COMMUNITY-BASED COLLABORATION TO SUPPORT THE OLDER PERSON IN THE WORLD OF HIV/AIDS

Martha Jacoba Watson

M Cur

Thesis submitted for the degree Doctor of Philosophy in the School of Nursing Science at the Potchefstroom Campus of the North-West University

Promotor: Prof H.C. Klopper

Co-Promotor: Prof A. Kruger

POTCHEFSTROOM

November 2008

ACKNOWLEDGEMENTS

I give praise to God the Almighty for being my rock and my fortress, my hope and confidence since my youth.

To the following people, my thanks and gratitude:

- Gerry for being there, as my unconditional source of love and support
- My children, Francois, Renée and Madi for bearing with me, and for their love, patience, help and resigned acceptance of being part of my studies
- Prof Hester Klopper for her wisdom and guidance, not only in completion of my thesis, but to give me the freedom to be, also in research
- Prof Annamarie Kruger for her experience as a quantitative researcher, who skilfully helped and supported me
- Prof Sarie Human who helped me to initiate my study and be my silent inspiration
- Dr Emmerentia du Plessis for her kind and friendly attitude during data collection
- The PURE-SA team for the opportunity to work with them in the field and be part of an excellent multi-disciplinary research team
- Prof Vera Roos for her input as a consultant and the opportunity she gave me to be exposed to new ways of thinking regarding data collection
- Marthyna for the opportunity to walk this path of hardship with a friend and for experiencing her inspiring example of discipline
- All my colleagues at the School of Nursing Science for their support and endless help to keep my ship sailing
- My extended family for their continuous love, support and active interest in my progress
- The North-West University, Potchefstroom Campus for financial support from various offices
- The European Union, Higher Education of SA, with the Higher Education AIDS program and the Department of Education for financial support
- Statistical services for their friendly help, patience and advice with the data analysis
- Christien Terblance for language editing, Francois Watson for formatting and Prof Casper Lessing for the correction and help with the reference list

COMMUNITY-BASED COLLABORATION TO SUPPORT THE OLDER PERSON IN THE WORLD OF HIV/AIDS

Martha Jacoba Watson

M Cur

Thesis submitted for the degree Doctor of Philosophy in the School of Nursing Science at the Potchefstroom Campus of the North-West University

Promotor: Prof H.C. Klopper

Co-Promotor: Prof A. Kruger

POTCHEFSTROOM

November 2008

ACKNOWLEDGEMENTS

I give praise to God the Almighty for being my rock and my fortress, my hope and confidence since my youth.

To the following people, my thanks and gratitude:

- Gerry for being there, as my unconditional source of love and support
- My children, Francois, Renée and Madi for bearing with me, and for their love, patience, help and resigned acceptance of being part of my studies
- Prof Hester Klopper for her wisdom and guidance, not only in completion of my thesis, but to give me the freedom to be, also in research
- Prof Annamarie Kruger for her experience as a quantitative researcher, who skilfully helped and supported me
- Prof Sarie Human who helped me to initiate my study and be my silent inspiration
- Dr Emmerentia du Plessis for her kind and friendly attitude during data collection
- The PURE-SA team for the opportunity to work with them in the field and be part of an excellent multi-disciplinary research team
- Prof Vera Roos for her input as a consultant and the opportunity she gave me to be exposed to new ways of thinking regarding data collection
- Marthyna for the opportunity to walk this path of hardship with a friend and for experiencing her inspiring example of discipline
- All my colleagues at the School of Nursing Science for their support and endless help to keep my ship sailing
- My extended family for their continuous love, support and active interest in my progress
- The North-West University, Potchefstroom Campus for financial support from various offices
- The European Union, Higher Education of SA, with the Higher Education AIDS program and the Department of Education for financial support
- Statistical services for their friendly help, patience and advice with the data analysis
- Christien Terblance for language editing, Francois Watson for formatting and Prof Casper Lessing for the correction and help with the reference list

- Louise Vos and the friendly personnel at the library, North-West University, Potchefstroom Campus for excellent help to obtain relevant literature
- Susan Legwete, not only for her dedicated help and support as a fieldworker, but also for her guidance to understand the socio-cultural context of the older persons
- James Mothosola for all his help as a gatekeeper with the key stakeholders and role players
- Finally, I extend my gratitude to the participants without whom this study would not be possible

I dedicate this study to Gerry,

my real support.

"Even when I am old and grey, do not forsake me, O God,
till I declare your power to the next generation, your might to
all who are to come" Ps 71:18 (NIV Student Bible, 2002:613)

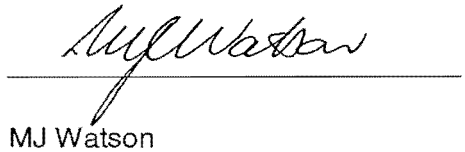
DECLARATION

I, Martha Jacoba Watson, student number 11819677, declare that:

- **COMMUNITY-BASED COLLABORATION TO SUPPORT THE OLDER PERSON IN THE WORLD OF HIV/AIDS** is my own work and that all the sources that I used or quoted are indicated or acknowledged in the bibliography.

- This study has been approved by the Ethics Committee of the Institutional Office of the North-West University (Potchefstroom Campus).

- This study complies with the research ethical standards of the North-West University (Potchefstroom Campus).



MJ Watson

November 2008

SUMMARY

Older persons as the fastest growing group form part of the vulnerable population groups in the North-West Province of South Africa of whom some are infected, but mostly affected by HIV/AIDS that yields them vulnerable due to biophysical-, socio-economic-, psychological-, environmental- and lifestyle factors. The researcher, active in the community, observed that support to the older persons is neglected. To provide sustained support to the older person in the world of HIV/AIDS is an enormous challenge for the local organisations in the community. In spite of existing structures and the ideal of joint efforts between the formal health services and the informal community structures, the prevalence of HIV/AIDS is increasing with a tremendous influence on the older persons as caregivers and the main supporters in their households. This should alert all communities and organisations at local level to initiate planned action towards forming partnerships within the community. It means stakeholders in the health services and the community of the older persons works together in an effective manner. There should be a partnership-relationship between the older persons in the community as key stakeholders and the local community-based-, faith-based-, non-governmental organisations, public as well as private community sectors as the other stakeholders who aim to generate a suitable climate where the older person's point of view is valued with the negotiation of key decisions.

The aim to explore the understanding of community-based collaboration for the support of the older person in the world of HIV/AIDS crystallised through the exploration and description of the needs and expectations of the older persons infected and/or affected by HIV/AIDS as well as the facilitating and impeding factors the older persons experienced in their households. To fulfil the aim ultimately, it was also necessary to identify and describe the existing networks and support programs available as well as the perceptions of the different stakeholders involved in mentioned networks and support programs on community-based collaboration.

A quantitative survey was executed to explore and determine the health profile of the older persons in the community and a qualitative research design was chosen to

explore, describe and interpret human experience. The older persons, as well as the different stakeholders in the community, express meaning to the researcher about their lived world of HIV/AIDS to assist the researcher in the quest to understand what community-based collaboration to support the older persons in the world of HIV/AIDS should entail. Data was collected through personal research interviews and focus groups during which unstructured and semi-structured questionnaires were used.

The findings in the study presents the reader with a summarised and clear understanding into the health profile, their needs, expectations, and experiences of existing strengths and impediments in the households of the older persons. The explored and described perceptions of the different stakeholders identified in the community on collaboration, contributed to the conceptualisation and formulation of guidelines to operationalise community-based collaboration to support the older persons in the world of HIV/AIDS.

OPSOMMING

Ouer persone vorm deel van die weerlose bevolkingsgroepe in die Noord-Wes Provinsie van Suid-Afrika. Hulle is die vinnigste groeiende bevolkingsgroep, en onder hulle is sommiges geïnfekteer met MIV/VIGS, en andere word daardeur geaffekteer, en dit laat hulle weerloos weens biofisiese-, sosio-ekonomiese-, psigologiese-, omgewings- en lewensstyl faktore. Die navorser, wat aktief is in die gemeenskap, het waargeneem dat ouer persone verwaarloos word. Die verskaffing van volhoubare steun aan die ouer persoon in die wêreld van MIV/VIGS is 'n enorme uitdaging vir die plaaslike organisasies in die gemeenskap. Ten spyte van bestaande strukture en die ideaal van samewerking tussen die formele gesondheidsdienste en die informele gemeenskapsstrukture, neem MIV/VIGS toe, en dit het 'n groot invloed op die ouer persone as versorgers en broodwinners in hulle huishoudings. Dit behoort alle gemeenskappe en organisasies op plaaslike vlak bewus te maak om beplande aksie te neem en vennootskappe in die gemeenskappe te vorm. Dit beteken dat belanghebbendes in die gesondheidsdienste en die gemeenskap van ouer persone moet saamwerk op 'n effektiewe wyse. Daar moet 'n vennootskapsverhouding wees tussen aan die een kant die ouer persone in die gemeenskap as sleutelbelanghebbendes, en aan die ander kant die plaaslike gemeenskapsgebasseerde organisasies, nie-regeringsorganisasies, openbare sowel as private gemeenskapssektore, met die doel om 'n geskikte klimaat te skep waar die ouer persoon se siening waardeer word tydens die onderhandeling van sleutelbesluite.

Die doel om gemeenskapsgebasseerde samewerking te ondersoek ten einde die ouer persoon in die wêreld van MIV/VIGS te ondersteun, kristaliseer deur die ondersoek en beskrywing van die behoeftes en verwagtinge van die ouer persone wat geïnfekteer of geaffekteer is deur MIV/VIGS, sowel as die fasiliterende en belemmerende faktore wat die ouer persone in hulle huishoudings ervaar. Ten einde die uiteindelike doel te bereik, was dit ook nodig om die bestaande netwerke, ondersteuningsprogramme en die persepsies van die verskillende belanghebbendes rakende gemeenskapsgebasseerde samewerking te identifiseer en te beskryf.

'n Kwantitatiewe opname is gedoen om die gesondheidsprofiel van die ouer persone in die gemeenskap te ondersoek en te bepaal, waarna 'n kwalitatiewe navorsingsontwerp gekies is om die menslike ervaring te ondersoek, beskryf en te interpreteer. Die ouer persone en die verskillende belanghebbendes in die gemeenskap het die betekenis van hulle geleefde wêreld van MIV/VIGS aan die navorser uitgedruk sodat die navorser beter kan verstaan wat gemeenskapsgebasseerde samewerking om ouer persone te ondersteun in hulle wêreld van MIV/VIGS moet insluit. Data is ingesamel deur persoonlike navorsingsonderhoude en fokusgroepe waartydens ongestruktureerde en semi-gestruktureerde vraelyste gebruik is.

Die bevindings van die studie bied aan die leser 'n opgesomde en duidelike begrip van die gesondheidsprofiel, behoeftes, verwagtinge en ervaring van bestaande fasiliterende en belemmerende kragte in die huishoudings van ouer persone. Die ondersoekte en beskryfde persepsies van die verskillende geidentifiseerde belanghebbendes in die gemeenskap aangaande samewerking het bygedra tot die konseptualisering en formulering van riglyne vir die operasionalisering van gemeenskapsgebasseerde samewerking vir die ondersteuning van ouer persone in die wêreld van MIV/VIGS.

ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
CBO	Community-based organisation
DOH	Department of Health
EICP	Enhancing Interdisciplinary Collaboration in Primary Health Care
FBO	Faith-based organisation
HAI	HelpAge International
HIV	Human immunodeficiency virus
LAC	Local AIDS Council
NGO	Non-governmental organisation
PHC	Primary Health Care
PhD	Doctor of Philosophy
PURE	Prospective Urban and Rural Epidemiological study
PURE-SA	Prospective Urban and Rural Epidemiological study in South Africa
SANGOCO	South African National NGO Coalition
SAOPF	South Africa Older Person's Forum
STI	Sexual transmitted infection
UN	United Nations
UNAIDS	United Nations Programme on HIV/AIDS
VCT	Voluntary counselling and testing
WHO	World Health Organisation

TABLE OF CONTENTS

CHAPTER 2

HEALTH PROFILE OF THE OLDER PERSON

CHAPTER 3

NEEDS AND EXPECTATIONS, FACILITATING AND IMPEDING FACTORS EXPERIENCED BY THE OLDER PERSON

CHAPTER 4

PERCEPTIONS OF EXISTING STAKEHOLDERS ON COMMUNITY-BASED COLLABORATION

CHAPTER 5

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

CHAPTER 6

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

APPENDICES

LIST OF TABLES

LIST OF FIGURES

LIST OF PHOTOS

CHAPTER 1

OVERVIEW OF THE RESEARCH

1.1 INTRODUCTION AND RATIONALE FOR THE STUDY

Since HIV was discovered in the early 1980's and isolated at the Institute Pasteur in France and the National Cancer Institute in the United States of America, the number of people, including the older person infected with the virus, has increased to a devastating 40.3 million worldwide (Abdool Karim, 2005:31; UNAIDS/WHO, 2005:1 & 78). However, the latest statistics of the WHO, show a decline in the number of people infected with HIV, and during 2007 it was estimated at 33.2 million people infected (WHO, 2008b:14). The World Health Report of 2004 indicated that this enemy of the past 20 years, HIV/AIDS, is only now seen for what it really is, an enormous burden that presents mankind with a significant challenge (Agyarko *et al.*, 2000; WHO, 2004:1). During 2004 more than 3 million HIV/AIDS-related deaths occurred worldwide and 22.5 million people were infected in sub-Saharan Africa (WHO, 2008b:13). This constitutes approximately 70 percent of the total number of the HIV-infected people globally (Campbell, 2004:22; Labonte *et al.,* 2004:176; UNAIDS/WHO, 2005:2, 78; WHO, 2004:1). South Africa is one of the only two countries worldwide that show an increase in HIV-prevalence and has the highest number of HIV-infected people worldwide (UNAIDS/WHO, 2004:23; UNAIDS, 2006a:11; WHO, 2008b:52). National Indicators for 2004 estimated that over 1.2 million South Africans had already died as a result of AIDS, slightly more than 5 million were infected with HIV and 500,000 were sick due to AIDS (Abdool Karim *et al.*, 2005:37; Connolly *et al.*, 2004:776; Dorrington *et al.,* 2004:17). Pelser *et al.* (2004:282) and the Department of Health (South Africa, 2003:6) estimate that the prevalence rate in the North West Province is 26.2%. Ten percent of these HIV - infections are found in adults aged 50 and older (Connolly *et al.*, 2004:778; Inelmen *et al.*, 2005:26; Waysdorf, 2002:49) of whom 4% is older than 60 years (South Africa, 2007:9, 24, 29).

This HIV/AIDS prevalence elevates the vulnerability of communities that have limited access to health care, shortages in nutritious food (NRF, 2006) and limited

resources. Additionally, the hospital care for AIDS patients is more expensive than the care of most other conditions (Pelser *et al.,* 2004:298-299). Sewpaul (2001:579) as well as Orner (2006:236) state that South Africa is failing to deal with this crisis, and therefore HIV/AIDS continues to be a major problem (Silvestre *et al.,* 2002:61) and the care for and support of people living with HIV/AIDS requires comprehensive community action (Campbell, 2004:26; WHO, 2004:43). Increasingly, families and communities take responsibility for caring for the person living with AIDS (Orner, 2006:236). Older persons in the families and communities are often the main caregivers, either of the terminally ill or of the orphans whose parents had died of AIDS (Kinsella & Phillips, 2005:23; WHO, 2002:2). Similarly, Agyarko *et al.* (2000) and Kimuna (2005:15) found that the combined effect of increased care-giving responsibilities and decreased economic support due to HIV/AIDS, created a "new situation" for older people who can no longer "retire" in their old age, but are forced into "skip generation parenting".

Global aging is another reality that aggravates the situation (Kinsella & Phillips, 2005:5; Kimuna, 2005:13). Isabella Aboderin from the Oxford Institute of Aging explains in her report that the sub-Saharan African population is ageing and projected to continue ageing over the next two decades. According to the United Nations (Aboderin, 2005:4-5; Joubert & Bradshaw, 2006b) the number of older people in sub-Saharan Africa is estimated at 36.6 million. Kimuna (2005:13) suggests that this figure will double to almost 63 million in 2025. The South African population aged 60+ will increase from 6.7% in 2005 to 11.0% in 2025, and will reach 12.4% in 2050 (Aboderin, 2005:4; Mohatle & Agyarko, 1999a:6-7). Redelinghuys and Van Rensburg (2004:270) note that 67% of the total aged population in South Africa is black, 22% white, 7% coloured and 2% Asian. Demographic statistics show that 71% of all deaths in the 15-49 age groups during 2006 were due to AIDS (South Africa, 2007:42) and might lead to a sharp rise in the number of older persons within the South African population (Aboderin, 2005:4). However, the extent of the problem in the older population is unknown (Cloud *et al.*, 2003:354), and an increase in the number of older persons can lead to an increase in HIV/AIDS amongst them (Kinsella & Phillips, 2005:16).

Programmes and services for the elderly have become necessary in order to follow the tide of these demographic changes and the increasing pressure placed on the older person (Caldas, 2004:16; Kinsella & Phillips, 2005:23). HelpAge Internationally Ageing and Development (Ferreira, 2004:8) stated that there is an urgent need to protect, support and educate older people in relation to HIV/AIDS. Unfortunately, despite the significant role that older people play in society, family and the community (Aboderin, 2005:4), they are often excluded from planning and decisions with regard to the crises surrounding the HIV-pandemic (Mohatle & Agyarko, 1999a:vii). Ferreira (2004:9) doubts that there are any policies available that are specifically aimed at supporting older relatives (grandparents) who care for their affected or infected grandchildren.

Older people who have their own health care needs (Agyarko *et al.*, 2000) are forced to become caregivers for their children, grandchildren or orphaned children (Turok, 2006:5). Freeman and Nkomo (2006:306) conducted a study on current and prospective South African caregivers in the Free State, Kwa-Zulu Natal and Gauteng (South Africa), and found that 81% of the grandparents interviewed said that they would take in all their grandchildren to look after them. Aboderin (2005:5) supports this finding with an estimation that 60% of AIDS-orphans live with their grandparents. Deaths in the 15-49 age group also force the older individuals back into the role of primary provider for these children (Kinsella & Phillips, 2005:16). The main caregiver in AIDS-affected households is usually a woman (Orner, 2006:236), which could be as a result of the reality that 73% of the population aged 60 and higher are women (Garbus, 2003:10). The HIV/AIDS and STI Strategic Plan (South Africa, 2007:37) refers to women as 'the soldiers at the forefront of community-based HIV/AIDS activities and that they take the brunt of caring for the sick family members'. In a traditional social security system it is the extended family, including older people's (grandparents), role to protect the vulnerable, care for the poor and the sick (Freeman & Nkomo, 2006:303; Im-em *et al.*, 2002:250; Van Rensburg, 2004:271). Traditionally, the older person should be cared for. However, the high prevalence of HIV/AIDS amongst economically active adults has contributed to reversing older people's roles as mentioned earlier (Kimuna, 2005:13; United Nations, 2003:3-7).

