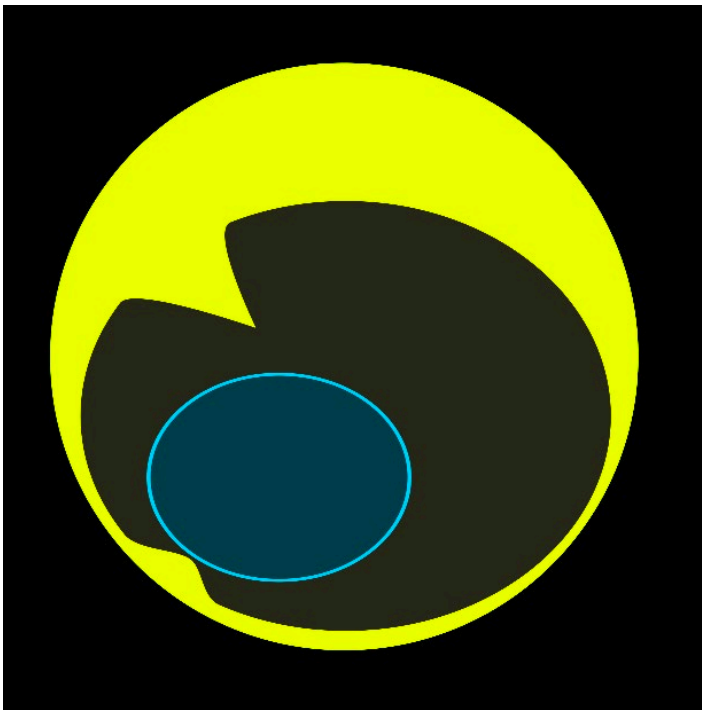

Figure 4-34: The HHs then push back to create movement space again

This was observed when the electrical connections in the nearby township created pressure on the grid, prompting the mothers in the area to seek the assistance of the community leader to remove the other illegal connections. This was an adaptive response in which the HHs were pushing back together.

The environmental system itself may also adapt. For example, in Mamelodi, the response to the surge of substance use is the COSUP programme. This is observed in the environment sphere decreasing in size again as the intervention assists the community. See figures 4-35 and 4-36.

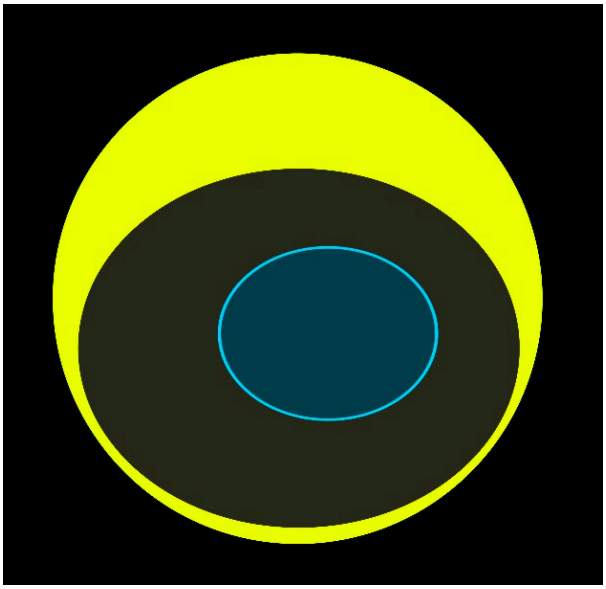

Figure 4-35: The changing size of the environment sphere observing a positive adaptation

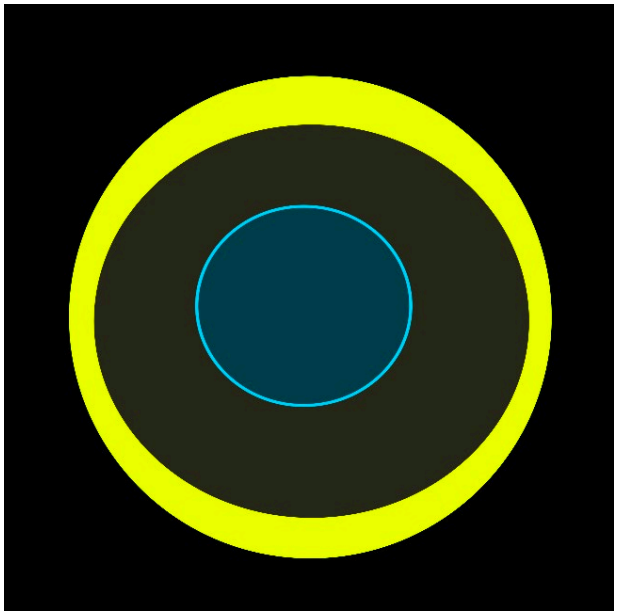

Figure 4-36: This allows the HHs to function within a larger space

Of relevance in a CAS is how small changes in inputs, stimuli or interactions can result in large effects or significant changes in outputs. For example, within Anna's HH, the single event of visiting her and our conversation resulted in the large change of her deciding that she wanted to live, return to receive her medication, and extradite the recycling point and the renters from her yard. The positive ripple effects of this are still being observed.

The HHCM applied by CHWs

Sturmberg[35(p12)], following a proposal of health and disease as dynamic complex-adaptive states, asks, "How do we ensure that health professionals broaden their approaches to patient care that enables them to explore the whole of their patient's disease and disease presentations?" We propose that the HHCM, following additional development, piloting, and evaluation, can be applied in HHs by CHWs to improve service delivery, health, and social wellbeing. Once a practical tool is available, the CHWs should be trained in its use and applicability.

The HHCM illustrates that HH members influence the wellbeing of each other, as well as the functioning of the entire HH. There is also a relationship of influence between HHs in a community and the environmental system in which they operate. When this dynamic model is shared with CHWs, we hope that as they enter the HH, they will question and observe the interactions between the HH members and determine with them what various factors are at play. If CHWs entered a HH such as Anna's, they would be able to consider the adaptations in this complex system as a response to food insecurity. A negative adaptation would be HH members stealing to obtain food. A positive adaptation would be, as Anna did, going to the rubbish dump and picking 'mfino' (a type of spinach which grows freely and is nutritious).

As has been described in the Mkhize HH, even if the individual potential is realised (Anna wanting to take ownership and change things) or providing the HH with social assistance (for example food aid), the individual determinants of her sons (their substance use disorder and often resorting to stealing to purchase substances) would limit her capability to engage in various tasks (for example being able to attend the clinic). She is limited not only by her physical impairment (her painful leg), her lack of psychological potential (her depression) and her alcohol use but also by the constraints of her children. Even if there had been a way to assist her with medication (for her depression) and an operation (for her leg), not being able to leave home (for the effects that it yields) would not create the opportunity. This HH interrelatedness is further seen in that the sons do not have the personally acquired potential because of their substance use disorder – even if they had physical means of wanting to overcome their challenges, there are cognitive and social fallouts. They also do not have soap to be able to wash their clothes. The social impacts, i.e. lack of job opportunities (high unemployment rate amongst the economically active population in Mamelodi) and the stigma surrounding substance use by the community, means there are numerous barriers to overcome.[36]

Sense-making[37] and problem-solving[13] have been conceptualised as assisting those facing a complex system and its uncertainties in making decisions. Training in this can be useful for CHWs to engage the HH to determine a plan forward. The HHCM is a tangible, visible demonstration of an abstract concept that hopefully facilitates an understanding of complexity. Participatory visual methods (PVM) have been shown to be successful in facilitating self-reflection and understanding of CHWs regarding health concerns.[38] As a by-product, it may also create opportunities for CHWs to build resilience within themselves and their own HHs.

Limitations and strengths

Even though the sample size was small, thick descriptions provided rich data. Since ethical approval had only been received for interviewing the women in the larger study, the informal conversations that arose in the HH have been reflected upon as opposed to conducting the life history interview with each HH member. Future research should be considered to examine the suggested model in HHs, with CHWs conducting the conversations and participating in the analysis. Ideally, there will be an opportunity to research these suggestions within the COPC approach and determine effectiveness in improving health promotion and managing health conditions in HHs, HH wellbeing, and community care pathways.

Conclusion

HHs should be viewed as CAS. The COPC approach lends itself to understanding HHs as such. A 'one-size-fits-all' approach to healthcare and HH wellbeing in resource-constrained settings does not allow for complexity to be incorporated. The greatest resource to COPC implementation, namely CHWs, could be trained in CAS-thinking. The HHCM, considering its visualisation, could assist in this regard. If CHWs develop this insight and understanding, they can determine where HH functioning is on the function-dysfunction continuum. When CHWs recognise whether positive or negative adaptations have occurred, they can, together with the HH, determine a way forward.

CHWs' exploration of the HH narrative, along with an improved understanding of mental health and enhanced perspective regarding complexity within a HH, could guide and improve the coordination of care pathways for individuals and HHs. With the introduction of the National Health Insurance (NHI) by the National Department of Health in South Africa, there is a unique opportunity to reimagine an improved understanding of HHs to facilitate greater wellbeing in communities.

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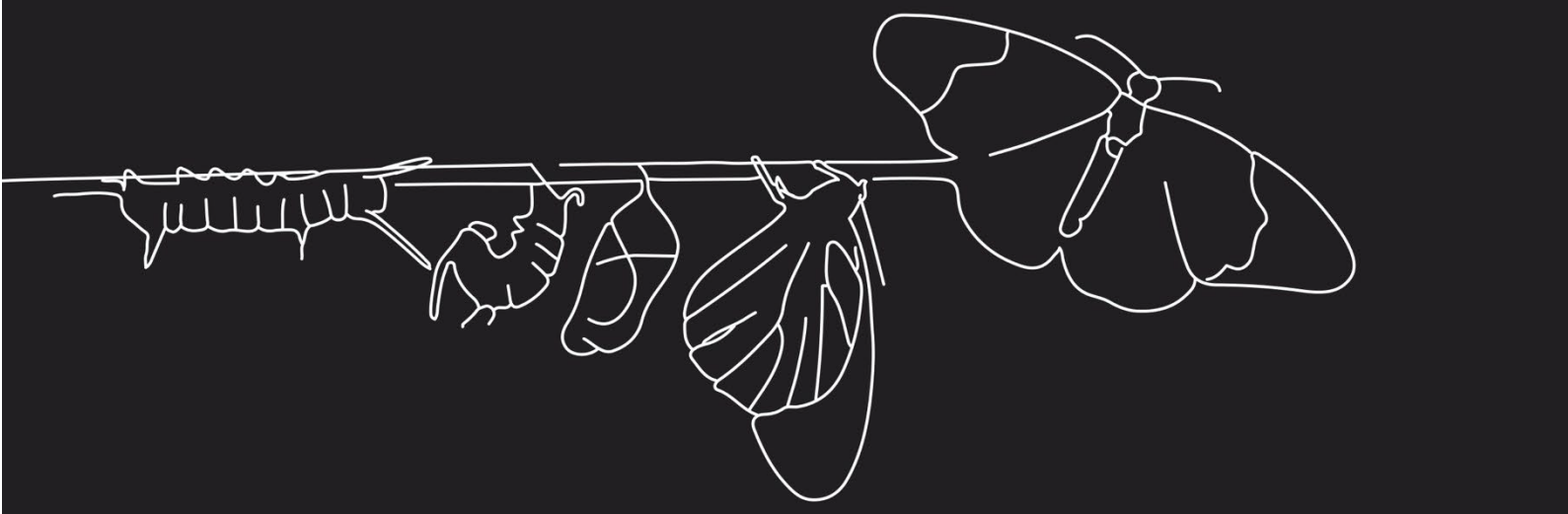
4.7 Epilogue

This article has shared the development of the Household Complexity Model (HHCM) that we can use to look at the household in its detail. In the existing work that I have done with CHWs in the community of Mamelodi, it has become apparent that abstract concepts are best described in concrete ways, when they are linked either to activities or to demonstrations. Therefore, it was essential for me, that the HHCM is also available as a video that can be watched, so that the changes that occur in the household can be seen dynamically unfolding. Importantly, since this is the first offering of the model, it is not yet in its final stage of development. Additionally, the model is only currently a visual offering, and does not include the use of a programme for data analysis. This could possibly be developed in the future, to translate specific measurements of the extent of disruptions and shocks and what their effects on a household and its members are to a specific degree of change in the properties of the bands. Section 5.7 (recommendations), provides additional detail of how this model will need to be tested, developed, reviewed, and applied, and validated through engagement with CHWs and other health care professionals.

In addition to the HHCM, the four contributions of this article will be useful for COPC and specifically for the development of the CHWs. However, the lessons learnt do not remain only at this level, as the final chapter will explore increased training and awareness creation in multi-strata service provision, across all health and social service providers. This includes public health specialists and policy makers. In this chapter, I will also draw further connections to the work that we have done, as well as link the article again to the entire research study.

Chapter 5: Synthesis

ukuguqulwa komzimba – isiZulu – n. metamorphosis



5.1. Summary

At the beginning of this thesis, I invited you into my story. This has been an enriching experience, and I hope that by sharing, it will ultimately lead to improved functioning of households and communities. In this chapter, I synthesise the research study by summarising the main findings. I then consider the significance of the study for public heath and forefront three important aspects:

Firstly, the value of the study for health professions and community health worker (CHW) education. As the first article showed, food security and disability need to be incorporated more overtly into health sciences education. This can be done by using examples, such as the life stories of Anna, Dikeledi and Boitumelo. To obtain an improved understanding of the household, the model that has been developed can be shared with all professions in the health care team. Importantly, it will still require further validation and development (which will be discussed in 5.7). The stories will hopefully also expand the knowledge of educators to enable a systems perspective of food security, health, wellness and functioning. This is of equal value in the training of CHWs.

Secondly, I engage with the value of narratives in public health. As already described in article three and what is evident from article two, narratives can become an important avenue of healing, sharing and transformation.

Thirdly, I posit various important ethical and practical considerations. These became most evident in the final stages of my research and need to be acknowledged and shared so that we continue to build on the body of evidence of African communitarian ethics. African communitarian ethics are based on the African worldview and philosophy of Ubuntu, which forefront the collective whole and one's connectedness with each other.[1-2] This collective is usually the family, the household or the community.[3] Since public health research is so deeply embedded within communities, we must constantly ask ourselves, which ethics systems' criteria are we using in Africa, and are they adequate?

