

CHAPTER 5

CONCEPTUALISATION AND GUIDELINES FOR THE OPERATIONALISATION OF COMMUNITY-BASED COLLABORATION TO SUPPORT THE OLDER PERSON IN THE WORLD OF HIV/AIDS

Chapter 5 focuses on phase 3, **step 6** and **step 7**, illustrated in the schematic layout (see figure 5.1) that indicates the chapter in relation to the phases, steps and objectives of the study.

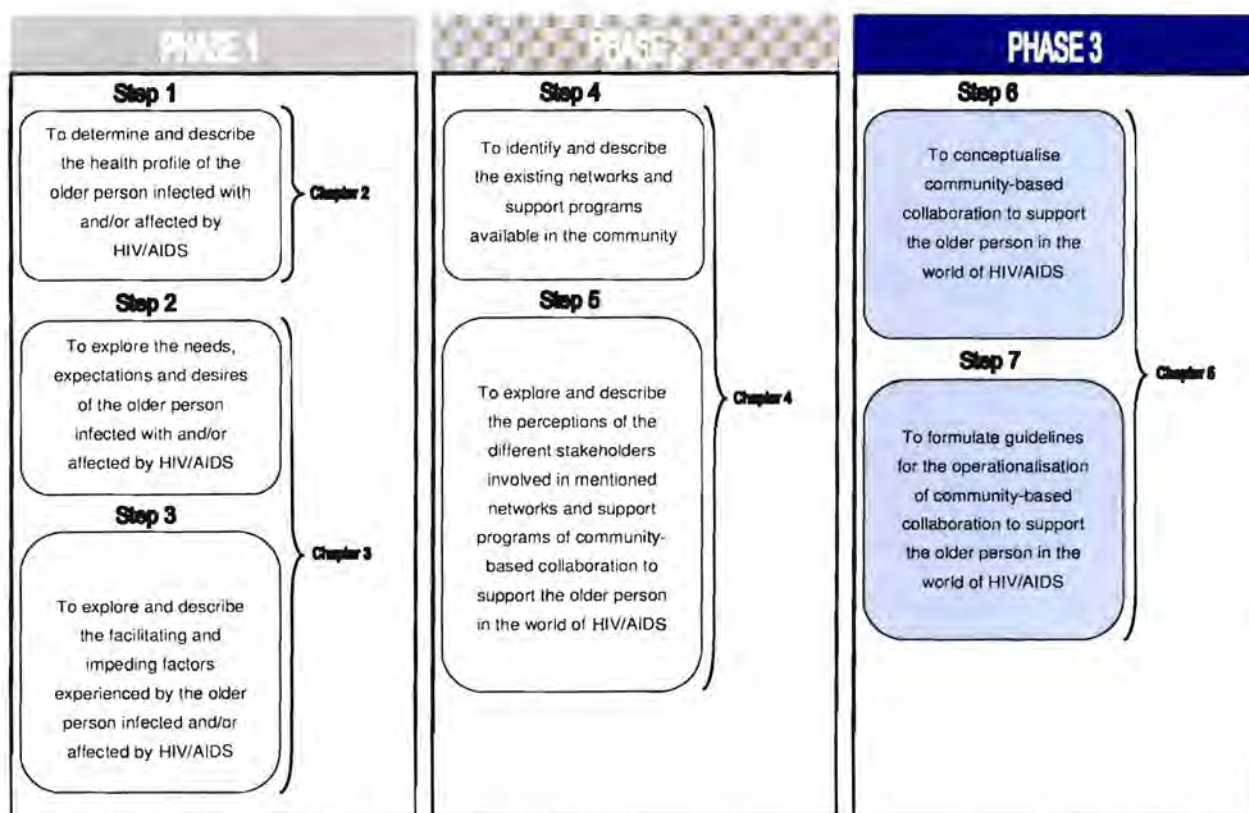


Figure 5.1: Schematic layout of the chapters in relation to the different phases and the steps of the research project

The sixth and seventh objective apply, namely

- *to conceptualise community-based collaboration to support the older person in the world of HIV/AIDS; and*
- *to formulate guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS.*

5.1 INTRODUCTION

The main aim of the study was to explore and describe what a community-based collaboration to support the older person in the world of HIV/AIDS entails. Chapter 5 is the conceptualisation and formulation of guidelines to operationalise this community-based collaboration. The chapter aims to align the key concepts identified from the empirical data (Henning *et al.*, 2004:26; Rossouw, 2003:11) collected through

- a survey to determine the health profile of the older person infected with and/or affected by HIV/AIDS (phase 1, step 1);
- the Mmogo-method™ (visual method) that involved focus group discussions regarding the needs, expectations, strengths and impediments of the older person infected with and/or affected by HIV/AIDS (phase 1, step 2 and step 3); and
- research interviews with the stakeholders and role players to identify and explore the existing networks and support programs available in the community, as well as to explore the perceptions of the stakeholders and/or role players regarding community-based collaboration to support the older person in the world of HIV/AIDS (phase 2, step 4 and step 5).

Systems theory is used as the main theoretical underpinning and framework. In other words, the conceptualisation of the community-based collaboration is embedded in the systems theory. As it is the intention of this research to improve the practice a functional approach (Klopper, 1994:16) is followed and therefore guidelines for

operationalisation of the community-based collaboration were formulated. The conclusions eminent from the empirical data were used to describe the conceptualisation in order to ensure content validity of community based collaboration. Figure 5.2 illustrates the process of conceptualisation and formulation of guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS.

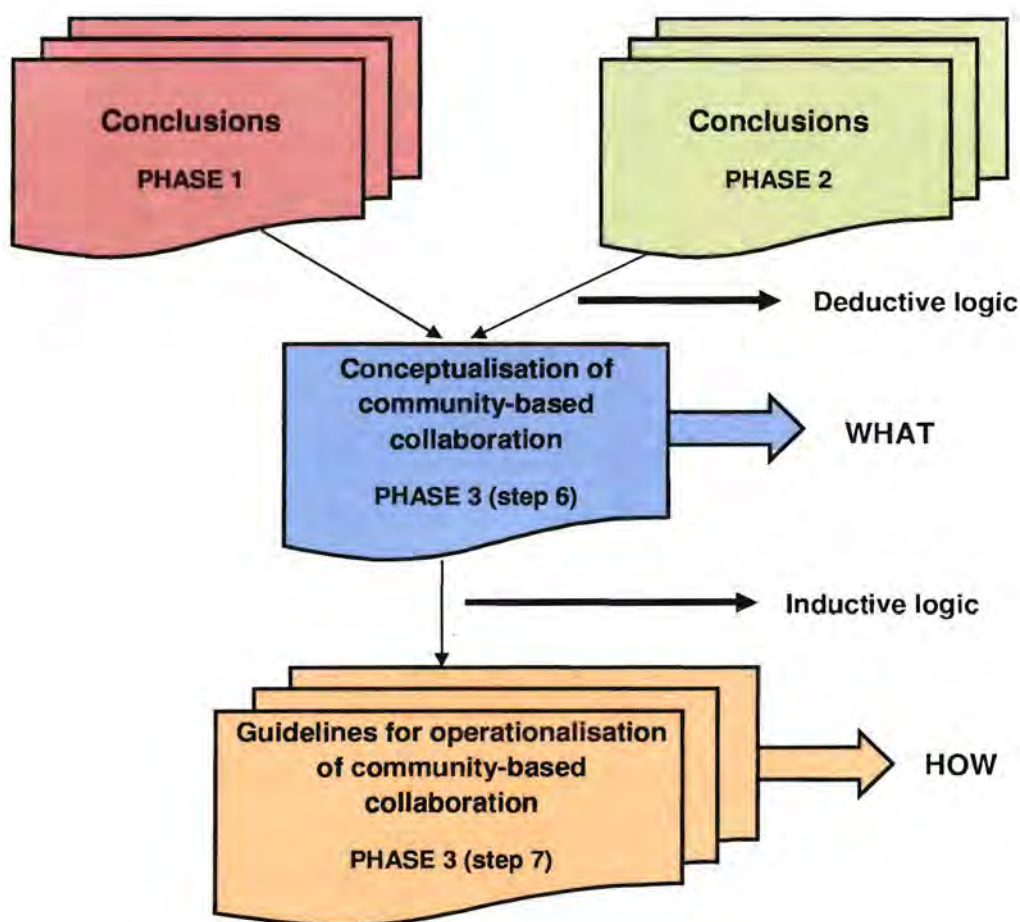


Figure 5.2: Process of conceptualisation of community-based collaboration to formulate guidelines for operationalisation

Following a process of deductive reasoning (Chinn & Kramer, 1999:71; Mouton & Marais, 1992:105) the researcher integrated the conclusions of each phase into the

final concept map through concept mapping with well-developed conceptual descriptions and the relationship between the concepts. Conceptual meaning refers to a cognitive developed “picture of what the phenomenon is like and how it is perceived in human experience” (Chinn & Kramer, 1999:56 & 61). Conceptual meaning was created through insight and understanding gained by theoretical definitions, information collected through surveys, visual images, focus groups and personal interviews that were analysed, interpreted and described. Throughout the study the sense of direction was managed by a clear aim, namely to conceptualise community-based collaboration to support the older person in the world of HIV/AIDS.

During the conceptualisation, guidelines for operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS became evident. In achieving this, the researcher followed her own unique systematic working procedure, namely the four steps of an integrated systematic concept mapping process to conceptualise and operationalise community-based collaboration to support the older person in the world of HIV/AIDS.

- *Step 1: Overview of findings, the conclusions* in table format derived from the empirical findings and literature scrutinised to substantiate evidence during each phase (see paragraph 5.2 and table 5.1).
- *Step2: Compile an integrated map* through the mapping of concepts from the conclusions from all the empirical findings from step 1 to step 5 of the study (see figure 5.1 above on the layout of the study and chapter 4, paragraph 4.3.3.1 on the process of concept mapping used during phase 2). The reason for the integrated map is to form a new and complete picture by means of deductive reasoning. Similar conclusions from step 1 to step 5 of the study that crystallized as the main concepts for conceptualisation of community-based collaboration to support the older person in the world of HIV/AIDS, were grouped and mapped together (see paragraph 5.3 and figure 5.3).

- *Step 3: Describe the main concepts* of the integrated map. The description of the main concepts provided the researcher with the theoretical basis of the guidelines for operationalisation. Paragraph 5.4 describes the assumptions (systems theory, participatory, hermeneutic and constructivism) on which the conceptualisation of community-based collaboration is founded, the purpose of community-based collaboration as well as the structure and the process of community-based collaboration to support the older person in the world of HIV/AIDS.
- *Step 4: Formulate guidelines* for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS as generated from the integrated systematic concept mapping process based on the principles of an open system cyclic in nature.

The management of each step follows as part of the integrated systematic concept mapping process. The four steps decided on by the researcher gave direction to the conceptualisation and formulation of guidelines for operationalisation.

5.2 OVERVIEW OF FINDINGS: CONCLUSIONS

The researcher presented the conclusions in three cells according to the chapter layout. There are fifty-six conclusions that apply to the study and they are numbered from 1 to 17 (refer to chapter 2), from 18 to 33 (refer to chapter 3) and from 34 to 56 (refer to chapter 4). The numbers given to each conclusion apply to the rest of the chapter and will be indicated as such where used (see integrated concept map, figure 5.3). Table 5.1 provides a summary of the conclusions from phase 1 and phase 2.

Table 5.1: Overview of results: Conclusions

Step 1: Health profile of the older person (Chapter 2)	
1.	Old age in the previously disadvantaged groups with the associated challenges of HIV/AIDS , proves to be a reality in the North-West Province of South Africa, with the greatest pressure on the women , who outnumber the men.
2.	The majority of older persons in the age group 60-73 years are household heads with a clear changing of roles forced on them.
3.	Not only do the women outnumber the men, the majority of them are widowed with the implication of increased responsibilities that include physical, emotional, financial and social responsibilities that warrant support.
4.	The majority of the older persons in the community have no or a low level of education , which makes them vulnerable with regard to participate effectively in health promotion programs and access to information pertaining to aspects like HIV/AIDS.
5.	The social pension that most of the older persons receive is their only hope to make ends meet. They are now challenged with extra financial burdens that HIV/AIDS puts on them to support their family members with material goods.
6.	Support from different organisations and groups are available in the communities where the older persons live, but because of the lack of a trust relationship , the majority do not utilise them and mainly focus on the religious support from groups and churches.
7.	The older persons infected with and/or affected by HIV/AIDS do experience stress because they give material support to their family members and cannot make ends meet with their money , which furthermore results in food scarcity and more stress.
8.	Family structure changes force the older person into role changes that place not only financial, but also social strain on them, like intra-family conflict , especially in a multi-generational family .
9.	A large number of older persons experience the feelings and thoughts that refer to risks for possible depression .
10.	Older persons perceive honesty, respect and payback treatment as important values pertaining to trust in their homes and the community. However, the majority do not experience mutual trust pertaining to their relationship with the different organisations in their neighbourhood and community.
11.	The ontology of older persons is rooted in religion and they experience a great deal of support from religious groups in the community.
12.	The older persons experience many difficulties and hardship within the world of HIV/AIDS that can contribute to the use of alcohol and tobacco , with more problems like decline in health, less money to provide in household needs, and family conflict .

Table 5.1: Overview of results: Conclusions (continued)

Step 1: Health profile of the older person (Chapter 2)	
13.	The older persons are vulnerable to infectious diseases; 4.8% tested positive for HIV and more than 25% of the older persons had a reproductive cough for longer than two weeks , which is indicative of a lung infection like Tuberculosis.
14.	Self-reported data revealed that the chronic diseases older persons most commonly present with were hypertension, cancer, diabetes mellitus, heart diseases, arthritis, asthma and/or other chronic lung diseases with associated risk factors namely tobacco- and alcohol use, as well as stress, which add to their vulnerability.
15.	The older persons with the responsibility to care for their sick children and grandchildren , as well as to raise and take care of orphans , were found to be challenged with physical disabilities like trouble to use their hands, walk, bend, hear and read, which in itself refer to difficulty with household and self-maintenance activities.
16.	Older persons are afraid of stigmatisation and only a small percentage revealed that they know someone with HIV/AIDS.
17.	Older persons do not have a problem to look after orphans and demonstrate their willingness because they can receive a child support grant .
Step 2 and 3: Needs and expectations; facilitating and impeding aspects of older person (Chapter 3)	
18.	Older persons infected with and/or affected by HIV/AIDS as stakeholders need to take part in decision-making processes in the community where all other stakeholders like the university, Department of Health, NGO's and FBO's should work together and co-ordinate their services.
19.	Older persons with extended experience and wisdom gain confidence through community participation and take the responsibility to " stand up and fight ", advocate and develop a dream for a better future despite HIV/AIDS.
20.	The older persons that render community-based home care as volunteers are aware of stigmatisation , have caring attitudes to the community with their different dimensional needs , and they need equipment and transport .
21.	The needs of older persons infected with and/or affected by HIV/AIDS within a socio-cultural context refer from personal health needs to coping skills in a multi-generational household and a well-defined need for interaction and co-ordination between the Western medicine and the traditional healers .