The South African study conducted by HelpAge International on understanding and responding to ageing, health and poverty and social change in sub-Saharan Africa in 1999 (Aboderin, 2005:5) and by Agyarko *et al.* (2000) of the Health Promotion/NCD Prevention and Surveillance Department, World Health Organisation (WHO), clearly indicate that the older person is faced with numerous unmet health-, financial-, and emotional needs. Booysen *et al.* (2004:110-111) echo the previous study in their results by saying that the older person taking care of their grandchildren have to carry an extra financial burden, and that they became trapped in a vicious circle of debt as a result. They are amongst the least educated, least healthy, have been overlooked in both service delivery and recruitment processes, despite their valuable experiences and skills. Since 1994 the focus shifted to mother and child care with no community nursing services for older persons in South Africa in place (Turok, 2006:3). It is thus inevitable that their lives will be affected when one or more family member(s) in their household is infected with HIV or sick with AIDS (Mohatle & Agyarko, 1999b:41; Turok, 2006:10-11). Nevertheless, it appears that the massive impact on older people and parents of adults with AIDS has been overlooked (Ferreira, 2004:2). There are also other realities that should be considered as the fact that more people will age with HIV as a result of effective anti-retroviral therapies (NAHOF CONNECTION, 2005).

The older person is also faced with chronic diseases such as diabetes, hypertension and heart diseases. The South African Demographic and Health Survey (SADHS) predict that the care-giving task older persons are faced with could affect their own quality of chronic disease care extensively (Bradshaw & Steyn: 2001:11).

Im-em *et al.* (2002:247) and the chairperson of the SA Older Person's Forum (SAOPF), Turok (2006:11), note that although older people are at a lower risk of contracting HIV, they are open to infections and their attitude and knowledge of HIV/AIDS have important implications for themselves, since:

- older people often provide care-giving to young adults with AIDS (often they are not aware of the status of the person) and are more likely to understate the risks of contracting HIV,

- they need correct knowledge of the risks that are inherent in the care-giving activities,

- in a developing world the older person is 'the respected opinion leader' and can influence others' attitude and behaviour in the family and community, and

- the older person remains sexually active and may engage in risky sexual practices.

Older persons often report that although they are educated about HIV/AIDS they still do not understand what HIV/AIDS is or how one can become infected with the virus (Mohatle & Agyarko, 1999b:41). The 2002 Health System Research Centre (HSRC) survey found that the oldest age group (50 and older) had the highest levels of incorrect responses in the survey on knowledge of HIV/AIDS (Garbus, 2003:50). Imem *et al.* (2002:248) confirm knowledge deficiencies among the older respondents in an HIV/AIDS related knowledge and attitudes study. The reality could therefore be a possible call for targeting older people with caretaker education and socio-economic support (Kinsella & Phillips, 2005:23).

The AIDS Policy Research Centre in California (Garbus, 2003:10) found that AIDS-affected households in South Africa spend an average of 34 % of their monthly income on health care. This figure is much higher than that spent on health care in non-AIDS-affected households. Ferreira (2004:3) adds that women who are older than 60 and who receive a social old age pension spend the greater part of their income on meeting the needs of adult children sick with AIDS, and/or affected grandchildren (Ferreira, 2004:2; Redelinghuys & Van Rensburg, 2004:270-271). Extreme poverty, physical and health problems due to the strain of care-giving, food deprivation, stigmatisation and prejudice are but a few aspects associated with the older person's household when affected by HIV/AIDS (Ferreira, 2004:3; Orner, 2006:237).

As discussed, much of the HIV/AIDS related care in South Africa is likely to become the responsibility of households and communities (Ferreira, 2004:4; Orner,

2006:237). It therefore explains the need for supportive community-based collaboration. However, experiences and awareness of community-based care and support are limited in South Africa (Tollman & Pick, 2002:1726) and could result in a struggle to apply progressive national policy effectively on provincial and local level. Community-based support focuses on health promotion (in this study health promotion of the older person), disease (in this study HIV/AIDS) prevention, services such as home-care (in this study it includes the spouse, children, grandchildren and friends of the older person) and active community involvement (in this study the community of the older person) (Penning *et al.*, 2002:1). Active community involvement implies that the older person should have a voice of their own and the government needs to include them in HIV/AIDS strategies (Turok, 2006:2-4).

In spite of the existing structures in the communities under discussion and the ideal of joint efforts between the formal health services and the informal community structures referred to by the HIV/AIDS and STI Strategic Plan 2000-2005 (South Africa, 2000:4), the prevalence of HIV/AIDS is increasing (WHO, 2008b:52). The real number of people living with HIV/AIDS (including the older person) in the community is uncertain and can increase the struggle of care and support practices on the local community level. However, the estimated prevalence of HIV/AIDS in South Africa should not be ignored. It should alert all communities and organisations at local community level to initiate planned action towards forming close partnerships within the community (Dorrington *et al*, 2004:2; Lindsey *et al*, 2001:829; WHO, 2004:43). The researcher views "close partnership with the community" as a community-based focus that facilitates participation in the planning of actions regarding health issues within the specific community's historical, social, economical, cultural and political framework (South Africa, 1997:180-183).

In South Africa translating progressive national policy into effective provincial and local practice continues to be a struggle and Tollman & Pick (2002:1726) argue that this is due to health workers' limited community-based experience. It is not only the government and Department of Health at National, Provincial, District and Local level who are responsible for the health of people living with HIV/AIDS. The HIV/AIDS and STI Strategic Plan 2007-2011 (South Africa, 2007:11) states that an

intensification of the multisectoral national response with the focus on better coordination and monitoring will be necessary. The government, non-governmental organisations, community-based organisations, faith-based organisations, private sectors and the people (including the older person) living with HIV/AIDS should employ a joint effort and be involved at all levels of this Strategic Plan (Pelser *et al.*, 2004:308-309).

Ferreira's study (2004:14) of HIV/AIDS and family well-being in South Africa recommends that government, NGO's and local communities work in partnership to meet the needs of the communities and their families (older persons and their families included in this study). Additionally, the research agenda on ageing for the 21st century has identified the integration of formal and informal care systems to support older persons as one of its topics, and more specifically the older person in the reality of HIV/AIDS (ANON, 2003:6). Winge *et al.* (2005:2) state that well-functioning communication and collaboration creates safe and reassuring care services.

The relevance of the study is clearly echoing in the previous statements and the researcher believes that support of the older person affected by HIV/AIDS could be accomplish through collaboration. However, it is important to investigate the concept of collaboration within the context under discussion.

The table on the following page depicts collaboration and its application in the context of this study, employing elements adapted from Winge *et al.* (2005:5):

Table 1.1: Elements of collaboration applied (Winge *et al.*, 2005:5).

Different elements	Context of this study
Who are the stakeholders in the collaboration?	The stakeholders in this study are from Potchefstroom in the North-West Province of South Africa and refer to • the older persons > 60 infected with and/or affected by HIV/AIDS • local health government • the local political leaders • non-governmental organisations (NGO's), • community-based organisations (CBO's), • faith-based organisations (FBO's) and • private business sectors
What is the aim of the collaboration?	To support the older person regarding the effect of HIV/AIDS on themselves, their families and communities
What is the object around which the collaboration is centred?	The older person in the world of HIV/AIDS
How is the collaboration carried out, and what information is communicated?	Through community-based networking, home-visits, referrals, education, focus groups, workshops, meetings, information exchange, policies, etcetera. See chapter 5 for the operationalisation of community-based collaboration guidelines

Considering the above elements (see table 1.1), the researcher believes that community-based collaboration is required to support the older person who faces tremendous challenges in their households and communities. Could collaboration assist the stakeholders in the health services and the community under discussion to **work together** in an effective and efficient manner (EICP, 2005:1) to strengthen the older person's support regarding the effect of HIV/AIDS on their lives? There should be a **partnership-relationship** between the older people in the community as key stakeholders and the other stakeholders (mentioned in table 1.1) who aim to **generate a suitable climate** (in this case to support the older person through group discussions, policies, education, etcetera) where the older person's **point of view is valued** with the **negotiation of key decisions** (Mash & Allen, 2004:21).

In order to understand the application and use of collaboration in this study's context, the researcher refers to Sullivan's definition (1998:6): *"Collaboration is a dynamic transforming* ***process*** *of creating a* ***power sharing partnership*** *for pervasive application in* ***health care practice****, education, research and organisational settings for the purposeful attention* ***to needs and problems*** *in order to achieve likely successful* ***outcomes****".*

The researcher, a university faculty member who lectures community nursing science, participates in various community projects and is also involved in a multinational Prospective Urban and Rural Epidemiological (PURE) study. The study is a prospective cohort study that will track changing lifestyles, risk factors and chronic diseases using standardised methods to collect data every three years in urban and rural areas of fourteen countries in transition, including South Africa (Kruger, 2005:4). In the South African leg of the PURE-study data was collected in the urban and the rural communities. The intention of PURE-SA is to facilitate the development of effective public health policies in South Africa that should, in turn, decrease the disease's burden. The Department of Health (South Africa, 2003:6) estimate the prevalence rate of HIV/AIDS in the North-West Province on 26, 2% (Relinghuys & Van Rensburg, 2004:282). It also considered that HIV/AIDS will then have a massive impact on the measurements and results of the 2021 participants in the PURE-SA study. For this reason the study added a component to the assessment phase to determine all participants' HIV/AIDS status. The researcher was actively involved in the data collection on a daily basis, responsible for the rapid HIV-testing that included pre-and post-counselling. The mentioned involvement is summarised to give the reader a clear understanding of the researchers' involvement in the research process. This involvement gave ample time for observation and interviews (see Table 2.1).

The School of Nursing Science, NWU (Potchefstroom Campus), was responsible for managing the assessment phase regarding all participants' HIV/AIDS status within the multidisciplinary research team. The assessment phase included the:

- logistics (ordering of most appropriate HIV/AIDS-testing kits, emergency kit, facilities, tents, etcetera);

- co-ordination of the teams responsible for the blood samples (for all data collection) of 2021 participants;
- the pre-and post test counselling of all participants;
- HIV-testing procedure;
- ethical issues applicable to all acts and omissions throughout the whole PURE-SA study;
- referral and co-ordination with the Department of Health; and
- conducting of follow-up home visits.

The researcher's involvement in the PURE-SA study raised an acute awareness of the reality that older persons are increasingly becoming victims of the HIV/AIDS epidemic. A study conducted by Waysdorf (2002:49) confirms this increase. Older persons are less likely than other age groups to be tested for HIV and many physicians do not suspect HIV in their older patients and therefore do not test these patients (Inelmen *et al.*, 2005:29). The problem of HIV/AIDS in the older person may be greater than reflected in the data on HIV/AIDS cases (Waysdorf, 2002:50). The HIV/AIDS and STI Strategic Plan indicates that there was an increase in HIV prevalence in older age groups and estimate it currently on 4% for people older than 60 (South Africa, 2007:24, 29).

During the counselling process before and after HIV-testing in the PURE-SA study, it became clear to the researcher that the older person is not only infected, but deeply affected by HIV/AIDS in their various communities of residence. In the researcher's personal interaction with the participants, (see table 2.1 for clarity on this interaction) it became clear that the older persons have needs and expectations for support in the world of HIV/AIDS in which they live. They feel left out by their communities. Although they take responsibility for caring for their children and grandchildren, they do not really know where to go to for help, and they do not fully understand the disease that they, their families and their communities were confronted with.

1.2 PROBLEM STATEMENT

Taking the staggering burdens that HIV/AIDS places on the older person, their families and communities and its complexity, the supporting literature examined and

the researcher's personal experience in various community projects into account, it is important to consider the older person within the world of HIV/AIDS. Although recognition has been given to the vital role that community intervention, driven by collaboration between different stakeholders, plays in the HIV/AIDS epidemic at large (Frohlich, 2005:368-369), little attention has been paid to the epidemic's impact on the older population (Waysdorf, 2002:47). Additionally, older people are not yet part of public discussions about HIV/AIDS issues (NAHOF.CONNECTION, 2005).

Older persons (central in the study) as the fastest growing group discussed earlier in the introduction of this study, form part of the vulnerable population groups in the North-West Province of South Africa. Some are infected, but they are mostly affected by the HIV/AIDS that yields them vulnerable due to social, economical, physical, psychological and political factors (Gilbert & Soskolne, 2003:105). The older person, and mostly the woman, plays an important role as caregiver and supporter in their households and communities. The needs and expectations that these older persons have in terms of aging should receive attention, including maintaining physical and psychological functions and continued involvement in social activities and relationships (Drewnowski *et al.*, 2003:300). The provision of sustained support to the older person in the world of HIV/AIDS is an enormous challenge for the local community organisations, all public and private community stakeholders, and needs to be structured into a workable collaborative partnership.

From the above-mentioned problem statement and supporting literature, the following central question emerges:

What does community-based collaboration to support the older person in the world of HIV/AIDS entail?

In answer of this question, the following research questions need to be answered:

- What is the health profile of the older person infected with and/or affected by HIV/AIDS?

- What are the older person infected with and/or affected by HIV/AIDS' needs and expectations?
- What are the facilitating and the impeding factors that the older person infected with and/or affected by HIV/AIDS experience in their households?
- What existing networks and service delivery programmes are available?
- What are the perceptions of the different stakeholders involved in mentioned networks and service delivery programmes on community-based collaboration to support the older person in the world of HIV/AIDS?
- How can community-based collaboration to support the older person in the world of HIV/AIDS be operationalised?

1.3 RESEARCH AIM AND OBJECTIVES

In an attempt to answer the research questions the overall aim of the study is to explore and describe what a community-based collaboration to support the older person in the world of HIV/AIDS entails. The overall aim will be achieved by means of the following objectives that will be pursued in three structured phases:

PHASE 1

- To determine and describe the health profile of the older person infected with and/or affected by HIV/AIDS.
- To explore and describe the needs and expectations of the older person infected with and/or affected by HIV/AIDS.
- To explore and describe the facilitating as well as the impeding factors the older person infected with and/or affected by HIV/AIDS experience in their households.

PHASE 2

- To identify and describe the existing networks and support programmes available.

- To explore a nd describe 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.

PHASE 3

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

1.4 CENTRAL THEORETICAL STATEMENT

The central theoretical statement of the study is that the description of the health profile of the older person infected with and/or affected by HIV/AIDS, the person's needs and expectations and the facilitating as well as the impeding factors that such a person experiences, the existing networks and support programmes available as well as the different community stakeholders' perceptions, form the basis to conceptualise community-based collaboration for operationalisation in order to reach the ultimate goal of supporting the older person in the world of HIV/AIDS.

1.5 RESEARCHER'S ASSUMPTIONS

Research and intellectual inquiry that is free from norms and values is impossible (Fowler *et al.*, 1990:174). However, it is important that the researcher's norms and values do not influence the research results (LoBiondo-Wood & Haber, 2002:129). The researcher's paradigm (ontological, epistemological and methodological assumptions) will be guided by the researcher's set of beliefs and feelings about the world and how it should be studied (Denzin & Lincoln, 2005:23). In this case the world of the older person infected with and/or affected by HIV/AIDS within their socio-cultural context. The meta-theoretical (ontological), theoretical (epistemological) and methodological assumptions of the researcher are stated explicitly to facilitate a clear and easy-to-understand process for readers who should note that the meta-theoretical assumptions of the researcher are non-epistemic

statements, and the study does not intend to test them (Mouton & Marais, 1992:192).

1.5.1 META-THEORETICAL ASSUMPTIONS

The following sources inspire the meta-theoretical assumptions underlying the study: the Word of God (Bible, 1934) and different theology-based nursing theories, other philosophers such as Mbiti (1990) Jeff Levine (*in* Hickman, 2006) and various discussion papers as in Lundmark (2007), Shelly and Miller (2006), Wilkenson (1997), Fawcett and Noble (2003), and Groenhout, *et al.,* (2005).

A Christian worldview shapes the underlying understanding of the infected with and/or affected by HIV/AIDS older persons, their families, communities and society and the belief that community-based collaboration can support the older person in the world of HIV/AIDS.

1.5.1.1 View of religion

God is the Creator who made the world and everything in it. He created the researcher, the older persons and the stakeholders and/or role players in the study and He is beyond-, but also with the researcher, the older persons and all other role players. God is love and He truly cares for those humans that suffer on the earth, He walks the older persons infected with and affected by HIV/AIDS through their suffering and guides the researcher and role players into truth through His teachings. The researcher, instrumental in His hand through obedience and faithfulness, believes to contribute to effective support of the older person in the world of HIV/AIDS through community-based collaboration.

1.5.1.2 View of nursing to support the older person

Nursing in the community is a calling inspired by moral values with ethical actions that focus on the interrelation between God, the communities of which the older person and their families, as well as the different role players, form part. The relationship is a dynamic process of mutual giving and sharing based on commitment between the researcher, the older person, the other role players and God. The researcher as a community nurse feels a personal sense of commitment and responsibility through moral ethos and God's love as the core value system of

nursing care to explore ways to support the older person in the world of HIV/AIDS to promote, maintain and restore health, not only of the older person, but also of the family and the community. The emphasis of this study falls on holistic health care, the whole person's being and overall quality of life as embodied in God. The researcher is concerned with the wellness of the older person and responds with compassion and care to their needs, with respect for the older persons and the other role players as created in the image of God. In this study on support for the older person in a world of HIV/AIDS, nursing refers to the value of hope inspired by the Spirit of God that can make a difference to the older person facing the rather despairing situation to be infected with and/or affected by HIV/AIDS.