When Archbishop Desmond Tutu was still alive and signing his biographies, I dropped off a copy of "Tutu, The Authorized Portrait" at his foundation's offices, together with a letter for him. I shared a little of my miracle story with him and asked whether he would sign it with one of his well-known quotes. In the figure below, I can be seen holding my book with his inscription:

"Helga, God bless you. My humanity is bound up in yours for we can be human only together." Desmond, 12/7/2012 Cape Town

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Figure 5-1: Holding my signed Archbishop Desmond Tutu biography in my office

In the next section, I consolidate the research process in this chapter, which is valuable for public health and all community-engaged research. Through it, I share lessons on how research can be transformative and how we can form and maintain relationships with the people we encounter throughout various community engagement and research initiatives. This is an important ethical principle, not emphasised enough in our traditional ethics approval boards. It is also essential for public health practitioners. This study has taught that being embedded within the community (even if you do not live in the same community) is necessary when researching vulnerable populations. This ensures that we better understand the networks and services that exist and how we work within them. It also ensures that we do not leave the community once the research has been completed but maintain a relationship as we all continue to navigate life.

In the fourth sub-section, I describe the critique of the study, followed by the strengths and considerations. There are some regrets that I have, and although this is not helpful, it is important to acknowledge them. Working in this sector becomes a difficult interplay between our daily lives and the responsibilities we take on as a result of the spaces that we enter into. We should therefore ensure that we constantly maintain this responsibility with integrity or that we maintain teamwork with the community, and that the ongoing challenges, as they arise, are not dependent on us to solve. A strength of this study lies in the value of the co-researcher training and contribution. As was already described on page xxiii, I believe that in studies of this nature, one has to demonstrate that it has not only been extractive but that there has been a significant contribution in its process, as well as an

investment into the people who have been involved in it. Judith's career trajectory has demonstrated how a study can develop multiple partners in sustainable ways, ensuring that we have ongoing interventions and support with the co-researchers and community members participating in data collection as well.

Lastly, I conclude this chapter with recommendations and a take-home message. It will be exciting to see what happens post-PhD, especially when there are still many unanswered questions. But what I know for sure, is that it will not be a lonely journey – there are so many people invested in improving the lives of the community of Mamelodi and the city of Tshwane. I cannot wait to share with the broader team and to see how we can implement what has been learnt.

5.2. Summary of findings

Disability and food security is an important nexus to consider in health care. Whilst the multiple vulnerabilities that exist when someone has a disability and is food insecure has received greater attention in recent years, in practice, it seems that this is still not being addressed. One of the reasons for this could be the training that health care professionals receive. The undergraduate training is being done by educators working in health sciences institutions.

Therefore, this first phase of the study explored educators' knowledge, attitudes, and practices regarding including food security and disability into curricula in the School of Health Sciences at the University of KwaZulu-Natal (UKZN). Through exploring the KAP survey's closed- and open-ended questions, quantitative and qualitative data yielded important findings. Whilst educators generally had a positive attitude regarding incorporating food security and disability into the curriculum, their own lack of understanding was one of the drivers to not including more in the theoretical teachings. Whilst educators and students are taught to critically evaluate individual needs, educators felt that health care students should learn more about food insecurity and disability and be able to problem-solve on a case-by-case basis, thereby ensuring person-centred health care. Already within this phase, it was realised that generic solutions to food insecurity for persons with disabilities would not be adequate. However, it seemed that there was not enough evidence in literature to really understand, through examples, how people with disabilities, who live within vulnerable contexts, experience food security.

The second phase of this study sought to answer that question. It also included additional delineators, namely focusing on women and those who have HIV/AIDS. These additional factors would address multiple vulnerabilities and disadvantages which so often exist within one person. Therefore, the research question was asked, "How do women living with HIV and disability in vulnerable contexts experience food security?" Although literature has potentially described the interrelatedness that may arise from these multiple factors, I achieved a deeper understanding of these barriers and facilitators by using life history methodology. Firstly, the women in the study demonstrated resilience. It was,

therefore, increasingly apparent how environmental factors, in the form of systemic challenges, had compounded their experience of food insecurity. This study, however, also raised an important question regarding our measurements of food security, whether individual or household-focused, since it was difficult to ascertain, throughout the data collection process, exactly whether the participants were food insecure. The data revealed that this question was no longer relevant, since food security may not mean nutrition security, and obtaining food may not mean that you would be able to benefit from the meal. Rather, the article suggests that one needs to understand the complexity of the household with the dynamic realities for intervention to occur. It also highlighted that the women in the household should be a part of the problem-solving process since they have demonstrated resilience and the ability to be able to seek their own solutions for improved wellbeing.

Through a period of prolonged engagement with a household, the story of Anna had shifted from a focus only on food security to all other aspects of complexity evident in the relationships with her children and the community. Although food security needs to continue to be understood as a complex household issue, I obtained a deeper understanding of the household wellbeing and functioning through the life history methodology. Anna's story demonstrated that her primary concern was not whether she had enough to eat. Rather, it was the concern of her sons and their substance use which was debilitating her. Therefore, in the third phase of this study, a spontaneous question was raised: What lessons can be learnt from exploring the complexities evident in a household, as well as engagement with the household, related to COPC implementation? It is through using life history interviewing, by further training CHWs on mental health, by improving care coordination and complexity management that COPC implementation can achieve a greater impact in improving household functioning. I garnered from the existing Meikirch model and the International Classification of Functioning, Disability and Health (ICF), that even though interactions, as well as the environment are considered, the interrelatedness of the household is poorly demonstrated. This resulted in me conceptualising a 3D model called the Household Complexity Model (HHCM). The HHCM demonstrates the various household members, their influence on each other and the complex adaptive system that exists as the household reacts to the demands and disruptions of life. When in use, perhaps CHWs and others in health care will be able to problem-solve with the household to achieve more sustainable solutions and improve overall functioning.

5.3. Significance for public health

The four main aspects that are significant for public health, in addition to the HHCM, include the value of the study for health professions and CHWs education; the value of narratives; the value of the co-researcher training and contribution; and considerations for ethics.

5.3.1 The value of the study for health professions and CHW education

This study has demonstrated that health care professionals and CHWs need to think about wellbeing systemically. In order to be able to do this, they need to be taught by well-informed educators. As the first article has shown, educators themselves need to receive guidance to become well-informed.

This study provides educators will information that can be critically analysed to include food security and disability discussions into curricula. Additionally, the systemic failures described in the second manuscript, can inform content into health professionals training across disciplines. This is to improve the services offered by health professionals when working and the systems in which they work.

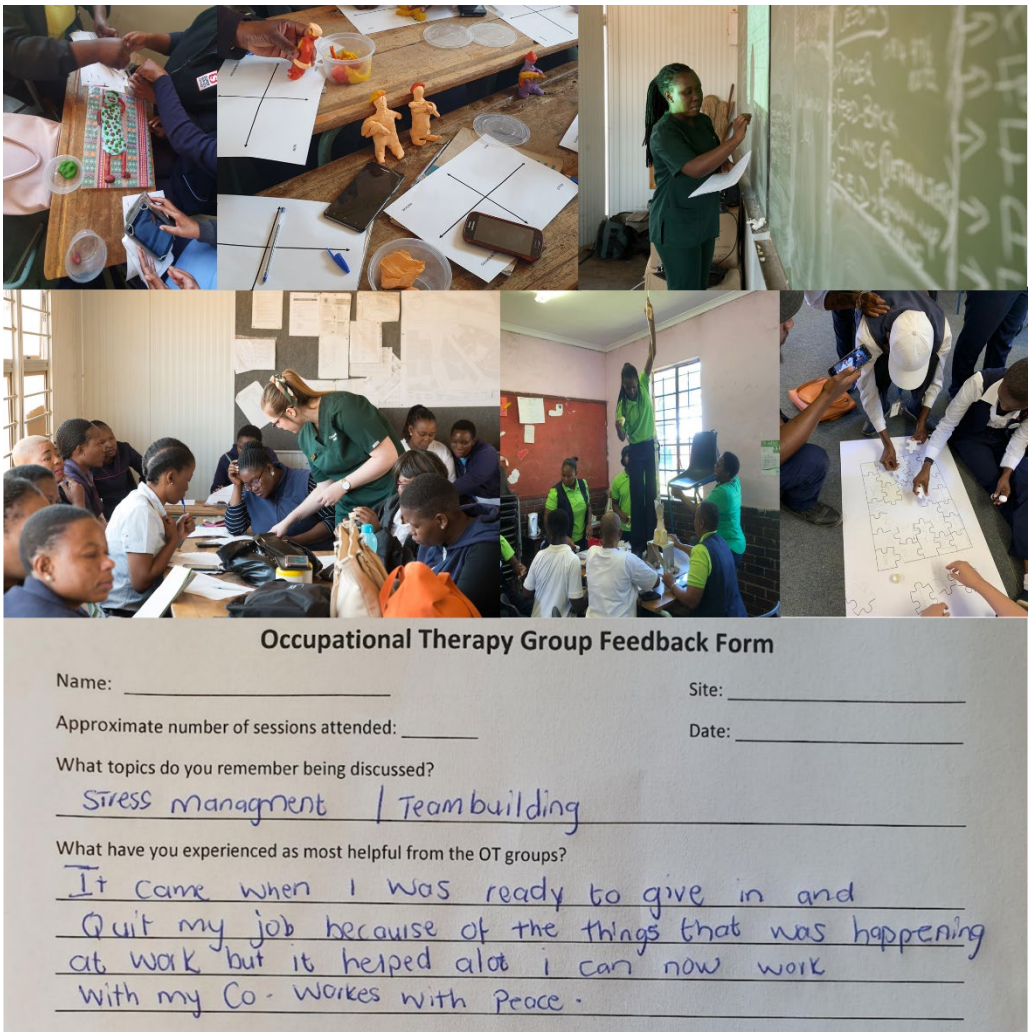
The three e-books are valuable learning materials which demonstrate the complexity evident in disability and food security, as well as overall household wellbeing. Additionally, the HHCM may be a tangible tool that can be used in the education of health care professionals, especially when these professionals remain working in secondary and tertiary levels of care and do not have the opportunity to observe the connection to primary health care and the daily realities of the patients and their households that they see in the hospital wards. It would be relevant to train working professionals too, so that existing multi-strata services provision can improve across all health and social service providers. These working professionals include amongst others, public health specialists, social workers, psychologists, community health nurses, and policy makers.

Additionally, the HHCM may be a tool for the training of CHWs in COPC to reinforce the household as the starting point for intervention (and not the individual). It is a visible impetus for CHWs to enter the household and not focus on only one member. Once the importance of the interrelatedness between the household members and their influence on each other has been established, the CHWs may have renewed focus in their evaluation. They would however require support through a simplified tool, to be able to process and intervene effectively to minimise becoming overwhelmed by the potential challenges.

As I alluded to in chapter four, I have been working with numerous groups of CHWs through occupational therapy student intervention in the community. This relationship was initiated at the beginning of my employment at UP. I connected with the team leaders, whom I had previously been in contact with whilst sourcing participants for phase two of the study, to ask whether they would be interested in occupational therapy student intervention with the CHWs they were overseeing.

Previously, the collaborative relationship I had been involved with as part of occupational therapy students and CHWs, consisted mostly of conducting home visits, referrals and providing training of skills required by CHWs, often with a disability focus. I hoped that we could establish a partnership and envisaged that the CHWs would benefit from skills training. However, following the initial discussion, the problems identified were not so much around skills they required but rather what to do about high levels of stress and anxiety. Many of the CHWs had difficulties coping with the high

stressors and workload that was required of them. The students, therefore, commenced with life skills training, focusing on the identified areas including, for example, conflict resolution, stress management, effective communication and time management.



Occupational Therapy Group Feedback Form

Name: _____ Site: _____

Approximate number of sessions attended: _____ Date: _____

What topics do you remember being discussed?

Stress managment / Teambuilding

What have you experienced as most helpful from the OT groups?

It came when I was ready to give in and Quit my job because of the things that was happening at work but it helped alot i can now work With my Co-workes with Peace.

Figure 5-2: CHW group therapy sessions and feedback form snippet

From top left to bottom: Creating soldiers from play dough as part of describing team roles; conducting training sessions; building of trust; demonstrating teamwork through puzzle pieces

One of the strengths of the occupational therapy sessions that we observed was the value of describing abstract concepts in concrete ways. This always ensured improved understanding and facilitated learning. Therefore, this HHCM is a tangible, visible demonstration of an abstract concept that hopefully will improve and facilitate the understanding of CHWs. Whilst I was unable to source literature to substantiate this, a systematic scoping review published in 2018 on the use of participatory visual methods (PVM) with CHWs, indicated that these methods successfully facilitated self-reflection and understanding of CHWs regarding health concerns.[4] PVM include digital storytelling and are especially useful in areas where culture and tradition include visual imagery and storytelling.[5]

This is relevant in our South African context as the HHCM is a form of visual imagery. I hope that as a by-product it will also create opportunities for the CHWs to see how they can build resilience within themselves and their own households. This would enable them to facilitate their service provision.

5.3.2 The value of narratives

Adding on to the previous point, I believe that incorporating narratives as a part of public health research and evaluation will significantly add to the understanding of household wellbeing and functioning. Some examples of the value of narratives in public health and COPC have been demonstrated elsewhere.[6-8]

I have been participating in additional narrative work, amongst others, within the COSUP programme. Here we initiated the storytelling project allowing clients to share their lived experiences. These stories were analysed thematically and converted into an e-book so that the city of Tshwane can develop greater insight into the realities that exist in many of these communities. The e-book is currently in its final stages of production and, thus, not yet available for sharing.

Figure 5-3: Implementation of the storytelling project with clients in the COSUP programme

From left to right: Clients at the COSUP site producing their personal timelines; a COSUP client sharing his story; a representation of a personal life story

In addition to this, two COSUP clients were trained in digital storytelling using we-video[12], by Dr Martina Jordaan. The videos are available for viewing here:

- https://www.youtube.com/watch?v=qjL_bmC2X5s (Story of Thabiso)
- https://www.youtube.com/watch?v=1yD89u02sfo&feature=youtu.be (Story of Sandile)

On the following page is an image of Thabiso and Sandile being trained in the Mamelodi computer laboratories. There is much work that can be done in incorporating narratives going forward. The three e-books that have been created through this PhD demonstrate varying complexities which require multiple interventions and a non-linear approach. I am not aware of detailed narratives such as these

[12] An online video editor programme

e-books having been developed within this context (peri-urban in the city of Tshwane). There are numerous other analyses that can be conducted from them. If more narratives are collected, we can garner further evidence to demonstrate interconnectedness and base our intervention on, rather than just individual disease-orientated statistics.

Figure 5-4: Training in digital storytelling using WeVideo

5.3.3 Considerations for ethics

Although this research does not focus on ethics, I do feel that there are some important ethical considerations that I need to share and how they could contribute to ethics. These are gleaned from the qualitative aspect of my study, focusing on the second and third research questions. Please note that this is not a conclusive analysis of African ethics. I will hopefully explore more of this in the future.