Table 5.1: Overview of results: Conclusions (continued)

Step 2 and 3:	Needs and expectations; facilitating and impeding aspects of older person (Chapter 3)
22.	A day-care centre is a high priority and functional as a central structure in the community for the older persons to be together , share their problems, give care and support to each other with a positive influence on the relationship between the older person and the younger generation with special inter-generational programmes in mind.
23.	The older persons at risk or already infected with and/or affected by HIV/AIDS have a low educational level and/or are illiterate with subsequently inadequate health-related knowledge that refers to HIV/AIDS.
24.	In order to participate effectively in continuing care for persons with HIV/AIDS, the older person needs health information and -education on matters like self-managment and basic treatment of HIV/AIDS symptoms.
25.	The older persons are the caregivers challenged by multi-generational households who need knowledge and skills regarding conveying messages to family members, young and old, pertaining to HIV/AIDS prevention matters in order to improve family coping with HIV/AIDS. They need life skills education to make own choices through empowerment .
26.	The older persons need support through knowledge on general precaution aspects when caring for persons infected with HIV .
27.	Older persons infected with and/or affected by HIV/AIDS share HIV/AIDS as a common phenomenon in the community and act together as a whole to manage the needs of their families , friends and neighbours.
28.	HIV/AIDS puts new challenges to older persons, their families , as well as the support system of the family through open and honest communication and collective actions to maintain balance in the community.
29.	The older persons' needs and expectations are reflected in their sense of Ubuntu , characterised by a need for collectiveness and traditional values .
30.	The strong religious systems of the older persons contribute positively towards the ability to cope amidst HIV/AIDS.
31.	The older person is not only responsible , but also willing to share material goods and give emotional support.
32.	The older persons infected with and/or affected by HIV/AIDS are central to the multi-generational or extended family system of the community as a whole , are voluntary stakeholders that need and expect to participate and co-ordinate with other stakeholders in decision-making processes involving care and support of all the older persons.
33.	Care and support of older persons aim at community-empowerment and involves a functional structure in the community where comprehensive care and support is delivered to the older persons, including enhancement of their knowledge regarding health-, social-, cultural-, economical- and educational issues.

Table 5.1: Overview of results: Conclusions (continued)

Step 4 and 5: Perceptions of stakeholders regarding community-based collaboration (Chapter 4)	
34.	Different formal and informal stakeholders exist, they are fragmented , duplicate services and do not focus on the older persons .
35.	The stakeholders held the possibility to compliment each other and form important networks in community-based home care if co-ordinated , and the Department of Health and political structures are the policy makers with the university as a key role player .
36.	The stakeholders recognise their networking role , although fragmented , between the University, the Department of Health, the CBO's, NGO's and FBO's as the more prominent existing networks involved in different programmes regarding HIV/AIDS in the community. The main stakeholder is the Department of Health as policy maker with certain political structures in place.
37.	Stakeholders should establish networking systems based on a participatory-trust relationship with awareness for research projects to generate knowledge and utilise the knowledge to develop and empower both the stakeholders and the older persons in the world of HIV/AIDS .
38.	Knowledge and information generation through research is perceived as vital in the community and poses a huge challenge to the university as stakeholder. It is multi-disciplinary in nature, and can implement research projects on a community-based participatory basis to enhance community development and build trust relationships between all stakeholders that exist in the community for effective knowledge utilisation.
39.	The CBO's, NGO's and FBO's are health supporting networks that are important for support programmes, advocacy, community mobilisation, health management , which includes home-based care , lack the basic principles for effective partnership like organisational and financial management, as well as operational guidelines to ensure correct and open communication.
40.	Relationships between the different stakeholders are interrelated and complimentary to each other , and the NGO's, CBO's and FBO's are important links in community-based home care between the household and the PHC facility.
41.	A partnership with a shared goal and adherence to the basic principles of effective partnership needs to be established in order to embrace the philosophy of collectiveness , culture of religion , experiences, wisdom, sense of responsibility for care giving and advocacy .
42.	The influence of religion on health issues cannot be ignored and should be acknowledged within the socio-cultural context of the older person infected and/or affected with HIV/AIDS.
43.	Most of the stakeholders involve themselves in social issues between different organisations in the community; they often assist people in the community with issues like death registrations and grant applications.

Table 5.1: Overview of results: Conclusions (continued)

Step 4 and 5:	Perceptions of stakeholders regarding community-based collaboration (Chapter 4)
44.	The conducting as well as the monitoring of health education built on a trust relationship is perceived as one of the most important roles of the stakeholders in the community and should address illiterate- as well as older persons with low educational levels to empower them with regard to older persons' rights and relevant health issues like HIV/AIDS.
45.	The stakeholders' needs include effective management and use of resources through effective skill development and empowerment strategies . The community care workers often work day in and day out without any payment or support and need counselling to cope with the demands of HIV/AIDS in the community. Effective community-based collaboration to support the older person is impossible without transport .
46.	The older persons in the community have their own socio-cultural value system with a strong spiritual calling to fulfil the caregiver role ; they are also the role models in the community, the ones with knowledge, personal influence and power, respected by the stakeholders .
47.	The needs of the older persons in their communities are perceived by the stakeholders as a need for social structures that focus on the needs of the older persons with explicit reference to a focal point where they can meet and have support groups, generate an income and so forth. This can be accomplished in the form of a day-care centre where their need for financial support can also be partially decreased.
48.	The stakeholders in the community know the older persons, and the health education role that they have in the community should fulfil the need of the older person regarding empowerment through knowledge on the prevention of infection, knowledge on health issues , knowledge and skills regarding child rearing and how to manage their role change.
49.	The university as academic institution should take a leading role in co-ordination and monitoring community-based education of health issues with a focus on HIV/AIDS, human rights and management skills .
50.	The older persons are also exposed to stigmatisation , which is still a reality in the community. They have a need for acceptance and functional social support as not to be isolated and ignored.
51.	The older persons are often victims of socio-economical abuse and have a need for protection against that, as well as needs regarding their health .
52.	Community-based collaboration refers to relationships between different organisations in the community that is open and transparent; it should be based on collectiveness and have a common goal , which means that the stakeholders should make joined decisions with shared responsibility .
53.	Community-based collaboration involves community participation as an overall motivational strategy in the development processes, and implies involvement in the community that is not possible without effective communication and linking between the stakeholders as partners .
54.	Community-based collaboration requires the identification of structures in the community such as databases as an imperative to know where to find the structures and how to utilize them in the support of the older person in the world of HIV/AIDS.

Table 5.1: Overview of results: Conclusions (continued)

Step 4 and 5: Perceptions of stakeholders regarding community-based collaboration (Chapter 4)	
55.	Collaboration in the community entails multi-disciplinary- as well as multi-sectoral networking and is not possible on one's own; the different stakeholders need each other , of which the ward committees and the extended family on community level form an integral part.
56.	Community-based collaboration should be sustainable and look to the future . It should not only meet the needs of today , but also the needs of tomorrow, and is only possible through co-ordination between the different stakeholders in the community, otherwise support of the older persons can be jeopardized through fragmented services.

5.3 INTEGRATED CONCEPT MAP: MAIN THEMES OF COMMUNITY-BASED COLLABORATION

The next step in the process towards conceptualisation of community-based collaboration to support the older person in the world of HIV/AIDS was to compile an integrated map derived from the content of table 5.1. Conceptualisation gives definite meaning (Babbie, 2007:125) to community-based collaboration. Through deductive reasoning and synthesising, the researcher used the conclusions from the empirical world embedded in the systems theory, and applied it to the practice of community health and collaboration to form and integrate unique combinations of concepts in order to have a clear description of community-based collaboration to support the older person in the world of HIV/AIDS. Supplementary models (refer to chapter 1, paragraph 1.5.2) were used where applicable.

The information from the older persons (including the health profile) and the stakeholders were the starting point for the conceptualisation that seeks to explain the relationship between the concepts that emerged from the researcher's interaction with the participants (Polit & Beck, 2006:32). The identification of the main concepts through the integrated concept map (see figure 5.3) bring forth **eight** main themes for community-based collaboration to support the older person in the world of HIV/AIDS. Space made it impossible to include the whole mapping process. With reference to the research findings in table 5.1, the reader can refer to the appendix for a bird's eye view on the total integrated concept map (see Appendix K for an example of one part of the integrated map).

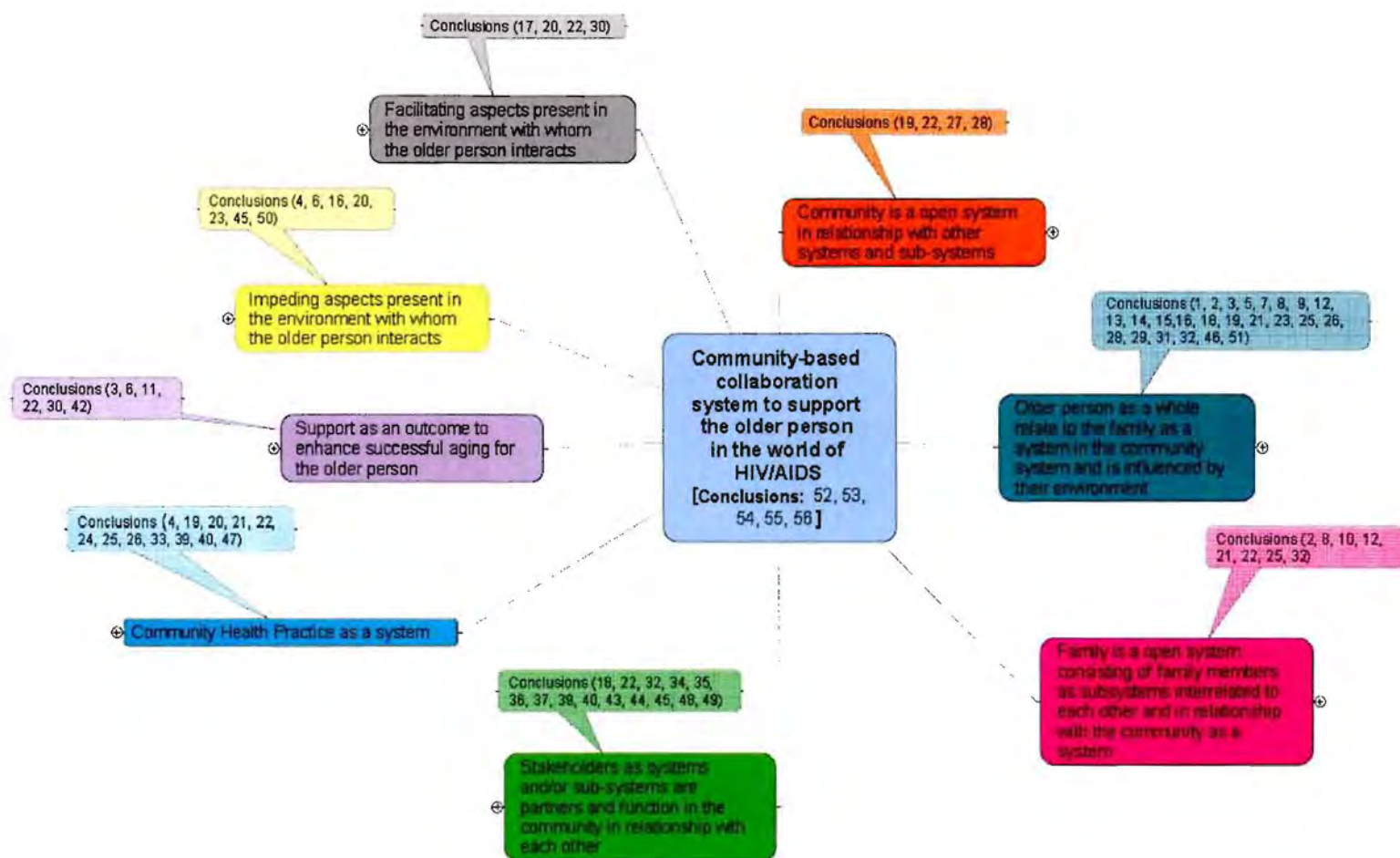


Figure 5.3: Integrated map with main themes of community-based collaboration

5.4 ASSUMPTIONS OF COMMUNITY-BASED COLLABORATION

The systems theory, participation, hermeneutics and constructivism as a way of looking at the world are included in the following theoretical assumptions regarding community-based collaboration.

- Community-based collaboration is a **socio-cultural system** known as an **open system** consisting of more than one sub-system where the **interrelationships** are based on information change necessary to operationalise community-based collaboration as a **sustainable** system to support the older person in the world of HIV/AIDS in the strive to **wholeness**.
- Community-based collaboration is a system and the desired outcome thereof is to support the older person and this is possible through community-based collaboration as a process where partners in the community health practice work together to fulfil the needs of the older persons as well as that of the stakeholders to **adapt to the challenges of HIV/AIDS** through **goal attainment** and the **integration** of different sub-systems to reach full **maintenance** of the support to the older persons in the world of HIV/AIDS.
- There is an existing relationship between HIV/AIDS as part of the environment (**context**), the older person infected with and/or affected by the disease with their needs and expectations, their families and the community, the stakeholders involved as partners within a practice of community health care. HIV/AIDS results in a negative relationship that is the opposite from an **open trust relationship** in a system that strives to wholeness. The relationship can be restored by community-based collaboration to support the older person and enhance successful aging as the **desired outcome**.
- The older person as a whole is **unique**, has the capacity to make choices, and gives meaning to community-based collaboration through the expressed needs, experiences and perspectives of their lived worlds. This enabled the

researcher to formulate guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS.

- The **participation** based on a **collective intention** refers to **interaction** between the older person and stakeholders in community-based collaboration that result in support through **open communication** and building of **trust relationships**. This enables focussing on the real problem and to develop a future-orientated **shared vision** to **construct a plan for support** through community-based collaboration.
- Chronic diseases, HIV/AIDS, physical impairment, food scarcity, financial deprivation and subsequent stress revealed in the health profile of the older person, form part of the environmental context in which community-based collaboration as an open system **functions to adjust to the environment**, and **control the deviances**.
- Community-based collaboration is **functional in the community by empowering** the older persons as a system. The **manifest functions** of community-based collaboration realises in information sharing and health education with the intention to treat the HIV/AIDS symptoms of family members. The **latent functions** of community-based collaboration are also unintentional, and give confidence and “a voice” to the older persons.
- HIV/AIDS does not only affect the health and thus the wholeness of the older person, but also the relationships and interactions between the older persons and other members in their households and the community. Community-based collaboration entails **multi-disciplinary and multi-sectoral networking** that will help the older persons to form new and stronger **social systems for support**.
- Community-based collaboration will **improve the quality of community-based health care** rendered by the older persons as caregivers to their

children and grandchildren, as well as by the stakeholders as support will realise when all involved in community-based health practices **work together to satisfy the existing needs** resulting from HIV/AIDS.

- Community-based collaboration is **functional** as it gives opportunity for the older persons as a social group and other social systems to interact and it **binds together** as members of their various families and community to **control HIV/AIDS that cause deviation** and threatens order.
- HIV/AIDS results in stigmatisation (isolation and discrimination) and subsequent decrease in interaction that hinders open communication and trust. Community-based collaboration focuses on **motivational strategies through community participation** that holds the promise to decrease stigmatisation.
- Facilitating aspects encountered in the households and community must be utilised to strengthen their **actions set upon planned goals**.
- Community-based collaboration needs **leadership** and the older person is the one that must be **capacitated to fulfil the advocacy role** in the community.
- **Partnerships** formed through community-based collaboration is functional and result in open communication and planned problem solving actions with the focus on capacity building and **information sharing** on different levels as needed.

5.5 PURPOSE OF COMMUNITY-BASED COLLABORATION

Community-based collaboration in this study refers to a system interrelated to other collaborative systems in the community. The contextual nature includes the practice of community-based health care as part of the comprehensive health care system

where the purpose of community-based health care in this study refers to the support of the older person in the world of HIV/AIDS.