1.5.1.3 View on the individuals and family

Individuals (the older persons and the role players) and families are God's creations that live, move and have their being in Him. The older persons as well as the role players are through the knowledge of God the examples in the community, and their relationship is based on loving kindness, faithfulness and trust. The researcher sees an individual (the older person, role players, family members and community members) as a holistic being that desires wholeness through an attempt for physical, spiritual, psychological (emotional and intellectual), as well as socio-cultural balance that not only lives in harmony with themselves, God and others, but is responsible towards the environment. Infecting with and/or affecting by HIV/AIDS influences not only the biophysical, but also other dimensions of the older person, like the psychological dimension. Hope provides a substantial link between active faith and psychological factors, and being hopeful can mobilise positive expectations. Jeff Levine (*in* Hickman, 2006) reminds that there is a positive link between the health of the older person, the relationships between them and the role players and religion. The following assumptions from Christian religion can improve the health and wellness of the older person, their family members, community members and role players in the world of HIV/AIDS:

- Religious affiliation (FBO's) and membership benefit health by promoting healthy behaviour and lifestyles;
- Support through regular religious fellowship decline the effects of stress and isolation and improve wellness;

- When the older person participates in worship and prayer, positive emotions develop from a physiological process and can result in resilience;
- Religious beliefs are similar to health-promotion beliefs and can benefit health;
- Hope, optimism and positive expectations comes from faith and benefit the wellbeing of people.

1.5.1.4 View of community

The older person and role players are, as part of a family and the community, socio-cultural beings within a certain socio-cultural context, as explained in paragraph 1.2. All creatures are one before God, irrespective of any individual differences or illnesses and they should not be stigmatised and discriminated against. The researcher relates to the African religion that is everywhere in the life of the community and society, of which the older person and the role players in this study form part, from a Christian point of view.

God created man with the capacity to make choices and community-based collaboration will support the older person as well as the role players to make informed choices to network as partners regarding their health and that of the others in their families and community. The researcher, as a community nurse, will play an active role to ensure that social justice is done and will encourage the older persons and all stakeholders and role players in the community to identify and utilise the available resources and information to their benefit in an ethical and fair way.

A discussion on the theoretical assumptions that include the theories and models used in the study follows hereafter.

1.5.2 THEORETICAL ASSUMPTIONS

Theories are a systematic way of looking at the world or like a map to observe a phenomenon (Covington, 1998:1) and to describe the events explored in the study. The Systems Theory forms the primary theoretical framework as point of departure. All the other theoretical and conceptual frameworks like the Social Theories of Aging and the Model of Successful Aging that apply to the study are integrated and

discussed complementary to the Systems Theory. A brief explanation of the main features of each follows hereafter. The decision to apply the different theories and models in the study are integrated into the discussions of the findings and specifically apply to the integrated systematic concept mapping process to conceptualise and operationalise community-based collaboration to support the older person in the world of HIV/AIDS (see chapter 5).

1.5.2.1 Systems Theory

The Systems Theory is most suitable for the study as the primary theory as point of departure because it is applicable to numerous settings, like community health. The main principle of this theory proposed by the socialists Comte and Spencer (*in* Cunningham *et al.*, 1998:54; Ritzer, 2008:327) refers to the fact that society is in many ways similar to that of a living organism. A society has **structure** made up by **groups, classes and institutions**. Like an organism a society is like a **system** whose **needs must be satisfied** if it wants to survive, their should be distribution of food and resources from outside the society and between the members of the society. The parts of a social system **work together** like the parts of a biological organism **in an orderly way to maintain the wellbeing of the whole**. The arrangements of the different parts and the order of their relationship to each other refer to their organisation (Stanhope & Lancaster, 1988:135). Parsons (*in* Cunningham *et al.,* 1998:54) adds to this, states that the parts of a society need to integrate, and that implies that people should accept their society's shared values.

The Systems Theory is appropriate in this study because of the following reasons given by Covington (1998:4-5):

- The researcher expect many unpredictable variables with reference to the complexity of HIV/AIDS;
- The theory is suitable to describe situations as they exist in the empirical world;
- The theory has the ability to show the complex interrelatedness that exists between the different systems in the community as a whole;
- The theory is not historically limited and future planned actions based on past experiences are possible.

Wholeness, organisation and relationships appear central in the systems theory (Marcellus, 2006:230). Betts (*in* Arries, 2002:3) sees a system as "a set of elements that function as a whole to achieve a common purpose". Systems can be open or closed. Openness or closeness of a system refers to how active or inactive the system is, and if there is effective interaction and exchange of energy between the system and the environment that is constantly changing, for proper functioning and homeostasis (Arries, 2002:3; Covington, 1998:11, 19; Sullivan, 1998:109).

For the sake of this study, the researcher refers to systems and/or sub-systems interrelated and interdependent on each other (Stanhope & Lancaster, 1988:136) as the older person, the stakeholders, the community and collaboration, each with its boundary that distinguishes it from its environment, which is everything external to the system (Sullivan, 1998:110).

All systems have specialised units, are goal-oriented, have different ways to reach the goal under the regulation of leadership (Covington, 1998:12) and need to give feedback. This is the process whereby the output of the system is redirected as part of the input of the same system (Stanhope & Lancaster, 1988:136). Collaboration is a whole, with four major system components or sub-systems, namely process, partnership, practice and outcomes as illustrated by Sullivan (1998:119).

See figure 1.1 below for application to the study.

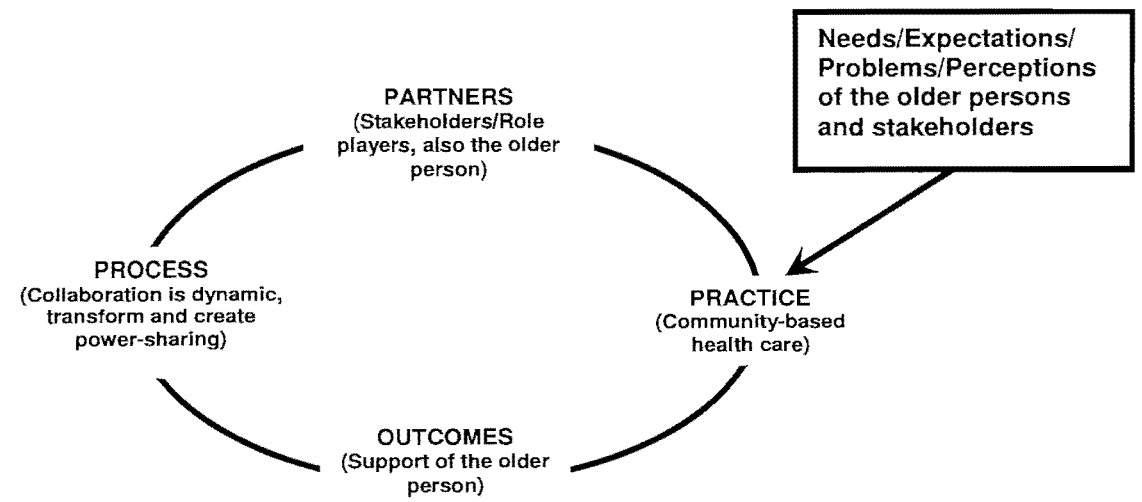


Figure 1.1: The collaboration system

The phenomena, community-based collaboration to support the older person in the world of HIV/AIDS is in relation to other components (see figure 1.1) continuously in interaction with each other to integrate. Community-based collaboration in the study investigated as a sub-system in the context of community-based health care forms part of the larger health system in South Africa. An investigation from the empirical world regarding the structures and their functions in the community is crucial to formulate guidelines true to the specific organisations, groups or communities in their context (Ritzer, 2008:254). The overall purpose of the study is to formulate guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS.

A function is "a complex of activities directed towards a need or needs of the system" (Ritzer, 2008:241). The need for a functional approach in the study to improve the practice of community-based health realises in the desired outcome to support the older person. The *how* is the focus of the study and is preceded by the *what* of the phenomena (Klopper, 1994:16). After the process of conceptualisation of community-based collaboration and the formulation of guidelines, the planned actions give direction to utilise the knowledge gained through the study. In order for a system to survive, the system must perform four functions, namely, adaptation, goal attainment, integration and maintenance.

1.5.2.2 Social Theory of Aging

The Social Theories of Aging (Role Theory, Disengagement Theory, Subculture of Aging Theory and Modernisation Theory) referred to by Kinsella & Phillips (2005:35) was used for a clearer understanding of the changing role of older persons central to the events in the study. HIV/AIDS puts new challenges to the role of the older persons in their households, neighbourhood and community. The older persons are often forced into new roles and therefore it is important for the researcher and reader to understand the main features of the Social Theory of Aging, which entails the following:

- The role theory refers to the variety of roles the older persons play in their lives. The retiree and grandparent role apply. Roles are often sequential; some are concurrent and individuals gain or lose roles

throughout life. The norm is that people should do or stop certain activities at certain ages, and this explains the challenges that the changed role can bring on the older person in the study.

- The disengagement theory refers to the process of mutual withdrawal between the older person and the community and the assumption is that this is unavoidable and universal. Could this explain why the older person is not part of decision making processes in the community and has lost their 'voice'?

- The Subculture of Aging theory refer to older persons maintaining their self-concepts and identities through membership in social groups and could explain why the older person in the community needs support groups of their own age like NGO's, CBO's, or FBO's in the community.

- Modernisation theory refers to a more general theory that refers to the negative effects on the roles and status of the older person if their knowledge, experience and skills are deemed less important or relevant in the modern world of which HIV/AIDS is a reality. The older person in the study is from the previously disadvantage group with no or a low education level that has an influence their roles and status. Westernisation can also have an impact on the more traditional older African person with rich cultural values and belief systems.

1.5.2.3 Model of Successful Aging

A brief reference to the model of successful aging can contribute to a clear understanding of the older person in the social and economic context of this study in relation to their psychosocial development; their feelings of self-esteem, value, and place in the family and society. Different factors have different effects on people and sometimes combined effects.

Figure 1.2 illustrates the model and the integration, and the flowing together of the main functions for successful aging is clearly visible: to avoid diseases and disease-

related disability; maintaining physical and mental functioning; and to be actively involved in the community (Kinsella & Phillips, 2005:34, 36).

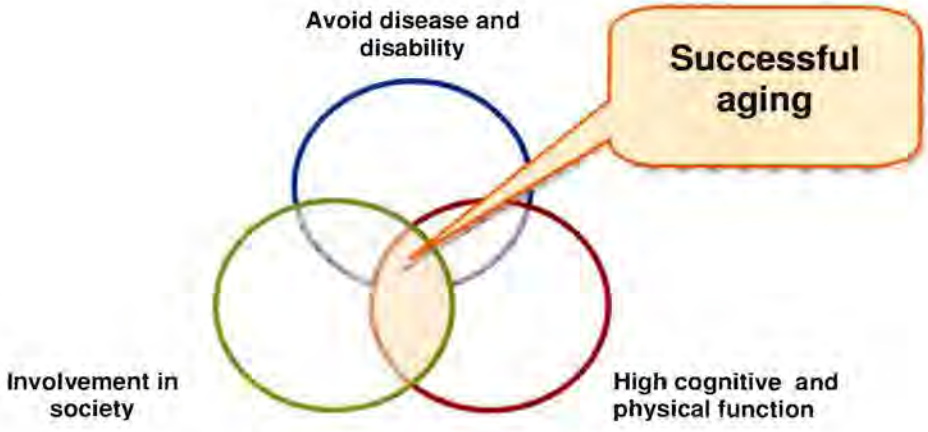


Figure 1.2: Model of Successful Aging (Kinsella & Phillips, 2005:36)

The older persons in the study are in the age group older than 60 years and already affected by the changes that accompany the aging process, which makes them also more vulnerable to chronic diseases. The literature in the introduction demonstrates that HIV/AIDS not only infects the older person, but it affects them on all the domains indicated in the above illustration (figure 1.2).

Different concepts can have different meanings and could lead to different interpretations. The researcher defined the concepts applicable to this study (community, community-based, collaboration, HIV-infected, HIV-affected, AIDS, older person, health profile, stakeholder, support, household, facilitating factors, impeding factors, operationalisation).

1.5.3 DEFINITIONS

Community:

The South African Concise Oxford Dictionary (2002:233) refers to a community as a group of people living together in one place that have something in common, like religion and race. The group of people share a common interest; they interact with one another and function collectively within a defined structure to address

communal concerns (Clark, 2003:4-5). Communities are structures within which people live and they provide a source of support and care to individuals and families in need, with shared values, cultural patterns, social problems and a group awareness that help the people to interact amongst each other in a way they would not interact with outsiders (Dennill *et al.*, 1999:84; Ncama, 2005:33).

The community referred to in the study consists of older persons from a previously disadvantage group that live in certain geographic and social boundaries, infected with and/or affected by HIV/AIDS. They share common problems like HIV/AIDS in the community where they live and support their children, grandchildren, families and neighbours. In the same community there are stakeholders and/or role players that provide support and care to individuals and families in need. Both the older persons and role players interact with one another and feel that they should address common concerns in finding ways to support the older person in the world of HIV/AIDS.

Community-based:

Community-based implies that 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 autonomous, preventive, protective and promotive health care.

Collaboration:

Collaboration is a dynamic process of power sharing between partners that work together/or is jointly working together on a project (South African Concise Oxford

Dictionary, 2002:226) that originated 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".

With reference to this study 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 experience, 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.

HIV-infected:

HIV is *Human* (it is only found in humans) *Immunodeficiency* (the immune system becomes increasingly less able to fight infection) *Virus* that weakens the immune system, ultimately leading to AIDS. HIV was the first member of the retrovirus family to occur in humans (Evian, 2003:5; Van Dyk, 2005:10). HIV-infected is a term that is usually used to indicate that evidence of HIV has been found via a blood test (UNAIDS, 2006b:6).

In this study, HIV infected refers to the older person and/or significant other that has been tested and evidence of the virus has been found via a blood test.

HIV-affected:

According to the South African Concise Oxford Dictionary (2002:18), affect means 'to have an affect on' or 'make a difference to' or 'to influence'.

In this study HIV-affected refers to the older person that has one or more persons living in their household, neighbourhood and/ or community who are infected with

the HI-virus. The person could be a child (also refer to an adult child), grandchild, other family member and/or friend that will have an affect on the older person's well-being and/or normal role in the community where they live. The older persons can be affected in different ways, either psychological, economically, socially and physically.

AIDS:

AIDS is the acronym for *Acquired Immune Deficiency Syndrome.* Van Dyk (2005:3) and Evian (2003:8) explain that the disease is *acquired* because it is not inherited and is caused by the HI-virus. *Immunity* is the body's natural ability to defend itself against infection and disease. *Deficiency* is a shortcoming and explains why the body can no longer defend itself against different infections. *Syndrome* refers to a collection of specific sign and symptoms that occur together and that are characteristic of a particular condition.

The older person or the significant other living in the household and/or community under discussion has AIDS when the HIV-related immune-deficiency is so severe that various life-threatening opportunistic infections and/or cancers occur that can be characteristic of a particular condition like pneumonia.

Older person:

The literature explains that being old can occur at different chronological ages, determined by the prevalent socio-culture milieu (May, 2003; Hattingh *et al.*, 2006:204). However, the concept of old age varies from country to country, from society to society and there are even a number of terms to describe people considered old (Kinsella & Phillips, 2005:6). May (2003:4) note that people in an African society falling in the 50-60 year age group are traditionally considered as old. The World Health Organisation (WHO) defines the older person as someone aged 65 years and over (WHO, 2004:9). In South Africa a person is at a pensionable age from 60 years for women and 65 years for men, but changes are taking place and in some organisations there is no distinction between men and women. According to the executive report by HelpAge International (May, 2003:vii), older people in South Africa continue to work well into the later stages of ageing to fulfil an important role in the economy.

However, for clarity and in the context of this study the "older person" is a male or a female from the age 60 years and older. The older person in the study could be infected with and/or affected by HIV/AIDS and lives in urban and rural areas.

Health profile:

The health profile of the older person consists of various aspects and all the dimensions of health should be considered, that is; biophysical, psychological, physical environment, socio-cultural, behavioural and health systems (Clark, 2003:257-259).

The health profile of the older person includes patient health history, demographic data, medication, diagnostic tests and history of current health problems, psychology data, social data and nutritional data.

Stakeholder:

A person, groups or organisations with an interest in projects or initiatives, who plays a role and/or have a function in the particular situation/project/initiative (South African Concise Oxford Dictionary, 2002:1012 &1143).

The stakeholders in the study are all involved in the support of the older person infected with and/or affected by HIV/AIDS as described in the study. The researcher views the older person as the key stakeholder and an extremely valuable resource in the community. Other stakeholders could be the additional household members, the older person's friends and neighbours, the local socio-political structures (Department of Health, -Education, -Agriculture, -Social services, -Home affairs, etcetera), allied health care professionals, the local community-based organisations (CBO's), the non-governmental organisations (NGO's) and faith-based organisations (FBO's).

Support:

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 support can "be of physical nature when the hand is placed on the abdomen when

coughing, it can be of psychological nature when you listen actively to another or holds the hand when someone is dying, or it can be of social nature when a person voluntary visits someone in the community that is in distress or housebound" (Brooker, 2006:234-235).

In this study support is a process aimed at helping, assisting and encouraging the older person in the world of HIV/AIDS through active involvement in their situation and needs. Such needs may be bio-physical, social, psychological, ecological, spiritual and/or with regard to health care needs.

Household:

Household is defined in terms of the standard definition given by Statistics South Africa sited in Booysen *et al.* (2004:29) that is "a person or a group of persons who live together at least four nights a week at the same address, eat together and share resources".

Household refers in the study to the house of the older person included in the study, and its other occupants, who conform to the mentioned requirements outlined by Statistics South Africa. The household owner could be the older person under discussion and the occupants could be adult children, grandchildren and/or other family members or friends.

Needs:

Is something that is very important and not just something desired (South African Concise Oxford Dictionary, 2002:778) by the older persons infected with and/or affected by HIV/AIDS. The older person has certain needs in order to have a satisfactory life (Cambridge Advanced Learner's Dictionary, 2008b).

The needs refer to the older persons' physical household needs like water and sanitation, necessities such as food, clothes and finances. The needs also refer to other dimensions of the older person, namely the biophysical needs like aging and physiologic functions, environmental dimension such as to be safe and secure in a home and psychological dimensions such as to be loved and accepted. Socio-cultural needs like family roles and responsibilities, social support, abuse and

violence, behavioural dimensions like medication use, tobacco and alcohol use and the fulfilment of their spiritual needs like religion, play a major role in the lives of the older persons (Clark, 2008:520-521).

Expectations:

Is the belief that something will happen (South African Concise Oxford Dictionary, 2002:404), a strong hope or a mental image of something expected (Encarta® World English Dictionary, 2007a), when the older person expects good things to happen in the future (Cambridge Advanced Learner's Dictionary, 2008a).

The older person infected with and/or affected by HIV/AIDS has no proof, but trust that the things they expect and hope for will happen.

Facilitating factors:

According to the South African Concise Oxford Dictionary (2002:412) to facilitate mean "to make easy or easier". Wissing (2007:12-14) refers to facilitating factors from a fortigenic perspective as the physical, cognitive, emotional, and social manifestations of strengths, capacity and protection factors.