As discussed in chapter one, I had thoroughly prepared myself for a long-term investment in the community, which included being aware of the importance of establishing long-term relationships and the challenges that I would face in working with a population of people who were experiencing food insecurity. However, there were other aspects I had not considered and could not have anticipated. These were forefronted whilst compiling the second and third manuscripts, where I experienced an ethical rollercoaster ride and was constantly second-guessing myself, wondering, checking, doubting, and confirming. Therefore, in making sense of this, I have realised it is important to move beyond procedural ethics and consider how we remain ethical in our practice.

Firstly, when I reviewed the informed consent form with Judith, she indicated that I should include an open-ended question at the end, asking whether the participants had anything else to add to the contract (see appendix K, “I have the following personal remarks:”). I had not anticipated the value of this. Dikeledi asked to include her chosen pseudonym in this section. When Judith and I visited her

family, we took a copy of the signed consent form with us, where she had indicated her chosen pseudonym. I do think that going forward, we should debate the value of video or digitally recording the consent process. This would have been even more valuable when interacting with Dikeledi's family, especially to provide evidence of her agreement to participate in this study and her understanding of the research and that there was no financial remuneration involved. Whilst Judith was explaining the aspect of consent and detailing information regarding the research with Dikeledi's family, one aunt was recording everything she said on her cellphone. Judith was very aware of this and ensured that she clarified and emphasised all aspects relevant to the research.

Secondly, when reflecting on the research process with Judith and wanting to member check the data and data analysis with Anna and Boitumelo, it became clear that the participants may not have fully understood the dynamics of qualitative research. Judith reinforced this by saying that in vulnerable communities, people are more used to quantitative research involving mostly yes/no questions. Life history research, such as mine, was probably not something they would have encountered or heard about from other community members. I suggest that in research of this nature, there is ongoing and continuous requests of consent. I believe that I did this, for example, every time I digitally recorded our conversations or took a photo, I reminded the participants and confirmed consent. Our roles as data collectors and voluntary community workers, even becoming friends (considering the informal conversations over WhatsApp), were, however so blurred. I never asked the participants whether anything they shared with me was "off-record" which I suggest we incorporate into our discussions about consent going forward.[9]

Thirdly, as this research has shown, I had to apply the ethic of care within this qualitative study.[10] Ethic of care arises from the discernment that research can cause harm to the participants and communities.[10] Therefore, the researcher needs to make important ongoing decisions that consider the wellbeing of the participants throughout the study. Although not a new addition to qualitative research, I have demonstrated how I have respected the process in potentially previously undocumented situations. This adds to the body of evidence on how to be compassionate with our participants, as Ellis[11(p441)] states, with the "goal to honour, care for, and support others we interview."

The boundary lines between narrative research and narrative interventions have been explored elsewhere, highlighting the importance of relational responsibilities and to openly acknowledge that narrative research can be transformative.[12] The consequences of applying this ethics of care were visible in Anna's story. When we asked her, towards the end of the final entries in the e-book about the CHWs that had initially referred us to her, she indicated that after we started visiting her, they stopped coming to visit her. I could not understand and clarified that it was not because they were no longer visiting the households in the area, but that they had stopped coming to her. However, she did not feel the need for their ongoing support because, as she said, "I have you".

This demonstrates that Anna felt cared for and supported by us throughout the research process. It will be important for me to contact the CHWs to follow up on this since it indicates that there may have been a misperception on the side of the CHWs regarding our role as researchers and the ongoing support they needed to provide as the first source of call in COPC. I am hopeful, however, that this research has, in all respects, considered the importance of making a positive change and contributing to making the world a better place.[13]

Fourthly, I consider the anonymity versus perceived empowerment achieved through ownership of the story. Mukungu[9] has interrogated life history data collection with women from post-conflict settings. In her case, two of the women refused the use of a pseudonym and instead wanted to use their own names ascribed to their story since they had been involved in activism addressing violence against women and girls (VAWG). In my research, I similarly considered Boitumelo and Anna using their own names as part of activism for women with disabilities. In my proposal development, I considered the participants to be a part of the dissemination of the research results and actively contributing to authorship and conference presentations. However, the sensitivity of Anna's story regarding the vulnerability of her household's journey with those selling illicit substances in Mamelodi meant they had to be protected. Therefore, in the e-books, I have, as much as possible, removed all identifiable factors (which include house numbers and areas in Mamelodi).

I did not have the same concern with Boitumelo. Instead, I perceived her as someone that may benefit from openly sharing her story with others and so being able to contribute meaningfully to creating awareness on the required rights of persons with disabilities, and especially women. I discussed the benefit of Boitumelo being a co-author of the second article with my supervisor. This, we believed, would be a valuable form of ownership and empowerment, where Boitumelo herself could decide whether she agreed with the themes derived, as well as the conclusion. Boitumelo was initially cautious when we discussed this with her, and I suggested that she otherwise publish under a nom de plume. However, on our way to Boitumelo, to go through the second article with her and discuss the themes, and the content and decide whether she wanted to be a co-author (in her own name, that of a nom de plume, or not at all), Judith remembered, that Boitumelo knew Dikeledi. Therefore, if we wanted to discuss the themes derived from their stories and read the synopsis of Dikeledi's story – which would be required in being a co-author – we would again be violating the ethics of anonymity that Dikeledi had requested. Even though we had carefully considered the personal benefit Boitumelo may derive from publishing an article and how her story could contribute to public health advancement, we had to consider the principle of not doing any harm, as well as not compromising the integrity of each of the research participants.[9]

A similar ethical dilemma arose during the methodological consideration of member-checking the participants' stories. Since Dikeledi had passed on, I considered the possibility of member-checking her story with Lerato. I then realised that her mother would probably not have wanted her to know

everything she told me. The important things that Lerato knew, and what we could reinforce with her and her extended family, was how much her mother cared for her; and how much she would make a plan to ensure that she looked after her daughters. This was the legacy that Dikeledi had left with her daughters.

With regards to the other two participants, I intended to, for qualitative rigour, member-check their entire story with Boitumelo and Anna. Firstly, Judith read through the synopsis of Boitumelo's story, as included in the second article, with her. What we very quickly realised as she read through the synopsis and translated every aspect was that this was entirely unfair and traumatic. Boitumelo had, during some of our engagements, been significantly impacted by her mental illness. Although, as we discussed with her, her illness and various events (for example, her trying to stab her boyfriend), going through the story again with her after some years would be, even as Boitumelo said, "painful". During the reading of the synopsis, she had already asked us to change some parts of the story, for example, where she had been in a relationship with a man who was then engaged to someone else. We spent much time after reading her synopsis with her, discussing these various aspects and the value in the lessons and understanding that are gleaned from her story, for the healthcare sector and particularly those who are working in these settings. Boitumelo agreed it was unnecessary to change or remove these past actions from the narrative; therefore, they have been kept in. However, in other studies, this could refer to life choices that the participants may not have wanted to be associated with.[9]

Instead, the responsibility lay with me, as the researcher, to constantly consider sensitively how each of my participants was portrayed. This brings me to the fifth point, namely that of participant disclosure. There have been some important articles written about self-disclosure in the online environment.[14] In fact, some editors recommend publishing under a nom de plume when conducting autoethnographic research.[15] Similarly, when we engage with vulnerable persons, we should ensure that they understand the potential consequences of disclosure when choosing to own their story. Tolich[15] suggests treating any autoethnography as one would an inked tattoo. A recent wave of literature has focused on the importance of people understanding their social media presence and how anything in the online arena is akin to branding yourself with a tattoo. This education should extend to those who may not understand how the electronic, social media or internet presence works or what it is.

I became very aware of my obligation to protect the participants when I read through the e-books and carefully made edits to my own reflections. I realised that I was uncomfortable with some things I had shared previously. At times, I had written my reflexive note more as a journal entry, voicing extreme frustration, which was not appropriate for academic writing. I realised that I was unable to afford this same luxury to my participants, and therefore had to, for them, ensure that anonymity was given the highest importance – so that their story could be told without them ever being implicated or harmed by it. Participants have been known to confess and express thoughts and feelings through narrative

methodologies that they may not have in response to a question-answer scenario.[16] Holloway and Freshwater[17] have debated whether informed consent is even possible with this type of research where stories are developmental.

We, as researchers, are often so cautious of what we are saying, we re-read our written work, change how we have written something, decide on a different sentence structure, have peer-reviewers guide us on what to include and then change things again before a final product is released. This could be seen for participants as being akin to process consent which requires informed consent throughout the course of the research process and including data analysis.[18] This study has highlighted that process consent[13] could be an important aspect of life history research but would have to be accompanied by a thorough understanding at the outset of planning the research and what this would require in terms of time, resources, training in research with vulnerable and, at times, illiterate individuals.

Therefore, even though we often, with qualitative research, ask individuals whether they would like to have their own names used, and for a long time this was seen as part of disability empowerment, the researcher must take the responsibility of ensuring that the participant really understands. If you have any doubt, then you should rather encourage them to remain anonymous.

In my research study I conducted this process together with Judith who was fulfilling her role of cultural insider and assisting me to integrate "other(ed) ways of knowing".[19(p5)] Thambinathan et al.[19] confirm these techniques and processes as a method of decolonizing qualitative research. We also together engaged in critical debate around the aspect of anonymity, keeping each other accountable throughout.

Sixth, I became aware of African communitarian ethics (specifically aspects of consent) only in the final stages of my research, which are relevant to Dikeledi's story.[3] Even up until the point of writing this synthesis, I was in WhatsApp communication with Lerato. She had stated numerous times how she and Naledi missed me. They were still living in Maganeng with their extended family, hoping to return to Mamelodi one day. When I considered asking her for a chosen pseudonym, I did not anticipate that Lerato would respond in the way in which she did. She said that, firstly, she would need to speak about it with her sister. Once she had spoken about it with Naledi, they said they would have to discuss it with their uncle. Since I was concerned about the information being misconstrued, I decided that we needed to go to Maganeng (about three hour's drive away) to ensure we could engage with the family and discuss our involvement with Dikeledi and her daughters. I prepared myself by doing what Ellis[13] suggests: critically reflecting on what had already occurred, asking important questions, and discussing the research with others. This included what would be culturally appropriate steps to take. I consulted with a colleague who understood Dikeledi's culture, who assisted me with deciding what to say, how to say things and what gifts to bring. We bought live chickens in Maganeng, before arriving at the

home. I had printed some pictures of Dikeledi, Lerato, Naledi and us, and showed an example of my reflexive note I made when Lerato had called me to tell me that her daughter had been born. I reflect on this experience and my engagements with the family in the e-book. In my review of existing literature, I have become more aware of African communitarian ethics within biomedical research.[3,20] However, I was unable to source literature related to this within life history research or in autoethnographic research, although, generally, research suggests caution when using the latter methodology.[21-22]

Going forward, I suggest that we consider the importance of African communitarian ethics within life history research. This may include that consent is sought from the immediate family (in this case, assent from Lerato and Naledi) or receiving consent from an elder in the family. Since public health research is so deeply embedded within communities, we must constantly ask ourselves what ethical criteria we are using in Africa and are they adequate.

Seventh, Dikeledi's story also highlights the ethics of conducting research in communities where people are living in poverty. The informed consent document that I used with the three participants had been approved by a rigorous ethics committee. When I discussed the consent form with Judith as part of the research-assistant training, she challenged me on the dangers of the following paragraph, "In terms of remuneration, if you have agreed to participate in the study, please can we have a conversation about how I could in some way return a favour to you for participating in the study. I am hoping that this relationship will be mutually beneficial." She said that creating an expectation for people that you would give them something for participating in the research process would skew the information you would receive. I did not interrogate this at the time and removed the sentence. I did not anticipate, however, that we would become as involved in voluntary community work as we did. However, we never provided the participants with any financial remuneration throughout the study.

It became clear later that especially Boitumelo would continue to believe that she would receive either food or money, months into data collection. Additionally, what became clear during our visit with Dikeledi's family in Maganeng is that Lerato (and possibly her aunts and uncle) had hoped that they would receive a financial benefit through the publishing of Dikeledi's story. Judith and I emphasised that, unfortunately, this was not like publishing another book where the author receives royalties. Instead, it was an available e-book free of charge and thus did not include any financial gain for us or for them.

I, consequently, reviewed the literature and realised that Gelinas et al.[23] (in a 2020 publication) concluded that payment for economically vulnerable populations is, more often than not, justified and even desirable. In a more recent 2022 publication, Różyńska[24] argues that researchers have a moral obligation to offer payment to their participants to compensate for their time and valuable

contributions that they offer. Since my relationship with the participants and their families is ongoing, I will review the payment aspect going forward.

The eighth ethical consideration is how to ensure the anonymity of the individual when family consent is received together with permission to share the story. Individualised autonomy stems from the West, whereas in Africa, we need to acknowledge this within collective, social or communal autonomy (which normally takes precedence).[3,25-26] An integrated, informed consent approach which is founded on the theoretical perspectives of Afro-communitarianism, should be considered.[25]

Literature reflects on African ethics and how a decision-making process is applied in an African community.[26] What has been argued is that the concept of individual autonomy is one from the West, whereas, in Africa, it is more important to understand social or communal autonomy.[26] African cultures include the importance of respecting the elders in the community, which is why I had to obtain permission from Lerato's uncle and aunt as part of building trust and ensuring that African ethics were taken into account.[27]

Hyder et al.[28] does highlight the importance of building trust with communities in long-term community-engaged research. However, this is mostly where the whole community is researched and does not focus on a situation like Dikeledi's. Trust is built by having open disclosure at the onset of the study, and continuously throughout the study. Similar ethics should be employed in long-term life history research with families and/or households.

Finally, I believe that it is our ethical responsibility to invest seriously in the relationships with our research participants. This includes being aware of the power differentials and where they do not honour the other person, doing what we can to reduce them.[29] One of the ways how this can be endeavoured is through vulnerably sharing appropriate personal information. An example of this is taken from Anna's story where I share,[30(p33-4)]

> *"It seemed as if she had just completely given up on life. That the loss she had experienced, had blinded her to life around her. I proceeded to tell her about the loss my sister had gone through last year, when her husband died from suicide. I shared the details of her household, with my sister having four children – the youngest of which was five months at the time of his death. I tried to explain how we cannot give up on life when we lose someone – we must continue for those who are around us. Anna looked at me with eyes of empathy – as she reached out and offered her condolences."*

The above quote demonstrates how I was able to establish a connection with Anna by sharing my own experience of loss and death. Through this, I was able to develop deeply interpersonal hermeneutic relationships. As such, I have not tried to separate my bias since, within the data collection, analysis and methodology, I am myself embedded and intertwined.

So, this answers an unintended question, namely, “How do we ethically research vulnerable populations in resource-constrained contexts?” I think we have an ethical responsibility here. Ethics committees have become so intent on protecting the community through some pre-defined criteria; however, as I have demonstrated by the consent I received to conduct this research, these criteria do not necessarily ensure that there is an ongoing relationship that has been proven to be more than extractive before the commencement of the proposal. This means that the questions that are asked may be determined from behind our laptops in our offices, in our ivory towers far away from where the people live. And, therefore, the research question being asked may not be the correct question at all. Had I met the various households in my study at the beginning, before going in with my pre-defined criteria, would their food security have been the starting point of our conversation?