- Community-based collaboration is an open system with different sub-systems that **function as a whole to achieve a common purpose** in relationship with the other systems in the community (older person, stakeholders, families, environment, and community health systems) **to support the older person** in the world of HIV/AIDS.
- Community-based collaboration must **function as an open system interacting** with the environment outside the systems of which HIV/AIDS forms part and have the purpose of support built on **trust relationships between open systems** that promise **hope to recover, maintain and promote the health** of a community as a whole and not only of the older person as a whole.
- Community-based collaboration ensures that the older persons **form formal and informal support groups**, social groups, be part of organisations and **form a social class** of their own in the community where they live.
- Community-based collaboration ensures through **communication as networking** system that the needs of the members, groups and organisations as systems in the community will be satisfied.
- Community-based collaboration of which the older person is part **contributes in an orderly way to maintaining the wellbeing** of the whole through sharing of identified resources, like knowledge, skill, food and time.
- The **stakeholders and/or role players strive to support** the older person infected with and/or affected by HIV/AIDS through community-based collaboration.

- Community-based collaboration systems in the world of HIV/AIDS will support the older person through **partnership** and effective networking between the partners.
- Community-based collaboration **enhances participation** between the older persons' infected with and/or affected by HIV/AIDS and the stakeholders in the community, which is a cyclic process where feedback ensures an ongoing long-term process to ensure **sustainable support**.

5.6 DESCRIPTION OF COMMUNITY-BASED COLLABORATION

The context, visual model, a brief explanation of the visual model and the structure of community-based collaboration follows hereafter.

5.6.1 THE CONTEXT OF COMMUNITY-BASED COLLABORATION

The conceptualisation and formulation of guidelines to operationalise community-based collaboration occurs in the context of community health practice where the understanding of the cultural, temporal, social and geographical influences of the environment with which the older persons and stakeholders interact with the community and the family should be taken into consideration. The context also entails community health practice as a system with smaller sub-systems. The visual model (refer to figure 5.4) illustrates the conceptualisation of community-based collaboration, the main themes thereof and their relationship to each other.

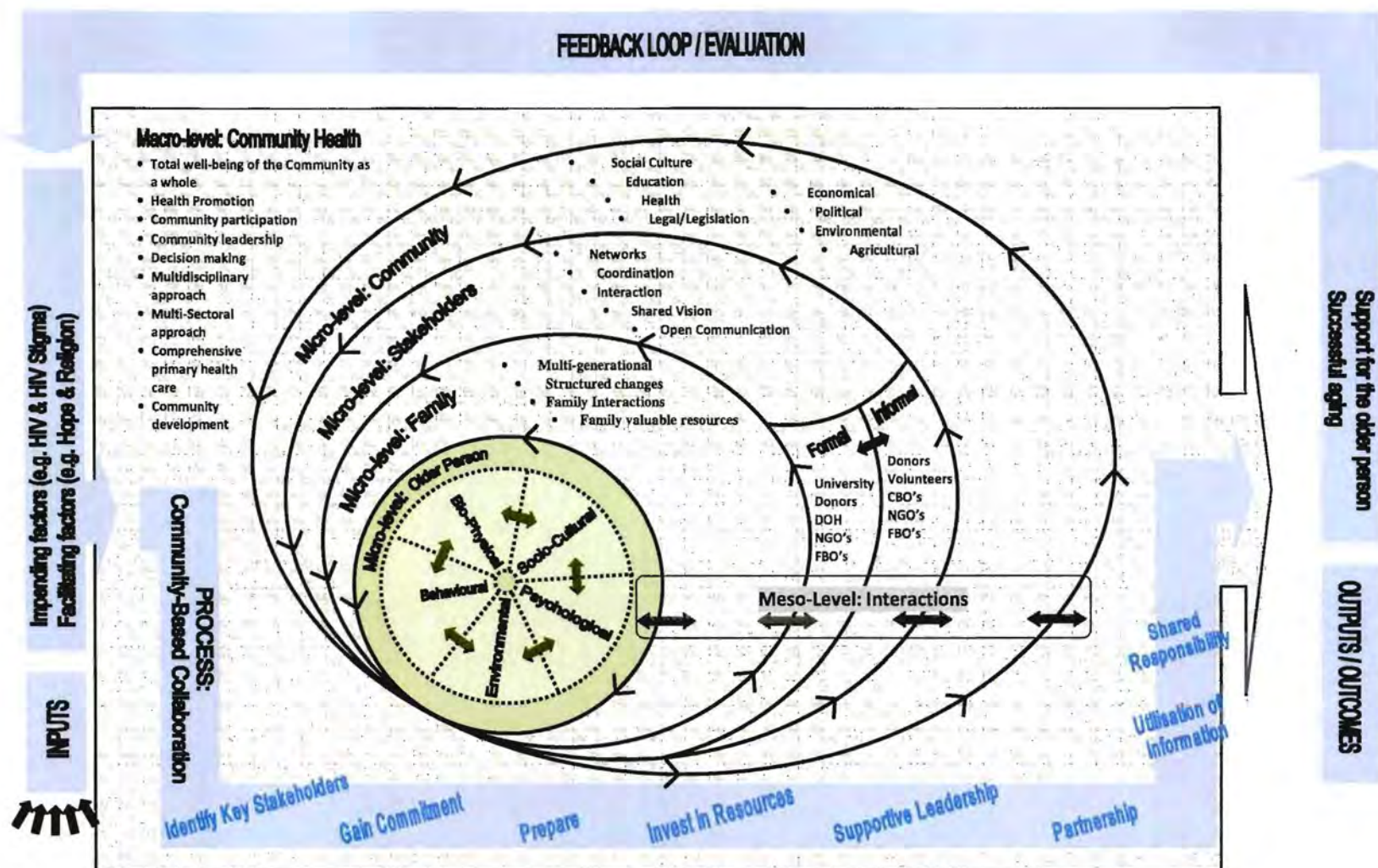


Figure 5.4: Visual model of community-based collaboration for support

5.6.2 BRIEF EXPLANATION OF VISUAL MODEL

The **context** for community-based collaboration to support the older person in the world of HIV/AIDS is **community health practice**. Community health practice as a system refers to the **total well-being** of the **community groups as a whole** where health promotion, community development and participation to empower the older person are smaller systems interrelated to each other.

The **older person** as a role player is central in community health and function as a system with interrelated **bio-physical, socio-cultural, psychological, environmental, behavioural sub-systems** influencing **wholeness**. There is constant **change and interaction** between the environment, older person as a system and the other systems such as **the community, the family, stakeholders and role-players**.

The **community is a social system** consisting of smaller sub-systems, functions collectively within the **macro-** (community health) **and meso-level** (relationships and different patterns of interaction), interrelating with sub-systems on **micro-level** where largest flow of energy occur. The **family**, nesting in the community as a larger system, is an important support system on micro-level and often the single most important community resource where the older person holds large responsibilities as key decision maker. Different **stakeholders** are part of the community, families and older persons interacting with each other, characterised by an **interface managed through coordination and collaboration**.

HIV/AIDS is a threatening disease in the environment with certain influences and impediments (stigmatisation) that relate to the community, family, stakeholders and older persons. The community, family and stakeholders, as well as the older persons recognise the influence of HIV/AIDS as a negative input on their well-being (wholeness) and seek ways to restore the balance in the different sub-systems or parts to reach comprehensive well-being as a community as a whole.

Through **community-based collaboration as a transforming cyclic process**, the older persons and other role-players involved have the opportunity to create a power-sharing **partnership with subsequent** widespread application in **community health practice** with the **purpose** to attend to the needs, expectations, facilitating and impeding factors recognisable from the context in order to achieve likely successful **outcomes**, that will support the older person in the world of HIV/AIDS and enhance successful aging. The success of the outcome is enhanced through interaction and participation that determine **the flow of energy between the stakeholders, the community, the family and the older persons** involved in the process of community-based collaboration, recognised by trust relationships and communication based on an important facilitating input to the process, namely **hope and unconditional love**.

5.6.3 STRUCTURE OF COMMUNITY-BASED COLLABORATION

Conceptualisation of community-based collaboration furthermore refers to the structure that consists of elements, the concepts and themes in relationship to each other. The relationship between the central concept and the other main themes give direction (Klopper, 1994:235) for the formulation of guidelines to operationalise community-based collaboration with the aim to support the older person in the world of HIV/AIDS.

To operationalise means to put something to **use** (South African Concise Oxford Dictionary, 2002:815) or to **plan an activity to achieve something** (Cambridge Advanced Learner's Dictionary, 2008). Operational guidelines help to ensure correct communication between stakeholders and/or other role players involved in projects. The guidelines compiled for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS as generated from the integrated systematic concept mapping process based on the principles of an open system cyclic of nature is integrated with each description of the main theme, is the last step of the process and hereby proposed to the reader in table 5.2 to table 5.9.

The central concept, community-based collaboration and the other main themes will be described in the following paragraphs. Guidelines and actions for operationalisation that apply to the main themes were listed and numbered (**twenty-four guidelines, from number 1 to 24**) in a table at the end of the discussion of each main theme.

Subsequently a description follows of the structure of community-based collaboration as well as the guidelines and actions for operationalisation to support the older person in the world of HIV/AIDS. The community as a system, the family as a system, the older person as a whole, the stakeholders as a system, community health practice as a system, and support as an outcome to enhance successful aging and the facilitating and impeding factors influencing the environment (context) of community health practice apply in the following paragraphs.

5.6.3.1 The community as a system

Communities are places where people live as a group together and **share a common interest that can also refer to needs and expectations; they interact with one another and function collectively within a defined structure to address communal concerns** (Clark, 2008:27; Dennill *et al.*, 1999:84; Ncama, 2005:33; South African Concise Oxford Dictionary, 2002:233).

The central element of a systems theory is captured in Sullivan (1998:109) and refers to "a whole which functions by virtue of the interdependence of parts is called a system". A system is open or closed, depending on the flow of interaction to and from its environment. The older person as a whole being lives in a community that is an open system where the ideal is to sustain order through interaction towards a shared goal. The openness or closeness of a system depends on the system's relationship with the environment (context), how active or inactive the system is (Arries, 2002:3; Bahg, 1990; Covington, 1998:11, 19; Sullivan, 1998:109). The community as a social system in which the individual (older person) interacts through communication with each other (Arthur & McMahon, 2005:212), is an open system that consists of other

smaller systems or sub-systems and forms a set of interacting sub-systems (Bahg, 1990). The older persons form groups of sub-systems that can function as a system on its own in the community.

The community as a whole functions on different levels or within more than one context – the micro-level context as the context where most frequent interaction takes place. The micro-level context is the space of interaction between the older person and other community members or between the stakeholders and the community systems (refer to chapter 1, paragraph 1.6.1.5 on the context of the study). The meso-level context refers to two or more micro-systems interacting with each other, it refers to relationships and patterns of interaction. The groups of older persons living in the urban or rural areas have needs and expectations (see chapter 3) regarding their living arrangements in the community within the larger macro-level context with its social, economical, educational, health, legal and political influences. In the community, culture as a system is interrelated between people and groups (the older person and the younger generation) and simultaneously affects and is affected by the environment and its activities (Bronfenbrenner *in* Fischer, 2008:22).

The community as an open system is constantly in a changing state, moving towards homeostasis or balance (Sullivan, 1998:110). Communities have been there forever, always working to maintain order, but HIV/AIDS was not always part of the community, and made its first appearances during the early 1980's. HIV/AIDS brought major changes and threats to the community as an open system; threats that influence the openness with minimum exchange of information due to stigmatisation (see chapter 2, paragraph 2.4.6). The older persons share a common problem in this study, namely concern about HIV/AIDS that infect and affect them. They can support each other through support groups where they can discuss relevant matters and function collectively within a defined structure to address communal concerns like HIV/AIDS.

The following guidelines and actions for operationalisation apply to the community as a system (see table 5.2).

Table 5.2: Guidelines and actions for operationalisation: Community as a system

Guidelines pertaining to the community as a system	Actions for operationalisation
1. The community should be an open system with social, economical, educational, health, legal and political sub-systems interrelated to each other, where the older persons as well as the stakeholders form part of	✓ Identify resources available in the community and among stakeholders with focus on political structures like street committee members in the wards ✓ The identifying of resources must take place early in the collaboration process and refer to: • natural resources like land and water • manufactured resources • human resources • organizational resources ✓ Join in at information days, e.g. pension days to start mobilisation process among the older persons
2. Older persons should form groups with shared concerns based on their needs and expectations in the community in order to support each other as social groups part of the community	✓ Plan and meet for workshop with older persons in community to identify where they would need the focus for support to be ✓ Establish support groups of older persons on decentralised bases; use established structures, homes, churches, community halls, schools.
3. Stakeholders and members of the community should recognise the influences of HIV/AIDS with the accompanying stigmatisation on the dynamic interaction and open communication between members and organisations of the community as a whole to consider solutions	✓ Support groups that are closed groups may work best as point of departure in case of HIV/AIDS and should be considered as such ✓ Support group facilitator should be skilled and knowledgeable to give in-dept emotional support ✓ Facilitator of support group should be aware of problems that may occur: unacceptable behaviour, punctuality, confidentiality, scapegoating, prejudice and withdrawal ✓ Focus interventions regarding stigmatisation on the identified levels it may occur • Consider social movements like public processions • Legislative inputs on civil and human rights, legal reform • Workplace, homes and individual level education to improve self-efficacy

5.6.3.2 The family as a system

The family is a system with patterns recognised by **different roles, status and power** assigned to the members of the family or group (Andrews & Boyle, 2003:510), nesting in the community as a larger system (Reed *et al.*, 2004:216) of which the **older person forms an integral part** in the socio-cultural environment (Sobo *et al.*, 2008:1530). The older person, near old age or in old age (see table 2.3) is mainly the **household head**, and therefore the **decision maker and central** to the multi-generational family in the community. The influences from the environment, with special reference to HIV/AIDS, socio-economical, educational, health and cultural aspects pertaining to the family as a system is of importance (Fischer, 2008:22).

HIV/AIDS deaths cause **family structural changes** (Population Reference Bureau, 2007:1) with social strain and a **need for coping skills** within the family. The family as a social system comprises of individual sub-systems interrelated to each other and to the larger macro-system, the community. The older person as part of the family system, value honesty and respect as well as to do well to others as important to maintain balance and **social cohesion** in the family (Gilbert & Soskolne, 2003:113). The families experience **family conflict** because of various factors, such as financial constraints aggravated by behavioural aspects like alcohol and tobacco use (refers to chapter 2, paragraph 2.4.4). Their level of energy or health status contributes to the state of the human system, and to the family as a whole. The conflict and other strains poses a threat to interaction and energy flow in the family on the one hand, but the **caring and loving attitude of the older person** and the sense of collectiveness on the other hand, can strengthen the **family as a support system**, the “closely-knit social web that promotes solidarity among people” (Basabe & Ros, 2005:190; De Villiers & Herselman, 2004:20). Strydom (2008:110) states that the family is the **most important resource available** for meeting the needs of older persons and is a valuable contributor within the socio-cultural reality of the older person and often the only support available to the infected with and/or affected by HIV/AIDS (Pequegnat & Szapocznik, 2000:3).

The following guidelines and actions for operationalisation apply to the family as a system (see table 5.3).