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 life easier. It is important to identify the factors to enhance the health and wellness of the older person infected and/or affected by HIV/AIDS.

Impeding factors:

Factors 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 different dimensions of man (Wissing, 2007:12-14).

HIV/AIDS is an "impeding factor" that infects or affects the older person central to the study. 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 (dis-ease) or future risks that can contribute to declining health and vulnerability of the older person.

Operationalise:

It 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, 2008c).

The researcher believes that the study leads to the conceptualisation of community-based collaboration that can be used as an activity to support the older person in the world of HIV/AIDS.

1.5.4 METHODOLOGICAL ASSUMPTIONS

The researcher's methodological assumptions are embedded in the **participatory** (co-operative) inquiry paradigm. The participatory inquiry paradigm included **hermeneutic** elaboration (the activity of interpreting, exploring and interpretation of meaning) embedded in the researcher's view of **constructivism** that will be possible in the study through interaction and discourse for consensus on more than one construct that could result in a conceptual framework (Botes, 1995:11; Guba & Lincoln, 2005:197). Participants (older persons and the stakeholders and/or role players) took an active role in the research process, from the question of interest to the outlets of findings (Guba & Lincoln, 2005:197).

The researcher believes that the participants should speak for themselves and the researcher listened and interpreted their message. The "voice" of the researcher contributed to empower the participants (older people and other role players) towards "human flourishment" (Guba & Lincoln 2005:202; Holloway & Wheeler, 2002:175) in their own lived reality (world of HIV/AIDS).

1.6 RESEARCH DESIGN AND RESEARCH METHOD

"Quantitative research is renowned for having breadth and qualitative research for having depth" (WHO, 2002:3). A quantitative and qualitative, explorative and descriptive research design was used in the study to propose and describe community-based collaboration to support the older person in the world of HIV/AIDS. To fulfil the aim of the study three phases were followed as discussed hereafter in paragraph 1.6.2 on "overview of research methods". Each aspect of the research design and research method is given.

1.6.1 OVERVIEW OF THE RESEARCH DESIGN

The design of this study is quantitative, qualitative, explorative, descriptive and contextual in nature. An outlay of the research design follows hereafter to justify the researcher's decisions.

1.6.1.1 Quantitative

Quantitative research methods were used in the PURE-SA study to gather empirical evidence (Polit & Beck, 2006:15) and are as such included in the phases explained hereafter with specific application in chapter 2. Quantitative non-experimental research explores, describe and compare trends in a population to make conclusions and/or generalise the sample (Creswell, 2003:153; LoBiondo-Wood & Haber, 2006:239). A typical descriptive method was used with the intention to give an accurate description (Van der Walt & Van Rensburg, 2006:103-104) of the health profile of the older persons infected with and/ or affected by HIV/AIDS living in urban and rural communities in the North-West Province.

The health profile of the older persons referred to demographical, socio-economical-, psychological-, biophysical and lifestyle/behavioural dimensions. According to Burns and Grove (2004:170) demographic variables or factors are important to collect a picture of the samples' characteristics. In a cohort study, the collection of the data was done through structured questionnaires, health screening (tests and measurements) and field notes (methodology-, personal- and observational notes). Descriptive statistics were used to summarise the large amount of information

obtained (Huysamen, 2005:12). Refer to table 1.2 for the summarised layout of the health profile of the older person infected with and/ or affected by HIV/AIDS (Phase 1, **step 1**).

1.6.1.2 Qualitative

A qualitative research design was chosen due to the naturalistic perspective and the interpretive understanding of human experience (Denzin & Lincoln, 2005:7). Qualitative research strives to study and interpret different phenomena in their natural environment in terms of the meaning given to it by the older persons (see chapter 3, paragraph 3.2.1) and the stakeholders (see chapter 4, paragraph 4.2.1), which is the "emic" view (Morse & Field, 1998:8). As highlighted by Cheek (2005:391) qualitative research "is a way of thinking", "to understand the human health experience", and as further stated by Denzin and Lincoln (2005:1;10) qualitative research (participation, interviewing) "serves as a metaphor for colonial knowledge, for power and for truth", "to seek answers to questions that stress how social experience is created and given meaning". The older persons as well as the stakeholders are the people with the practical experience of the problems (Mouton and Marais, 1992:45) in the community, such as HIV/AIDS.

An open and honest working relationship between the researcher and the participants was one of the building blocks of the qualitative nature of the study. The researcher spent a great deal of time with the participants to know aspects of their world and learn about the way they live in that world (in this study the older person in the world of HIV/AIDS) (Cheek, 2005:401). The researcher focused on the dynamic and individual needs and expectations, as well as the facilitating and impeding factors experienced by the older persons and perceptions of the stakeholders and/or role players regarding community-based collaboration to support of the older person in the world of HIV/AIDS. A qualitative research design was used primarily, to conceptualise and operationalise community-based collaboration to support the older person in the world of HIV/AIDS.

1.6.1.3 Explorative study

To explore in a qualitative study means to shed some light on the full nature of the phenomenon and features related to it (Polit & Beck, 2006:21). The research had a hermeneutic intension with the purpose of interpretation that accompanies description (Cohen *et al.*, 2000:2 &10; Kvale, 1996:46). The close relationship between the researcher and the participants in the research situation helped the researcher to explore the lived world of the population under study. The full nature of the phenomena in this study refer to the health profile of the older person (see chapter 2, paragraph 2.2 and figure 2.3); needs and expectations as well as the facilitating and impeding factors (see chapter 3, paragraph 3.2); the role of the stakeholders and their perceptions on community-based collaboration to support the older person in the world of HIV/AIDS (see chapter 4, paragraph 4.2).

1.6.1.4 Descriptive study

Description of a phenomenon is another important purpose of research (Polit & Beck, 2006:21) which applies to both the quantitative and qualitative research. The quantitative design and methods assisted the researcher to describe the health profile of the older person in the study. Quantitative description focuses on the prevalence, incidence, size and measurable attributes to a phenomenon. Against the quantitative nature of the study, in-depth qualitative studies revealed information for rich description (Mouton & Marais, 1992:46) on the needs and expectations experienced by the older persons infected with and/or affected by HIV/AIDS. Qualitative description in the study also referred to the perceptions of the stakeholders and/or role players as groups, organisations and/or sub-systems and their social interaction in the community. The researcher endeavours through accurate description of the findings to conceptualise a community-based collaboration framework to support the older person in the world of HIV/AIDS.

1.6.1.5 Contextual

The study is contextual in nature and therefore descriptive and explorative (Mouton & Marais, 1992:123). Context sensitivity implies that the researcher gains insight and recognises the cultural, temporal, social and geographical setting within which

the research occurs (Holloway, 2005:275). The South African leg of the PURE-SA study was conducted in one of South Africa's nine provinces, the North West, which is further divided into four health regions; the Southern- Mafikeng-, Bojanala- and Bophirima regions. The first phase of the PURE-SA study (establishing urban and rural cohorts for physical, socio-economical and psychological assessment) took place in the Southern region, which consists of urban and rural areas.

The North West Province has four provincial hospitals, two psychiatric hospitals, fourteen district hospitals, thirteen community hospitals, 330 clinics and health centres and ± 100 mobile clinics (Department of Health, North West Province *in* Pienaar, 2004:23). The areas where the PURE-SA study took place have one district hospital, one community hospital, three 24-hour health centres and nine primary health care clinics. The urban and rural areas under discussion are located far apart (± 400 kilometres). In the rural area the distances between the older persons' homes and the clinics and between clinics and hospitals were large, and this influences accessibility to the health services and other services and/or sectors.

The participants were mainly from a black African socio-cultural background with aspects like religion, traditional beliefs and customs, extended families as well as the value of collectiveness that form part of their lives (Mbiti, 1990:2-3). As expected, a large portion of the participants were part of the older population (older than 60 years) because the inclusion criteria for PURE-SA participants were 35 years and older. The researcher discovered during her involvement (taking of blood samples, pre-and post counselling, home visits, and informal discussions), that many of the older participants were either infected with and/or affected by HIV/AIDS. They live in a world of HIV/AIDS and form part of the statistics that indicate that 4-10% of HIV infection occurs in adults aged 50 and older (Inelmen *et al.*, 2005:26; South Africa, 2007:29; Waysdorf, 2002:49).

The Apartheid period was a lived reality of 44 years for the majority of South Africa's older persons and the result is that the larger groups of older persons today are part of the previously disadvantaged group. They were disadvantaged because the majority were politically marginalised and had unequal access to social services. Although progressive transformation has been facilitated by Government to restore

the past imbalances since 1994, 55% of older persons still live below the country's poverty line of R800 per month (Joubert & Bradshaw, 2006a). Additionally, the same authors refer to aspects they found in a study in 2001 that summarised the older person's situation and context in this study:

"Among those 60 years or older, 21% had no piped water in their households; 49% had no access to a flush toilet (including 14% with no toilet); 27% lived in informal or traditional housing; 43% had no school education and 50% had no electricity for cooking purposes".

However, despite their own health problems, the older persons in South Africa have been recognised as those who contribute to development in the community:

"through alleviating financial and asset needs in households; the upbringing and social nurturing of grandchildren; providing care for sick, disabled and frail household members, and financially and materially supporting their offspring, including the AIDS-sick" (Joubert & Bradshaw, 2006a).

The research was conducted in the areas indicated in the PURE-SA study and involved the households of identified older persons, different stakeholders and/or role players in the area from different organisations from the public sector, private sector, NGO's, CBO's and FBO's. The findings of this study are valid in the context of the older person infected with and/or affected by HIV/AIDS living in urban and rural communities. The participants (older persons) were all Black Africans and from previously disadvantaged communities with their own cultural and historical background (Holloway & Wheeler, 2002:11). The researcher was aware and sensitive to the known fact that older persons from the urban community (Ikageng) lived under Apartheid in South Africa before 1994 and that the older persons from the rural community (Ganyesa and Tlakgameng) was part of Bophuthatswana, an independent system with no Apartheid where they still respectfully apply the traditional tribal law. The contextual framework of the research furthermore refers to the environment and the conditions (physical location) where the research took place (Burns & Grove, 2004:170; Holloway & Wheeler, 2002:34).

The research location was divided into four chosen areas (two urban and two rural):

- the older more established part of **Ikageng,** a suburb of Potchefstroom (between the police station, devil's corner, tar road to Mohadin and boarder to Top City area), referred to in this study as urban community;
- informal squatter areas: Zonder water, Extension 11 and Extension 7, referred to in this study as urban community;
- **Ganyesa,** a village 70 km from Vryburg in the North-West Province of South Africa, 450 km West of Potchefstroom on the highway to Botswana and 70 km from the Botswana boarder with good infrastructure, referred to in this study as rural community; and
- **Tklagameng,** a deep rural village, situated 30 km from Ganyesa and 40 km from the Botswana boarder with almost no infrastructure, referred to in this study as rural community.

The researcher formed part of the research process and was involved in an acceptable manner in the research process to honour the mutual relationship of the theory and practice (Botes, 2003:12).

1.6.2 OVERVIEW OF RESEARCH METHODS

The researcher followed three phases in the process to conceptualise community-based collaboration to support the older person in the world of HIV/AIDS and propose guidelines for operationalisation. A summarised outlay is given in Table 1.2 for an overview on the research design and research method. A detailed description of each phase and its steps are provided in the beginning of each subsequent chapter that deals with the particular phase and steps.

Phase 1 consists of 3 steps and focused on the exploration and description of the unknown lived world of the older person in the world of HIV/AIDS; health profile (Chapter 2), needs and expectations of the older person, as well as the facilitating and impeding factors that they experience (Chapter 3).

Phase 2 focused on the existing networks and support programmes that are available in the community and included the perceptions of the stakeholders and/or role players in the identified networks and support programmes in the community applicable to the study (Chapter 4).

Phase 3 focused on the conceptualisation of community-based collaboration to support the older person in the world of HIV/AIDS and guidelines for operationalisation (Chapter 5).

For consistency, the reader is reminded that each phase and accompanied steps outlined in table 1.2 hereafter was discussed in detail in each chapter as indicated and where applicable.

Table 1.2 hereafter depicts a layout to briefly orientate the reader to the methodology that will be incorporated to reach the aim of the study.

Table 1.2: Research design and research methods

PHASE 1			
Step 1: To determine and describe the ***health profile*** of the older persons infected with and/or affected by HIV/AIDS (Chapter 2)			
Population and sampling	**Data collection**	**Context**	**Data analyses**
• All inclusive purposive sampling, all the older persons as participants selected from PURE-SA study (older than 60 years) • N=333	• Data of PURE-SA - prospective longitudinal study (Creswell, 2003:158-162): ✓ household survey (adult, household and family census questionnaire) ✓ diagnostic tests (HIV-status) • Field notes during pre- and post- counselling regarding health profile	• PURE-SA study was conducted in communities in one of South Africa's nine provinces, the North West Province. • An urban and rural area located far apart (± 400 km) • The participants were either infected with and/or affected by HIV/Aids and part of the statistics that indicate that 4-10% of HIV-infection occurs in adults aged 60 and older. • The population of older persons were all from African socio-cultural background and historical from previously disadvantaged groups. • The researcher was involved in the data gathering process of PURE-SA every day over a period of 12 weeks through which experience of the realities in the different communities accumulated and a trust relationship was formed.	• Descriptive statistics (Van der Walt & Van Rensburg, 2006:171)

Table 1.2: Research design and research methods (continued)

PHASE 1			
Step 2: To explore and describe the ***needs and expectations*** of the older person infected with and/or affected by HIV/AIDS (Chapter 3) **Step 3:** To explore and describe the ***facilitating and impeding factors*** experienced by the older person infected with and/or affected with HIV/AIDS in their households in the community (Chapter 3)			
Population and sampling	**Data collection**	**Context**	**Data analyses**
• Purposive sampling (Creswell, 2003:185) participants selected from PURE-SA study (older than 60 years), urban area that is accessible (WHO, 2002:6) • Step 2 and 3 focused on the population of the urban area that was part of the PURE-SA study where the researcher is a community nurse specialist actively involved in various projects for the past eleven years with a well established trust relationship in the community. • The researcher's methodological assumptions embedded in the participatory (co-operative) inquiry paradigm (Botes, 1995:11; Guba & Lincoln, 2005:197) influenced, from there the decision made to continue with the urban area. • Because most qualitative (naturalistic) studies involve a relatively small group of participants (Polit & Beck, 2006:17) it was possible to continue with the study on a smaller sample • The size of the sample was determined and guided by the data. The principle of data saturation applies (Polit & Beck, 2006:273). • N=10	• Mmogo-method™ that consist of visual presentations (Roos, 2008:3), to stimulate data generation in a focus group (Babbie, 2007:308) • Field notes made during and after the focus group (Holloway, 2005:292)	• The participants were infected with and/or affected by HIV/AIDS and formed part of the statistics that indicate that 4-10% of HIV-infection occurs in adults aged 60 and older. • The population of older persons as key informants (Holloway, 2005:293) were all from an African socio-cultural background and historically from previously disadvantaged groups with which the researcher is familiar.	• Analyses of visual and textual data was done by semiotics and content analyses (Banks, 2001:11; Manning & Cullum-Swan, 1998:251-252; Roos, 2008:12; Streubert Speziale & Carpenter, 2003:63)

Table 1.2: Research design and research methods (continued)

PHASE 2			
Step 4: To identify and describe the ***existing networks and support programmes*** available (Chapter 4)			
Population and sampling	**Data collection**	**Context**	**Data analyses**
• Population: all available networks and support programmes in the community of the urban area • Inclusion criteria (Polit & Beck, 2006:259): all stakeholders involved with HIV/AIDS in the community and/or involved with older persons and education level, gender and age did not exclude anyone • Snowball sampling was used (also referred to as network sampling) to identify early sample members to refer others who met the eligibility criteria (Polit & Beck, 2006:262) • N=28	• Survey (telephonic or personal visit) to identify existing networks and support programmes (Polit & Beck, 2006:251) • Semi-structured questionnaire (Polit & Beck, 2006:291) • Field notes were taken to add important incidents that occurred during the telephonic or personal visit	• Stakeholders and/or role players are from different socio-cultural backgrounds working in the community against HIV/AIDS, some are highly professionally qualified and others can barely read and write • The stakeholders and/or role players are either employed or work voluntary in the different organisations in the community that are representative of international, national, provincial and district level. • All stakeholders invited were involved in some or other way with HIV/AIDS	• Descriptive data analyses (Van der Walt & Van Rensburg, 2006:104)

Table 1.2: Research design and research methods (continued)

PHASE 2			
Step 5: To explore and describe 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 (Chapter 4)			
Population and sampling	**Data collection**	**Context**	**Data analyses**
• Purposive voluntary sampling (Babbie *et al.*, 2004:166-167) of stakeholders and/or role players identified through the network sampling as described in step 4 and invited to participate voluntary (also refer to the context in this table) • N=18	• Research interviews through semi-structured questionnaire (Kvale, 1996:3) • Field notes, personal, demographic and methodological (Holloway, 2005:253)	• The university in this specific community is involved in many community-based projects and was therefore as a key stakeholder with multi-disciplinary role players invited to participate • The Department of Health with the different services were also perceived as vital to the study (see 1.2 for detail on the health services in the area) • From personal experience and literature the researcher was aware that there are the minimum services and support organisations available that focus on the older person in the urban area	• Content analysis (Denzin & Lincoln, 1998:43) as thematic analysis (Morse & Field, 1998:111) in the form of mapping was used as a technique to organise the data into a map to visualise relationships among different themes (Burns & Grove, 2004:552). • The whole process was done with the help of a software program Mindjet® MindManager® 6

Table 1.2: Research design and research methods (continued)

PHASE 3			
Step 6: To conceptualise community-based collaboration to support older persons in the world of HIV/AIDS and propose guidelines for operationalisation (Chapter 5). **Step 7:** Guidelines for operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS (Chapter 5).			
Research method	**Data collection**	**Context**	**Data analyses**
• Conceptualisation (Babbie *et al.*, 2004:111; Denzin & Lincoln, 1998:43)	• Empirical findings of phase 1 and 2 (Chapter 2, 3 and 4) • Literature integration (Creswell, 2003:30-31)	• The social, cultural and economical context of the older person and different stakeholders as interrelated sub-systems function as a whole in the community according to the Systems Theory.	• Logic deductive and inductive inference from phase 1 and 2 (Mouton & Marais, 1992:109) • The integration process was done with the help of a software program Mindjet® MindManager® 6

1.6.3 RIGOUR

Rigour was addressed as it applies to the three phases of the study in each chapter. A general framework follows hereafter to raise awareness of the aspects the researcher considered throughout the whole process of the study. In chapter 2, rigour refers to the validity and reliability of the prospective longitudinal study (PURE-SA) and in chapter 3 and chapter 4, to trustworthiness as applied in qualitative research. The guidelines in Krefting (1991:214-222), Morse *et al.* (2002:1-19), Lincoln and Guba (1985:289-311) and Botes (2003:177-184) as well as other authors, stated in the text, helped the researcher to adhere to and describe rigour in the study. The product or knowledge of a research process should be valid and therefore accountable to the truth (Botes, 2003:176).