I do not think it would have been. Far more so, the situation of Anna’s depression, the abuse that Dikeledi was facing and the vulnerability of her daughters, Boitumelo’s boredom and lack of employment, leading to the voices consuming her thinking – I believe these would have been forefronted. This would have provided more insight into the complexity that was evident from the beginning and the need for an action-based research study. Yes, participatory action-based research studies have gained significant momentum over the last number of years, and the importance of relationships and partnerships with the community has been demonstrated.[31] The principles of participatory action-based research should be adopted within other research methodologies (both qualitative and quantitative).

5.4. The face of the other: Transformative ethical research

I was nervous when I commenced this journey. I suspected it might involve risk-taking, the biggest of which was willing to merge various schools of thought with my own spiritualty and a deep desire for transformation through the research process. Early in the proposal development stage, I had been challenged in my authenticity about whether I – who had not experienced rape, living in a shack with a leaking roof, or having to feed three children without an income, had any authority to talk about the lives of vulnerable women. I remembered my supervisor detailing that I would come under attack being a white woman researching black lives during this research process. Questions started arising of whether I really could do this research, whether what I was going to try and do, was supposed to be done by me, or rather someone else with a different skin colour, different socioeconomic status, differently abled, different outlook of the world. Someone who would be able to tell the story better, with less bias and greater accuracy.

Since I knew that I had committed to this particular question, I was led on a quest to establish my positionality and to fully prepare myself for the challenges that might arise. I gleaned guidance from researchers writing retrospectively on the research process, their personal journeys and what they discovered, or providing an autoethnographic account of what they learnt ‘doing’ the research.[32-34] I

also perused literature which outlined specific research processes and preparation that the researcher could do.[35-36] Various aspects of this were discussed in the introductory chapter. I present here how I tried to prepare myself and the consequent lessons I learnt as I undertook the research.

5.4.1 Dealing with difference

There has been a continuous debate over the last 25 years about white women researching black lives.[37] Feminist literature responses in favour of this research argued that researchers empower those who may otherwise not have access to public forums by providing them with a voice.[38] Sometimes, the researchers have certain characteristics in common with the participants and thus can represent them.[38]

There are numerous accounts of white researchers researching black lives,[39-40] as well as black researchers researching black lives.[32] Ochieng[32] argued that because of her commonality with her research participants, in being black, from African descent and living in the United Kingdom and the participatory approach that she utilised, she was able to establish a baseline of trust and openness for their conversations. In addition to this, she was able to empathise with their struggles, understand the families better and create a safe environment for the participants to examine each other's values and experiences.

I am a white, able-bodied, HIV-negative woman living in an upper/middle-class home in Pretoria, South Africa. I have a steady income and have never known involuntary hunger that could not be satisfied through obtaining or purchasing food. Thus, I am different in every way (except being a woman) to the inclusion criteria for my participants in the research study.

The intersectoral feminist approach allows for differences in race, gender and class. Therefore, it was important to examine this in the context of power differentials.

5.4.2 Power

Feminist literature has been concerned with the power relations between participants and researcher. Henry[35] summarises much of this complexity in power, including privilege, academics' positionalities, and that power is fluid and shifts. I had previously encountered some of these power differentials in my academic work whilst supervising students on community-situated WIL in peri-urban communities. Some of the students expressed that those who were white, working within black communities, held more power to evoke change than those students who were black. Conversely, they felt that the black students were able to get a clearer picture of the lives of the black clients because of the assumption of commonalities, expressed in "You know how it is". Hall[41] has challenged commonalities of gender to being power-diminishing, since she has experienced ethnicity to be a more powerful difference in certain interactions, which has to be accounted for. Therefore, I needed to be aware that my whiteness could be seen as providing power beyond what my femaleness would be a commonality. I

consider myself fortunate that I had gotten married since embarking on this PhD journey and now have a daughter. I used this as an additional commonality that may be held with women in the field since culturally, motherhood is seen as an important rite of passage in womanhood.

Henry[35(p76)] notes again that "without authority and authenticity, it is difficult to occupy a position within which to exercise agency. Agency stems from autonomy and provides a researcher with the ability to take action but is contingent upon the specificities of the field and 'home'". I needed to be aware of the ever-changing spaces of the different participants and communities to ensure that authority and power do not negatively limit relationships. However, by being authentic and real, the data collection process will be more thorough and representative.

Power can also be used for good. I used the perceived power I held three times when it came to the intervention required: In making the psychiatric appointment for Anna, I used my power as a health care professional and employee of the University to request for her to be seen as soon as possible; when taking Andries to the casualty unit where, under ordinary circumstances, he would not have been taken into the line, I relied on my whiteness, as being seen to be different in the unit; when entering the ward where Andries was, I used the power that was held in my UP staff badge, and hospital staff (without question) assumed I was a doctor and thus able to enter the ward outside of visiting hours.

5.4.3 But what does it really mean to be different?

Plaskow[42] brings forward the questions that were asked at the 1991 annual meeting of the American Academy of Religion in Kansas City, Missouri in a session titled "Appropriation and Reciprocity in Womanist/Mujerista/Feminist Work" in interrogating how to deal with difference which goes beyond a narrow list of our own particularity. During this meeting, Toinette Eugene asked, "When is acknowledgement of one's own social location a starting point for genuine engagement with other perspectives, and when does it surreptitiously function as a disclaimer of responsibility for the effects of one's own history, as if acknowledging the existence of sexism, racism, and so on were an end point rather than a beginning?"[42(p91)]

Therefore, I cannot just list the differences I held compared to my research participants. I need to ask what does this mean? How could my differences guide me in the research?

I found an answer in Walker's[43] explanation of third-wave feminists where she explained that the lines which separate them and us often become blurred and, instead, it is possible to have multiple positionalities and ambiguous identities. This was building on the second-wave U.S. postmodern feminists who had criticised the second-wave U.S. global feminists for their binary viewpoints of the world and that they appeared incapable of overcoming these oppositions, for example, "developed nation/developing nation, White/non-White, rich/poor".[44(p31)]

5.4.4 A new way

At this point, I realised that I needed to enter the research process with a new way of looking at it. Perhaps non-academic texts which resonated with my spirituality could provide some insights. Bell[45] states that love is giving away power. He goes on to explain that if we take loving another person seriously, then we have to surrender any desire that we may have to manipulate the relationship.[46] Therefore, I needed to enter the community from a position of love.

> *"When I respect the image of God in me. When Jesus speaks of loving our neighbour, it isn't just for our neighbour's sake (Matthew 22:39, which is from Leviticus 19:18). If we don't love our neighbour, something happens to us. And in trying to protect the image of God in them, we just might be protecting the image of God in ourselves in the process. Because with every decision, conversation, gesture, comment, action, and attitude, we're inviting heaven or hell to earth."*[45(p14)]

If I came forward with love, then I could also look at the situation from a unified way, which does not posit dualities at the forefront.

> *"In the beginning, God created us "in his image." So first, God gave us an image to bear. Then God gave us gender: male and female. Then God gave us something to do, to take care of the world and move it forward, taking part in the ongoing creation of the world (Genesis 1-11). Later, people began moving to different places. It takes years and years of human history to get to the place where these people are from here and those people are from there. Different locations, skin colours, languages, and cultures come much later in the human story."*[45(p9)]

This would not mean that I would not be critically aware of the political processes that come with researching 'the other'. Herein I was again brought back to my daily readings and perusal of contemporary Christian literature, where there has been a focus on the face of the other.

5.4.5 The face of the other

The following extract from Richard Rohr is illustrative hereof:

> *"In Jesus, God was given a face and a heart. God became someone we could love. While God can be described as a moral force, as consciousness, and as high vibrational energy, the truth is, we don't (or can't?) fall in love with abstractions. So, God became a person "that we could hear, see with our eyes, look at, and touch with our hands" (1 John 1:1). The brilliant Jewish philosopher Emmanuel Levinas says the only thing that really converts people is "the face of the other." He develops this at great length and with great persuasion. When the face of the other (especially the suffering face) is received and empathized with, it leads to transformation of our whole being. It creates a moral demand on our heart that is far more compelling than the Ten Commandments. Just giving people commandments on tablets of stone doesn't*

change the heart. It may steel the will, but it doesn't soften the heart like an I-Thou encounter can. So many Christian mystics talk about seeing the divine face or falling in love with the face of Jesus. There is no doubt that was the experience of Francis and Clare. I think that's why Clare uses the word "mirroring" so often. We are mirrored not by concepts, but by faces delighting in us, giving us the face, we can't give to ourselves. It is the gaze that does us in!"[47(para2)]

Throughout the research process, I have become increasingly aware of human suffering and how this has become a transformative process. Morley[48] gives possible responses to suffering, namely compassion for others, learning patience, becoming holy and engaging. Of course, there are also negative responses to suffering. Richard Rohr has been quoted widely as saying that if your pain does not transform you, you transmit it.

5.4.6 Transformative research

As Tong[44] expressed for herself, I also realised *my own* lack of feminist consciousness and/or feminist action. Does my research call me to action at the same time? Before I commenced data collection, I started asking myself questions, "Do I need to start volunteering at a soup kitchen or start a food distribution service? Would that in some way make my research more valuable because I would show that I really care about who and what I am studying?"

What occurred during the research process would be far different from volunteering at a soup kitchen. That is the transformational process that can occur in embedded relational research. As the Bible states, love is action. Therefore, my initial lack of action could attest to a lack of love. Since love in many ways is the answer to ensuring power dynamics are limited, and sincerity is brought forward, my action needs to be acute and telling.

Coffey[49] has noted that it is necessary, and even desirable, for us to recognise that we are a part of our study, that we are affected, shaped and changed by what we experience whilst conducting fieldwork. Therefore, this type of research can bring us to a point where we are forced to re-conceptualise ourselves. This goes beyond a narrow understanding of fieldwork. Bridging this with Rohr's construction of the small (false) self and the true self, one can, thus, potentially, through the research process, discover the true self.

Rohr[50(para5)] also states, "When you have not yet learned what transformation feels or looks like, someone – perhaps some loving human or simply God's own embrace – needs to hold you now because you cannot hold yourself. *When we experience this radical holding, and even deep loving, this is salvation!"*

5.5. Critique of the study

Regarding the descriptive exploratory design used for the first objective, it would have been more valuable, had the population been the educators in UP's School of Health Care Sciences. This would

have provided contextual information for the implementation of my recommendations. This could have been further improved, if a mixed-methods national research study had been conducted, to determine the state of education for healthcare professionals across the country.

The life history research should have included all household members, to obtain a holistic household narrative from all members of the household. Currently, the narrative remains focused from the perspective of the women in the household. Going forward, as far as possible, consent should be included for all household members at the outset of a qualitative study. When doing data collection within someone's home, the dynamics are so fluid and unpredictable. The study would have benefitted from in-depth interviewing with all household members instead of working only through one person and Judith and my reflections.

In terms of the narrative part of the study, a necessary component for trustworthiness, as described by Guba in Shenton[51], is that of confirmability – namely, for myself to admit my own assumptions and beliefs and be able to recognise that the study has shortcomings, in both its methods and the potential effects of these methods. I therefore here share the very painful limitations about this study and the work that Judith and I did as volunteer community workers.

I wish I had known about Dikeledi's illness and subsequent death earlier to be able to offer greater support to Lerato. I still wonder whether, had I known what I know now in terms of how the system works and if I had the connections I now have, would Dikeledi have died, or could I have intervened earlier and ensured that the potential causes of her death would have been prevented? Could I have assisted Lerato more so that she would have received intervention earlier to ensure that she did not have to deal with the trauma of the loss of her mother on her own? Currently, I am working at trying to provide ongoing assistance as is possible, with the research participants.

Conducting data collection intermittently over a four-year period means that the analysis was an ever-changing dynamic. This has also resulted in a significant delay in the dissemination of the data, which has ethical dilemmas. For example, when I spoke with the various CHW groups in trying to source participants for the study, I said that after the study was complete, I would return to them and share the information that had been found with them. I have not yet done so. I returned to the CHWs a year into my data collection when I started working at UP, to provide an opportunity for the students to work with the CHWs. Over the next three years, we worked with all the different CHW teams, over and above the two I had visited as part of the recruitment procedure. This included the CHWs as already described in the previous section.

The final critique would be that I would like to have completed detailed training of the participants in information ethics prior to the commencement of the data collection and implemented process ethics throughout the study.

5.6. Strengths and considerations

Even though I did not complete thorough training in research with the research participants in the study, I have, however, conducted ongoing training for Judith regarding different methodologies, reflexivity, data analysis and academic writing. In addition, Dr Michelle Janse van Rensburg and I co-wrote an article with Judith on her experiences as a community worker (see: Mahlangu JM, Lister HE, Janse van Rensburg MNS. My experiences in health science education and research: a community worker's autoethnographic account. In: Moeti T, Padarath A, editors. South African Health Review 2019. Durban: Health Systems Trust; 2019. Available from: http://www.hst.org.za/publications/Pages/SAHR2019).

Training and development of a community worker is a significant strength of this study. This is also an important part of my activist role.[19] Whilst COPC incorporates the PAR process, it does not incorporate training of the community members to become co-researchers. Judith has experienced significant growth since becoming a research assistant in 2017. As described in the preamble, Judith has since established her vital role as both an academic, as well as a community liaison. Even though we continue advocating for posts for community members as non-academics within the field of community-engaged research, her journey has become an important example of someone who will succeed, despite the human resource system not enabling their inclusion.

As a consideration of this study, I acknowledge that it is not probable for someone else to have sourced the same themes or similar interpretations from having conducted a life history study with these women for the reasons described previously. This is because I became so deeply embedded within their lives, and through consistent interpretation, influence and discussions, the life history of both women changed. As mentioned, this was largely based on who I am, my spirituality, being an occupational therapist and becoming, first, a volunteer community worker and then working for the UP within my profession in the community.

Since narrative studies do not come from a positivistic framework, I do not aim to generalise the findings statistically. Also, the study does not attempt to obtain data saturation. The small sample size allowed for data that has richness and expresses multiple layers, detailed information, and explains the complicated and intricate details.[52]

Addressing food security at an educational level at the entry-point of the study may seem in stark contrast to the narrative nature of the remainder of the study. However, in that lies the beauty of this study: that highly qualitative research can enrich and showcase traditionally quantitative public health studies.

5.7. Recommendations

There are several important recommendations that I have prioritised below with some suggestions for timeframes.