Table 5.3: Guidelines and actions for operationalisation: Family as a system

Guidelines pertaining to the family as a system	Actions for operationalisation
4. Family structures are the most important resource for support available in the world of HIV/AIDS for the older person and should form part of community-based collaboration as a system	✓ Start with awareness campaign (media) to sensitise the community regarding the importance of family structures and their functionality ✓ Identify community organisations for family counselling ✓ Identify team members from social services and psychology to form a sub-group to focus on family representation
5. Coping skills should be introduced to support the older person exposed to role changes and family structure changes (multigenerational family) as a result of HIV/AIDS infections and deaths that cause social strain	✓ Encourage older persons as head of households to lobby and advocate the importance of the role of the older persons ✓ Initiate workgroups between the social-, psychology-, health-, education- and legal departments to brain storm on the best way forward to combat the changes in the family structures
6. Family functioning as a whole should be strengthened by awareness raising actions amongst the members in the family on behavioural aspects like tobacco and alcohol use that can influences the wellbeing of the family of which the older person is part	✓ Initiate behavioural change programs based on values clarification as a starting point for all age groups in the family ✓ Involve members from traditional medicine and western medicine ✓ Involve the church support groups ✓ Involve recreation department for possible initiatives to start with informal social sport groups

5.6.3.3 The older person as a system

The older person is in an **interdependent relationship to the family and the community** as systems and strives continuously to a state of **wholeness** (Sullivan, 1998:109). Systems perspectives emphasize both the parts within a whole system and view the whole system as greater than the sum of its parts (Arthur & McMahon, 2005:208; Spruill *et al.*, 2001).

The **traditional role** of the older person viewed as the role models in the community, the hard working and important links to the community because they know the community (de Villiers & Herselman, 2007:20) **is deviating as a result of HIV/AIDS** and the younger generation with westernised ideas. The older persons form a system on their own, depending on their interaction with the environment (Fischer, 2008:22) as well as the **many social regulations that apply in some communities**, like to respect the elders (Mbiti, 1990:208). The older person as a whole, consisting of sub-systems or dimensions that should be considered before any interventions to promote health (Clark, 2003:257-259), like community-based collaboration, can be considered. The different dimensions interact with each other as sub-systems in a relationship towards successful aging (see chapter 1, paragraph 1.5.2.3 and figure 1.2). The level of energy or **health status contributes to the state of the older person as a whole** in relation to their environment, they **do not live in isolation**, are part of a much larger contextual system (Arthur & McMahon, 2005:212).

In systems thinking **all influences are both cause and effect**, like HIV/AIDS that occur in the older person as an individual whole system, the family and community as systems. HIV/AIDS is a problem or a situation that occurs in the world of the older person, in systems, as a cause with an effect and thus an ongoing process and not merely a once-off event (Sullivan, 1998:111). The older person as an open system is a highly complex entity in the midst of their own aging process and role changes. The social theory of aging refers to the retiree and grandparent role, the process of mutual withdrawal, and the subculture of aging theory refers to older persons maintaining their self-concepts and identities through membership in social groups and the modernisation theory that subtly result as reality. In this study the researcher took a snapshot of HIV/AIDS as an event in the environment with which the older person is interacting within a certain time and space that makes it contextual by nature (refer to chapter 1, paragraph 1.6.1.5 on the contextual nature of the study) Holloway (2005:275). Because of the **dynamic complexity of the situation** (HIV/AIDS that not only infected, but also affected the older person), it can be easy to focus on the detail

and to lose the focus and opportunity to improve the system and support the older person through community-based collaboration.

Refer to paragraph 1.5.3 in chapter 1 on the different views and definitions on “old”. In the context of this study the “older person” is a man or a woman from the age 60 years and older that could be infected with and/or affected by HIV/AIDS. Systems, like the human body, have complex sub-systems (also referred to as dimensions), and the sub-systems affect the performance of the whole, directly or indirectly related to at least some other sub-system (dimension) in a causal network in a more or less stable way within any particular period of time (Ritzer, 2008:328). **HIV/AIDS as a bio-physical infection in the human body is directly related to the other dimensions and can cause instability to all the other dimensions**, like the influence it has on the household (physical environment) of the older person as well as the stress and depression experienced (psychological dimension) by the older person infected with and/or affected by HIV/AIDS.

Considering the sub-systems (dimensions) of the older person on its own can make sense, but as for the interactions and interventions like community-based collaboration to support the older person, it does not make sense to stop there. Therefore the researcher agrees with Ackoff's systems approach as stated by Reed (2006:11) to understand the relevance of the health profile as analyzed (refer to chapter 2) and synthesized (refer to chapter 5) in relation to community-based collaboration as a system.

The researcher identified the health system (health profile integrated with the needs and expectations of the older person) and found a rather complex and dynamic system that needs support. The fact that the women outnumber the men, that they are widows who live longer than men (Bradshaw & Steyn, 2001:11) and confronted with various responsibilities caused by HIV/AIDS is but one of the examples that emerged from the study as a complex and dynamic system with possible influences on the other systems like the health care systems.

- **Health profile, needs and problems of the older person**

The **socio-economic-cultural dimension** of the older person is under tremendous pressure as the older person are often victims of socio-economical abuse, whether intentional or not, they only have an old age pension to live on and have the responsibility to support the family (refer to chapter 2, paragraphs 2.4.2 and 2.4.2.6). As May (2003:18) and Chinn & Kramer (2004:230) state, the total health (wholeness) of the older persons are influenced by basic factors like housing, health and income. The older person in the study is from the previously disadvantage group with no or a low education level (see chapter 2, paragraph 2.4.2.1), which has an influence on their roles and status. With reference to the modernisation theory, this refers to a more general theory that refers to the negative effects on the roles and status. Westernisation can also have an impact on the more traditional older African person with rich cultural values and belief systems. Education as the gateway to development show vulnerability in the older persons' low educational level, and the older persons need health education to understand and manage the magnitude of the effect of HIV/AIDS in their households, not only on health-related HIV/AIDS issues, but also on life skills education (Clark, 2008:260; Sukati *et al.*, 2005:185 & 191).

Psychologically the older person experiences stress about the financial constraints (Drewnowski *et al.*, 2003:304; Orner, 2006:236), the role change, and the food scarcity (Ferreira, 2004:30&34) and the loss of children and grandchildren, as well as care giving responsibilities (Hosegood & Timaeus, 2005:433). This leads to feelings and thoughts that refer to risk for depression (refer to chapter 2, paragraphs 2.4.3. and 2.4.3.5).

The **bio-physical health dimension** of the older person revealed vulnerability (refer to chapter 2, paragraph 2.4.5 and 2.4.5.6), they are infected with HIV/AIDS, have lung diseases like tuberculosis, hypertension and diabetes mellitus (SA, 2004:10; Stellenberg & Bruce, 2007:992-993) that is aggravated by certain

lifestyle patterns like alcohol and tobacco (refer to chapter 2, paragraph 2.4.4.3) use and sex practices without protection.

Together with this reality, the older persons, especially the women, have difficulty with household chores and self-maintenance because of **physical impairment** (refer to chapter 2, 2.4.5.5 and figure 2.15) that could be part of the normal aging process, but which holds the promise of even more hardship to cope with care giving responsibilities that involve a range of physical activities.

- **Expectations of the older person**

The older person infected with and/or affected by HIV/AIDS trusts that the things they expect and hope for will happen, as the dictionaries describe expectations as “the belief that something will happen” and “when the person expect good things to happen in the future” (Cambridge Advanced Learner’s Dictionary, 2008; South African Concise Oxford Dictionary, 2002:404).

Limits to grow and **passing the blame** are two systems archetypes commonly encountered (Sullivan, 1998:115) in the community and families that could impede on the older persons’ positive outlook. The older persons made it clear that they **hope and wish for a better future** amidst HIV/AIDS that is constantly a threat from the environment to them as a system or group of older persons, as well as to other systems in relationship with them. An example of a systems archetype that emerged from the study was evident in the views of some of the participants who strongly believed that the **people should stop blaming the government regarding HIV/AIDS and act as a group together**. Passing the blame can be negative and needs to be avoided. In the context of this study the researcher as well as the participants, from a systems line of thinking, had the ability to see through the complexity of the world of HIV/AIDS to the underlying **structures that can generate change** (Sullivan, 1998:117).

The expectations of the older persons has a futuristic nature with the promise that they will have a change in future to **participate in decision making processes**,

to be in an **advocate role**, to live up to their expectations and **exercise their traditional values** in the form of collectiveness (refer to chapter 3, paragraph 3.4.2.1). Parsons (*in* Cunningham *et al.*, 1998:54) state that the parts of a society need to integrate and that implies that people should accept their society's shared values. Reed (2006:11) refers to the systems thinker retaining focus on the system as a whole. In this study, it refers to the older persons, burdened with HIV/AIDS in the community consisting of groups as systems and/or sub-systems with certain roles. The researcher as well as the older persons in this situation is systems thinkers because they did not only analyze the problems, but the abstract possibilities in terms of the overall purpose of the system to operationalise community-based collaboration to support the older person in the world of HIV/AIDS. The older persons experience a **need to share problems** like HIV/AIDS and act as a whole through open and honest communication to maintain balance in the community. How the older person interacts with their environment, as well as the influences of the environment on the older person and how they act on that, is part of the complex dynamics that will create a better description of the need for community-based collaboration to support the older person in the world of HIV/AIDS (Fischer, 2008:23).

The guidelines and actions for operationalisation that apply to the older person as a system follows on the next page (see table 5.4).

Table 5.4: Guidelines and actions for operationalisation: The older person as a system

Guidelines pertaining to the older person as a system	Actions for operationalisation
7. The older person, specially the women, should receive socio-emotional and tangible support as caregivers to cope with the role changes that deviate from their normal aging role changes because of HIV/AIDS and the accompanied responsibilities placed on them	✓ Identify the CBO's involved in community-based home care to clarify their scope of work duties ✓ Involve the neighbours, initiate neighbour buddy system ✓ Mobilise the younger generation to help with every-day chores ✓ Training of older persons as caregivers on home-based diagnosis and treatment of opportunistic infections with trained volunteers and community health nurses as facilitators and mentors in the field
8. Comprehensive PHC services should be accessible, based on health promotion strategies to reach total health (wholeness) of the older person who's health profile revealed deviations in more than one sub-system indicated in the list below: ✓ Bio-physical = diabetes mellitus; hypertension; other cardiovascular diseases; lung diseases; HIV/AIDS ✓ Psychological = stress; depression; isolation; low self-esteem; distrust in fellow members ✓ Socio-economical = financial constrains; food scarcity; abuse of older persons for financial support ✓ Social-cultural = religion and FBO's (church) plays important role in support; role changes no longer traditional roles; family structures, multi-dimensional ✓ Environmental = chores around household difficult for the women; unsafe practices like open fires ✓ Behavioural = chronic diseases are aggravated by certain lifestyle patterns, like alcohol and tobacco use and sex practices without condom use	✓ The point of departure should be to start with socio-emotional support which can realise through screening of older persons at decentralised facilities ✓ Screening of older persons at decentralised places should include for hypertension, blood sugar ✓ Tuberculosis and other lung diseases and HIV/AIDS screening can follow on request and be initiated later in the program or as the need arises ✓ Physical exercises given by bio-kinetic department ✓ Project should be multi-disciplinary include nurses, social workers, dieticians, psychologist, bio-kinetics ✓ Initiate a well functioning day-care/drop-in centre where • socio-emotional support can realise and the older persons can get together for relaxation, love, hugs, to give advise, share problems, feel wanted • tangible support through structured organised help can realise and help available to take to the doctor, help with household chores, prepare meals, help with bedridden people
9. The older persons that are mostly from the previously disadvantage groups, should be given the opportunity to enhance their educational level, and all support programs should entails a section on health education	✓ Develop educational package with focus on the older person's needs and expectations on: • Human rights • Interpersonal skills

regarding their health needs	• Coping skills • Safety precautions regarding physical environment (open fires), working with blood-borne diseases, general safety • Self-care activities in management of chronic diseases • Self-management of HIV/AIDS and other opportunistic infections at home • General health education on hygiene, general diseases, childhood diseases and immunisation, STI's, reproductive health, woman's' health • End-of-life care and support
10. The traditionally acknowledged role of the older persons as the strong ones with hope in the future should be focused on and they should have the opportunity to participate in decision making processes	✓ Establish, identify leadership for the project ✓ Goals and objectives established through consensus on shared vision for community ✓ Establish communication networks, weekly notice board in the Gazette to promote the older person as the role model in the community
11. Programs with an inter-generational intention should be developed to strengthen the older person's set of traditional values based on religion that is currently threatened by the westernised influences of the younger generation	✓ Invite the youth to forums and group meeting of older persons ✓ Invite prominent leading figure like Nelson Mandela to talk on the valued role of older persons ✓ Start intergenerational programs at schools

5.6.3.4 Stakeholders as a system

Stakeholders in the study refer to an **open system that functions as partners in the community**; they are in an interactive relationship to each other. A stakeholder refers to a person, groups or organisations with an interest in projects or initiatives and plays a specific role and/or has a function in a particular situation/project/initiative (South African Concise Oxford Dictionary, 2002:1012 &1143). **The stakeholders in the community refer to informal and formal systems.** The University, the Department of Health, the CBO's, NGO's and FBO's are the more prominent existing **networks** involved in some or other program regarding HIV/AIDS with the main stakeholder, the Department of Health, as policy maker with certain political structures in place (refer to chapter 3, paragraph 3.4.2.1; chapter 4, paragraphs 4.4.3.1 and 4.4.3.2).

The mentioned stakeholders need to network with each other, which means to interact for the exchange of information and to develop useful contacts (SACOD, 2002:782). The viability of organisations as stakeholders to function as a system of partners depends on its ability to acquire energy through information transmission (Fitch, 2004:498). Without open communication to convey information, the interrelations within the organisation as well as between the organisations will not exist. Energy exchange refers to interaction and when energy does not exist in an organisation, entropy develops (characterised by decreased interactions between stakeholders). An open system on the other hand that facilitates energy is characterised by increased interactions and referred to as negentropy.

Relationships furthermore depend on interaction between the older persons and the stakeholders as networks of relationships on their own part of larger networks (Reed *et al.*, 2004:216-217). Effective interaction and co-ordination would benefit both systems and referrals made from the one to the other when they reach their limits (Tjale, 2004:6). When a stakeholder functions as an open system, the areas of contact refer to an interface managed through coordination and collaboration (Fitch, 2004:489). Boessenskool and Schutte (2005) argue that there should be "presupposed causality between organisational structures and a culture of ownership" regarding HIV/AIDS that adds to the concern that the stakeholders should start to coordinate their fragmented, duplicated services (refer to chapter 3, paragraph 3.4.2.1 and 4.4.3.1) in the community (Mitchell & Crittenden, 2002:2). From systems thinking Fitch (2004:490) refers to autopoietic behaviour when different organisations do not coordinate their services and duplicate it. All the services in the community rendered by the stakeholders identified should be integrated to form part of the whole regarding the needs of the older person infected with and/or affected by HIV/AIDS.

The following guidelines and actions for operationalisation apply to the stakeholders as a system (see table 5.5).