The researcher used Lincoln and Guba's framework (as stated by Botes, 2003:177-184) and questioned herself throughout the whole study, using to the following basic standards and measures:

- Were the research well described to ensure **theoretical validity**?

- Can the research findings be trusted? Was **internal validity and credibility** assured during selection of the population and sampling, during data collection and data analysis? What was the researcher's authority?

- Can the research findings be applied elsewhere? Did the study comply with the primary standards to ensure **external validity**? Were the findings **transferable** to a larger population where the older persons live in a world of HIV/AIDS?

- How consistent were the research findings? Was **dependability** ensured, will the data be consistent if it had to be repeated elsewhere where the older person lives in a world of HIV/AIDS? How dense was the description of research methodology? Was an investigative audit conducted? Were more than one method of data collection used for triangulation?

- Was **inferential validity** clear throughout the research process? Were the arguments logical and can the researcher justified the research decisions and findings to convince the research community of its validity?

The reader should take note that it was the researcher's intention to comply to the basic standards and measures that apply to rigour as outlined in each following chapter.

1.6.4 ETHICAL CONSIDERATIONS

The study is rooted in the PURE-SA study (discussed in the introduction and problem statement) and has been reviewed by an institutional review board; the ethical committee of the North-West University (Potchefstroom Campus). The exploration and description of what community-based collaboration to support the older person in the world of HIV/AIDS entails were not a planned outcome of the PURE-SA study, but a responsibility of the researcher. Ethical consent was acquired from the North-West University (Potchefstroom Campus) during 2005, **Number 04M10** (see Appendix A). Written approval from the Department of Health to conduct the study was given (see Appendix B).

Ethical issues could manifest in the study, the researcher was sensitive to it, aware of what is right and what is wrong in any given situation (Babbie *et al.*, 2004:520) and special care taken concerning confidentiality because HIV/AIDS issues were involved since stigmatisation can be extremely harmful to the older person, their household and family members. Cognisance was taken of different ethical issues that may occur in the interaction with the household members, community members, stakeholders in community and specific organisations involved in the study. The researcher's experience during the multi-disciplinary PURE-SA study made her acutely aware of the importance of general agreements amongst researchers about what is right and wrong when conducting scientific inquiry, as stated by Babbie *et al.* (2004:521). Specific considerations applicable to the different phases of the study were addressed (refer to paragraph 2.3.6, paragraph 3.3.6. and paragraph 4.3.6).

The ethical principles as identified by Burns and Grove (2005:181-230), Babbie *et al.* (2004:520-546), Strydom (2005:56-69) and Creswell (2003:11-12) guided the researcher to carefully consider and respect possible ethical dilemmas that may occur during the study. A premature overview of the main ethical considerations as adopted from Burns and Grove (2005:181-230) are provided in the following summary and was applied and explained by the researcher in the chapter applied to each phase of the study.

- Protection of human rights (right to self-determination; right to privacy; de-identifying protected health information under the privacy rule; limited data set and use of data agreement was in place). As a community nurse the researcher advocates the human rights of patients in the community and is familiar with it.

- Autonomy and confidentiality (breach of confidentiality; maintaining confidentiality). This aspect was honoured during the PURE-SA study and the researcher continued to adhere to this principle during the follow-up phases of the study.

- Fair treatment (fair selection of participants and fair treatment of participants). In the context of the study the researcher will take the responsibility of treating all participants the same. All participants in the PURE-SA study > 60 years will be included. The researcher feels strongly that one cannot promise a participant something that was undeliverable and was cognisant of the aspect. The participants received their results timeously and home visits were done if requested.

- Protection from discomfort and harm (no anticipated effects; temporary discomfort including unusual levels of temporary discomfort; risk of permanent damage). The fact that disclosure of HIV status permanently impact on the participants' lives was taken into consideration. Participants were protected in the PURE-SA study since they had been referred to health services if needed. During this study the researcher continued to manage this aspect to prevent any harm.

- Balancing benefits and risks were assessed and was very relevant in the PURE-SA study as the participants had to consider a HIV-rapid test for further participation in the study. A thorough explanation was outlined to each participant for informed choices.

- Informed consent (introduce research activities; describe the risks and discomforts; describe the benefits of study; disclosure; assurance of anonymity and confidentiality; compensation for participation in study; answering of questions; option to withdraw). It was clear during PURE-SA that the participants and the fieldworkers had difficulty with this aspect and the researcher implemented valuable lessons learned such as providing the fieldworkers with more training in the answering of questions and disclosure.

- Comprehension of consent information and assessing whether the participants understand all the information was a principle the researcher is a community nurse with many years of experience in the community, was well aware of and used a translator who knows the community.

- Voluntary consent and competency to give consent applied because some of the older persons were illiterate and did not understand the language of the researcher. All aspects that involved the participant were clarified with them and they had the right to decline the opportunity to participate. In this study the researcher considered competency and did not include participants who are not competent for whatever reason.

- Documentation of informed consent was adhered to and all consent forms were kept for future references in each participant's file for an example.

- Research misconduct (could mean fabrication, falsification, plagiarism, or other practices that are unacceptable in the scientific community).

The researcher, also a faculty member in a lecturing capacity and responsible for teaching fully understand the aspect of misconduct and the researcher's promoters of the study are highly qualified to monitor this aspect.

In addition to the authors mentioned, the researcher found it necessary and valuable to investigate studies with reference to ethical issues concerning the older person living with HIV/AIDS. It was thus throughout the study, the researcher's intention to follow the suggestions of Levinas described in Henderson (2005:78-89). In his words: *"solicitude precedes a manner of speaking, of thinking, precedes the desire to know, and precedes objective thematisation"*. He also says that evil is unable to destroy *"....goodness in the human, the compassion preceding from one private man to the other....outside all redemptive institutions...."*

For clarity the researcher, propose to the reader the following layout of the research report.

1.7 RESEARCH REPORT LAYOUT

The thesis consists of the following structure:

Chapter 1: Overview of the research

Chapter 2: The health profile of the older person infected and/or affected by HIV/AIDS

Chapter 3: Needs, expectations facilitating and impeding factors experienced by the older person

Chapter 4: Perceptions of existing stakeholders on community-based collaboration

Chapter 5: Conceptualisation and guidelines for the operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS

Chapter 6: Evaluation of the study, limitations and recommendations for community health science practice, nursing education and nursing research

1.8 CHAPTER SUMMARY

The reader was orientated to the total study in this chapter. The background and rationale of the study was described whereafter the problem statement was clearly indicated. The research aim and objectives formulated from the research questions were described as well as the central theoretical statement of the researcher. The researcher's theoretical assumptions that entail the meta-theoretical-, theoretical- and methodological assumptions underlying the study were clarified. An outlined description of the research design and method followed in table format to summarise the research design and method of the study conducted in three phases.

In chapter 2, phase 1, step 1, a discussion follows on the health profile of the older person infected with and/or affected by HIV/AIDS that was conducted through the implementation of a survey study to explore and describe trends in a population to make conclusions and/or generalise the sample (N=333 persons >60 years) by means of quantitative research methods. The researcher explored and described to generalise an understanding and insight into the real life situation of the older person in the world of HIV/AIDS.

CHAPTER 2

HEALTH PROFILE OF THE OLDER PERSON INFECTED AND/OR AFFECTED BY HIV/AIDS

The aim of this chapter is to describe the health profile of the older person infected with and/or affected by HIV/AIDS with the intention of providing research evidence to conceptualise community-based collaboration to support the older person in the world of HIV/AIDS. The following schematic outlay (see figure 2.1) indicates the chapters in relation to the phases, steps and the objectives of the research project for the sake of consistency and clarity.

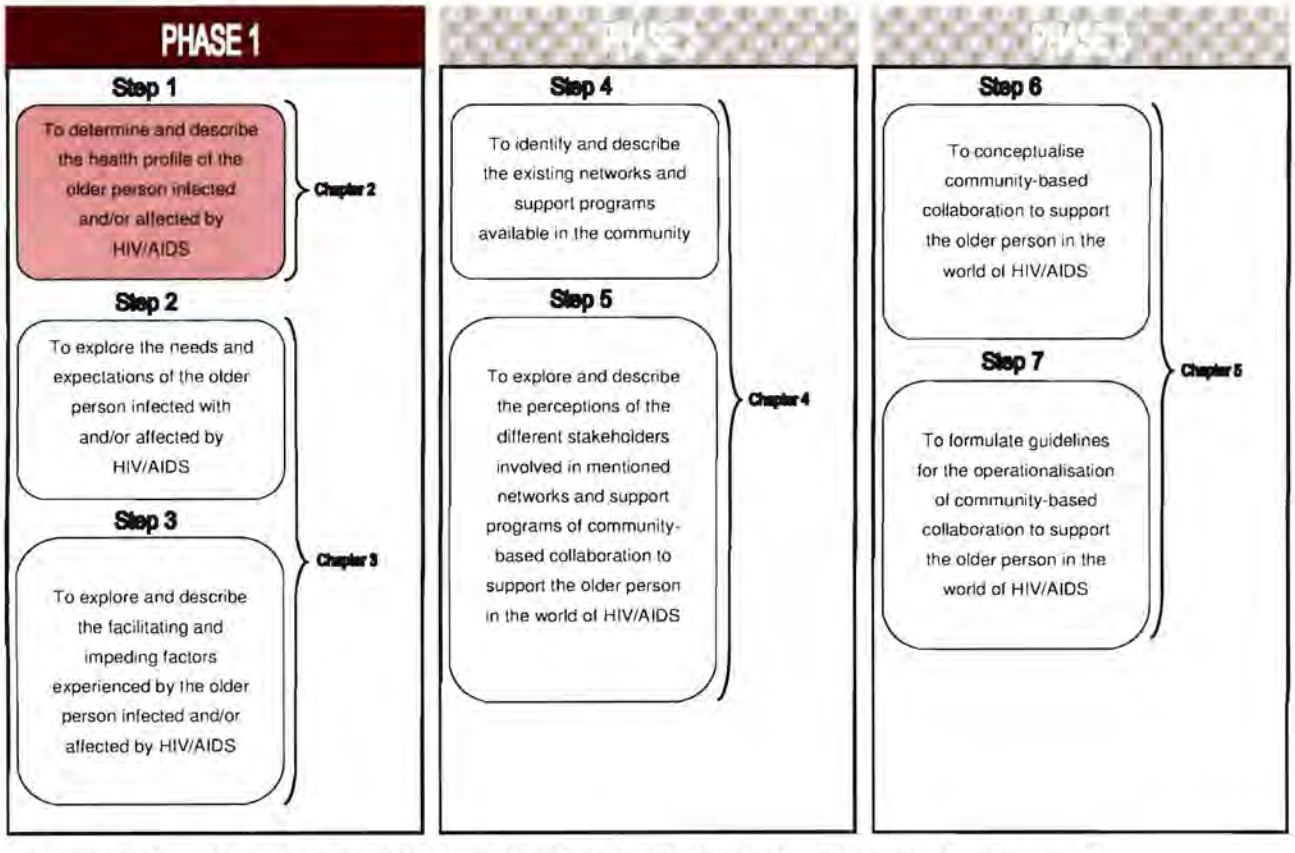


Figure 2.1: Schematic layout of the chapters in relation to the different phases and the steps of the research project

The research design, method, results and conclusions of phase 1, **step 1** form the focus of chapter 2 as indicated in figure 2.1 and refer to the first objective of the research, namely *to determine and describe the health profile of the older person infected with and/or affected by HIV/AIDS.*

2.1 INTRODUCTION

The care giving role of the older persons of their children and other relatives with HIV/AIDS in their households and the community has been relatively well documented. However, only a few studies have been done in Africa on the impact of HIV/AIDS on the health and well-being of the older person (Hosegood & Timaeus, 2005:432). Not only does HIV/AIDS infection in older persons place an extra burden on their physical body, but also on their total human existence, of which their psychological-, social-, economical-, and behavioural dimensions form an integral part. Many older persons in developing countries live with their children and/or grandchildren and often rely on them for financial help or other assistance. Since the HIV/AIDS pandemic, these support networks are scarce because of the increased mortality of working-age adults (Adamchak *et al.*, 1991:403). The older person experiences stress because of different reasons like financial-, emotional- and psychological burdens (WHO, 2002:23).

A model can help structure the process of exploring and describing the health profile of the older person in the world of HIV/AIDS (Van der Walt & Van Rensburg, 2006:23). Chapter 1, paragraph 1.5.2 discussed the theories and model used in this research. The Model of Successful Aging used by Kinsella and Phillips (2005:34, 36) states that the main functions for successful aging lies in the avoidance of diseases and disease-related disability; maintenance of physical and mental functioning; and to be actively involved in the community.

This model was used in relation to the Systems Theory with the central focus on wholeness, organisation and relationships (Marcellus, 2006:230) as well as the Social Theories of Aging (Role Theory, Disengagement Theory, Subculture of Aging Theory and Modernisation Theory) referred to by Kinsella & Phillips (2005:35) for clarity and understanding of the changing role of older persons

central to the events in the study. Drewnowski *et al.* (2003:300) note that needs, expectations and desires of the older persons can not be separated from the maintenance of their physical and psychological functions, as well as their continued involvement in social activities and relationships.

Figure 2.2 indicates how the older person is viewed for the purposes of this study after considering the literature in chapter 1 and the mentioned theories and models.

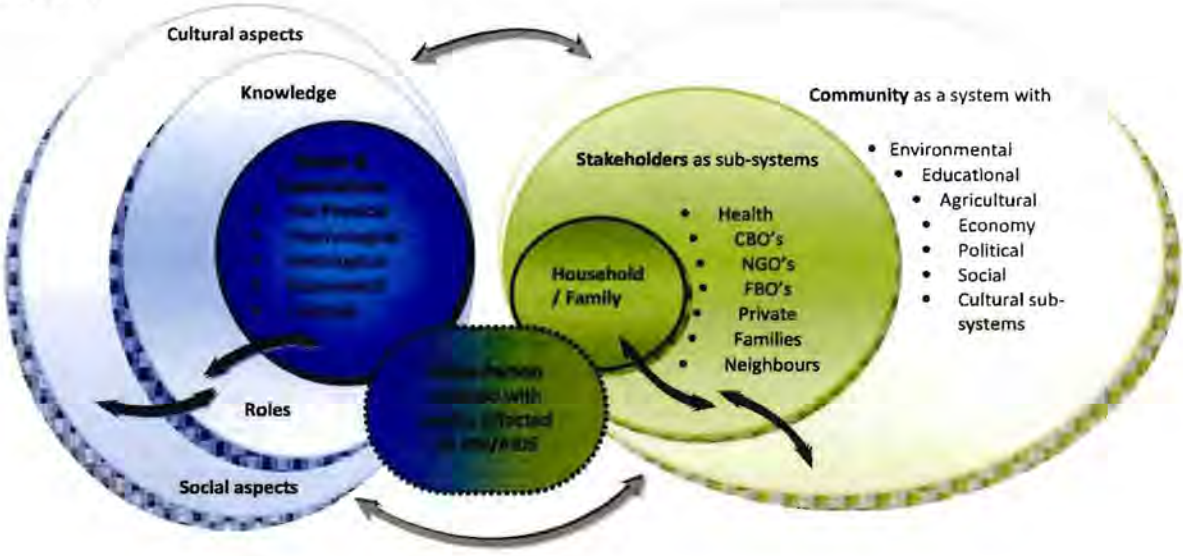


Figure 2.2: Older person as a whole structure in relationship to the community as a system

The older person is a unique holistic system that refers to wholeness with a dynamic composite of demographic, socio-economic, psychological, lifestyle/behavioural dimensions with their various factors that determine the health status of the older persons. The community is a system with sub-systems that are in a relationship to each other and that can affect the older persons in the community through their specific organisational functioning. A study done in Soweto shows that although only some of the older persons are infected, they are mostly all affected by HIV/AIDS, and that makes them vulnerable due to social, economical, physical, psychological, lifestyle/behavioural and political factors (Gilbert & Soskolne, 2003:105). The older persons and their households, as the research sample from the communities under discussion, form the basic structures

of the community and should be maintained to ensure survival and balance (Clark, 2003:190). Older persons can have a variety of roles; they gain and/or loose some of the roles throughout their lives (see chapter 1, paragraph 1.5.2.2 on the Role Theory). The vulnerable older person in the world of HIV/AIDS is confronted with role changes; they are likely to become the main caregivers with new responsibilities placed on the role of the older person (WHO, 2002:9). They also share their material goods as well as their emotional strengths to care for their sick children and orphaned grandchildren. The orderly way in which the different parts of a system work together towards wholeness, thus wellness, refers to the human body, and when one or more of the sub-systems (like the psychological dimension of the older person) is under stress, the balance of the system or structure can be in trouble and experience "dis-ease" or discomfort as the opposite of "ease" or comfort (Wissing, 2007:19). The interrelations of different sub-systems inside- and outside the older person will indicate the ability of the older person to deal with the situation, whether infected with and/or affected by HIV/AIDS. It is thus important to determine and describe the health profile of the older person in relation to their household and community arrangements in order to reach the overall aim of the study, namely to conceptualise community-based collaboration to support the older person in the world of HIV/AIDS.

As indicated in figure 2.1, chapter 2 deals with the health profile of the older person infected with and/or affected by HIV/AIDS. The outlay and discussion on the research design and method for chapter 2 follows hereafter.

2.2 RESEARCH DESIGN

Phase one, **step one** was an auxiliary study within the larger PURE-SA study. *A non-experimental quantitative research design* was conducted through the implementation of a survey study to explore and describe trends in a population to make conclusions and/or generalise the sample (Creswell, 2003:153; LoBiondo-Wood & Haber, 2006:239). Refer to chapter 1, paragraph 1.6.1 for a detailed description on the research design.

The researcher selected all older persons from the population included in the PURE-SA study (see figure 2.4) and followed a non-experimental decision path in the study as illustrated in Figure 2.3 below.