5.7.1 The HHCM

I recommend that the newly developed model, the HHCM, undergoes further development and review. It will initially need to be reviewed by a pilot group of CHWs in the community. Given my existing relations with the CHWs in Mamelodi, a training programme can occur over a period of six weeks with a specific team and incorporate the following:

- Introduction to the HHCM and how it was conceptualised
- Using the HHCM to describe a household that each CHW is overseeing
- Making additions or changes to the HHCM as feedback is received from the CHWs
- Setting tasks that involve collective problem-solving with the household to determine an array of interventions for the various challenges experienced and observed
- Engaging in feedback on the use of the HHCM

Once this has been completed, it will be valuable to make any required adjustments to the HHCM based on the feedback received from the CHWs. Following this, additional feedback will be required from a wider audience. This will hopefully also arise when the third article is published and allows for changes and improvements.

The above-mentioned may be completed as a further research project, or once the HHCM has been critiqued, its application and value should be researched. This can be completed within the COPC research unit at the University of Pretoria.

Throughout this process, the HHCM should include the development of a practical tool that can be used in the health care system. This will require the investment of additional interprofessional team members as well as the CHWs, to ensure the tool is user-friendly, practical, useful, and can be used in the evaluation and to provide evidence-based practice regarding its implementation. Of special consideration here are the timeframes that exist for HH visits, and the current challenges that CHWs experience. Ensuring that CHWs are co-creators of the tool, would aid the relevance and use of the model.

As discussed in the epilogue of the second manuscript, the model currently solely serves as a visual tool and does not incorporate a programme for data analysis. However, there is a possibility of future development to enable precise translation of measurements of disruptions and shocks' magnitude and their impact on households and individuals to quantifiable changes in the properties of the bands.

This would also allow for very specific research in validation of the use of the model, as well as evidence on how it can be used to improve health care services and wellbeing of the household.

Following this, the HHCM can be incorporated into health professions education. At the University of Pretoria, the health care sciences students participate in a shared module called Integrated Healthcare Leadership (IHL). This module is compulsory for all health care sciences students, including physiotherapy, occupational therapy, speech-language pathology, audiology, nursing, radiography and human nutrition. Assessment in this module could include a long-answer in a test or an essay about how students would best support the household. Further, existing health and social care professionals, including public health specialists, social workers and psychologists, would benefit from being trained in the model.

5.7.2 Policy recommendations

I recommend that we continue advocating for rigorous community ethics within our ethics boards so that there is more co-researching occurring with the community, where community members are partners in the research process. Even though previously, health ethics research review boards have undergone scrutiny about their representation of community members, this should come to the forefront again.[53]

Policy that is derived from statistical information received from existing food security measurements, should be interrogated to assess how the statistical data derived from food security questionnaires and metrics has been interpreted. It is pertinent to incorporate studies based on qualitative methodologies into the development of policies, to ensure that the complexity evident on the ground is addressed.

5.7.3 Practice recommendations

I recommend that the e-books are shared with educators in health professions education to be used as resources or case studies for student review. I am a member of the Southern African Association of Health Educationalists (SAAHE) and could use this as a means of disseminating the information about the e-books. They can also be used during the training of the HHCM with the CHWs. The e-books could also be a data source for other research questions, including researching African community ethics.

Beyond the HHCM, I recommend that food security and disability should receive more rigorous attention in health professions education and CHW education, within training institutions nationally and internationally. Locally, this will also be possible within the UP IHL curriculum, either in their second year or third year, which would allow for all allied health care professionals to be exposed to and understand the complexity and incorporate it within their evaluation and intervention strategies. I will suggest this addition into the curriculum in 2024. It will be valuable to conduct a study then to

determine whether incorporating food security into this module has made a difference in the understanding of the students and in their professional practice.

I suggest that the community of Mamelodi receive training in digital wellness and information ethics, specifically related to self-disclosure. I have previously been part of a project in Mamelodi with the African Centre of Ethics for Information Ethics (ACEIE) of the University of Pretoria. This centre coordinates teaching, research, contracts, projects, and other activities relating to Information Ethics in the Department of Information Science. When this training has been completed, we can determine who would want to share their stories themselves.

5.7.4 Research recommendations

There are numerous research recommendations that have been made within the HHCM. Besides this, other research studies are suggested below:

- Community members who have been trained in research ethics should be incorporated into research studies and specifically into co-designing of the research studies. This could include CHWs, in researching their training received and their wellbeing.
- A mixed-methods study where the first objective of this study's population is extrapolated to all the healthcare professionals across South Africa, to determine the education of disability and food security. This would provide updated information since the study has been conducted and create conversations with persons from all institutions, to take the recommendations of this study forward.

5.8. Take-home thoughts

Initially, when I developed the proposal, I had hoped to be presenting a new model of understanding food security that could be taken forward into programmes such as the World Food Programme (WFP). I did not anticipate that, through the research process, the focus would shift from food security to the complex adaptive system that is evident in the household.

Fortunately, from the time that I commenced the study to its completion here now, there has been a transformation in research evaluation that has also occurred since my biggest concern was whether I had followed and done everything I was supposed to do for a PhD? Did I do the right thing? Is this what the examiner will need to read? In doing so, I spent years trying to make sense of what had happened, compared to writing it down already in the early stages, and represent a PhD on food security.

However, I believe that it is through this time that I have been able to demonstrate that love and love in action are necessary to occur in research conducted in vulnerable communities. Additionally, I am not sure that I would have been able to develop the HHCM earlier since I did not have the

understanding and insights that I have now. I hope that, as the years continue, I will be able to add value to it and that through this, it will really benefit our COPC approach within the community and the many households we serve.

5.9. References

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APPENDIX A: Full ethical approval (Research question 1)

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

7 December 2016

Mrs Helga Elke Koch
School of Health Sciences
Westville Campus

Dear Mrs Koch

Protocol reference number: HSS/1740/016
Project title: Teaching about disability and food security in the School of Health Sciences, University of KwaZulu-Natal

Full Approval – Expedited Application

In response to your application received 14 October 2016, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

.....

Dr Shenuka Singh (Chair)
Humanitities & Social Scinces Research Ethics Committee

/pm

cc Supervisor: Dr Jacky van Wyk, Dr Karien Mostert & Prof Mershen Pillay
cc. Academic Leader Research: Professor Mershen Pillay
cc. School Administrator: Ms P Nene

APPENDIX B: Full ethical approval (Research question 2 and 3)

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

1 November 2016

Mrs Helga Elke Koch 209541532
School of Nursing and Public Health
Howard College Campus

Dear Mrs Koch

Protocol reference number: HSS/1064/016D
Project title: Food Security: An exploration of women living with HIV and disability in vulnerable contexts

Full Approval – Expedited Application

In response to your application received 14 July 2016, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

.....

Dr Shenuka Singh (Chair)
Humanities & Social Sciences Research Ethics Committee

/pm

cc Supervisor: Professor Mershen Pillay
cc. Academic Leader Research: Professor B Sartorius
cc. School Administrator: Ms Caroline Dhanraj

APPENDIX C: Gatekeeper – Registrar permission

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

12 October 2016

Ms Helga Lister (nee Koch)
School of Health Sciences
College of Health Sciences
Westville Campus
Email: kochh@ukzn.ac.za

Dear Ms Lister

RE: PERMISSION TO CONDUCT RESEARCH

Gatekeeper's permission is hereby granted for you to conduct research at the University of KwaZulu-Natal (UKZN) provided Ethical clearance has been obtained. We note the title of your research project is:

"Teaching about disability and food security in the School of Health Sciences, University of KwaZulu-Natal".

It is noted that you will be constituting your sample as follows:

- with a request for responses on the website. The questionnaire must be placed on the notice system http://notices.ukzn.ac.za. A copy of this letter (Gatekeeper's approval) must be simultaneously sent to (govenderlog@ukzn.ac.za) or (ramkissoonb@ukzn.ac.za).

Please ensure that the following appears on your questionnaire/attached to your notice:

- Ethical clearance number;
- Research title and details of the research, the researcher and the supervisor;
- Consent form is attached to the notice/questionnaire and to be signed by user before he/she fills in questionnaire;
- gatekeepers approval by the Registrar.

Data collected must be treated with due confidentiality and anonymity.
You are not authorized to distribute the questionnaire to staff and students using Microsoft Outlook address book.

Yours sincerely

MR SS MOKOENA
REGISTRAR

APPENDIX D: Ethical approval – Tshwane Research Committee

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Dr. Lufuno Razwiedani
Tel: +27 12 451 9036
E-mail: lufuno.razwiedani@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE: CLEARANCE CERTIFICATE

MEETING:
PROJECT NUMBER: 80/2017
NHRD REFERENCE NUMBER: GP_201708_007

TOPIC: Food Security: An Exploration of Women living with HIV and disability in vulnerable contexts

Name of the Researcher:	Mrs. Helga Elke Koch
Name of the Supervisor:	Prof. Mershen Pillay
Facility:	Stanza Bopape CHC
Name of the Department:	University of KwaZulu-Natal

NB: THIS OFFICE REQUEST A FULL REPORT ON THE OUTCOME OF THE RESEARCH DONE AND

NOTE THAT RESUBMISSION OF THE PROTOCOL BY RESEARCHER(S) IS REQUIRED IF THERE IS DEPARTURE FROM THE PROTOCOL PROCEDURES AS APPROVED BY THE COMMITTEE.

DECISION OF THE COMMITTEE: APPROVED

.....
Dr. R. Oyedipe
Acting Chairperson: Tshwane Research Committee
Date: 03/11/2017

.....
Ms. M. Lerutla
Acting Chief Director: Tshwane District Health
Date: 04/11/17

APPENDIX E: Ethics amendment (Research question 1)

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

17 January 201

Mrs Helga Elke Koch
School of Health Sciences
Westville Campus

Dear Mrs Koch

Protocol reference number: HSS/1740/016
Project title: Teaching about disability and food security in the School of Health Sciences, University of KwaZulu-Natal

Approval notification – Amendment Application

This letter serves to notify you that your application for an amendment dated 16 January 2017 has now been granted **Full Approval**.

- **Amendment to Research Project Regarding Data Collection: Use of Telephone**

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Best wishes for the successful completion of your research protocol.

Yours faithfully

.....

Dr Shenuka Singh (Chair)
Humanities Social Sciences Research Ethics

/pm

cc Supervisor: Dr Jacky van Wyk, Dr Karien Mostert & Prof Mershen Pillay
cc. Academic Leader Research: Professor Mershen Pillay
cc. School Administrator: Ms P Nene

APPENDIX F: Ethics approval – recertification 1

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

18 January 2022

Helga Elke Lister (neé Koch) (209541532)
School of Nursing & Public Health
Howard College Campus

Dear HE Lister,

Protocol reference number: HSS/1064/016D
Project title: Food Security: An exploration of women living with HIV and disability in vulnerable contexts

Approval Notification – Recertification Application

Your request for Recertification dated 09 April 2021 was received.

This letter confirms that you have been granted Recertification Approval for a period of one year from the date of this letter. This approval is based strictly on the research protocol submitted and approved in 2016.

Any alteration s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study must be reviewed and approved through the amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

All research conducted during the COVID-19 period must adhere to the national and UKZN guidelines.

HSSREC is registered with the South African National Research Ethics Council (REC-040414-040).

Yours sincerely,

Professor Dipane Hlalele (Chair)

/ms

APPENDIX G: Ethics approval – recertification 2

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

21 September 2022

Helga Elke Lister (neé Koch) (209541532)
School of Nursing & Public Health
Howard College Campus

Dear HE Lister,

Protocol reference number: HSS/1064/016D
Project title: Food Security: An exploration of women living with HIV and disability in vulnerable contexts

Approval Notification – Recertification Application

Your request for Recertification dated 12 September 2022 was received.

This letter confirms that you have been granted Recertification Approval for a period of one year from the date of this letter. This approval is based strictly on the research protocol submitted and approved in 2016.

Any alteration s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study must be reviewed and approved through the amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

All research conducted during the COVID-19 period must adhere to the national and UKZN guidelines.

HSSREC is registered with the South African National Research Ethics Council (REC-040414-040).

Yours sincerely,

Professor Dipane Hlalele (Chair)

/ms

APPENDIX H: Information letter to academic staff

Dear Respondent,

Project title: Teaching about disability and food security in the School of Health Sciences, University of KwaZulu-Natal.

My name is Helga Lister (nee Koch) and am a staff member in the Occupational Therapy Department, School of Health Sciences, at UKZN. The aim of this study is to determine information about the teaching about disability and food security in the School of Health Sciences, at UKZN. This project forms a part of the Sub-Saharan Africa FAIMER Regional Institute (SAFRI) fellowship and is being supervised by Dr Karien Mostert, Physiotherapy Department, University of Pretoria and Prof Mershen Pillay, Speech and Language Pathology Department, UKZN. I am managing the project, and should you have any questions, my contact details are:

- Cell: 072 2526 313
- Email: kochh@ukzn.ac.za

My supervisors contact details are:

- Telephone: 0823127159
- Email: Karien.Mostert@up.ac.za

This project has been provided with ethical clearance by the HSSREC, ethical clearance number HSS/1740/016 as well as from the UKZN registrar. The Research Office contact details are:

HSS Research Office

- Govan Bheki Building
- Westville Campus
- Contact: 0312604557
- Email: mohunp@ukzn.ac.za

Your participation in this project is voluntary, and you may refuse to participate or decide to withdraw at any time with no negative consequence. There will be no monetary gain from participating. Your details will remain confidential at all times, and where necessary, pseudonyms will be used.

The questionnaire survey should take you about 30 minutes to complete. I hope you will take the time to complete this survey. Your participation will help me to understand what is taught about food security and disability in the School of Health Sciences at UKZN. The results are intended to contribute to understanding the complicated relationship between disability and food security, and to establish whether further input into the undergraduate Health Science curriculum is required.

If you agree to participate, please proceed to the completion of the online questionnaire. By doing this, you provide consent to participate in the research project.

APPENDIX I: Sourcing participants interview guide

Good morning. Thank-you so much for allowing me into your home and making the time to meet with me. I am very excited to learn more about you. I believe you have met Judith who is going to be working with me. My name is Helga Lister. Is there anything that you would like to know about me?

Since this is a research process, there are a few things that we need to discuss first, before we actually start talking. I want you to know exactly why I am here, and what is the purpose of this study. I also am hoping to make it clear that I care for your wellbeing, and that throughout this entire process that will be the most important thing to me. So please let me know if at any stage you are unhappy or uncomfortable with the research or do not want to continue with the research.

Today I would just like to meet with you and have a chat about who you are. I am meeting a few women, but I will not be working in the long run with everyone. It all depends on how you see me, and what we talk about today, to see whether we will have some more conversations into the future. If you feel like you don't want to work with me or proceed working with me you are welcome to say. I may also find that I need to talk with someone else for the research, and then I will let you know. You might or you might not be part of the final three people that I will be working with in the end.