Table 5.5: Guidelines and actions for operationalisation: The stakeholders as a system

Guidelines pertaining to the stakeholders as a system	Actions for operationalisation
12. Stakeholders as an open system should function as partners in the community, each with their specific interest, role and functions that can contribute to the support of the older person infected with and/or affected by HIV/AIDS	✓ Establish, identify leadership for the project ✓ Invite youth activist to join as partners ✓ Share the findings with the people in the community that participated as the first step build on needs assessment
13. The Department of Health as the key role player should be acknowledged and should indicate clearly their level of involvement in all decision making processes regarding support of the older person	✓ University should be invited as key role player with multi-disciplinary team available to initiate action – opportunities for "learn-and-serve" ✓ Set meeting with the Department of Health to inform of operationalisation plan ✓ Invite political leaders of wards that apply (ward councillors) ✓ Investigate all possibilities for funding
14. Networking systems that play a vital role in community-based collaboration should focus on the effectiveness of the information transmission	✓ Feedback should be given to all stakeholders on findings to start mobilization of partnership ✓ Partnership should start small – initiate meeting between university, Local authority, LAC, DOH ✓ Inform international possible donors who visited the area and are aware of the situation and predicament of the older persons in the community
15. Autopoietic behaviour (un-coordination and duplication of services) of the stakeholders in the support of the older persons should be avoided by an interface managed through coordination and collaboration	✓ Goals and objectives established through consensus on shared vision for community ✓ Joint planning of the project activities (set plan, time frame, responsibilities, facilities, services, equipment and budget) ✓ Develop links and community systems on grassroots level ✓ Establish databases within and between the stakeholders and organisations

5.6.3.5 Community health practice as a system

The focus of community health (biological, psychological and social) is the **total well-being of the community groups as a whole**, for example a community of older persons and older persons as individuals. It refers to knowledge and opportunities given to the members of the community to make informed choices that **improve health**. To **promote healthy communities** is to foster open communication among the older persons in the community and engage in action based on **shared vision** (Clark, 2008:29) of the community (refer to 3.4.2.5), or to "share our ideas and feelings" (Andrews & Boyle, 2003:21; Parry, 2004:107). **Health promotion programs and community participation** lead to confidence and empower the older person to make his or her own choices (refer to chapter 2, paragraph 2.4.2.5). This results in community leadership that fosters collaboration and partnership. Community participation refers in this context to the older persons that are involved in the decision making process with regard to the identification of needs, planning to meet the needs and personal contributions in solving the needs (Dennill *et al.*, 1999:93; Swanepoel & De Beer, 2006:28-29). From a systems perspective, short-term improvements foster dependency and lessened abilities for the older persons in the world of HIV/AIDS to solve their own problems (Spruill *et al.*, 2001:110) and should be avoided.

A healthy community also refers to the support of diversity among community members. In socio-cultural systems the interrelationship between members or other parts of the system depends on **information exchange**, are open systems with the tendency to have tension built into them (Ritzer, 2008:329). Tension can exist in a community between traditional healers as stakeholders and the Western medicine systems (refer to chapter 3, paragraph 3.4.2.1) that is part of community health practices. The assessment of needs and the assets help to raise awareness among the community members of what they need and what they have for effective prioritizing and planning of interventions like community-based collaboration to support the older person in the world of HIV/AIDS. **A healthy community means that the community members are linked to community resources and that there**

is a sense of responsibility and cohesion among the community members (Clark, 2008:29). Health management as adapted for this study from Clark (2008:277) refers to it as "a collaborative process that directs, links and co-ordinates with the person in need, the family, healthcare professionals, service providers and NGO's, CBO's, FBO's to assess, plan, implement, advocate, co-ordinate, educate, monitor and evaluate options to support and care" (refer to chapter 4, paragraph 4.4.3.1).

The contexts of community health practice where community-based collaboration takes place to support the older person in the world of HIV/AIDS is complex in nature and also **refers to the environment** (Arries, 2002:172; Fischer, 2008:5-8), of which community-based home care forms an integral part (Uys & Cameron, 2003:5-6). Refer to chapter 3, paragraph 3.4.2.1; chapter 4, paragraph 4.4.3.1 and 4.4.3.2. Community-based home care is defined as care given to the sick people in their homes (Ncama, 2005:34) and aims at community empowerment (De Villiers & Herselman, 2004:20). A comprehensive approach to primary health care is necessary to improve the health of the community (Dennill *et al.*, 1999:4) and the stakeholders form an important link to the primary health care clinics (refer to chapter 4, paragraph 4.4.3.1).

One of the strategies is to make information available to the members of a community concerning health problems, in this study, HIV/AIDS. It is the first component for the implementation of primary health care in South Africa (SA, 1997:4). Not only is networking for the exchange of ideas and information necessary, but also resource allocation to provide and produce health information on the identified health education needs in the community, as well as knowledge of "self" (Dennill *et al.*, 1999:36-37). Health education often misses the purpose to educate people for free choice or for empowerment. It should rather focus on life skills education that enables individuals to become more empowered (Coulson *et al.*, 1998:78). Refer to the health profile and needs of the older person infected with and/or affected by HIV/AIDS that clearly indicate the aspects of health education needs. Community health practices

include effective community development and therefore systems' thinking is necessary to implement any community intervention effectively, be part of the feedback process and from a systems view "grasp the ways in which knowledge can improve their lives, be encouraged to seek out new knowledge and become agents of change themselves" (Spruill *et al.*, 2001:106 & 110).

The following guidelines and actions for operationalisation apply to the community health practice as a system (see table 5.6).

Table 5.6: Guidelines and actions for operationalisation: Community health practice as a system

Guidelines pertaining to community health practice as a system	Actions for operationalisation
16. The older person should be included in community health practice concerned with the total wellbeing of the community which entails health promotion programs	✓ Prioritize and reach consensus on needs through participatory decision making process that should include the older person ✓ Re-focus on gerontology services at clinics as part of PHC services ✓ Make health workers aware of the valuable contribution the older person can make to the health and wellbeing of the family and community as a whole and train them in gerontology
17. Partnerships should be developed between the traditional and Western medicine as smaller sub-systems in the community to decrease tension between the two systems to support the older persons who are concerned with the situation	✓ Invite the traditional healers to the meetings and group discussions with the older persons ✓ Identify the needs and expectations of the traditional healers ✓ Initiate a training schedule regarding westernised management and treatment of chronic diseases and HIV/AIDS as well as tuberculosis
18. The older person as caregiver should be recognised as an integral part of community-based home care, a sub-system of community health practice and receive the necessary support from the informal and formal stakeholders involved with community-based home care	✓ Community-based home care for older persons should be coordinate from a central structure ✓ Increase the number of visits to homes to explore more on the real life situation ✓ Improve "learn-and-serve" action through the home-visit process in community nursing curriculum in theory as well as the practice of the students

19. Community-based collaboration entails community-development that involve feedback on regular bases to evaluate if the support programs of the older persons is working and is effective	✓ Health education that focus on interpersonal skills, life skills, role change, HIV/AIDS issues, financial management, grievances management
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5.6.3.6 Support as an outcome to enhance successful aging

To support somebody is “to bear all or part of the weight”, it is “to give assistance, to encourage, to be actively interested” (South African Concise Oxford Dictionary, 2002:1178). According to the Churchill Livingston’s Dictionary of Nursing (Brooker, 2006:234-235), support is to “be of physical nature when the hand is placed on the abdomen when coughing, it can be of psychological nature when you listens actively to another or holds the hand when someone is dying. It can also be of social nature when a person voluntary visits someone in the community that is in distress or housebound”.

HIV/AIDS places increased responsibilities on the older person, especially on the women that warrant support (refer to chapter 2, paragraph 2.4.1.5) with regard to bio-physical-, physical environmental-, social-, financial-, and emotional needs. Care and support of older persons aim at empowerment and involve a functional structure that could be a day-care centre in the community where comprehensive care and support is delivered to the older persons that includes the enhancement of their knowledge regarding health-, social-, cultural-, economical- and educational issues. The older persons and the stakeholders as systems are perceived as in a mutual supportive relationship (Reed *et al.*, 2004:276) where interaction takes place. An open system refers to a trust relationship, the older persons lack that trust in the social support system in the community. HIV/AIDS with the accompanied stigmatisation as complex elements related in a causal network (older persons, families, community members, stakeholders) reveals the possibility to change into a close system, lack interaction with subsequently characteristics of a entropy system (Ritzer, 2008:328).

Older persons find their support in sharing problems, they are from an African socio-cultural background with a strong sense of belonging and sharing, and the believe

that whatever happens to the individual, happens to the whole group (Basabe & Ros, 2005:190; Mbiti, 1990:106). Interaction between the older persons as a group refers to inter-connectedness and symbolises the African culture regarding sharing with the community. They should act collectively because of the need, crises and urgency (Swanepoel & De Beer, 2006:37) placed upon themselves, their families, neighbourhood and community by the complex affects of HIV/AIDS (refer to chapter 3, paragraph 3.4.2.5). A collective relationship refers to the interrelationship between the older persons themselves as a group that share a common problem; HIV/AIDS that involve them with a sense of duty and obligation towards the group (Basabe & Ros, 2005:191) to ensure harmony in the group (refer to chapter 3, paragraph 3.4.2.1). Human interaction is characterised by harmonious participation and co-operation that reinforce the important role of the family for support and security of the older person infected with and /or affected by HIV/AIDS (De Villiers & Herselman, 2004:19).

Important in the context of this study is to note that religion cannot be isolated, it is present in life and runs like a golden thread in the African worldview, "Africans are notoriously religious" (Mbiti, 1990:1). The older persons experience a great deal of support from religious groups in the community where everyone has its own religious system with a set of beliefs and practices (refer to chapter 2, paragraph 2.4.2.4; chapter 3, paragraph 3.4.2.5 and chapter 4, paragraph 4.4.3.1).

The guidelines and actions for operationalisation that apply to support as an outcome to enhance successful aging follows on the next page (see table 5.7).

Table 5.7: Guidelines and actions for operationalisation: Support as an outcome to enhance successful aging

Guidelines pertaining to support as an outcome to enhance successful aging	Actions for operationalisation
20. Support to the older person should be of physical nature, psychological nature and social nature	✓ Establish a referral system (booklet) with the PHC facilities that is informative on resources available, services and contacts and specific on the needs of the older persons ✓ Create an awareness among older persons of their rights ✓ Advocate access for the older persons to information and their participation in community development actions and policy development
21. A functional structure is a shared vision of the older persons and should be a day-care centre in the community where health care can be rendered as well as comprehensive support and health education could be feasible	✓ Propose the well planned idea with facilitating and impeding considerations spelled out to the local policy makers (Local Government, DOH, LAC and University) ✓ Identify central structure for comprehensive care & support (day-care) for small scale implementation ✓ Identify and prioritise the different needs and type of support expected by the older persons at such a centre ✓ Create sense of belonging and give leadership for planning to the older persons ✓ The process must be facilitated by small groups of key stakeholders with specialised abilities (multi-disciplinary team)
22. Religious organisations as an important support system for the older person in the community should be acknowledged and utilised in socio-emotional as well as tangible support	✓ Set meeting with local FBO's leaders to give feedback on the findings of the study as an entry point to build a trust relationship ✓ Utilise churches as decentralised structures for screening of hypertension, BP control is an effective way to initiate socio-emotional support and build trust relationship

5.6.3.7 Facilitating factors that are part of the environment

To facilitate means to make the situation regarding HIV/AIDS as a reality in the environment of the older person easier through physical, cognitive, emotional, and social manifestations of strengths, capacity and protection factors (SACOD, 2002:412; Wissing, 2007:12-14).

Factors that help the older person to cope and retain resilience in the world of HIV/AIDS can be identified as facilitating factors in the study. The strengths the older person reveal within themselves (bio-physical, cognitive, emotional) or in their immediate environment such as the household (ecological, social, physical), the church (social) and relationship with something bigger than themselves (spiritual) can make the situation regarding HIV/AIDS easier. It is important to identify the factors to enhance the health and well-being of the older person infected with and/or affected by HIV/AIDS.

The older persons not only have a culture of, but also a willingness to care for members in their families and communities infected with and/or affected by HIV/AIDS. These realities place them in the midst of responsibilities they seem capable of meeting, regardless their own needs and problems. The older persons are willing to look after orphans as they are aware of the grant that they can receive, but furthermore rely largely on the ontology of religion that give them the ability to cope with the mentioned responsibilities.

The guidelines and actions for operationalisation that apply to the facilitating factors that are part of the environment follows on the next page (see table 5.8).

Table 5.8: Guidelines and actions for operationalisation: Facilitating factors that are part of the environment

Guidelines pertaining to the facilitating factors that are part of the environment	Actions for operationalisation
23. The stakeholders, community and family members should appreciate the older persons that demonstrate a culture of care and therefore can easily take the responsibility to care for their children, grandchildren and the sick in their households	✓ Create public awareness on this aspect and the privilege it generated to the younger generation and the community as a whole ✓ Create an awareness at the schools through a drawing/painting competition ✓ Give a graffiti wall for the youth somewhere in the centre of the town/area of residence to thank the older generation for their unconditional care and support – all the graffiti should convey a gratitude message to the older persons

5.6.3.8 Impeding factors that are part of the environment

Aspects that “block, hinder, delay or obstruct the progress or action” are impeding factors (South African Concise Oxford Dictionary, 2002:573). Impeding factors can also be seen as symptoms of illnesses, risk factors and can also refer to vulnerability that occurs within the different dimensions of man (Wissing, 2007:12-14). It is important to have cognisance of what to expect in the community regarding aspects that can hinder or delay the “action” that refers to community-based collaboration to support the older person in the world of HIV/AIDS.

HIV/AIDS on its own is an “impeding factor” that infects or affects the older person, their family and community in relationship to the environment with whom they interact. There can be various risk factors manifesting in and around the older person in their world of HIV/AIDS, and they should be identified and evaluated to prevent low quality of life or future risks that can contribute to declining health and vulnerability of the older person. The most prevalent aspects derived from the conclusions is the fact that the older persons are illiterate or have a low educational level, they lack trust towards the community organisations, the reality of stigmatisation and transport.

The following guidelines and actions for operationalisation apply to the impending factors that are part of the environment (see table 5.9).

Table 5.9: Guidelines and actions for operationalisation: Impeding factors that are part of the environment

Guidelines pertaining to the impending factors that are part of the environment	Actions for operationalisation
24. All partners involved with the care and support of older persons should take cognisance of the various risk factors that the older person is exposed to that can impede on community-based collaboration to support them in the world of HIV/AIDS	✓ Information should be made available in various ways, at the clinics and in the media on risk factors prevalent in the community, for example the rise in prices of foodstuff and to combat the problem by initiating food gardens ✓ Education sessions as mentioned to build capacity and promote the older persons' rights to information and participation ✓ Resource allocation should be done with special reference to aspects like transport necessary to do home visits

The description of the main themes identified in the preceding paragraphs, gave a clear picture of the older person as a system, infected with and/or affected by HIV/AIDS, their interrelatedness to their family, the community, the community health practice and the stakeholders as partners to render effective support. It furthermore gave the researcher an integrated picture, taken into account the impending and facilitating aspects for the final conceptualisation of community-based collaboration to support the older person in the world of HIV/AIDS. The description of community-based support will be accompanied by a visual model (refer to figure 5.4).

5.6.3.9 Community-based collaboration as a system

The community members with their own experience entrust themselves towards **meaningful and active involvement** and participation throughout the entire process of any program establishment (Crist & Escandon-Dominguez, 2003:267) with the **focus on co-operation and collective action** (Dennill *et al.*, 1999:124) that should include home support (Frolich, 2005:351; Penning *et al.*, 2002:1, 3). It means that the

individuals, the groups and families of a community have an active voice in matters of importance to them (Mardiros, 2001:76). The older person infected with and/or affected by HIV/AIDS, their family, other household members and significant stakeholders in the community, considering their historical, social, economical, cultural and political framework interact with each other. Active community participation strengthens their support systems in the world of HIV/AIDS with the focus on preventative, protective and promotive health care.

Collaboration is a **dynamic process of power sharing between partners** who work together/ or is jointly working together on a project (SACOD, 2002:226) originating from needs and problems to reach desired outcomes/or common purpose successfully (Sullivan, 1998:6; Winge *et al.*, 2005:2) through well functioning communication. Collaboration **creates a sense of shared autonomy between groups** (partnerships) to achieve either explicit or implicit mutually identified goals (Crist & Escandon-Dominguez, 2003:266) that would otherwise not be possible. According to Leddy and Pepper (*sited in* Hutchison & Quataro, 1995:112) collaboration means "shared responsibility for planning, problem-solving and evaluation with clients and others in the health care delivery system". Collaboration is a process in which the older persons infected with and/or affected by HIV/AIDS is central to the problem and work together with other stakeholders as partners. All involved participate actively, share decision-making, voice their experiences, knowledge and thoughts to contribute through effective communication structures towards a common goal to strengthen the older person's support regarding the effect of HIV/AIDS on their families and communities.