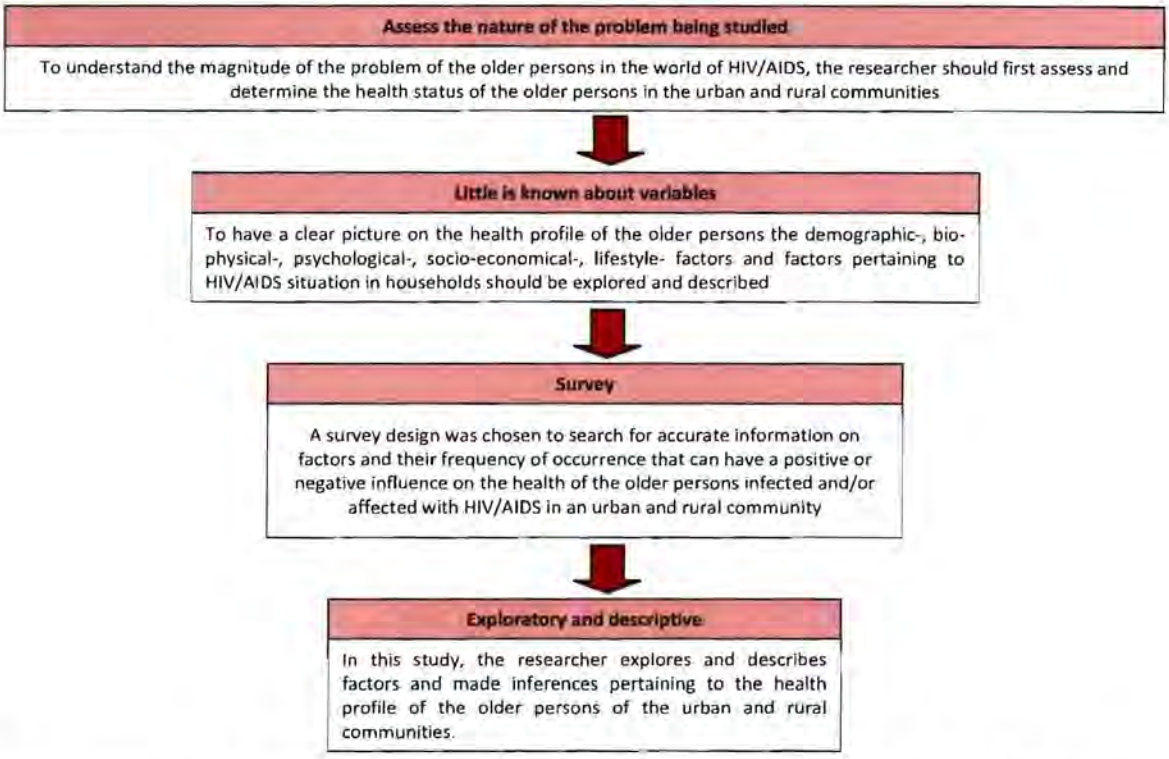


Figure 2.3: Non-experimental decision path (adapted from LoBiondo-Wood & Haber, 2006:240)

In phase one, **step one** (see figure 2.1), the study used a typical explorative and descriptive method with the intention of giving an accurate description (Van der Walt & Van Rensburg, 2006:103-104) of the health profile of the older persons infected with and/or affected by HIV/AIDS living in urban and rural communities in the North-West Province. Refer to chapter 1, paragraph 1.6.1 for a detailed description of the research design.

A detailed explanation of the research method follows hereafter.

2.3 RESEARCH METHOD

The research method used in this study and described in this chapter introduces the reader to the role and involvement of the researcher in the PURE–SA study, the selection of the population and sample size, methods used for data collection, the data collection tool and the data analysis.

2.3.1 INTRODUCTION

As already indicated in the introduction of chapter1, this study with the focus on the older persons as sub-population, form part of the South African leg of the multi-national Prospective Urban and Rural Epidemiological (PURE-SA) study that investigates the health transition on non-communicable diseases over twelve years. All the baseline data for South Africa was collected from August to November 2005 with follow-up data collection a continuous process. The research took off from a pre-established plan (Van der Walt & Van Rensburg, 2006:54). A protocol with a specific hypothesis for South Africa and an instruction manual adopted for South Africa were co-ordinated by the project leader. The South African research team was appointed according to their field of expertise and interest in the study with certain responsibilities (Kruger, 2005:1-6). The researcher was actively involved in the research process of PURE-SA on a daily basis, responsible for the rapid HIV-testing that included pre-and post-counselling. The mentioned involvement is summarised in table 2.1 hereafter to give the reader a clear understanding of the researchers' involvement in the research process.

Table 2.1 Responsibilities of researcher as research nurse in relation to the level of involvement

	Responsibilities of researcher as research nurse	Level of involvement
PURE study (South Africa)	**HIV-rapid testing**, compile protocol, organise teams for blood samples, took blood samples (80ml from every participant), help with rapid testing in lab	**High**
	HIV-pre-counselling done in groups	**High**
	Referral management with follow-up visits to health facilities and participants' households	**High**
	Feedback on results during the **post-counselling** session	**High**
	Home visits to possible participants re recruitment, in this study the researcher formed part of annual home visits for PURE-SA	**High**
	Follow-up home visits to participants with needs/worries/other problems	**Moderate**
	Training of fieldworkers re basic health education	**High**

2.3.2 POPULATION AND SAMPLING

The population for this study included all older participants (≥60 years) infected with and/or affected by HIV/AIDS that were part of the PURE-SA study, N=333 (see figure 2.4).

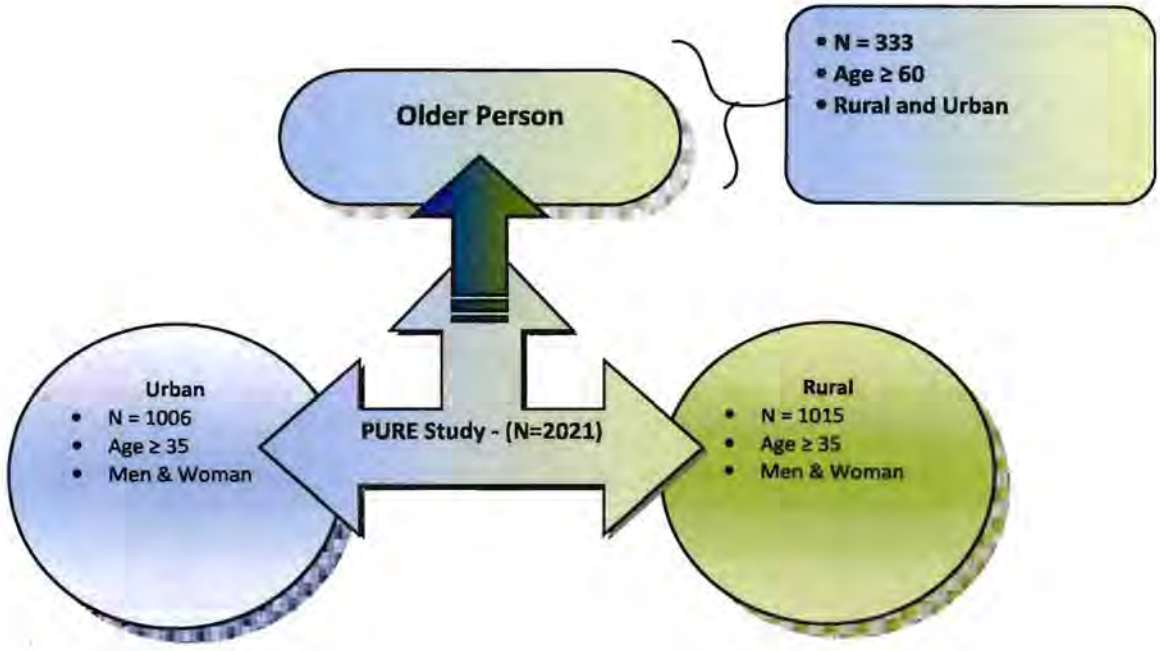


Figure 2.4 **Schematic presentation of the sampling process of the older persons as sub-population**

The 2021 participants in the PURE-SA study were randomly selected to give each volunteer in the selected population an equal probability to be part of the study and provide the ability to generalise the sample to the greater population (Burns & Grove, 2005:348). A group of 2021 volunteers older than 35 years with no reported medicine use, chronic diseases, tuberculosis or HIV/AIDS, no pregnant women and no alcoholics, were randomly included. A household census to determine the number of people in each household, their ages and health profile was done in 6000 houses in both urban (3000 households) and rural (3000 households) communities. Every head of the household gave written consent for the census questionnaires to be completed by trained fieldworkers.

Each fieldworker (eight in urban and eight in rural) started from a point selected to cover the total urban and rural communities, and if a person refused or was not home, they moved on to the next house and a non-complier questionnaire was completed. A paper selection of all the questionnaires were executed to select 3000 possible participants (1500 in urban and 1500 in rural) that met the inclusion criteria. All 3000 participants were visited at home and after giving voluntary and informed consent, an extensive adult questionnaire regarding their bio-physical, psychological health, socio-economic background, lifestyle practices and support systems were completed (Kruger, 2005:6-7). These 3000 participants were invited to attend the research site on a specific day for blood samples and other health measurements. In the end a total of 1006 urban and 1015 rural volunteers participated in the PURE-SA study of whom (989 urban and 1002 rural) a blood sample were taken.

A **sub-population** of individuals; men and women, older than 60 years were identified as possible participants for this research (see figure 2.4). It was an all-inclusive sample selected from the total population of 2021 participants in the PURE-SA study. The data from the mentioned participants were analysed to give a picture of the health profile of the older persons infected with and/or affected by HIV/AIDS. The baseline data gathered through the questionnaires, selected tests (HIV-rapid test) field notes (observational, methodological and personal) made during pre- and post-counselling, as well as follow-up home visits, were analysed by means of descriptive and inferential statistics.

A detailed discussion on the data-collection process to determine and describe the health profile of the older person infected with and/or affected by HIV/AIDS will follow next.

2.3.3 DATA-COLLECTION PROCESS

A survey was conducted with standardized, interviewer-based questionnaires to collect detailed information on community-, family- and individual level. The same basic questionnaires were used in all countries, but it was country specifically validated and standardised. Some country specific items/questions were also

included. A brief outlay of the questionnaires will be given later in this chapter (see paragraph 2.3.3.1).

As stated earlier in the problem statement in chapter 1, some of the older persons in the community are infected with, but mostly affected by the HIV/AIDS that yields them vulnerable due to social, economical, physical, psychological, behavioural and political factors. Thus, for the researcher to conceptualise community-based collaboration to support older persons in the world of HIV/AIDS, it is believed that the point of departure should be to explore and describe the dimensions of health (as indicated above) and their various factors influencing the health of the older persons with the purpose to provide a picture of the health profile of the older persons.

Table 2.2 gives an overview of the descriptive data used to describe the health profile of the older person in the world of HIV/AIDS. After the selection of the needed descriptive data, all the questions in the questionnaires with the codes that apply were selected from the database.

Table 2.2 Descriptive data on health profile of the older person in the world of HIV/AIDS

Demographic profile	Total sub-population of older persons	N=333
	Age groups	≤64; 65-73; 74-83; >84
	Gender groups	Men/Women
	Community/Location/Context	Urban / Rural
	Marital status	Married, stay together, etc.
	Ethnic group	Only black Africans
	Is household head the older person?	Yes / No
Socio-economic profile	Educational level	None; Primary; Secondary; Other
	Main source of income	What is source? Pension; Salary; Grant
	Number of individuals in household	Adults >18; Children <18
	Does the older person care for anyone in the household?	Orphans; Other
	Household conditions of older persons	Electricity; Roof; Water facility
	Social activities, membership groups in community	Self-help groups, religious groups, how regularly attended?
	Support groups in community	Civic and religious organisations
	Crime in the neighbourhood	Robbery; Murder; Violent attacks; Vehicle hijacking; House breaking; Theft; Rape; Women abuse; Child abuse
Psychological profile	Stressful events	Retirement; Family conflict; Illness; Death of spouse; Food insecurity; Financial
	Stress at home	Scale
	Financial stress	Scale
	Depression signs & symptoms	Tired; lost interest in almost everything; weight loss; sleep; loss of concentration; etc.
	Perception of older persons	Trust people; Respect
Lifestyle/Behavio-ral profile	Tobacco	Usage
	Alcohol	Usage
	Rest & sleep	Pattern
Bio-physical profile	HIV/AIDS-status of the older persons	Diagnosis through rapid tests, blood samples done
	Disability	Grasp; Walking; Bending and picking something up; Walking stick use; Trouble reading; Trouble speaking; Hearing
	Hearing aid	Yes; No
	Use Glasses	Yes; No
	Other health history	Cough at least 2 weeks; Sputum if cough; Blood in sputum; Breathlessness; Loose stools; vomiting; Loss appetite; Bleeding teeth; Weight loss
	Diagnosed with	Tuberculoses; Diabetes; Hypertension; Heart disease; Cancer; HIV
	Medication history	Blood pressure; Diabetes; Asthma; Arthritis;
HIV-related data	Know people with HIV	Children; Grandchildren; Spouse; Family members; Friends; People in community
	Who is primary caregiver in your household if HIV-positive	Spouse; Parents; Family member; Children; Friends; Volunteer

2.3.3.1 Data collection tools

The data collection tools used in the research were standardised, structured questionnaires with measurements, blood and urine samples for analysis and field notes to complement the data and fill in some missing gaps.

a) Standardised structured questionnaires

The fieldworkers were intensely trained on the questionnaires and completion thereof; they rotated between the households and compared their answers to ensure internal consistency of all the questionnaires applicable to the study, including the family census questionnaire, household questionnaire and the adult questionnaire. The fieldworkers conducted all interviews in Setswana with a knowledgeable adult in the household who could provide information about the household and its members. A brief description of the questionnaires follows hereafter.

Family census questionnaire: Was used with the purpose to identify all eligible household members and/or participants by enumerating all household members of the urban and rural cohort. The most knowledgeable member of the household completed the questionnaire. General instructions were included in the training program of the fieldworkers, like the use of a black pen, handling of corrections, and so forth. Specific instructions on the completion of different questions helped to minimise misinterpretations. Codes on the facing page of the questionnaires provided easy reference.

Household questionnaire: The purpose of the household questionnaire was to cover basic descriptive characteristics of the household, to record the medical history of parents and siblings of the household head and spouse, to make some future assessment of the clustering of

medical conditions within families. A knowledgeable member of the household completed this questionnaire with the help of the fieldworker.

Adult questionnaire: Was used with the purpose to determine the health profile of the participants, including the demographic aspects, medical history, medication use, lifestyle patterns and support systems, physical disability, psychological aspects, HIV-knowledge, access to facilities around the house. A knowledgeable member of the household completed this questionnaire with the help of the fieldworker.

All the research team members received a detailed work plan that also included the training of the fieldworkers in different aspects;

- Technical aspects of how to complete the questionnaires, definitions of concepts like *household* for communal understanding. All the fieldworkers are Setswana-speaking and trained to use the English questionnaire.
- How to build rapport with your respondent, this is especially important as PURE is a prospective longitudinal study that necessitates follow-up on all the participants for ten to twelve years.
- Guidelines on how to conduct an interview.
- The fieldworkers were subjected to sensitive and confidential matters as they entered the personal space of the participants in their homes. Training on basic health issues were given that included an overall introduction on HIV/AIDS and basic home-based care principles. The training was given during the first quarter of 2006 for one week before they started with follow-up home visits to the participants.

b) Measurements

Physical measures were done accordingly to the specified protocol. For the aim of this research regarding the health profile of the older persons, the

researcher only referred to the data gathered directly from the participants on what they revealed.

c) Sample collection

An 80 ml fasting blood, 4 ml urine and a hair sample were collected from each participant. The research team from the School of Nursing had the responsibility to co-ordinate this task. There was a clear protocol available on the collection and management of the different samples that were immediately handed to the field laboratory staff for preparation and testing. The only blood sample that applies for this study was the HIV-test as a vital variable to describe the health profile of the older persons. However, for clarity to the reader, the whole process of engagement of the researcher and older persons as participants in the blood sampling process will subsequently be explained.

The following principles in the collection of the blood samples were adhered to:

- A detailed explanation was given to the participants with regard to the blood sampling procedure;
- Participants had a choice to withdraw from the research at any stage, if they refused to continue with the blood sample procedure, all the other measurements were completed, the feedback available were then given to the participant with a referral letter to a health facility if necessary;
- All baseline samples were collected from 08:00 to 11:30 to control the effect of the environmental temperature and circadian rhythms on the level of variable. It was also necessary to keep the period of fasting relatively constant;
- All blood samples were collected from the participants in a clean, private environment with a sterile disposable butterfly infusion needle (No. 22 G);
- In the urban as well as the rural communities, all hospitals, clinics and especially the AIDS co-ordinators of the Department of Health were involved in the research process during the time of data collection;

- The researcher trained in Voluntary Counselling and Testing, adhered to the UNAIDS/WHO Policy Statement on HIV-testing (UNAIDS/WHO:2004:1-3) as well as to the protocol of the Department of Health after the researcher had personal discussions with them on which type of HIV-rapid test to use;
- Referral letters did apply for further management of participants if it was necessary, but no results was stated on the referral letter. The researcher worked according to the protocol of the health facilities in each area regarding the referral procedures and confirmed it with all the supervisors of the different Primary Health Care (PHC)-facilities in each area. Discussions and clarifications was a continuous process between the researcher and the mentioned health personnel;
- Follow-up visits were done at the clinics to clarify any misunderstandings;
- Confidentiality was a high priority and every result was plotted to the unique number of the participant;
- The participants had a choice whether their blood should be tested for HIV or not (during completion of the adult questionnaire they were asked to give their informed consent. Before they engaged in the research they received information during the pre-counselling session that includes their right to choice, after that they register for inclusion in the project and give written consent to participate);
- The participants had the right to stop at any time during the process and withdraw from the project;
- The participants had a choice to know the results and during the feedback session they could ask that the HIV-results be ignored;
- The researcher and the team made themselves available when the participants had any need or questions; and
- Feedback on the results (blood pressure, blood sugar, HIV, lung function and ECG) was done, after which post counselling on the HIV-results was intensively covered.

d) Biochemical analysis

Only the rapid HIV-test applies under the biochemical analysis for this study on the health profile of the older person and is subsequently explained.

A rapid HIV-test was done according to the National Department of Health of South Africa's protocol. If the First Response test was positive, it was repeated with the Pareeshak test for confirmation. A needle prick was done if a blood sample could not be obtained.

e) Field notes

Field notes were part of different sources of data collection that contributed partly in answering the research question. It was made within a certain context, during different times of the day and with different purposes during the weeks of data collection.