Do you have any questions so far?

So let us get through the formal part, which is to talk about your consent to be a part of this study. I will read through it, and if at any part you have any questions, please interrupt me, or ask me at the end.

To be followed by information document (annexure B) and informed consent (annexure C)

Let's start.

1. Please tell me more about yourself.
2. (Prompt – who are you, where are you from, do you have a family?)
3. (Prompt – how old are you, did you go to school, what disability to you have?)
4. What does food mean for you in your life?
5. How do you get food?
6. How do you store food?
7. How do you prepare food?
8. How do you eat?
9. Do you know of any food that is available which you cannot get for some reason?
10. In the past 12 months, did you go hungry because there wasn't enough food?

11. Did you or your household run out of money to buy food during the last 12 months. If this happened, has it occurred 5 or more days in the last 30 days?
12. Did you cut the size of meals during the last 12 months because there was not enough food to eat in the house? If this happened, has it occurred 5 or more days in the last 30 days?
13. Did you skip any meals during the last 12 months because there was not enough food in the house? If this happened, has it occurred 5 or more days in the last 30 days?
14. Did you eat a smaller variety of food during the last 12 months than you would have liked to, because there was not enough food in the house? If this happened, has it occurred 5 or more days in the last 30 days?
15. How would you describe your disability?
16. When did you get disabled?
17. How has your disability influenced you getting or eating food?
18. How is your family / household involved?
19. Can I talk about something more sensitive – How does your illness influence your life (HIV)?
20. Do you get ARVs?
21. How do they influence your life?
22. Is there anything else that you would like to talk about for now?

Thank-you so much for your time. I am going to have a chat with the other women, and then let you know about our way forward.

APPENDIX J: Information document for narrative data collection and consent to participate

(Again) My name is Helga Lister (nee Koch) (student number 209541532). I am doing research on a project entitled Food Security: An exploration of women living with HIV and disability in vulnerable contexts.

(As I said) It is a pleasure to meet you and I am hoping that after I have read through this document, and if you agree to participate to the study, that we will be able to establish a good relationship. I am looking forward to getting to know you better.

This project forms a part of my PhD thesis and is being supervised by A/Prof Mershen Pillay, Department of Speech Language Pathology, University of KwaZulu-Natal. I am managing the project and should you have any questions my contact details are:

- Cell: 072 2526 313
- Email: kochh@ukzn.ac.za

Before we start I would like to emphasize that your participation in the study is entirely voluntary and you may discontinue your participation at any time i.e. if you do not wish to answer any question I have asked you to, you are in no way obliged to do so.

The first interview will be approximately one to one and a half hours to complete. After this, I may wish to return and have more interviews with you, in order to get more clarity and further information. You will not encounter any risks or discomforts during the study and the study will benefit us, as public health practitioners, to better understand food security of women living with HIV and disability in vulnerable contexts. This in turn should benefit the women who will be in a similar situation such as you.

The interview will be kept strictly confidential and will be available only to members of the research team. Excerpts from the interview however will form a part of the final dissemination of results. Unless you have agreed to otherwise, pseudonyms will be used.

This discussion and any documents will be digitally recorded (or video-recorded if you agree) and once utilized in the results and analysis, will be stored securely for a period of five years as stipulated in the University research rules, after which they will be deleted or disposed of appropriately.

Please sign the informed consent form to show that I have read the contents to you and that you have understood them.

Please sign the informed consent form to show that I have read the contents to you and that you have understood them.

Study Title: Food Security: An exploration of women living with HIV and disability in vulnerable contexts

Please accept terms by ticking the following boxes.	**Tick**
I have been asked to participate in the above research study	
I have been informed about the study by Mrs. Helga Lister, from the Department Public Health, whom I may contact on 072 2526 313 if I have any questions about the research.	
I am aware that I may contact the Ethical Clearance Office (Human and Social Sciences) where inquiries may be directed to Ms. Phumelele Xiba on 031 260 4538 if I have any questions about the research.	
I am aware that my participation in this research is voluntary and I will not be penalised in any way if I refuse to participate or decide not to answer every question. I retain the right to withdraw at any time and am aware that my details will be kept confidential.	
I agree to video footage being taken and used in the dissemination of the research results to the academic community and policy makers.	
I agree to digital recordings being taken and used in the dissemination of the research results to the academic community and policy makers.	
I agree to photographs being taken and used in the dissemination of the research results.	
I would like my personal details to be disclosed and my personal name utilised in the dissemination of results.	

I have the following personal remarks:

Declaration:

The research study, including the abovementioned information has been explained to me in the information document. I understand what the study means and I voluntarily agree to participate.

_____	_____
Signature of Participant	Date
_____	_____
Signature of Research Assistant	Date
_____	_____
Signature of Researcher	Date

APPENDIX K: Information document for narrative data collection and consent to participate (Sepedi Translation)

Karolo ya mathomo: Dokumente ya go hlalosa kgobakano ya kanegelo

Karolo ya bobedi: Kwano ya go tsenela kgobakanyo ya kanegelo

(Gore e badiwe ke mo nyakišiši ge mo tseneli a palelwa ke go bala, pele bothomong bja poledišano)

Leina laka kenna Helga Lister (nee Koch) (nomoro ya moithuti: 209541532). Ke dira di nyakišišo ka go bolokega ga dijo: Go lebelela basadi bao ba phelago ka bolwetši bja HIV le ba golofetšego mo mafelong a bokoa.

Kea itumela go kopana le lena gomme ke tshepa gore morago ga go bala dokumente ye, gomme ge le dumella go tsenela dinyakišišo, gore retla kwišišana ka boitshepegi. Ke ekemešeditše go šoma lewena.

Projekte ye, e ka le hlakoreng la di thuto tsa PhD ye ke e dirago ka tlase ga Prof Mershen Pillay yo a tšwa go le fapeng la Speech Language Pathology, Yunibesithi ya KwaZulu Natal. Ke hlokomela projekte gomme ge o nale dipošišo o ka letsetsa

- Nomoro: 072 252 6313
- Email: kochh@ukzn.ac.za

Pele reka thoma ke rata go gatelela gore ga ke gapeletši motho go tsenela dinyakišišo, gomme o ka kgona go thlogela nako engwe le engwe. Ge o sa batle go araba dipošišo tse ke go bošišago o nale tokelo go se arabe.

Poledišano ya ma thomo e tlo ba gare ga iri ye tee le iri ye tee le metsotso ye lešome tharo. Morago ga se, nka lakaletsa go ba le dipoledišano tše dingwe le wena go gwetša kwišišo. O kase tsene mathateng goba o sa ekwe gabotse mo dinyakišišong. Dinyakišišo tše ditlo thuša rena babereki ba Public Health go kwišiša ka go bolokega ga dijo tsa basadi bao ba phelago ka bolwetši bja HIV le ba golofetšego mo mafelong a bokoa.

Poledišano ye le dikomente di tla bolokiwa ka sepiri gomme di tla kgwetšagala go baleloko ba dinyakišišo. Ditemana mo poledišanong ditlo somišwa mo di karabo bofelelong bja dinyakišišo. Eupsa ge o dumetsi ka tsela engwe, mabitso a boralokišo a tlo šomišwa.

Poledišano ye gomme le di dokumente di tlo rekodiwa gomme morago dia šomišwa go gwetša dinyakišišo, ditla bolokiwa mo sepiring mengwaga ye mehlano katsela ye ehlališitšwego mo melaong ya Yunibesithi, morago dia tlošiwa kamolao.

Ge o dumetši go tsenela di nyakišišo, re ka boledišana ka tsela yenngwe ya gore nka bosetša bjang maitemogelo gore o tsenele dinyakišišo. Ke tshepa gore kamoka ga rena retlo gweša mepotso.

Ke gopela gore le saine kwano ya go tsenela go bontsha gore ke go baletse ditla morago gape gore o a di kwišiša.Hlogo karolo ya dinyakišišo: Go bolokega ga dijo: Go lebelela basadi bao ba phelago ka bolwetši bja HIV le ba golofetšego mo mafelong a bokoa.

Ke kopa o dumele ka go maraka ka leswao mo mabokising a latelago	**Leswao (✓)**
Ke kopilwe gore ke tsenele dinyakišišo tša karolo ya tšeo di hlalositshego mo godimo?	
Ke boditšwe ka dinyakišišo tša karolo ke Mrs Helga Lister, yo a tswago Lefapa la ba šomedi ba Public Health, yo nka mo letšetšago go 072 252 6313, ga ke nale di potšišo ka dinyakišišo.	
Ke a tseba gore nka letšetša ba Ethical Clearance Office (Human and Social Sciences) mo di potšišong di ka fetisetšwa go Ms Phumelela Xiba go 031 260 4538 ga ke nale di potšišo ka di nyakišišo.	
Ke a tseba gore go tsenela dinyakišišo, a ka gapeletšwa ebile ga ke tlo tsena mathateng le ge ke sa dumele go araba dipotšišo. Ke nale tokelo ya go tšwa nako engwe le engwe gomme kea tseba gore di tlabakelwana tšaka ga di tlo tsibišwa.	
Ke a dumela gore di video tše di tšhwerego di šomišwe go hlalosa di karabo tsa di nyakitšišo.	
Ke a dumela gore di nepe tše di tšhwerego di šomišwe go hlalosa di karabo tsa di nyakitšišo.	
Ke kopa gore di tlabakelwana tsaka di šomišwe gomme le mabitso aka gore a šomišiwe go hlalosa di karabo tsa di nyakišišo.	

Ke na le ditshwayotshwayo tse di latelago:

_____

_____

_____

Tsebišo:

Di nyakišišo gomme le tseo di ngwešigo godimo di hlalošišwe gonna ka se si ngwešigo mo dokumenteng. Kea kwišiša dinyakišišo gomme ke dumella go tsenela kabo nna.

_____	_____
Signature ya motseni	Letšatšikgwedi
_____	_____
Signature ya mothuši wa monyakišiši	Letšatšikgwedi
_____	_____
Signature ka monyakišiši	Letšatšikgwedi

APPENDIX L: Information document for narrative data collection and consent to participate (Setswana Translation)

Karolo ya ntlha: Dokumente ya go thlalosa kgobakano ya kanegelo

Karolo ya bobedi: Kutlwano ya go tsenela kgobakanyo ya kanegelo

(Gore e badiwe ke mo mmatlisisi fa mo tsenedi a palellwa ke go buisa, pele go ka simololwa ka puisano)

Leina la ka ke Helga Lister (nee Koch) (nomoro ya moithuti: 209541532). Ke dira di patlisiso ka polokego ya dijo: Go lebelela basadi ba ba tshelang ka bolwetse ba HIV le ba golofetseng mo mafelong a bokoa.

Ke itumella go kopana le wena mme ke tshepa gore morago ga go bala dokumente e, mme fa o dumela go tsenela dipatlisiso re tla utlwisisana ka botshepegi. Ke ikemiseditse go dirisana le wena.

Projeke e, e mo letlhakoreng la di thuto tsa PhD e ke e dirang ka fa tlase ga Prof Mershen Pillay yo o tswang kwa lefapeng la Speech Language Pathology, Yunibesithi ya KwaZulu Natal. Ke thlokomela projeke mme fa o na le dipotso o ka letsetsa

- Nomoro: 072 252 6313
- Email: kochh@ukzn.ac.za

Pele reka simolola ke rata go gatelela gore ga ke pateletse ope go tsenela dipatlisiso, mme o ka kgona go tlogela nako nngwe le nngwe. Fa o sa batle go araba dipotso tse ke go botsisang, o na le tokelo ya go se arabe.

Puisano ya ntlha e tlo ba gare ga ura e le nngwe kgotsa ura e le nngwe le metsotso e lesome tharo. Morago ga se, nka eletsa fa go ka nna le dipuisano tse dingwe le wena go fitlhelela kutlwisiso e botoka. O ka se tsene mo mathateng mme gape o ka se tlhoke phuthulogo mo patlisisong. Dipatlisiso tse di tlo thusa badiri ba Public Health go utlwisisa ka go bolokega ga dijo tsa basadi ba ba phelang ka bolwetse ba HIV le ba golofetseng mo mafelong a bokoa.

Puisano e tla bolokiwa ka sephiri mme e tla bonwa ke ba leloko ba dipatlisiso. Kwa bofelong ba dipatlisiso, ditemana tse dingwe tsa dipuisano di tla dirisiwa jaaka karolo ya di karabo tsa dipatlisiso. Ntle ga gore o dumetse ka tsela e nngwe, maina a boitlhamelo a ile go dirisiwa.

Puisano e le didokumente di tlo rekodiwa mme morago di a dirisiwa go fitlhela dipatlisiso, di tla bolokiwa mo sephiring dingwaga tse tlhano ka tsela e e tlhalositsweng mo melaong ya Yunibesithi. Morago di a tloswa ka molao.

Fa o dumetse go tsenela di patlisiso, re ka buisana ka tsela e nka go busetsa jang maitemogelo gore o tsenetse dipatlisiso. Ke tshepa gore botlhe re tla bona meputso.

Ke kopa gore o saine kutlwano ya go tsenela dipatlisiso go bontsha gore ke go buiseditse di tla morago ebile gore o a di utlwisisa.Tlhlogo karolo ya dipahlisiso: Polokego ya dijo: Go lebelela basadi ba ba tshelang ka bolwetse ba HIV le ba golofetseng mo mafelong a bokoa.

Ke kopa o dumele ka go maraka ka letshwao mo mabokising a a latelang	**Letshwao (✓)**
Ke kopilwe go tsenela dipatlisiso tse dithlalotsitsweng mo godimo.	
Ke boditswe ka dipatlisiso ke Mrs Helga Lister, yo o tswang Lefapha la ba diri ba Public Health, yo nka mo letetsang mo 072 252 6313, fa ke na le dipotso ka dipatlisiso.	
Ke a itsi gore nka letsetsa ba Ethical Clearance Office (Human and Social Sciences) moo dipotso di ka fetisetswang go Ms Phumelela Xiba go 031 260 4538 fa ke na le di potso ka di patlisiso.	
Ke a itsi gore go tsenela patlisiso, ga ka gapeletswa ebile ga ke tlo tsena mo mathateng le ge ke sa dumele go araba dipotso. Ke na le tokelo ya go tswa nako e nngwe le e nngwe mme ke a itsi gore di tlabakelwana tsa ka ga di tlo itsisiwe.	
Ke a dumela gore di video tse di tserweng di dirisiwe go tlhalosa di karabo tsa dipatliitsiso.	
Ke a dumela gore di nepe tse di tserweng di dirisiwe go tlhalosa di karabo tsa dipatliitsiso.	
Ke kopa gore di tlabakelwana tsa ka di dirisiwe mme le maina a ka gore a dirisiwe go tlhalosa di karabo tsa dipatlisiso.	