Community-based collaboration is a **process** characterised by constant change and interaction, and therefore it is transforming and creating a power-sharing **partnership** for a widespread application in **community health practice** with the purpose to attend to the needs, expectations, facilitating and impeding factors from the environment in order to achieve likely successful **outcomes**, which is to support the older person in the world of HIV/AIDS. The process is illustrated in chapter 1, figure 1.1 as adapted from Sullivan, 1998:119).

5.6.4 COMMUNITY-BASED COLLABORATION AS A PROCESS

Community-based collaboration is a **circular process**, and although the collaboration relationship in community health practice should begin somewhere, **there is no real starting point**. One needs to take the first step and identify key stakeholders, gain their **commitment**, including that of the older person. Now the process can continue to **prepare the stakeholders as collaborators** and **invest in needed resources**. Through **supportive leadership** community-based collaboration **partnerships** will realise in community health practice.

Community-based collaboration as a open system **utilise the gathered information** in community health practice to **diagnose, describe, understand, define, prioritise and decide collectively on the shared responsibilities or objectives** to reach the desired **outcome**, namely support of the older person to enhance successful aging. **Feedback** is another important principle in the process, it is a circle of **cause-effect relationships** that takes place when certain **inputs** (facilitating and impeding factors) are given in a system and connections and relationships take place during community-based collaboration.

5.7 CHAPTER SUMMARY

In chapter 5 the conceptualisation process followed by the formulation of guidelines to operationalise community-based collaboration to support the older person in the world of HIV/AIDS was discussed. Four steps were followed in the conceptualisation and formulation of guidelines for operationalisation, namely

- *overview of conclusions* of all the findings of the study in table format;
- *compiling of an integrated map* through the mapping of conclusions from all the empirical findings from step 1 to step 5 of the study;
- *description* of the main themes derived from the integrated map; and
- *compiling of guidelines* for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS.

In chapter 6 the evaluation, limitations and recommendations for community health science practice, nursing education and nursing research are provided.

CHAPTER 6

EVALUATION OF THE STUDY, LIMITATIONS AND RECOMMENDATIONS FOR COMMUNITY HEALTH SCIENCE PRACTICE, NURSING EDUCATION AND NURSING RESEARCH

6.1 INTRODUCTION

This study owes its beginning to the sensitivity of the researcher working with older persons in the community. The older persons are left vulnerable by the reality regarding HIV/AIDS that includes them as a generation with a deep-seated cultural value system. They are confronted with a killer disease threatening to disrupt their whole existence. The observations made were that the older persons are trapped in a unique situation; they are not only *infected* with HIV/AIDS, as observed through the HIV-testing results, but also *affected* by HIV/AIDS, as could be heard when listening to their stories. It became clear that the older persons need support in the world of HIV/AIDS, and an in-depth investigation started to gain insight into this phenomenon. The investigation developed into what is proposed to the reader from chapter 1 to chapter 5.

This chapter presents a systematic evaluation of the study, referring to the following:

- Review of the study
- Limitations of the study
- Recommendations for community health science practice, nursing education and nursing research

6.2 REVIEW OF THE STUDY

An overview of the study served as an introduction to the background and familiarised the reader with the problem statement (chapter 1). The aim of the study, to

conceptualise and formulate guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS, was achieved successfully through the following objectives:

- the health profile of the older person infected with and/or affected by HIV/AIDS was determined and described,
- the needs and expectations of the older person infected with and/or affected by HIV/AIDS were explored and described,
- the facilitating as well as the impeding factors the older person infected with and/or affected by HIV/AIDS experience in their households were explored and described,
- the existing networks and support programmes available were identified and described,
- the perceptions of the different stakeholders involved in mentioned networks and support programmes on community-based collaboration to support the older person in the world of HIV/AIDS, were explored and described.

The research process comprised of three phases and seven steps. Step 1 included the health profile of the older persons, central to the research (chapter 2). Steps 2 and 3 explained the needs, expectations, facilitating- as well as impeding factors with regard to the older persons infected with and/or affected by HIV/AIDS, as experienced in their households (chapter 3). Steps 4 and 5 referred to the perceptions of the different stakeholders from existing networks and support programmes on community-based collaboration for the support of the older person in the world of HIV/AIDS (chapter 4). Phase 1 and 2 involved the investigation for quality research evidence to complete phase 3, which involved conceptualisation and formulation of guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS.

A quantitative and qualitative research design, with the aim to explore, describe and interpret the findings within a specific context, was used. Sensitive issues under investigation, like the older person in the world of HIV/AIDS, compelled the researcher to consider the time, culture and history of the older persons involved. Although the research design and research method for the study were expounded in chapter 1 (see table 1.4), the details of each design and method was discussed during the course of the study in each applicable chapter.

The systems theory was used as the main theoretical basis and point of departure. The community as system consists of the families, older persons and stakeholders as sub-systems that function in an open trust relationship with each other. HIV/AIDS form part of the environment constantly in interaction with the system at large as well as the smaller systems, with a threat to disturb the balance in the world of the older person (wholeness). The older person as a system with interrelated sub-systems or health dimensions (bio-physical, psychological, socio-cultural, environmental and behavioural) is central to the study, together with the person's needs and expectations. Support is possible through community-based collaboration that includes all stakeholders to work as partners to reach a common goal through the operationalisation of events in a cyclic manner to support the older person in the world of HIV/AIDS.

The results and discussion of the first objective (see chapter 2), stem from an auxiliary study within the larger PURE-SA study. A sub-population of older persons (n=333) infected with and/or affected by HIV/AIDS were selected from the 2021 participants in the PURE-SA study (2005) compilation of a health profile. A survey study to explore and describe **the health profile of the older person** was executed by means of a non-experimental quantitative research design. The survey study was unique as it was the first time that a health profile was compiled for the older person in the community under discussion in the North-West Province. The results were categorised according to the dimensions of health as sub-systems. The demographic-, socio-economic-, psychological-, lifestyle/behaviour-, biophysical-, and HIV-related

sub-systems confirmed the debilitating influence of the HIV/AIDS epidemic on the aging process of the population in South Africa. **Seventeen conclusions** originated from phase 1, step 1 and contributed to the unfolding picture of the reality faced by the older person in the world of HIV/AIDS.

The Mmogo-methodTM, a visual cultural-sensitive method, was used in focus group discussions to explore and describe the **needs, expectations, facilitating and impeding aspects as experienced by the older person infected and/or affected by HIV/AIDS** (see chapter 3). Individual interviews (2) were conducted to “test” the researcher’s sensitivity to the older persons’ feelings and the applicability of interviews as a data collection method. The interviews were found to be unsuccessful as data collection method for the purpose of this study. The interviewees were found to be non-responsive and reserved when asked to reveal appropriate data on HIV/AIDS issues. After consultation with the promoter, a decision was made to use the Mmogo-methodTM with the assistance of a psychologist specialized in community psychology and founder of the Mmogo-methodTM. Although an unfamiliar method in nursing research, the Mmogo-methodTM and accompanying focus group opened a complex issue and resulted in rich data regarding the needs, expectations, facilitating and impeding aspects experienced by the older person infected and/or affected by HIV/AIDS. The researcher noticed the relaxed atmosphere and group interaction triggered by the Mmogo-methodTM. The older persons had the opportunity to verbalise how they feel and it became clear that they are a neglected group who can still contribute, if allowed, to the effective functioning of their communities. An outstanding aspect identified throughout the data collection process was the hunger of the older persons for knowledge on health issues, the need to act and advocate against the problem as a group, and the unconditional love and hope deeply rooted in religious beliefs that they feel can conquer HIV/AIDS. **Sixteen conclusions** originated from phase 1, step 2 and 3, which will form an integral part of the conceptualisation process needed to formulate guidelines to operationalise community-based collaboration to support the older person in the world of HIV/AIDS. The use of the Mmogo-methodTM was never been used in nursing before as

mentioned earlier in this paragraph and proof to be a unique visual method that can be successfully adapted for future nursing research where sensitive issues apply.

Individual interviews were conducted with the **stakeholders of the existing networks and support programs available in the community to explore and describe their perceptions regarding community-based collaboration to support the older person in the world of HIV/AIDS** (see chapter 4). Phase 2, step 4 and 5 apply to chapter 4, and these resulted in the final set of data collected from the empirical world. The data collection process of phase 2 was an experience that proved that the success resulted from well planned scheduling of research interviews; eighteen were conducted during a period of ten days. Data collection continued until enough stakeholders and role players were interviewed for a full and rich description of their perceptions on community-based collaboration. From the twenty-six stakeholders and/or role players (N=26) identified for participation, eighteen (N=18) were interviewed. Thematic mapping was a new but exiting technique used to organise the data from the voice recorder and transcriptions into a map to visualise the relationships among different themes and to stimulate the generation of ideas and communicate them as related themes. The whole process of thematic mapping add to the uniqueness of the study and was done with the help of a software program Mindjet® MindManager® 6 to transform and bring together diverse views and values of the stakeholders and role players to conceptualize and represent complex constructs in a clear and systematic manner (Sutherland & Katz, 2005:257).

The uniqueness of this phase lies in the richness of the data, the open communication and initiating of a trust relationship with futuristic expectations for collaborative partnership with the university demonstrated by the stakeholders. It was an enriching experience for the researcher as well as for the interviewer, for the opportunity exists to observe the effectiveness of some of the stakeholders, especially the NGO's and FBO's. Amidst difficult circumstances, they are willing to serve and help others in the community. Both the researcher and the interviewer became aware of the expectations the older persons and stakeholders have of the

university for support, not financially, but mostly to educate and build capacity. **Twenty-three conclusions** crystallized from the findings, which add great value to the uniqueness of the study. The perceptions of the stakeholders regarding community-based collaboration contributed to the final evidence needed from the empirical world to conceptualise community-based collaboration to support the older person in the world of HIV/AIDS.

The conceptualisation process resulted in **guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS** (see chapter 5), based on the theoretical basis of the systems theory as point of departure. The researcher integrated the conclusions of each phase through deductive reasoning and utilized concept mapping into the final conceptualisation with well developed conceptual description of the main themes and the relationship between them. Guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS came to the forefront during the conceptualisation process.

The **central theoretical statement** offered below, based on the objectives as discussed, was **successfully carried out**.

The description of the health profile of the older person infected with and/or affected by HIV/AIDS, their needs and expectations and the facilitating as well as the impeding factors that they experience, the existing networks and support programmes available as well as the different community stakeholders' perceptions form the basis to conceptualise community-based collaboration for the formulation of operationalisation guidelines to reach the ultimate goal to support the older person in the world of HIV/AIDS.

The data derived from various data collection methods (survey study, Mmogo-methodTM as focus group interview, individual interviews, as well as literature control) enabled the conceptualisation to be investigated from different viewpoints and to be supported by national and international literature. The purpose of this study was to conceptualise and formulate guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS.

The study contributed to community health science, id est:

- The unique contribution in this study is the attendance to a real problem in the community, namely to investigate possibilities to support the older person in the world of HIV/AIDS. What made it special further was the fact that it opened a deeper understanding of what community-based collaboration entails, based on a multi-disciplinary approach, which holds the promise for operationalisation in the years to come.
- The researcher had the opportunity to fulfil a dream and started a participatory research project in the community where the university and School of Nursing Science are involved over a long period of time for practical experiences. This study has the opportunity to enter into the community with a well written plan, to give back to the community where the research took place, and build a healthy trust relationship to the advantage of the older persons, the stakeholders, the policy makers, the nursing students and the university as a whole regarding service in the community.
- Three different methods to collect data were used. The findings of a quantitative research design and method (household survey) were used to identify and describe the health profile of the older person. The findings were successfully integrated and combined with findings of qualitative design and methods (Mmogo-methodTM as focus group and individual interviews) pertaining to the needs and expectations of the older person, as well as the perceptions of the stakeholders to conceptualise community-based collaboration that ensured trustworthiness.

- The Mmogo-methodTM was new, a visual image made with clay, straw and beads to trigger and energise discussion during a focus group interview. The culturally sensitive method was successfully implemented and ensured rich data from older persons reserved on sensitive issues like HIV/AIDS.
- Thematic mapping was a unique way of dealing with data and was adapted from concept mapping. A software program did clustering of concepts and themes, Mindjet® MindManager® 6 and this can contribute to the orderly management of data in future studies where the need is for concept or thematic mapping.
- The findings of the research that resulted in the conceptualisation of community-based collaboration give the opportunity for collaboration based on partnership between the university and the community (older persons) towards sustainable support of the older person in the world of HIV/AIDS.
- The focus on mother-and-child health, HIV/AIDS, tuberculosis and diseases like malaria in primary health care, resulted in the exclusion of the older persons from decision-making processes in policy matters. The findings of the research will contribute to and give opportunity for older persons in the community to advocate the valuable role they play in the community affected by HIV/AIDS.

6.3 LIMITATIONS

The following limitations were identified:

- The context of the study was limited to the urban area from phase 1, step 2, and the data is therefore restricted to the urban community. The guidelines to operationalise the conceptualised community-based collaboration from the empirical world and may not apply to the rural area. Further investigation is required to ascertain whether the guidelines for operationalisation of

community-based collaboration to support the older person are transferable to the rural area.

- Language seems to be a barrier. The researcher and interviewers conducted all interviews in Afrikaans or English. Some participants, especially the older persons, found it difficult to express themselves and the researcher runs the risk of missing the important meaning of Setswana words if not correctly translated and interpreted by the fieldworker. All the interviews had to be controlled by a Setswana speaking community nurse researcher with high cost implications.

6.4 RECOMMENDATIONS

Recommendations for community health science practice, nursing education and nursing research are provided.

6.4.1 COMMUNITY HEALTH SCIENCE PRACTICE

Recommendations are provided for the implementation of community-based collaboration in community health science practice:

- Policy makers on district, provincial and national level need to be informed on the guidelines formulated for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS.
- The planning and implementation of community-based collaboration according to the operationalisation guidelines should realise in the following years to come in the Potchefstroom area.
- The School of Nursing Science and the nursing students should participate in community actions and/or projects that can benefit the older person.
- The possibilities for the implementation of sustainable decentralised structures in the community where the older persons can interact with each other and with members of the younger generation should be considered.

6.4.2 NURSING EDUCATION

Recommendations for nursing education include important aspects identified in the study that should be included in the curriculum:

- Influences of HIV/AIDS on the older person's normal ageing process.
- The management (self-care and health-systems care) of chronic diseases in older persons with special reference to diabetes, hypertension and lung diseases.
- Cultural congruent interaction with the older person in the community with the focus on the role of the traditional healer in the management of HIV/AIDS.
- Community-based home care principles with the focus on the older person as caregiver.
- Ethical dilemmas that might be encountered in care and support of the older person in their household.
- Implementation of a community project to start informal structures in the community to do basic screening of the older person in the community with the aim to build trust relationship through service learning practice.

6.4.3 NURSING RESEARCH

Some recommendations are made for further research regarding community-based collaboration to support the older person in the world of HIV/AIDS.

- Participatory action research is necessary to investigate, plan, implement and monitor a sustainable collaborative partnership over the following five years on care and support of older persons.
- The same investigation on needs and expectations, facilitating and impeding aspects experienced by the older persons as well as the perceptions of the stakeholders should be done to conceptualise and formulate guidelines to

operationalise community-based collaboration to support the older person in the world of HIV/AIDS in the rural area.