The researcher kept field notes during the course of each day in an effort to record information and to have a better understanding of the data after the PURE-SA study (see Appendix C). The field notes were categorised in *methodological-, observational-*, and *personal notes* (Polit & Beck, 2006:306-307) to give a written account of what the researcher saw, heard, experienced and thought (Morse & Field, 1998:91-92) during the whole study.

During the feedback sessions with the participants, the researcher and the team responsible for post-counselling made field notes on a record developed according to the protocol of the Department of Health. These notes contributed to the health profile because it gave extra information on which clinic the participants used to visit, notes on Tuberculoses as a risk, indicated if the participants wanted follow-up home visits, personal notes on the participants' reaction on the counselling process and the medical reason for being referred to a health facility.

After data collection, the next step of the research method was to organise all the raw data into a meaningful body that answers the research question asked, namely how does the health profile of the older person infected with and/or affected by HIV/AIDS look?

Subsequently the data that was gathered in phase one, step one (see figure 2.1) that refer to the exploration and description of the health profile of the older persons infected with and/or affected by HIV/AIDS, was analysed and summarised by means of tables and graphs.

2.3.4 DATA ANALYSIS

Data analysis is the process to organise and manage all the raw data collected through the above-described data collection tools. There should be a plan to summarise, categorise and order the data so that they could be understood and give answers to the question (Bodkin, 2004:38; Huysamen, 2005:12; Van der Walt & Van Rensburg, 2006:170). The question to be answered was what the health profile of the older person infected with and/or affected by HIV/AIDS looks like. In order to answer this question the data was analysed at individual (the older person) and household (the households' circumstances and living arrangements of the older person) level.

- Statistical analysis of the data was done with the SPSS 15.1 for windows (program of the SPSS Inc., Chicago, IL 1989 – 2008) with assistance of the Statistical Consultation Services of the North-West University, Potchefstroom Campus. Through descriptive and inferential statistical strategies together with comparative means and standard deviations, the health profile of the elderly was described. Non-parametric T-Tests (Man-Whitney U test) was done to determine significant differences between the urban and rural communities. The level of significance was defined at a probability value of $p=<0.05$ for significant difference and $p=<0.01$ for highly significant difference.

Data from both urban and rural areas were included so as to create a clear general picture on the health profile of the older person. However, the reader

should note that this is not a comparative study and the researcher will use this opportunity to only highlight interesting differences and aspects between the two areas for a clearer understanding on the real situation of the older person in the urban area. Phase one, step one was the first step in an endeavour to gain understanding of the reality with which the older person is confronted in their community of residence, and to conceptualise community-based collaboration to support the older persons in the world of HIV/AIDS.

The data were summarised and visually presented in table and/or graphic format to form a clear picture of the research report (Huysamen, 2005:12; Statsoft, 2008; Van der Walt & Van Rensburg, 2006:171).

2.3.5 RIGOUR

The following measures were implemented with the intention to ensure validity and reliability during the research process:

Content-related reliability	Standardised, interviewer-based questionnaires were used to collect detailed information at the community, family and individual level. Core questions were identical across the countries to allow for inter-country comparisons. Some country specific items/questions were included.
Face validity	A standardised protocol was used by all team members with clear instructions on the use of each questionnaire. The fieldworkers were trained by the researchers in the team regarding their speciality on the use and clear understanding of the questions. The fieldworkers rotate with the questionnaires and compared the answers at the end of day one to clarify the correct understanding of questions

and their constructs.

Sensitivity and specificity

The researcher used the same HIV-rapid test proposed by the National Department of Health and each positive test was confirmed by another test from a different provider and make.

The questions had the ability to assist the researcher to describe the health profile of the older person as correctly as possible.

Reliability

Was maintained by ensuring **consistency** in data collection and was addressed by the adherence to the data collection tool.

Stability was assessed by administering the same measure to another sample of people in the community, and that was possible by rotating the fieldworkers to see if the same scores were obtained.

Equivalence was estimated and adhered to through the consultation of two different statistical specialists to observe whether the scores of the results and the phenomenon was congruent.

2.3.6 ETHICAL CONSIDERATIONS

The ethical considerations were outlined in chapter 1, and for clarity the reader should refer to paragraph 1.6.4. The following explanation applies specifically to phase 1, step 1. Before the onset of the PURE-SA projects' data collection process in August 2005, permission was obtained from the following organisations and decision makers in the applicable communities:

- Department of Health of North-West Province. Meetings were scheduled and held with the sub-district managers and the hospital medical officers of both the urban and rural communities regarding the research process and

special attention was paid to the management of the participants who need referral to the health clinics and/or hospitals;

- The mayor and ward councillors of the urban and rural communities;
- Additional permission was obtained from the traditional leader of the rural community; and
- The ethical committee of the North-West University (Potchefstroom Campus), **Number 04M10**.

Specific permission was obtained from the participants at the following levels:

- **Household census**: Before any household census was completed, the head of the household gave written permission after the project was explained by the fieldworker;
- **Adult census**: After the paper selection and before the adult questionnaire was completed each participant gave written consent that they were informed and that they understand the research process as well as the role that they are going to play in it.
- **Before measurements with special reference to HIV-rapid testing**: After the participants arrived with the transport at the location where the research was conducted, before the onset of the research procedures after the pre-counselling session, during registration, each participant had an informed choice to continue with participation (see Appendix D).

The **conditions of the '3 Cs'** applied during HIV-testing:

- confidential,
- be accompanied by counselling,
- only conducted with informed consent, meaning that it is both informed and voluntary, as well as

Ensuring **a rights based approach** with the following key factors:

- ensuring an ethical process for conducting the testing,
- addressing the implications of a positive test result,
- HIV/AIDS-related stigma and discrimination,
- a supportive legal and policy framework (service seeking), and
- ensure that the healthcare infrastructure is adequate to manage referrals (UNAIDS/WHO, 2004:3)

2.4 RESULTS

Results from the data collected were categorised according to the sub-systems/parts/dimensions of the older person (refer to paragraph 1.5.2.1 on the person as a whole) demographic data, socio-economic data, psychological data, lifestyle/behaviour data, biophysical data, and HIV-related data. Refer to table 2.2 for an overview of the data collected regarding the description of the health profile of the older persons, men and women in rural and urban areas (also referred to as the area of residence). The reader should note that where the reflection of the results does not add to 100% during the discussions thereof, it was because of missing data.

2.4.1 DEMOGRAPHIC DATA OF THE OLDER PERSON

In the study, demographic data of 333 older persons that participated, included variables of the community of the population included in the study, the age, gender, marital status and the total of people living with in the household of the older persons. The older persons included in this study was mainly from the black previously disadvantage groups (see chapter 1, paragraph 1.2) in the communities of which the description follows hereafter. Frequency tables summarised the results in manageable proportions for discussion and presentation.

The discussion presented a summary of the demographic profile of the older persons in the urban and rural communities by different characteristics. The summary highlighted using different applicable tables, graphs and pie charts to explain the demographic profile of the older persons in the world of HIV/AIDS.

2.4.1.1 Older persons in the urban and rural areas with reference to their age and gender

Table 2.3 indicates that 333 participants were older than 60 years and lived in two different areas/communities, the rural and urban areas (see chapter 1, paragraph 1.2 and 1.6.1.5 on a discussion pertaining to the different areas described as the context of this study). The researcher used chronological markers (see grouping in

table 2.3) attached to the process of aging (Stellenberg & Bruce, 2007:975) to group the older persons (May, 2003:4) for systematic discussion of results.

Table 2.3: Percentage distribution of the older persons in the urban and rural communities by age and gender

Characteristics	Rural 40.5% (n=135)						Urban 59.5% (n=198)					
	Men 43.7% (n=59)			Women 56.3% (n=76)			Men 37.9% (n=75)			Women 62.1% (n=123)		
Age in years	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD
60-64 (near old age)	27	61.9	1.3	39	62.0	1.4	39	61.5	1.3	45	61.9	1.4
65-73 (old age)	26	68.3	2.7	25	67.9	2.6	27	68.3	2.7	60	68.5	2.5
74-83 (late old age)	5	77.2	2.8	10	76.6	2.5	8	76.0	1.9	15	76.7	1.8
>84 (frail old age)	1	87.4	0.0	2	86.5	0.7	1	94.0	0.0	3	88.0	4.4
Total (N=333)	59	66.4	5.8	76	65.9	6.2	75	65.9	6.1	123	67.5	6.2

All *p* values are >0.05 unless further noted
SD=standard deviation; n=number

In the urban area, the number of older persons added to 59.5% of the total older persons' sample, of whom 62.1% presented women. Less than half of the older persons' (40.5%) lived in rural areas, of which 56.3% were women. Women presented 59.8% of the total of n=333 older persons that participated in the study.

The mean age of the older men living in the rural area was 66.4 years (SD=5.8); for women it was 65.9 years (SD=6.2) and in the urban area the mean age for older men was 66.6 years (SD=6.1) and for the women 67.5 years (SD=6.2). The mean age of all the older persons included in this study, was 66.6 years. There was no significant difference in the average age of rural and urban older men (66.4 years vs. 65.9 years, p=0.711) and rural and urban older women (65.9 years vs. 67.5 years, p=0.577). Of the group from the "near old age", 65 men and 84 women participated (44.7% of the total older population), the 'old age" group, were 38.1% men and 44.2% women from both rural and urban areas (41.7% of the total older population) that participated. 11.4% older persons that participated were from the age group 74 to 83 years, or the "late old age", and they were more often the group where a shift in roles has taken place as they are no longer the principal decision makers, but the nominal decision makers (May, 2003:4). The age group >84 years of age represents 2.1% of the older person's population in the study,

referred to as the "frail old age" that could become very dependable on other family members for care and support.

The sample of older persons in this study pertaining to the representation of women, confirms the reality in Southern Africa that there are more women than men (Holzemer *et al.*, 2007:1006). In a report of HelpAge International (HAI) it was stated that there are greater numbers of women than men, and that the proportion increases in the higher age groups (Joubert & Bradshaw, 2004:153; May, 2003:14-15). Table 2.3 reflects the reality of this statement.

The men from the rural area (43.7%) were slightly more than the men from the urban area (37.9%), as the opposite apply to the women (56.3% for the rural area and 62.1% for the urban area). However, not statistically significantly different, the reason for this could be that the men in the urban area in the near old age were still part of the working group and that the women were those on old age pension with more flexible time to participate in the research.

2.4.1.2 Marital status of the older persons

The results of the data on the marital status of the older participants are summarised in table 2.4.

Table 2.4: Marital status of the older persons of both genders in rural and urban areas

Category	n=	Percent
Never married	55	16.5
Currently married	127	38.2
Common law/live together	31	9.3
Widowed	85	25.5
Separated/Divorced	14	4.2
Not answered	21	6.3
Total	**333**	**100%**

Responses to questions regarding the marital status were voluntary and 21 (6.3%) of the older persons chose not to answer this question. In the group of participants, 16.5% never married (n=55), 38.2% were currently lawfully married

(n=127), and 31 (9.3%) live with their partner according to common law. Apart from the 14 (4.2 %) separated or divorced older persons, 25.5% are widowed (n=85).

2.4.1.3 Head of the household of the older persons

The results on the relation of other people in the household to that of the household head will be demonstrated by means of a bar chart.

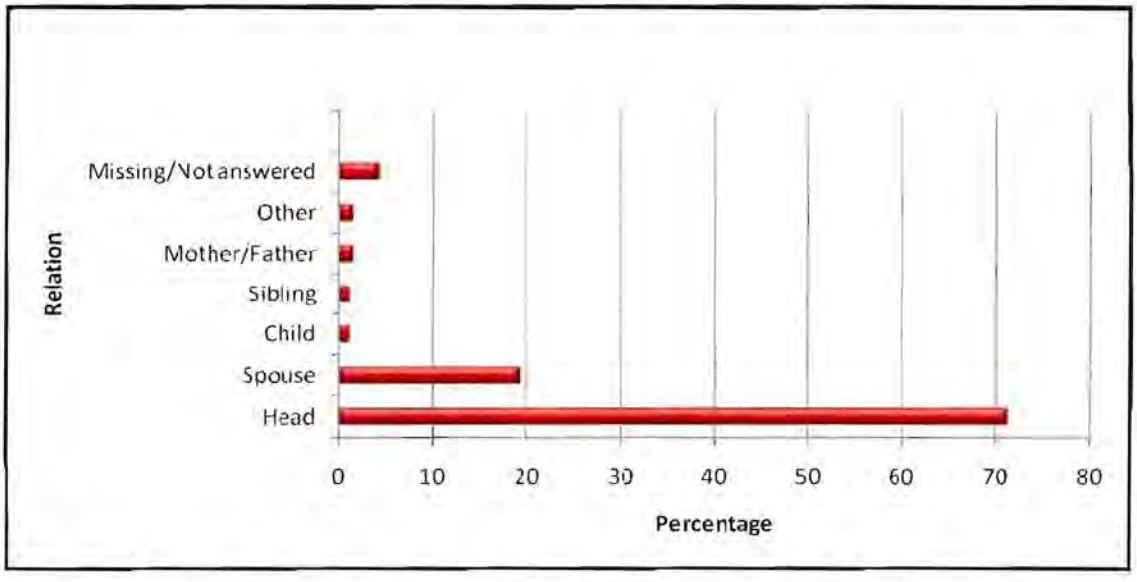


Figure 2.5: Older persons' relation to the head of the household for both rural and urban areas

On a question regarding the older persons' relation to the household-head, the results in this study indicated that 71.2% of the older persons were the head of the household, thus the decision makers, and 28.8% were spouses, children, a mother, father, or a sibling. Mohatle and Agyarko (1999:24) found in a South African study that the older person, in most living arrangements, are put into a household-head role with its attached pressure with the minimum support of the family members. The absence of the men increases the growing occurrence of older women-headed households (Ferreira, 2004:30) and it is stated that 42% of all African households are women-headed or "granny households" (May, 2003:14-15).

The demographic aspects pertaining to the older persons gave an overall picture regarding the distribution of the area where they live, their age, gender, marital status and position in the households and follows hereafter.

2.4.1.4 Discussion on the demographic data and the health of the older person

In the study, all the older participants (16.6% of total participants) with a mean age of 66.6 years were from the black previously disadvantaged groups in South Africa, and their area of residence were in the rural (40.5% of sample) or the urban area (59.5% of sample) as described earlier in the study (see paragraph 1.2 and 1.6.1.5). The total well-being of the older persons in the mentioned population groups are influenced by basic factors like housing, health and income (May, 2003:18). The same author is of opinion that the older persons that reside in the rural area are easier satisfied with their living arrangements than their urban counterparts. Care and financial security as well as the extended family for support can be important aspects for the older persons from both areas. Housing, health and income are some of the external environmental factors that have the potential to disrupt the lives of the older persons (Chinn & Kramer, 2004:230).

The majority (45% and 41.4%) of the older participants were from the age groups 60-64 years and 65-73 years respectively. Being this age the older persons should start to scale down on their responsibilities, but the perceived idea that old age is the period when the older person is scaling down on independency and moving towards increased dependency has changed. HIV/AIDS changed this perception due to the devastating influences it can have on the housing, health and income of the older persons (Mohatle & Agyarko, 1999: x). The older persons can no longer expect the younger family members and their children to care for them. The situation overturned and the older persons are caring for their children and grandchildren (Bradshaw & Steyn, 2001:11; UN, 2003: xi). Social, economical, and demographic changes impose on the traditionally defined family roles of the older persons (Caldas, 2004:20). The reality of this finding is a classic example of the Social Theory of Aging pertaining to the Role Theory (see chapter 1, paragraph 1.5.6.2) and confirms the new challenges that the changed roles (they lose some and gain some) can bring on the older persons in this age group.

The women outnumbered their counterparts and represent 59.2% of the sample. In almost all countries worldwide, women live longer than men. This is also true for South Africa and is expected to increase within the next two decades (Joubert & Bradshaw, 2006:208; Turok, 2006:6). This possibly explains why the women in this study are more than the men. The 25.5% widows also add to this reality. Although HIV/AIDS affects both men and women, women are particularly vulnerable to HIV/AIDS, and the responsibility to care for the HIV/AIDS victims, whether in the household, neighbourhood or community, place a tremendous burden on the women in the community where they live (UN, 2003:9-3). Older persons in developed countries are often seen as a burden, in Africa their willingness to help with and share the responsibility of caring for the orphans and others in their households make them a valuable asset to family life and society (Stellenberg & Bruce, 2007:975).

An outlay of the summarised statements drawn on the demographic data of the older person follows hereafter.

2.4.1.5 Conclusions pertaining to the demographic data

- Old age among 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 challenge put upon the women, who outnumber the men.
- The majority of older persons in the age group 60-73 years are household-heads with clear changing of roles forced upon them.
- Not only 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.

In the following section (see chapter 2, paragraph 2.4.2), results and discussions follow on the socio-economic aspects concerning the health profile of the older persons in the study.

2.4.2 SOCIO-ECONOMIC FACTORS THAT CAN INFLUENCE THE HEALTH OF THE OLDER PERSONS

The socio-economic data gathered from the 333 older persons in the communities as indicated above (see paragraph 2.3.2 and figure 2.4), refers to the socio-economic factors that influence the health profile of the older persons. Different social as well as economical factors can influence the total health, the functioning and well-being of the older persons (Ferreira, 2004:29). Table 2.5 to table 2.7 with their accompanying discussion provides a general socio-economic structure of the older persons included in this study from the urban and rural areas where they live.

2.4.2.1 Level of education, source of income and number of people living in the household of the older person

Frequency table 2.5 summarises the results in manageable portions for discussion on the educational level, main source of income that reflect the engagement in employment and the total people living in the households.