Boikanyo:

Dipatlisiso mme le tseo di kwetsweng mo godimo di tlhalositwe go nna ka se si kwetsweng mo dokumenteng. Ke tlhaloganya gore dipatlisiso di raa goreng mme ke dumela go tsenela ka boithaopo.

_____ _____

Signature ya motseni Letsatsikgwedi

APPENDIX M: Research assistant information sheet

My name is Helga Lister (nee Koch) (student number 209541532). I am doing research on a project

This project forms a part of my PhD thesis and is being supervised by A/Prof Mershen Pillay, Department of Speech Language Pathology, University of KwaZulu-Natal. I am managing the project, and should you have any questions my contact details are:

- Cell: 072 2526 313
- Email: kochh@ukzn.ac.za

Before we start I would like to emphasize that your participation in the study is entirely voluntary and you may discontinue your participation at any time.

The methodology chosen is a life history methodology, which will consist of a number of interviews with three research participants. At first, I would like to you contact at least six potential participants who would be available for an initial discussion. This will form a pilot interview, during which their suitability will be evaluated. Following this, at least a further three interviews will occur, during which the life story as well as reflections will occur.

You will not encounter any risks or discomforts during the study and the study will benefit us, as public health practitioners, to better understand food security of women living with HIV and disability in vulnerable contexts.

The discussions we will have, will be kept strictly confidential and will be available only to members of the research team. Excerpts from these discussions however will form a part of the final dissemination of results. Unless you have agreed to otherwise, a pseudonym will be used.

This discussion and any documents will be digitally recorded and once utilized in the results and analysis, will be stored securely for a period of five years as stipulated in the University research rules, after which they will be deleted or disposed of appropriately.

In terms of remuneration, if you have agreed to participate as the research assistant, you will be remunerated for your time in alignment with the university payment structure.

During this research study, you have the following rights:

1. The right to safety: I will try and ensure that your risk of harm from participants and the environment will be minimized. Please let me know if at any stage you are concerned about where an interview is going to take place.
2. The right to informed consent: This right is being addressed in this information document and the informed consent sheet.

3. The right to refuse to participate in data collection activities that one finds objectionable: You can refuse to engage in any activities that you find objectionable.
4. Right to withdraw: You have the right to withdraw during an interview or the study at any point, without penalty.
5. Right to counselling and notification of incident if harm occurs: You have the right to have any incident reported to either my supervisor or the research ethics committee if you experience any form of harm. You also have the right to counselling, if required.
6. Right to proper training: You have the right to be trained before commencing your research duties.
7. Right to feedback: You have the right to receive feedback about your performance. We will go through a process of continuous evaluation based on the requirements of the research and your performance herein.
8. Right to debriefing: You have the right to know the outcome of this study.
9. Right to receive benefits form the work performed: As discussed, you will be remunerated for the work that you have done. You will not receive remuneration for the work you have withdrawn from.
10. Right to choose confidentiality in public acknowledgements: You have the right to keep your name unassociated from this study and for it not to be published in any reports or presentations associated with it.

Please sign the informed consent form to show that I have read the contents to you and that you have understood them.

APPENDIX N: Research assistant informed consent

Study Title: Food Security: An exploration of women living with HIV and disability in vulnerable contexts

Please accept terms by ticking the following boxes.	**Tick**
I have been asked to participate as a research assistant in the above research study	
I have been informed about the study by Mrs. Helga Lister, from the Department of Public Health, whom I may contact on 072 2526 313 if I have any questions about the research.	
I am aware that I may contact the Ethical Clearance Office (Human and Social Sciences) where inquiries may be directed to Ms. Phumelele Xiba on 031 260 4538 if I have any questions about the research.	
I am aware that my participation in this research is voluntary and I will not be penalised in any way if I refuse to continue to participate as research assistant. I retain the right to withdraw at any time and am aware that my details will be kept confidential.	
I agree to digital recordings being taken of our conversations.	
I would like my personal details to be disclosed and my personal name utilised in the dissemination of results.	

Declaration:

The research study, including the abovementioned information has been explained to me in the information document. I understand what the study means and I voluntarily agree to participate.

_____ _____

Signature of Research Assistant Date

APPENDIX O: Research assistant confidentiality agreement

I, _____, agree to assist the researcher of this study, Helga Lister, in completing the following tasks: community entry, obtaining research participants for the study, organizing interviews, translating research interviews, explaining cultural and linguistic nuances, and any other aspects which may arise ad hoc during the research process. I agree to maintain full confidentiality when performing these tasks.

Specifically, I agree to:

1. keep all research information shared with me confidential by not discussing or sharing the information in any form or format with anyone other than the researcher;
2. hold in strictest confidence the identification of any individual that may be revealed during the course of performing the research tasks;
3. not make copies of any raw data in any form or format, unless specifically requested to do so by the researcher;
4. keep all raw data that contains identifying information in any form or format secure while it is in my possession. This includes:
    - keeping all digitized raw data in computer password-protected files and other raw data in a locked file;
    - closing any computer programs and documents of the raw data when temporarily away from the computer; and
    - permanently deleting any e-mail communication containing the data;
5. give, all raw data in any form or format to the researcher when I have completed the research tasks;
6. destroy all research information in any form or format that is not returnable to the researcher (e.g., information stored on my computer hard drive) upon completion of the research tasks.

Printed name: _____

Address: _____

_____ _____

Signature of Research Assistant Date

_____ _____

Signature of Researcher Date

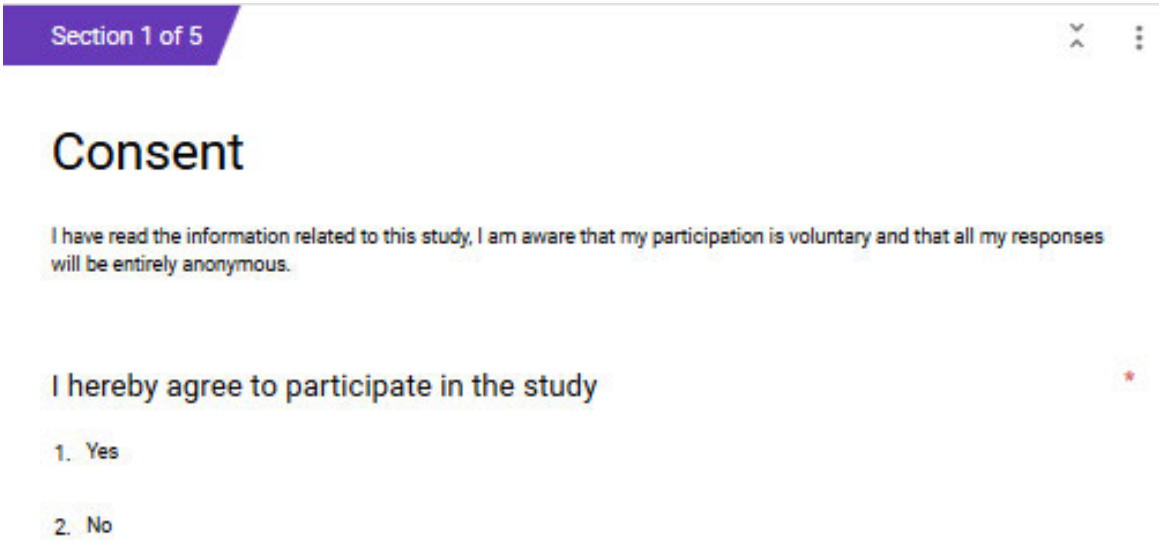
APPENDIX P: Research assistant job description and research participation

Please find a summary of the job description included for this research study, as well as the request for research participation. Please note that this list is not exhaustive, and further responsibilities may be required from time to time as directed by the principal researcher.

- Recruitment of research participants
- Translator within interviews
- Manage and respond to project related emails
- Attend meetings with the principal researcher
- Arranging meeting and ensuring consent from gatekeeper
- Participate in discussions regarding the context of the participants
- Feedback regarding the interviews on cultural nuances and understandings
- Keep notes of meetings and write personal reflections regarding researcher-research assistant relationship
- Provide ongoing feedback to the principal researcher regarding the research process
- Arrange transport as necessary to the various interviews
- Performance of other related duties as required
- Contribute to the writing up of a publication as discussed during the research process (this will not be remunerated)

As a research assistant, you will be required to have the following job skills:

- Communication: You need to be able to speak and write about your findings clearly as well as understand instructions. Communication may occur orally, in writing or electronically.
- Attention to detail: Finding the right information requires concentration
- Critical thinking: Use decisive reasoning to determine the best course of action within the data collection
- Technical skills: Use computers to aid in the research process
- Liaison and networking
- Pastoral care: Showing consideration to others and appreciating the neds of individuals
- Work environment: Be aware of the risks in the work environment and their potential impact on their own work and that of others.



Section 1 of 5

Consent

I have read the information related to this study, I am aware that my participation is voluntary and that all my responses will be entirely anonymous.

I hereby agree to participate in the study *

1. Yes
2. No

1. Biographical Data

Description (optional)

1.1 UKZN email address *

Short answer text

1.2 Full Name

Short answer text

1.3 Discipline

1. Audiology
2. Occupational Therapy
3. Optometry
4. Physiotherapy
5. Speech Language Pathology
6. Sports Science

1.5 Employment Level

1. Senior Tutor
2. Junior Lecturer
3. Senior Lecturer
4. Associate Professor
5. Professor

1.6 Employment

1. Part-time
2. Practical supervision only
3. Full-time

Section 3 of 5

Section 2 - Knowledge about food security and disability

Description (optional)

2.1 Please provide a definition of food security, as you understand it

Long answer text

2.2 Please provide a definition of disability, as you understand it

Long answer text

2.3 Explain the relationship between disability and food security as you understand it

Long answer text

Section 4 of 5

Section 3 - Attitude about teaching food security and disability in teaching

On a scale of 1 to 5, with 1: definitely exclude from teaching; 2: possibly exclude from teaching; 3: neutral; 4: important to include in teaching; 5: essential to include in teaching; how important do you think it is to teach students on the following:

3.1 The definition of food security

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.2 The shifting ways in which food security has been defined

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.3 The field of food security within its broad historical and developmental contexts

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.4 The influence of the wider current social, political, environmental and economic contexts on food security

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.5 The prevalence of food insecurity

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.6 The measurement of various aspects of food insecurity

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.7 The consequences of food insecurity

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.8 National and international policy and programme responses

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.9 The macro factors influencing the food security of persons with disabilities

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.10 The micro factors influencing the food security of persons with disabilities

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.11 How to incorporate food security into the assessment of persons with disabilities

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

3.12 How to incorporate food security into the treatment of persons with disabilities

	1	2	3	4	5	
Definitely exclude in teaching	○	○	○	○	○	Essential to include in teaching

Section 5 of 5

Section 4 - Current practice of teaching about food security and disability

4.1 What do you currently teach that incorporates disability and food security?

Long answer text

4.2.1 Do you think students are currently equipped with treating and advising persons with disabilities with food insecurity problems?

- No
- Somewhat
- Yes

4.2.2 Justify your answer to the previous question

Long answer text

Thank-you for participating in this study.

Description (optional)

Chapter 6: POSTLUDE: ACKNOWLEDGEMENTS

It takes a village…

When you spend so many years on your PhD, there are many, many people to thank. Each one of them, offering a unique contribution, care, sacrifice or loving word. Whilst the list will never be exhaustive, once I started writing, I realised the endless amount of love and care in my life that has contributed to this final thesis. I could not do it on my own – and therefore want to acknowledge the extended support I have received, direct or indirect; known or unknown.

To my husband, Bruce

Figure 6-1: My husband

I believe that this PhD is only possible because one plus one equals seven. For God knows the plans he has for us… plans for a hope, a future, life in abundance. Thank-you for asking me to be your wife. Thank-you for where we've been, where we are, and where we are going. Thank-you for sticking by me, even though it was hard. Thank-you for being a man of integrity, wisdom, and courage. I love you. I will strive to be more and do more. You have my heart.

Figure 6-2: Hope endures (credit Heiko von Fintel)

To my dearest angel daughter, Rachel

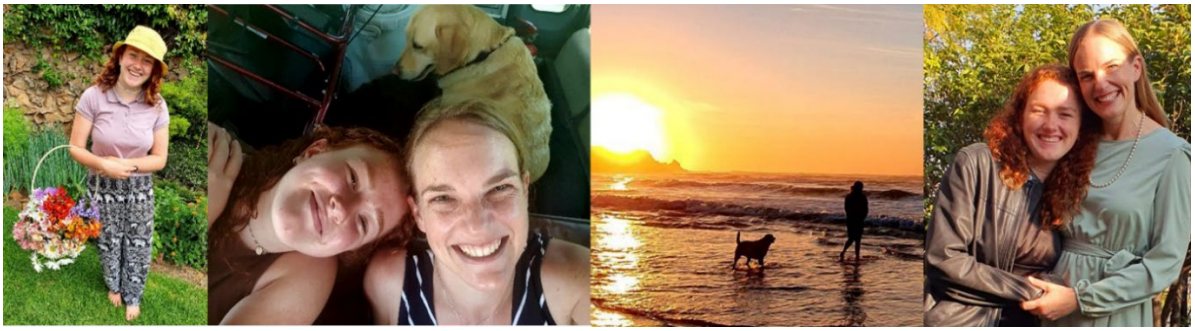


Figure 6-3: My daughter

You are the loveliest, most wonderful human. You embody everything I strive to be. The world is your oyster. So many things you have still to experience, and so many mistakes you don't have to make. You have all the skills you need in life to make really good choices – to flourish; to become a blessing to all around you; and to live our life in fullness and meaning. I cannot wait to see how you will use your incredible character and wisdom to make a difference in this world.

To my parents

Figure 6-4: My parents

Thank-you for praying for me without fail, every single night. It's time we replace this picture with a new one! Thank-you Dad, for staying alive for us. Danke fuer Eure Treue. Ihr seid die Besten.

To Prof Mershen Pillay

Figure 6-5: My supervisor

My dear supervisor, who was there throughout. You were the most encouraging and supportive supervisor I could have asked for. Thank-you for not getting tired of saying, “You will do this, Helga. You will get there!” Your critical thinking and creativity continue to inspire me to search deeper.

To my participants and their families who became friends

Figure 6-6: My participants

From left to right: Boitumelo; Dikeledi and Anna

Thank-you for entrusting me with your lives, for sharing so vulnerably; for not giving up on me, for caring. Thank-you for your effort to understand the research process. Thank-you for persevering. Thank-you for giving of yourself, so that others may be helped.