- Research is needed to identify possible ways to secure the older person against socio-economical abuse.
- An investigation is needed to determine the level of knowledge regarding health issues that include basic aspects of home-based care, universal precautions when caring for the sick at home, management of HIV/AIDS symptoms, with the possibility to engage in a participatory research project.
- Health education is imperative as concluded from the study, participatory active research should be conducted in a project development and capacity building of the older persons as a community.
- The older persons and the younger generation in the multi-generational households need to take responsibility for their own actions and health. Health promotion strategies with the focus on multi-generational programs should be explored.
- An investigation regarding the impact of HIV/AIDS combined with other chronic diseases, namely hypertension and diabetes on self-care activities of the older person is needed.
- Further research will be necessary to evaluate the community-based collaboration process for sustainability.

6.5 CHAPTER SUMMARY

The aim of this study, to conceptualise and formulate guidelines for the operationalisation of community-based collaboration to support to the older person in the world of HIV/AIDS, has been achieved. The chapter ends the research project with a review of the study, discussion of the limitations to the study and recommendations for community health science practice, nursing education and nursing research.

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NWU **see** NORTH-WEST UNIVERSITY

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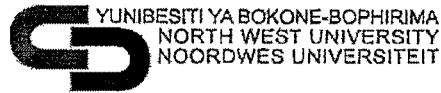
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APPENDICES

APPENDIX A
ETHICAL APPROVAL NORTH-WEST UNIVERSITY, POTCHEFSTROOM
CAMPUS TO CONDUCT THE RESEARCH



Dr A Kruger
Bussie 594
Noordwes-Universiteit
(Potchefstroomkampus)

Etiëkkomitee
Tel (018) 299 2558
Faks (018) 297 5308
E-Pos dnveair@puk.ac.za

2 September 2004

Geagte dr Kruger

GOEDKEURING VIR EKSPERIMENTERING MET MENSE

Hiermee wens ek u in kennis te stel dat u projek getiteld *"PURE study (Prospective Urban and Rural Epidemiology study)"* deur die Etiëkkomitee goedgekeur is met nommer 04M10.

Gebruik asseblief die nommer genoem in paragraaf 1 in alle korrespondensie rakende bogenoemde projek en let daarop dat daar van projekteleers verwag word om jaarliks in Junie aan die Etiëkkomitee verslag te doen insake etiese aspekte van hulle projekte asook van publikasies wat daaruit voortgespruit het. U sal in Mei 2005 die dokumentasie hieroor ontvang.

Goedkeuring van die Etiëkkomitee is vir 'n termyn van hoogstens 5 jaar geldig (volgens Senaatsbesluit van 4 November 1992, art 9.13.2). Vir die voortsetting van projekte na verskryking van hierdie tydperk moet opnuut goedkeuring verkry word.

Die Etiëkkomitee wens u alle voorspoed met u werk toe.

Vriendelike groete

PROF. NT MALAN
VOORSITTER: ETIEKKOMITEE



POTCHEFSTROOMKAMPUS
Private Sak X6001, Potchefstroom, Suid-Afrika, 2520
Tel: (018) 299-1111 • Faks: (018) 299-2799
Internet: <http://www.nwu.ac.za>



APPENDIX B

CONSENT FROM DEPARTMENT OF HEALTH TO CONDUCT THE RESEARCH



North West Province

NORTH WEST DEPARTMENT OF HEALTH

Healthy Living for All



Republic of South Africa

3rd Floor Tirolo Building
Dr Albert Luthuli Drive
Mafikeng, 2745
Private Bag X2088
MMABATHO, 2735

OFFICE OF THE DDG

Enq: K. Mangonyane
Tel: (018) 387 5833/5
Tel: (018) 387 5816
cat@nwodp.org.za
www.nwhealth.gov.za

Fax: (018) 387 5709

29 August 2005

Dr A Kruger
North West University, Potchefstroom Campus
North West Province

SUBJECT: Approval for Research- Prospective Urban and Rural Epidemiological Study

Approval is granted to conduct the above study in the North West Province, kindly make relevant arrangements with the management for suitable dates and times. Detail at the bottom of this letter has to be completed by you and returned to the Knowledge Management Directorate before your study may commence.

Regards

.....
O. Mongale
NWDOH Head of Department

KMx

Page 1
1

29/08/2005

The NWDoH will be furnished with final research report by

Please note that this is a prospective study over many years. We will submit a report 6 months after we did the baseline and again 6 months after each follow-up.

...July 2006.....
Submission date of the first report



.....
A. Kruger



APPENDIX C

FIELD NOTES DURING PURE-SA STUDY

1 September 2005

Start: 07:55

Methodological notes

The first group arrived with taxi organised by the research coordinator. Three groups attend the research session; 24 people, 15 people and 5 people.

There is to a small extend some noise, but the participants listened intently and participate actively in discussions. The interpreter is confident with the content of the discussion.

Observation notes

The groups are calm and participate actively in the discussion. Although they demonstrate with their heads that they know what HIV is, no body tried to answer the questions. The participants asked the researcher to explain in detail aspects of HIV/AIDS. The participants clarify their questions on the disease, especially regarding confidentiality and the home-based care process. The interpreter helped to clarify uncertainties.

Personal notes

The room is not private enough. The interpreter takes me into consideration and there is harmony between us. Each session took about 20 minutes. All the participants go through for the voluntary participation.

You will take part only if you feel free to do it. You have a choice. I am now going to explain the Mmogo-methodTM to you. The following steps apply:

- You will be placed around Susan's table in a group of ten people
- You can talk to each other, but you should share also with me or Susan what you say if you are asked to do so
- Susan will be the person that helps you with your concerns and questions, please ask immediately if you do not understand something or do not feel comfortable
- Each one of you will receive some material to work with, a mat to work on, clay, sticks and beads
- The question "please make a picture to tell us how you experience HIV/AIDS in the world you live in" will now be posed to you
- You should complete your visual presentation and then you can discuss it with each other to give meaning to it
- All of us will now discuss your presentation and you will have the opportunity to explain it to me and the group
- Throughout the whole process I will take photos and make pen and paper notes

All discussions during the session will be done in the language you feel comfortable with and for that reason I will be accompanied by Susan, you all know her, she will also be the translator from Afrikaans and/or English to Tswana and the other way around. The process will last about 2 hours, but you can stop anytime when you feel like it. Your permission is also asked to voice record the discussions so that it could be saved on the computer and be transcribed for analyses afterwards. All the recorded data will be kept on a database to whom only the researcher will have access through the use of a personal pass word.

Approval to do the research

This study is part of the PURE study that you are familiar with and was submitted to the Ethics committee of the Faculty of Health Science of the Potchefstroom Campus of the North-West University and approval has been granted. The provincial authorities and the person in charge of the different clinics in Potchefstroom are also aware of this research.

Risk or discomfort involved

The researcher will conduct the Mmogo-methodTM together with Susan that you know from the PURE study. She will also intervene as a translator where needed. I am aware of the

APPENDIX D

INFORMED CONSENT FOR PARTICIPANTS, PURE-SA STUDY

PURE-SA Project (Prospective Urban and Rural Epidemiology) INFORMED CONSENT FORM (including the PRIMER-study)

I, the undersigned (full names)

read / listened to the information on the project in PART 1 and PART 2 of this document and I declare that I understand the information. I had the opportunity to discuss aspects of the project with the project leader and I declare that I participate in the project as a volunteer. I hereby give my consent to be a subject in this project.

I agree to be tested for HIV	Yes	No
I want to know my HIV-status	Yes	No
I agree to give a blood sample	Yes	No

I hereby also declare that I am aware that:

1. this blood sample will be used for the purpose of
 - a. Isolating DNA to look at genetic factors that are currently associated with Type 2 Diabetes (i.e. the Calpain10, Adiponectin, Leptin and Leptin Receptor genes), or genetic factors that may be associated with Non Communicable diseases in the future. We give the assurance that all genetic tests and experiments will only focus on genotypes suspected to contribute to an increased risk of non communicable diseases of lifestyle.
 - b. Testing for liver function by determining liver enzymes such as AST, GGT,
 - c. Analyses of other than genetic parameters for Diabetes Mellitus such as HbA_{1c}, Blood glucose and insulin
 - d. Analyses of clotting factors and hypertension markers
 - e. Analyses of iron and nutrition status
 - f. And may be stored until such time as the above measurements/analyses will be done.
2. A two hour glucose tolerance test will be done
3. Body measurements such as height, weight, skinfold thicknesses, arm and leg circumferences will be taken
4. Electrocardiograph be taken
5. Blood pressure to be taken
6. Pulse wave velocity measurements will be made
7. A urine sample to be collected to analyse for the presence of heavy metals such as lead and mercury,
8. A Spirometer test to be performed to determine lung function
9. A handgrip test to be performed to test muscle strength
10. A hair sample to be taken to test for fumonisin mycotoxins.

.....
(Signature of the subject)

Signed at ... Potchefstroom / Ganyesa ... (delete not applicable option) on/...../ 2005

Witnesses

1. 2.

Signed at ... Potchefstroom / Ganyesa ... (delete not applicable option) on/...../ 2005

APPENDIX E

INFORMED CONSENT FOR OLDER PERSONS, MMOGO-METHOD™

Tel (018) 299 1838
Fax (018) 299 1827
E-Mail: Mada.Watson@nwu.ac.za

5 November 2007

Dear participant

INFORMATION LETTER AND CONSENT FORM FOR THE OLDER PERSON TO PARTICIPATE IN THE MMOGO-METHOD™ (FOCUS GROUP)

I am a PhD student of the North-West University, Potchefstroom Campus. You are invited to participate in a research study regarding community-based collaboration (it means ways of working together in the community through partnership) to support the older person in the world of HIV/AIDS.

The nature and purpose of the study

The purpose of the study is to look at a framework of community-based collaboration (to work together as partners) to support the older person in the world of HIV/AIDS.

You are asked to participate in phase 1 of the study during step 2 and step 3 during which the researcher will use the Mmogo-method™ to explore and describe your needs (something very much required or an urgent necessity), your expectations (what you belief should happen) and desires (strong feeling of wanting to have something or wishing for something to happen) in the world of HIV/AIDS. Your experiences regarding the things that hinders or help you to manage HIV/AIDS in your everyday life will also be explored by the researcher.

The Mmogo-method™ is used in my research because it refers to togetherness (you are here gathered together as a group of older persons in Susan Legwete's home). You are going to share with each other and with me what your lived experience in the world of HIV/AIDS is. You are in other words going to share with me your knowledge to help me to discover the best way to support you and the other older persons in Ikageng regarding HIV/AIDS.

sensitivity of the topic, but do not foresee that you will experience any discomfort. If you wish however after the session for psychological support, counselling will be made available.

Confidentiality

Any information that is voice recorded by the researcher will be kept strictly confidential. The researcher can however not be held responsible if the fieldworker, who is also the translator, do not keep to the rules of confidentiality. The fieldworker did sign a contract to keep all information regarding the whole PURE study that refers to this study as well, confidential. The results will furthermore be published and presented in such a manner that all participants will remain unidentifiable.

Right to withdraw

Your participation to this study is your own choice and you can refuse to participate or stop at any time without a reason. There will be no discrimination against you if you decide not to participate.

Possible benefits of the research

Your contribution will add to the knowledge of and insight into the factors influencing the support of the older person in the world of HIV/AIDS. All that you demonstrate during the Mmogo-methodTM with the material given to you, will help me to discover ways for community-based collaboration to support the older person in the world of HIV/AIDS. This new knowledge gathered from your lived world will be presented to the policy makers and may benefit not only all the older persons in your community, but also their neighbours, friends and families.

Information

If you have any questions about the research, you can contact the researcher, Mrs Mada Watson at 082 460 7813 or Mrs Susan Legwete at 084 613 5787 that will convey your message to me. You can also indicate if you would like me to do a home visit afterwards and if you want to receive a report of the study after it has been completed.

CONSENT TO PARTICIPATE IN THE RESEARCH INTERVIEW

I, the undersigned, _____ have read and have explained to the participant, named _____, the participant information letter, which has indicated the nature and purpose of the research in which I have asked the older person to participate. The explanation I have given included both the possible risks and benefits of the research. The participant indicated that he/she understands that he/she are free to withdraw from the research interview at any time for any reason and will not be discriminated against.

I hereby certify that the older person has agreed to participate in the research interview.

Participant's name

Participant's signature

Person obtaining informed consent

Witness

Date

I would like to receive a report of the research: "Community-based collaboration to support the older person in the world of HIV/AIDS", after it has been completed.

Address:

APPENDIX F

INTERVIEW SCHEDULE FOR OLDER PERSONS, MMOGO–METHOD™

INTERVIEW SCHEDULE TO EXPLORE AND DESCRIBE THE NEEDS AND EXPECTATIONS AS WELL AS THE IMPEDING AND FACILITATING FACTORS TO SUPPORT THE OLDER PERSON INFECTED AND/OR AFFECTED BY HIV/AIDS

Introduction to the interview	
<i>Introduction to the older person - that participate in the qualitative research interview</i>	The researcher clarify that the respondent and the researcher understand (interviewer) and agree to the context as well as the concepts used in the research. As Kahn (2000:64) said, "it is simply a matter of translating professional jargon" ➤ The context of this study refers to the older person in the world of HIV/AIDS, that is Ikageng, that is infected (has been tested and evidence of the virus has been found via a blood test) and affected (has one or more person living in their household, neighborhood and/ or community who are infected with the HI-virus) ➤ Concepts that apply as themes to the research interview are as follows: • A <i>need</i> is something very much required or an urgent necessity • <i>Expectation</i> is to belief that something should happen or that something should be the case • <i>Facilitating</i> factors (to make easy or easier) • <i>Impeding</i> factors (block, hinder, delay or obstruct the progress or action) • <i>Experience</i> is the practical contact with and observations of HIV/AIDS in Ikageng (facts or events)

Section A (Phase one, step two): To explore and describe the needs, expectations and of the older person infected and/or affected by HIV/AIDS.	
<i>Explore the needs of the older person</i>	What do you see as the needs or urgent necessities to support the older persons in Ikageng regarding HIV/AIDS? O bona eng e le ditlhokego kgotsa dilo tse ditlhokegang ka potlako go tshegetsa / thusa batho ba ba godileng ma Ikageng mabapi le HIV/AIDS?
<i>Explore the expectations of the older person</i>	What are your expectations (what do you belief should happen) in Ikageng regarding HIV/AIDS to support the older person? O le beletse gore go diragale eng (o dumela gore go tshwanetse gore go diragale eng) mabapi le HIV/AIDS go tshegetsa/thusa batho ba ba godileng ma Ikageng?
<i>Explore the desires of the older person</i>	What do you wish for if you think about support for the older person regarding HIV/AIDS in Ikageng? O e letsa eng ga o nagana ka tshegetsa/thusa ya batho ba ba godileng mabapi le HIV/AIDS ma Ikageng?

Section B (Phase one, step three): To explore and describe the facilitating and impeding factors as experienced by the older person infected and/or affected by HIV/AIDS.	
<i>Explore the impeding factors as experienced by the older person</i>	Can you tell me about the things that hinders or block you to manage/handle HIV/AIDS in your everyday life here in the house, in the neighborhood or the community of Ikageng? O dira eng go dira botshelo java gago bafefo mogo wena mo lefatsheng la HIV/AIDS
<i>Explore the facilitating factors as experienced by the older person</i>	What do you see or observe in your household, neighborhood and community that help you as an older person in the world of HIV/AIDS? What do you do to make life easy for yourself in the world of HIV/AIDS? O bona eng mo lelapeng la gago, boagisaneng le mo baaging tse di go thusang jaaka motho yo a godileng ma lefatsheng la HIV/AIDS? Can you tell me about the things that help you to make it easier regarding HIV/AIDS in your everyday life here in the house, in the neighborhood or the community of Ikageng? A o ka mpolelela ka dilo tse di go thusang go dira dilo bafefo mabapi le HIV/AIDS mo botshelong java letsatsi ka letsatsi ta ntlong, mo boagisaneng, kgotsa mo baaging ba Ikageng?