To my Funders

Figure 6-7: My funders

The work conducted in this PhD, as well as life associated with it, would not have been possible without the generous financial support from the following organisations:

The South African Medical Research Council: Thank-you for selecting me as a beneficiary of the National Health Scholars Programme. Your ground-breaking support (through the Public Health Enhancement Fund) for post-graduate students in health-related studies has paved the way for many lives to be changed.

To the Sub-Saharan Africa-FAIMER Regional Institute (SAFRI): Thank-you for your support of the first article, by granting me a fellowship.

To the National Institute for the Humanities and Social Sciences (Catalytic Project CRP20-1032): Thank-you for sponsoring the writing retreat, during which I was able to refocus and do the groundwork for my third article.

Thank-you so much to both University's (UKZN and UP) for at varying stages, funding some of my yearly registration fees.

To those who have actively been involved in contributing to this PhD

Figure 6-8: My helpers

From top left to bottom right: Prof Karien Mostert, Judith Mahlangu, Marizanne Booysens, Nabeela Kharva, Dr Margot Graham, Martin Giebler, Kirstin Niebuhr, Glenda Makate, Dr Jo Hunter Adams, Dr Michelle Janse van Rensburg, Prof Kitty Uys, Prof Sue van Zyl, Dr Karin van Niekerk, Sagren Naidoo

- Michelle – Thank-you for being there throughout; from the original days we started talking about CHWs, to the many PhD working sessions, to UP supervision assistance, and now, just a heart and heart collaborative world to help change things for the better. I am forever indebted to you, for your endless late nights and extra work that you have done to support me. Thank-you for tackling everything with such dedication.
- Judith – wow, what a journey it has been. Thank-you for always getting me to think again, to remember and to fight (in the right way) – you have such an incredible heart. I really pray that the future will become just ever so slightly easier.
- Kitty – the best boss anyone could ever ask for. Thank-you for supporting and encouraging me in all my endeavours; for believing in me, and for allowing me to fly. Thank-you for all the assistance specifically in getting this done. I really hope to make you proud.

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To UKZN Public Health Department

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To my Lister Family

Figure 6-9: The Lister Family

From left to right: The Lister family; Gordon and Helga; Charlie and Olly; Matthew

Douglas, Jamie, Oliver, Charlie, Roger, Karen, Tessa, Pete, Connor, Neil, Mikaela, Cameron, Jack and Matthew. Thank-you for your love and support. Gordon, thank-you for your interest and encouragement that you have for my work.

To my Floyd Family

Figure 6-10: The Floyd Family

From left to right: Having fun; Pa George and Ma Maud; the extended Floyd and Channon family

Colin, Susan, Nicola and James, Steve and Lezelle. Thank-you for taking me in as your own. Pa George and Ma Maud, you have been there for me through all of this, thank-you!

To my Koch family

Figure 6-11: The Koch family

From left to right: The marathon at the start in Pietermaritzburg; somewhere along the way; at the finish

My siblings (Ronell and Johann), their spouses (Thinus and Marianne), my nieces and nephews (Mikayla, Vaugn, Clara, Erin and Mattie), thank-you that you never stopped believing that I would finish. Thank-you for all your love, care, and endless cheer-leading. To Jabu, thank-you for all you did for us growing up.

To Betty and Lukas

Figure 6-12: Memories with Betty and Lukas

From left to right: Visiting the aeroplane museum; Lukas on his birthday

For being a part of the story. Thank-you for helping to keep the house running, whilst I was busy working!

To our dogs and cat

Figure 6-13: Our pets

Ben, Kino, Holly, and Lisa… For all the times you sat by me on the bed or floor or couch, whilst I plodded along on the laptop. Thank-you for making life such fun.

To all my friends (and family), who have always asked, "How is it going with your PhD?"

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To my current and past community team

Figure 6-14: The community team

From top left to bottom right: Nthabiseng Phalatse, Dr Michelle Janse van Rensburg, Judith Mahlangu, Joenita Frederichs, Renske Senekal, Marike Smit, Mashudu Nemakanga and Heila Fourie

You are and have been the best teams I could have wished for. What an absolute joy to work with you who are women (and men) of my heart. Thank-you for holding the fort when required, for not giving up, for taking all the crazy ideas and supporting me through them.

To my extended community team

Figure 6-15: The extended community team

From top left to bottom right: Muneiwa Rachel Ramakuwela, Silo Kunene, Ina Grobler, Malebo Moshokoa, Sindiswa Thandeka Ntshingila, Sebenzile Msibi, Judith Mahlangu, Nthabiseng Phalatse, Mpho Christinah Netshilavulu, Helga Lister, Mpho Teresa Makeka, Shika Ndhundhuma Joenita Friedrichs, Menantau Pierneef, Kagiso Mathabathe

For helping improve mental health in the city of Tshwane. Thank-you for your dedication to the development and growth of our students.

To my previous colleagues at UKZN

Figure 6-16: The UKZN-staff team

From left to right: Research presentation day - Prof Deshini Naidoo, June McIntyre, Andiswa Mbtha, Mathias Müller-Nedebock, Helga Lister, December Mpanza (soon to be Dr), Deepa Sing, Chantal Christopher (soon to be Dr), Shan Dhasiar, Thavanesi Gurayah (soon to be Dr), Stanford Mandlenkosi Phehlukwayo, Debbie Fester (soon to be Dr); My farewell day at UKZN – additionally in second photo: Ntokozo Cele, Gina Rencken (soon to be Dr), Julie Lingah; Colloquium – additional in third photo: Dain van der Reyden, Prof Robin Joubert

For being a part of the family that grounded me in my love for academia and community work. Thank-you for sharing so generously, and your support, especially for the extra work you did during the time of the grant. Thank-you also for all those from other departments and the community members with whom I worked in the Valley of 1000 Hills and KwaDabeka.

To my current (and previous) colleagues at UP

Figure 6-17: The UP-staff team

From top left to bottom right: Boitumelo Kube, Suzanne Nel, Prof Daleen Casteleijn, Jenna d'Oliveria, Monique Franks, Raashmi Balbadhur, Mashudu Nemakanga (soon to be Dr), Dr Karin van Niekerk, Helga Lister, Prof Kitty Uys, student Marelie Germishuys being awarded with the vice-chancellor's medal of academic excellence, Tania Buys, Helga Lister, Bontle Morulane, Tania Buys, Henry Msimango, Jodie de Bruyn, Veronica Ramodike, Mashudu Nemakanga, Eileen du Plooy, Dr Enos Ramano

- Tania: I remember coming to your office many years ago – and you providing me advice (2009?) – fly on the wings of your masters to your PhD. At that stage it seemed an impossibility – and now it is here. Thank-you for always having an open door, a listening ear, for giving so much of yourself.
- Daleen: Thank-you for coordinating OTX100 for me in 2021 and all your extra help with post-graduate supervision
- Suzanne: Thank-you for your peer mentorship, kindness and checking-in
- Raashmi: Thank-you for all your extra help with post-graduate supervision, and motivational messages

- Tumie: Thank-you for being such a fantastic administrator

And everyone else (Jodie, Jenna, Enos, Veronica, Henry, Eileen), who took on extra work to help during some of the darkest months of my life and for providing me with support, so that I could work on my PhD. To my new colleagues, Sharifa Moosa Tayob and Ntombi Hankwebe, I look forward to working with you.

Figure 6-18: Colleagues in other disciplines and faculties

From left to right: Dr Martina Jordaan, Prof Lize Kriel, Dr Suzi Malan, HW Snyman Building (Health Sciences Campus), Administration Building (Mamelodi Campus)

- Martina: Thank-you for all your words of wisdom, and for providing me with so many opportunities.
- Lize: Thank-you for arranging the NiHSS Writing retreat which got me back on track again
- Suzi: Thank-you for your support, encouragement, and care
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To my COSUP colleagues and friends – past and present

Figure 6-19: Colleagues and clients from COSUP

From left to right: Melusi Shabalala; having a shisa nyama with students and COSUP colleagues, Thabiso Phakathi working with a client in creating a video; group session activity

Thank-you for your partnership. You inspire me every day in the work that you continue doing. To Melusi – one day we will meet in heaven again. And we will laugh and cry together. And it will be glorious.

To my AfrIPEN family

Figure 6-20: AfrIPEN memories

From left to right: At the interprofessional.global symposium; the AfrIPEN board; at the AfrIPEN conference in Kenya

Elize Peterson, Dr Champion Nyoni, Dr Christmal Christmals, Dr Gerard Filies, Dr Farhin Delawala, Prof Firdouza Waggie, Gibson Masasche, Hanlie Pitout (almost Dr), Jana Muller, Judy Khanyola, Dr Moselene du Plessis, Nthabiseng Phalatse, Dr Renata Eccles, Dr Luzaan Kock, Fiston Kitema, Shalote Chipamaunga-Bamu, Estelle Viljoen, Penny Orton, Juliet Savanhu, Paula Jardim and Dr Stefanus Snyman. Thank-you for being awesome!

To my SAFRI Family

Figure 6-21: SAFRI memories

From left to right: On my birthday and day of engagement at the in-person sessions for SAFRI; SAFRI graduation 2017; receiving my certificate

SAFRI, the Sub-Saharan Africa-FAIMER Regional Institute. Thank-you for the opportunity and privilege to be part of the fellowship programme and for all your support in publishing the first article of this study.

To my church family

Figure 6-22: Representing the church family

From left to right: Heather Phillips during children's church; crafts activities; child engaging in crafts; John and Ann van der Valk; Alan and Cathy Cordes

Thank-you to our biblestudy group: Myles and (Dr) Christy Davidson, Theunis and Karin Stoffberg, (Dr) Johann and (Dr) Claire Rossouw, Danie and (Dr) Mariza de Villiers, Kristof Zielinksi; John and Ann van der Valk, Alan and Cathy Cordes, Rev Grant and Ann Thistlewaite, for your constant love. Thank-you to Heather Philips, who took over leading and managing the children's church ministry at St Wilfrid's Anglican church.

To my past, present and future occupational therapy students

Figure 6-23: Students past and present

From top left to bottom right: End of block Community WIL closure; celebrating a birthday in Mamelodi, working with clients in a temporary shelter; reflection sessions; Siyathemba clinic; Holy Cross Old Age Home; RakNomination at UKZN; painting at COSUP; with COSUP clients

Thank-you to all my past and present students, both at UKZN and at UP, postgraduate, and undergraduate… you have inspired me to keep on going. I am here because of you.

To my granny club

Figure 6-24: The Granny Club

Anja Küsel, Brigitte Böhmer, Kläre Dell and Liska Hambrock. You are my oldest friends. You know me intimately. Who would have thought that things would go the way that they did. Thank-you for your continued encouragement. Much pain we have experienced individually and collectively. May we continue to be transformed in our pain, so that we can use it to touch others.

To my dearest OT friends

Figure 6-25: Erika Hinze and Karen Powell

From left to right: Winning a computer; with Dr Ilse Eggers at our oath taking; Midmar Mile 2014

Erika: you were there when I won my first computer. Karen: we did all our fourth-year fieldwork together. Both of you were there when Dr Ilse Eggers said at our oathtaking ceremony at the end of our fourth year, one of you will make it to where I am today. And so, I become the first one in our class of 2004, to submit my PhD. And then, dear Karen and Alex, were the ones to introduce me to my husband. Thank-you, Erika and Karen, for your friendship, memories and love over all these years. You have been the most wonderful and precious friends.

To the Ortmann Family

Figure 6-26: The Ortmann Family

What a life we've shared! Thank-you for being a special family. Thank-you, Imke, for your extra help.

To my Omi

Figure 6-27: My Omi

I wish you were still here. Your love for others shines on! Thank-you for all you taught me.

To Osborn Nkosi – the King

Figure 6-28: Memories with Osborn Nkosi during my year in Vryheid, 2005

From left to right: Osborn's first ever birthday party; attending disability awareness events; in Cape Town visiting Robben Island

You gave me my name. I would never have known that this name I would carry with me, wherever I went. Thank-you for choosing with such wisdom. Thank-you for everything.

To my past self

Figure 6-29: Growing up

From top left to bottom right: My first day of kindergarten; reading at home; in front of our home on the farm; in my room growing up; master's degree ceremony; Ted-X event in Durban – "Share your story"

Embrace what has brought you here; learn from your mistakes; and never-ever stop growing.

To my present self

Give back to all those who helped you.

Ripples

When you create a difference
In someone's life,
You not only impact their life,
You impact everyone influenced by them
Throughout their entire lifetime.
No act is every too small.
One by one,
This is how to make an ocean rise.

Author unknown

Do all the good you can, in all the ways you can, to all the souls you can, in every place you can, at all the times you can, with all the zeal you can, as long as ever you can.

John Wesley

To my future self

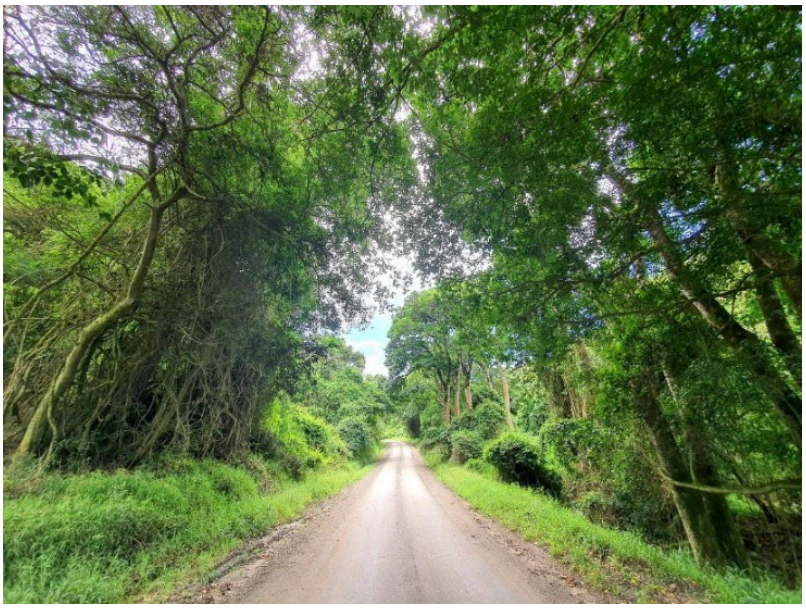

Figure 6-30: A Canopy of trees in a portion of the National Addo Elephant Park

May you continue to paddle hard; swim upstream, and never give up.

"Each of you should use whatever gift you have received to serve others, as faithful stewards of God's grace in its various forms." 1 peter 4:10 NIV

To my triune God

To my heavenly Father, thank-you for being with me in the darkest of hours. In the place where nobody goes. For being with me there and holding me tight.

To Christ, for being my best friend.

To the Holy Spirit, for working in and through me. Thank-you, that I know without a doubt, I am living my calling.

God Bless Africa;
Guard our children;
Guide our leaders
And give us peace, for Jesus Christ's sake.
Amen.

Soli Deo Gloria