APPENDIX G

EXAMPLE OF TRANSCRIPTION, MMOGO–METHOD™ (FOCUS GROUP)

P1	A table
R	A table?
p	Umm
R	Good. Explain to me how does your table look like. The feet
P	The feet(hesitant) ?
R	What is the....? How does your table work? Explain to me.
P	(Hesitant)... What did she say? (Asking the group)
GM	She says what does the table do?
GM	They eat on it
R	They eat on top of it. They eat hear, they it on top of it
GM	What do you do on the table? It means why did you make the table?
P	It means I made it because I eat on eat, I work on top of it.
R	Good. Good
GM	He eats on top of the table, and he works on top of it.
R	Good, Good. Good. Now tell me, where is the table? Is the table upside down?
P	Yes, it is upside down
R	Upside down?...Good, why is the table upside down?
P	I cannot pick it up
R	Oh!! It is just that you cannot pick it up. Good. Tell me what does the table mean then for the understanding of HIV/AIDS? How do I understand the table with regards to HIV/AIDS? What does the table help me to understand? What did you think when you made the table?
P	No answering?
GM	Why did you make the table regarding this disease? It means what is the meaning of this table on this disease..that is of HIV
P	Oho (meaning I do understand)...It means I made it so that other can eat on top of it...who does not have HIV
GM	Interpreting but contradicting what the respondent has said..."So that when they eat, they should eat on top of the table. The people who are sick due to HIV.
R	Good. (To the group)....."Can you help me understand? Can you also explain the

	meaning of the table? Can you help me a little?
GM	He did that so that people can sit on the table, example so that the people who are sick can sit around the table. We should not say that this one is sick, this one is OK , we should all sit around the table and eat.
R	Ok, ok. The table means that we are all together? It does not matter if you are HIV or not HIV, we are all together?
GM	Yes
R	Good. (To the participant) Is it the people that you sat hear . That everybody is together?
P	Yes
GM	All the colours. Everybody i
R	All the colours, everybody is there and we do it together, it doesn't matter from one to the other. Good. Can you now tell me..the table that you made, how can we get everybody there? What can we do so that everybody is at the table? How are we going to get it right. What can we do?
GM	To P What can we do so that we can get together as we did now and sit around the table?
G taking at once	I think we should come together
P	Yes, we should come together. That is what we have been saying.
GM	The people should come together and talk about this. About this table so that we should not differ about this table
R	To P, Is this what you were saying? Is this right
P	Yes
R	Now I want to understand. Isn't it happening currently
GM	Mm (No) The people are still there that says to other "you are HIV". They isolate them. There are still people who isolate the HIV people. They say you are sick, I can sit with you.Or when you sit on the table, then they don't want to sit with you, they want to sit elsewhere.
R	Ok, this place on the table that we want to , this beautiful table..but it does not happen currently?

GM	Not yet. The old people...we the old people, we still hide these people, we hide them behind, we don't talk the truth, even if my child is like that, we talk about other diseases. That, we still don't talk about. But we can all go there and talk about this.
R	Ok
GM	So that we can make it better, so that it can be reduces.
R	Good. So we hide the information? We keep it away, why do we do that?
GM	Because we laugh at each other. When my child has it, she is going to go and say " did you hear that her child has HIV...WHISPERING. the stigma is still there
R	So the stigma is still there? So to get to that table, what are we going to do, if we are still shy and laugh at each other? We hide it, what can we do to get everybody to this table?
GM	It's just to talk. The one who laugh can laugh
R	Ok
GM	Those who gossip can continue gossiping . We must come out of that room We must come to this table. The people should know that I am sick, I have this disease, the people should know.
R	Ok. Do we think it is going to be easy?
GM	Like Jesus sat with his disciples around the table, they had sat around the table
R	So we should try to do like Jesus did to get everybody around the table? Is that what mam....
GM	And share that piece of bread
R	To share with each other?
GM	But even with that, there was one disciple who hide all those years , that one who betrayed Jesus
R	Good
GM	Just like us now, we still hide.
R	I am just wondering that if we still hide things, then it says that we are a little scared and embarrassed. But how are we going to get over it? What is it that is going to make it possible for us to get over it so that we can sit together and...
GM	Share, talk these things..talk..Let the other people know. If you talk you are going to get healthy. You are not.....Now the stigma you are going to die. If you have the disease you are going to die. It is all that the people are scared about

R	Is there anything else you think we can do ? You said we can share, we can talk, what else can we do?
GM.	It just to talk, to talk these through. We must stop to blame the government because if we have to talk the truth, we talk about Mbeki. What is Mbeki going to do with this? , he hasn't done this, he doesn't have this (sarcastic). What must he do because we talk so with the children, these children doesn't listen. No one here. The TV talk to the children. If the baby play with fire, they are going..they know they are going to burn. But our children we talk to them but they stick their fingers in the fire. We don't know what to do. They have been talked to but they don't hear. From there we blame the government. Hey hey government this . We don't hear. We don't protect ourselves because we want that money. At the end you pay.
R	So it sounds as if there are lots of things we can do to get everybody at the table. Thank you it is a beautiful table. Can we talk to participant 2. Ae you ok with Afrikaans?

APPENDIX H

VISUAL IMAGES WITH THEIR ASSOCIATED EXPLANATIONS



A table with four legs was presented. The top of the table was made of clay and decorated with different colours of beads. The table was presented up-side down because she could not pick it up, the clay was too soft. At the sides of the table there were beads of different colours that represent different people, especially with reference to people with HIV/AIDS and people without HIV/AIDS. The table is in the house and is made for the people to work and eat on top of it.



A participant used the dry straws to write the words "Fight HIV/AIDS IT KILLS" on the clay.



A visual image of a house builds with straw and clay. The house has a roof, a door and a window and represents a drop-in/day-care centre where basic care is available on a daily basis for the sick and for the children. A bed and a chair made from straw can be seen. The furniture presented in the image is the most basic furniture to care for a sick person that illustrates the need for basic health care.



A mother is ill in hospital. The mother is lying on a hospital bed made of clay and coloured beads with cot sides made of straw. Her heartbroken child, a girl, is made of clay with straw legs and arms and she stands and looked unto her mother. There is also a care giver made of clay with them in the room, she sits on the ground.



A participant created a young man (lost son) with a clay body and straw arms. The second image is that of a pig made of clay that is eating pig food (coloured beans on the ground before the pig). The child is eating with the pig because he did not listen to his father and listened to the people on the streets. Pigs do not care what they eat and that is what happened to the child, he did not listen and that is brought into relation with his behaviour that followed his ignorance.



An older person made the visual image that present herself. It is a woman made of clay that is sitting flat on the river bank between the reeds made from straw and little pieces of clay. She is waiting there for someone to help her in the water so that she can be healed. She cannot go in by herself and need to ask someone for help. The woman that sits there is quiet and does not speak up for help, so no one is helping because they do not know that she needs help.



This older female created a handbag made from clay and decorated with many coloured beans. The bag is use to put medication in and to carry the bag to the people where she did home-based care in the community. The bag has a further meaning to the female in that she is also sick and she carries her own medicine she received from the doctor in the bag. There was also food and porridge from the clinic in the bag to visit people that is ill. .



A participant created several images all made from clay only. The images she made were an old, lonely man lying on a bed, there is a chair next to the bed, around him there are a plate of porridge, a cup of water, bread made from clay, bowl with fruit (apples and tomatoes illustrated by means of beads in the clay bowl), milk jar and a traditional African pot that the older persons prefer to drink their water from.



The participant made a round chair from clay with straw legs. She created a chair next to the table also made from clay with straw feet. A man is sitting on the chair. On the table is a Bible and the man reads from the Bible.



The female created a veranda from straw and clay, beautified by a lot of beans that give it a happy appearance. The veranda is in relation to the sick people at the hospital. They can sit under the veranda if they want some fresh air. Difficult to make it stand – difficult to create something on their own – needs support from others

APPENDIX I

EXAMPLE OF FIELD NOTES OF STAKEHOLDERS

Interview 12

11 Junie, 09:00

60 minutes (including introduction)

Personal notes

I perceived this participant as calm and an authority. Her appearance is professional and 'no nonsense' with empathy. She has 30 years experience as a professional nurse, and is very open and knowledgeable about HIV-related issues. I thought that someone like her, being an 'older person' herself (above 60 years) could be a key person in the support for the older person; as I heard in previous interviews, as well as from her, that older people prefer talking to their peers about HIV-related and sexual issues. She has personal experience of a family member with HIV, and could also share positive approaches in supporting family members with HIV.

Before the interview she mentioned that she was 'frightened' about the interview, as she never participated in such an interview before. I reassured her that there is no right or wrong answers, and that we view her as an expert in her field, and want to learn from her what her opinion is.

Methodological notes

Informed consent was obtained. We used the interview schedule as a guide, but did not follow it strictly. I used communication techniques such as reflection, clarification, minimal verbal response and summary to elicit elaboration on responses. She answered spontaneously and provided valuable information.

Demographical notes

The interview was held in the board room of a primary health clinic. She welcomed me and ensured that I was comfortable (gracious host). The door was closed, ensuring privacy. We sat at one end of the board room table, facing each other comfortably. We were interrupted by patients looking for her, but this did not interrupt the flow of her thoughts or the conversation.

APPENDIX J

EXAMPLE OF TRANSCRIPTION OF INTERVIEW OF STAKEHOLDERS

INTERVIEW 6

I	Mmm?	
P	Ja it needs to be broaden up...	
I	OK	
P	Although the focus would be eh...the elderly people.	
I	Mm	
P	But once you come to those elderly people you often often find that there are orphanage children.	
I	OK...can I just interrupt you before....	
P	OK	
I	This is this is important information that you ae sharing now and I would like to record that...	
P	OK no that's fine	
I	Is it fine	
P	No that's fine	
I	OK, I just want to inform you that there is a consent form that you need to sign	
P	OK	
I	So can we carry on with the interview and then after we	
P	And then I would look after the consent form there after.	
I	OK. I just would like to confirm that it is confidential and only Mada has access to this information	
P	OK	
I	And that your name will not be ehm....	

P	OK, no that's fine	
I	OK, thanks... OK so you say that it should not only focus on older people but also look at orphans and children.	
P	Ja...but eh but I think it i that there are maybe dimension	
I	Mmhmm	
P	To ...the kind of support and that eh...eh... the project wants to adress. In such a way that eh you will also find that there are also social aspect. Maybe in those household that there are those older people.	
I	Mmm	
P	Eh...maybe children do not have Birth certificate others are also not receiving grants and that sort of things	
I	Mmm	
P	But you also find that there are also other older people that would not be registered. Do not receive you know old age pension....But I also think, linked to that, it's also the question of housing	
I	Mmhhmmm	
P	You know adequate housing...that if maybe they are they are sta they are staying in sink houses you know informal settlements.	
I	Mhmm	
P	Maybe that issue needs to be taken up with the municipality. So that adequate housing could be provided for them	
I	Mm	
P	So that eh, with the children, you know social department, could also you know play a role in terms of the indigent policy of municipality if they're unemployed.	
I	Mm	
P	They could also be receiving I think it's 50 megawatt of electricity they should be receiving 60 eh...60 no 6 kilo of ..millilitre of water or	

	kilograms of water. You know through the indigent policy.	
I	Mmm	
P	Now I think the programme itself is fine. But once it start kicking it would also have to look di eh you know in the diversity	
I	Mmm	
P	Of the problems that actually encircle those particular communities.	
I	Mm	
P	You'd also find that there results of problem with regards to food. Maybe they don't have, they're not in a position t put bread on their table	
I	Mm	
P	So... eh..I've been informed. In the past there was this programme that was called eh...that was run from the office of the mayor, Food parcels	
I	Mmm	
P	And I...eh I just heard, I'm not sure when it will start rolling out. That the mayor intends to introduce it again. That maybe they could also be enlisted to benefit from that.	
I	Mm	
P	Eh...but I think also that the issue of collaboration, because it is not only that we can be looking at municipalities	
I	Mmm	
P	The other organisations...The... Baptists childrens...I'm not quite conversant with the name, but I know that the Baptist church ... eh is running a programme for the children...	
I	Mmm	
P	Those who are affected and those who are taht are infected. They are running a food programme, that whenever the children come from school, they are able to go to church, you know receive meal	

	after school...and then go somewhere else.	
I	Mmm	
P	So I think those can be collaborations	
I	Mmm	
P	So that their names can also be given to that eh...to that eh... organisation. So that they are also in the process being helped.	
I	Mm	
P	I'm also aware that the Methodist church here in town, It's also running a similar programme. Where they actually give food parcels. I'm not quite sure wether they have discontinued that or what.	
I	Mmm	
P	But I think also the church do play that critical role.	
I	Mmm	
P	So eh...I think it is very important that those organisations are identified so that those linkages and collaboration...it's actually there	
I	mmm and you you are focu focussing specifically on the socio-economic support.	
P	Exactly	
I	Em, housing, social services, food parcels	
P	Mmhmm	
I	And it's not a isolated problem, or or project but it should include the diversity of the problems related to HIV and AIDS.	
P	Ja ja	
I	Children orphans and so on	
P	You know I think from the nursing eh eh aspect...they're also dealing with issues of health. So it's more of a combination.	
I	Mm	

P	You know of a number of issues. Eh...they be health, they be...you know, sometimes when you look at the kind of houses or the tin houses that they are staying in	
I	Mmm	
P	They're also not you know environmentally conducive	
I	Mmm	
P	I mean children that are growing up in those particular you know in that particular environment. Their chances of growing up being lively children are very limited	
I	Mmm	
P	You know because the environment it's not healthy for living. It's not healthy for growing. Maybe the electricity might be there, but the problem it's actually the environment. The walls that are not eh eb eh I mean it's not adequate housing it's a sink house.	
I	Mmm	
P	And maybe when it rains, like it's been raining it's maybe a crisis for the family. Sometimes maybe the items in teh house might be soaked up by water. So it's a problem and I think it's something that the municipality also would need to come to the table. To ensure through their ward communities, because they also have what we call the.... community development workers, But if you you you ...you look around, and you find that I mean that the houses that that those families have not been visited, then it i, that actually say very little about the kind of work that the the community developmet workers ...maybe have not actually done enough.	
I	Mm	
P	You know to visit those houses. I mean also if you, we relate to ehh...ward communities, so it means that the people, do not actually understand the wards that they are staying in. Because it would have been long ago that they have actually identified	

I	Mm	
P	You know those families that are actually living there... but I think it's more of a programme that eh...would also have to look at not necessarily you know people being dependant...on the programme itself. It needs to be a programme that assists those communities	
I	Mmm	
P	Also to catch fish, rather than be given fish	
I	Mm mm mmm	
P	It's a programme that would also need to make people conscious of their basic human rights. And once people understand their rights, they will be able to defend and use their rights and protect them. And I think the programme in a whole, should also be looking around that.	
I	Mmm	
P	So that people can understand...you know there are so many things that government is actually producing, there is a booklet it's 'Know your rights' that has been produced by the ehh... .. department of Public service commission. That that that the minister Garandine Frasier Moeleketi actually published eh you know spoke lengthly about that. But the programme access to information.	
I	Mm	
P	How do you make information accessible. So that people know exactly where they could actually touch base. These are the kind like, know your service rights...you know	

APPENDIX K

PART OF INTEGRATED MAP, PERCEPTIONS OF STAKEHOLDERS ON COMMUNITY-BASED COLLABORATION