Table 2.5: Percentage of older persons with regard to education, source of income and number of people living in the household

Characteristics	Rural 40.5% (n=135)				Urban 59.5% (n=198)			
	Men 43.7% (n=59)		Women 56.3% (n=76)		Men 37.9% (n=75)		Women 62.1% (n=123)	
Education								
None	57.6	(n=34)	55.3	(n=42)	37.3	(n=28)	23.6	(n=29)
Primary	20.3	(n=12)	28.9	(n=22)	41.3	(n=31)	62.6	(n=77)
Secondary and more	11.9	(n=7)	9.2	(n=7)	10.7	(n=8)	9.8	(n=12)
Missing	10.2	(n=6)	6.6	(n=5)	10.7	(n=8)	4.0	(n=5)
Source of income								
Pension / Grant	57.7	(n=34)	85.6	(n=65)	60.0	(n=45)	78.9	(n=97)
Employed by themselves/other person/other organisation	0	(n=0)	0	(n=0)	9.3	(n=7)	5.7	(n=7)
Family	0	(n=0)	0	(n=0)	9.3	(n=7)	1.6	(n=2)
No income	30.5	(n=18)	10.5	(n=8)	14.7	(n=11)	5.7	(n=7)
Missing	11.8	(n=7)	3.9	(n=3)	6.7	(n=5)	8.1	(n=10)
Number of people living in houses of older persons								
≥6	33.9	(n=20)	39.5	(n=30)	25.3	(n=19)	20.3	(n=25)
<6	47.5	(n=28)	46.0	(n=35)	69.4	(n=52)	75.6	(n=93)
Missing	18.6	(n=11)	14.5	(n=11)	5.3	(n=4)	4.1	(n=5)

- **Level of education**

  It appears that the older persons in both genders in the rural areas have lower education levels than their peers in the urban area. About 56.5 % of the older persons have no schooling in the rural area while about 30.5 % of the older persons in the urban areas have no schooling. The results indicate that women in the age group older than 60 years in both rural and urban areas are slightly more literate than the men are. Men with some education are about 30.8 % and women with some education are 45.8 %.

  In terms of educational vulnerability of older persons and more specifically the women, it is important to note the education levels of the vast majority of older persons, in both genders and the rural and urban area that are low. The percentages that reflect proper education to strengthen the older person vary from only 9.2 % to 11.9% as illustrated in table 2.5. The low educational level of this rather large proportion of older persons probably still reflects on the influence that apartheid education policies have on the older persons today (Gilbert & Soskolne, 2003:110; Joubert & Bradshaw, 2004:153).

- **Sources of income of older persons in the rural and urban areas**

  The results summarised in table 2.5 indicate that of the 333 of the older persons, approximately 70.6% do receive older persons' pension or a grant, while 15.4% of them have no income. In South Africa, at the stage during data collection, women received old age pension from the age of 60 years and men from the age of 65 years. About 90% of the black and coloured population are dependent on their old age pension (Bradshaw & Steyn, 2001:11; Burns *et al.*, 2005:103). As shown in table 2.5 it is clear that older persons' pension, as a source of income, is lower for the men than for the women. The reason could be that the men in South Africa did not qualify for older persons' pension during the time of the survey, because they were under the age of 65 years (Burns *et al.*, 2005:103).

  South Africa has a well-developed social assistance grant system that is among the most generous in the developing world. Ferreira (2004:27)

stated in a report prepared for a United Nations policy workshop that pension benefits are an important source of income and have been noted to have a significant impact on reducing vulnerability and poverty in households where someone receives pension.

The respondents that live in the urban area gave a wide variety of different sources of income to their households. The researcher grouped them together as incomes from either themselves as self-employers or other persons or organisations as employers. A meagre 9.3% of the older men and 5.7% of older women from the urban areas received an income through work and employment. The researcher noted from the results that 30.5% older men and 10.5% older women from rural areas are not employed. It could be that there are no or fewer opportunities to work for the older persons than in the urban areas.

The results show that only 5.45% of the older persons and again only in the urban areas, receive money from their family, which includes children and grandchildren. Older persons, age group ≥60 years, will likely be the principal breadwinners as well as caregivers to grandchildren (Ferreira, 2004:26; May, 2003:4; Mohatle and Agyarko, 1999:24).

- **Number of people living in the households of the older persons**

The occurrence of larger numbers of people (≥6 people per household) living in the households was in the minority. In the rural areas 37% of older persons responded that six or more people live in their households against the 46.7% that said less than six people live in their households. In 22.2% of the older persons' households six or more people live in the household. On the contrary, 73.2% of the older persons in the urban area indicated that less than six people live in their households. The reason for smaller households in the urban area can be that the effect of HIV/AIDS on the middle generation family members are resulting more rapidly in changed smaller family structures, the so-called skip generation family unit (Ferreira, 2004:29-30).

In order to understand and describe the health profile of the older persons infected with and/or affected by HIV/AIDS, it is important to explore external factors like the household condition as part of the socio-economical factors that can influence the health of the older person.

2.4.2.2 Household conditions and the older person

The characteristics of the household conditions that were analysed refer to factors such as whether the house is traditionally built with a solid roof, does the household have electricity available, what is the primary source for cooking and heating in the colder weather and water as a necessity for health. The household conditions can be an indicator of socio-economic vulnerability of the older persons. The results of the data gathered through the household questionnaires are outlined in Table 2.6 hereafter.

The researcher noticed during fieldwork in the community, that the survey was done in the older, more established areas and it became apparent that most of the older persons live in formal housing (council houses). The majority of the houses' roofs were galvanised iron sheets or made of other solid roofing material, as 87.1 % of the total of older persons included in the study, responded. A small proportion, 3.6%, of the older persons indicated that they life in an informal house with non-solid roofing material.

Of the 333 older persons, 85.5% have electricity in their households as indicated in table 2.6. Although a small percentage, is it worth mentioning that 5.4% of all households of the older persons in both rural and urban areas do not have electricity. Although the majority of older persons have electricity in their households, it is remarkable that less than 50% use it for cooking purposes and that in the rural areas less than 10% of the household utilised electricity as a primary heating source when the weather is cold.

It is furthermore apparent that many households made use of open fires with wood or coals for cooking as well as for heating purposes. This result raised concern, and will be discussed later in the study as to underline this factor. The use of electricity as source of cooking is higher in the urban area than in the rural area (41.6% and 29.8% respectively) and that the older persons in the rural area still

cook on open fires (39%). The researcher also observed this reality during the home visits in the rural area. The older persons cook outside their houses in a shelter made for that purpose. Paraffin for the use of cooking is rather high in the urban area to that of the rural area (29% and 7.8% respectively); the reason could be that paraffin is more availability and accessible in the urban area. Gas is not regularly used and is 5.4% in the rural area against the 0.8% in the urban area.

Table 2.6: Percentage of older persons with regard to household conditions

Characteristics	Rural 40.5% (n=135)				Urban 59.5% (n=198)			
	Men 43.7% (n=59)		Women 56.3% (n=76)		Men 37.9% (n=75)		Women 62.1% (n=123)	
Traditional house with solid roof								
Yes	78.0	(n=46)	80.2	(n=61)	90.7	(n=68)	93.5	(n=115)
No	3.4	(n=2)	6.6	(n=5)	5.3	(n=4)	0.8	(n=1)
Missing	18.6	(n=11)	13.2	(n=10)	4.0	(n=3)	5.7	(n=7)
Electricity								
Yes	74.6	(n=44)	85.5	(n=65)	80.0	(n=60)	92.7	(n=114)
No	3.4	(n=2)	1.3	(n=1)	14.7	(n=11)	3.3	(n=4)
Missing and not answered	22.0	(n=13)	13.2	(n=10)	5.3	(n=4)	4.0	(n=5)
Primary fuel for cooking is								
Electricity	25.4	(n=15)	34.2	(n=26)	19.7	(n=15)	63.4	(n=78)
Paraffin	5.1	(n=3)	10.5	(n=8)	32.0	(n=24)	26.0	(n=32)
Wood	42.4	(n=25)	35.5	(n=27)	1.3	(n=1)	1.6	(n=2)
Gas	6.8	(n=4)	4.0	(n=3)	0	(n=0)	1.6	(n=2)
Coal	0	(n=0)	0	(n=0)	5.3	(n=4)	2.4	(n=3)
Missing and not answered	20.3	(n=12)	15.8	(n=12)	6.7	(n=5)	5.0	(n=6)
Primary heating source								
Open fire wood/coal	66.1	(n=39)	67.1	(n=51)	37.3	(n=28)	24.4	(n=30)
Electricity	1.7	(n=1)	3.9	(n=3)	18.7	(n=14)	46.3	(n=57)
Gas	1.7	(n=1)	5.3	(n=4)	5.3	(n=4)	6.0	(n=7)
Other	0	(n=0)	0	(n=0)	14.7	(n=11)	7.3	(n=9)
None	10.2	(n=6)	10.5	(n=8)	18.7	(n=14)	12.0	(n=15)
Missing and not answered	20.3	(n=12)	13.2	(n=10)	5.3	(n=4)	4.0	(n=5)
Water as primary drinking source								
Piped water	13.6	(n=8)	11.8	(n=9)	76.0	(n=57)	69.1	(n=85)
Community well/bore hole	66.1	(n=39)	65.8	(n=50)	17.3	(n=13)	26.0	(n=32)
Fetch from river/dam/other	1.7	(n=1)	9.2	(n=7)	0	(n=0)	0.8	(n=1)
Missing and not answered	18.6	(n=11)	13.2	(n=10)	6.7	(n=5)	4.1	(n=5)

From the results it is clear that the primary source of heating in the rural area is an open fire, nearly 70%. More than 30% older persons also use open fires in the urban area for heat in cold weather. Remarkable small number of older persons uses electricity for heating purposes in the rural area (2.8%) against the 32.5% of those in the urban areas. Although the number of older persons whom indicated that they use nothing as a heating source is low, 10.4 % and 15.4 % respectively for the rural and urban area, it is arguable that it could have an influence on the health profile of the older person.

Water means life and although the majority of older persons in the urban area have access to clean running piped water (72.6%), only 12.7% of all rural households of older persons have running piped water. The opposite count for the accessibility to clean water from a community well or bore hole, 21.7% of the older persons in urban area against the 66% of older persons in rural households respectively. Only 5.9% of older persons in rural and urban areas use either water from a dam or river.

2.4.2.3 The household of the older person as a victim of crime

The health of the older persons included in the study can be influenced by external factors like crime in the area of residence and therefore was a question on crime included in the investigation and description of the health profile of the older persons. The question whether the older persons' household was a victim of crime during the previous twelve months referred to armed robbery, violent attacks, murder, vehicle hijacking, housebreaking, theft, rape, women and child abuse.

An overview summary pertaining to the results on crime as a social aspect affecting the older persons' health shows that 4.5% choose not to answer the question, an average of only 2.4% older persons said that their households have been victims of crime during the indicated period. Against this results, an average of 93.1% older persons state that their households have not been a victim of crime during the indicated time.

2.4.2.4 Social support and the older person

External factors such as the environment and the society, as a supportive social network (Drewnowski *et al.*, 2003:300; Gilbert & Soskolne, 2003:113) are considered important in the health profile of the older persons. Social support may arise from either informal (family members, friends and neighbours) or formal (health and social service providers) social networks and may include financial, emotional or material support. Religious affiliation may provide a form of social support that often bridge formal and informal networks (Clark, 2008:509). In figure 2.6, figure 2.7 and figure 2.8 the social engagement of the older persons in both the rural and the urban areas are summarised and scrutinised with reference to data collected on the older persons' membership of social groups, from whom they received support, total support received from civic organisations, membership and level of support from religious groups.

- **Membership of social-/self help groups in the community and participation in the activities thereof**

  On the question asked if the older person is a member of a self-help group, a social club, a sport club or any other co-operative clubs in the community where they live, 91.4% and 87.4% answered from the urban and rural area respectively. It is notable that only one man (1.7%) and no women from the rural area was a member of any social groups against the 14.7% men and 30.1% of women from the urban area that were members of a social group. The reason for this could be the distances in the rural areas and the lack of transport. There is a prominent link between the low percentage older persons belonging to social groups and the psychological risk factors that can be indicators and warning signs that the older persons are or can become depressed. The older persons from the rural area that does not belong to any social groups are prone to depression (see figure 2.9).

- **From whom the older persons receive support in their area of residence**

The older persons responded poorly to this question and the researcher does not know the reason why. Only 33.3% of the older persons in the rural area responded and 29.8% of the urban area. Figure 2.6 illustrate from whom does older persons receive support in their area of residence.

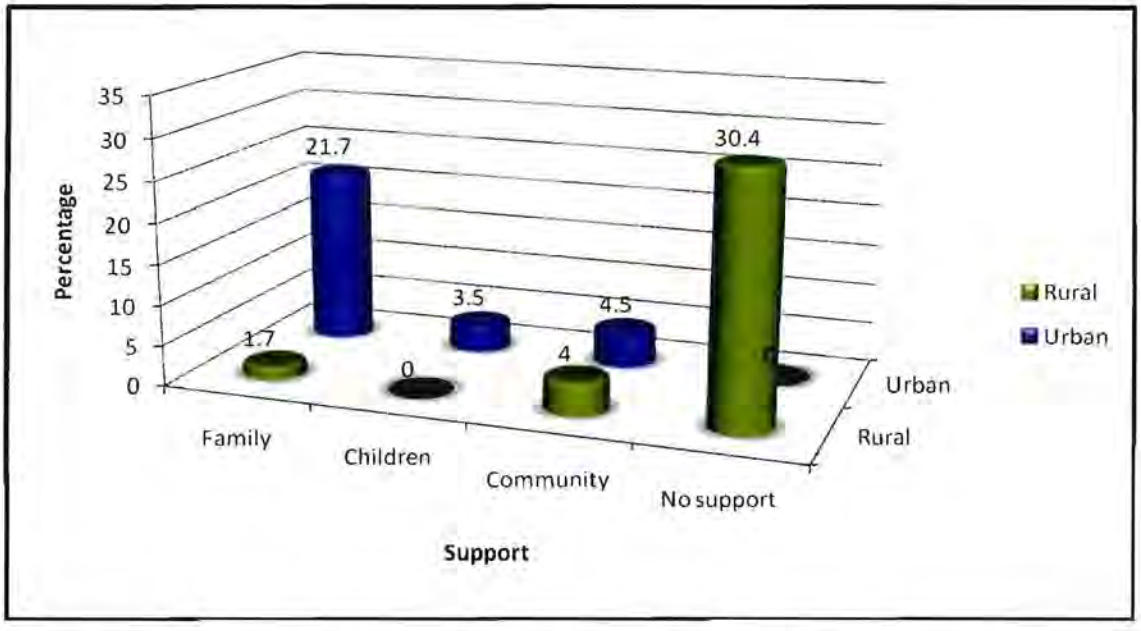


Figure 2.6: Percentage of support from whom the older persons receive support

A striking result noted by the researcher (see figure 2.6) is the large number of older persons from the rural area (21.7%) that indicated against the 0% of the older persons of the urban area that they have no support. It is also notable that only 1.7% of the older persons in the rural area say that they receive support by their family against the 21% of the older persons in the urban area. Only the older persons in the urban area responded that they receive support from their children that is 3.3%. The older persons from the rural and urban areas responded more or less the same regarding the support from the community that they receive, namely 4% and 4.5% for the rural and urban area respectively. There seem to be a link between the 21.7% older persons in the rural area that indicate that they have no

support in their area of residence and the results that indicate that the majority of older persons in the rural areas do not belong to a social group in the community where they stay. The presence of social support in the form of social networks of friends and family contribute to good health and well-being (Gilbert & Soskolne, 2003:113).

- **Total support from civic organisations**

A question was asked on the degree of support that the older persons receive from civic organisations, namely the political organisations, such as street committees and ward councillors, burial societies, the police and social services in the community. The answer was categorised in none/little support, moderate support and a great deal of support.

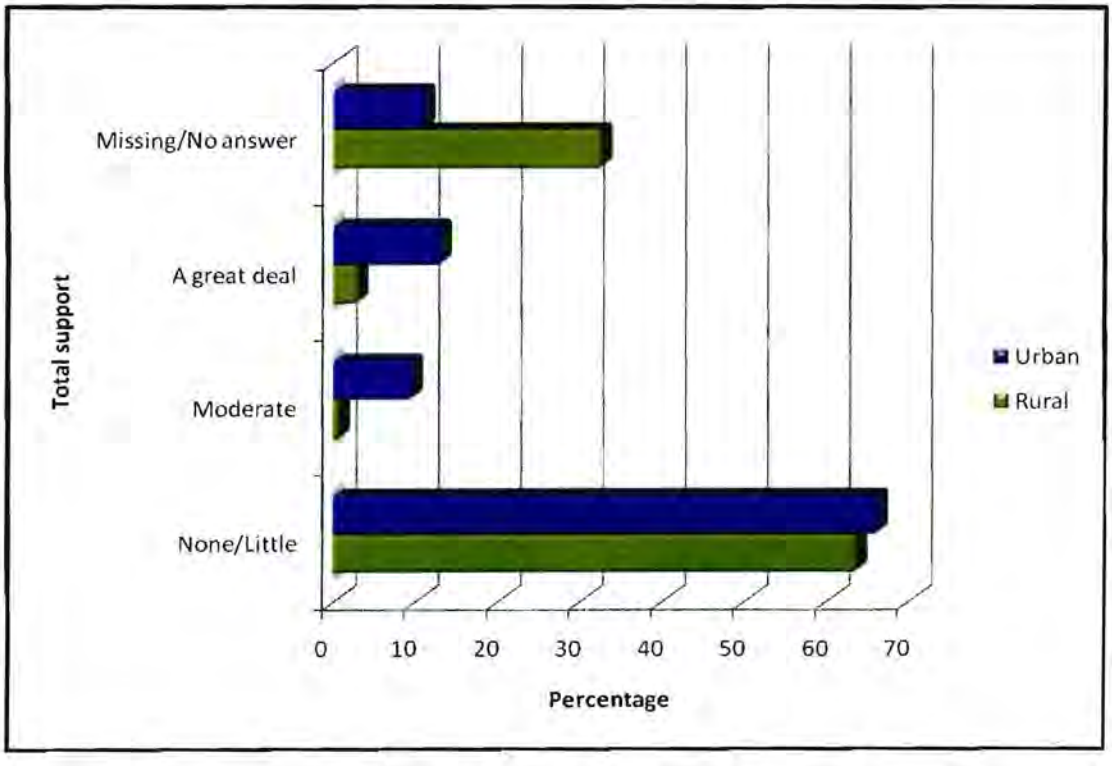


Figure 2.7: Total support the older person receive from civic organisations

The results show that the majority older persons from both areas (63.7% from the rural and 66.2% from the urban area) feel that they receive none or little support from civic organisations. Some of the older persons (between 9.6% and 13.1%) from the urban area indicated that they get

moderate to a great deal of support from the civic organisations against the 0.7% and 3% of the older persons from the rural area.

- **Membership of religious groups in the community and participation in the activities thereof**

There was also a question added regarding religious support as part of the older persons' social support. The same regarding the concept clarification apply to religious organisations that PURE-SA defined as different types of formal and informal groups set up on a religious basis. Different churches, religious leaders, and family are amongst the religious organisations the older persons referred to under this question as their religious support groups. They revealed that they find their support in the groups from their ancestors, God and the Holy Spirit.

The level of support they receive from the religious groups when they are in need, are presented in a column chart (see figure 2.8).

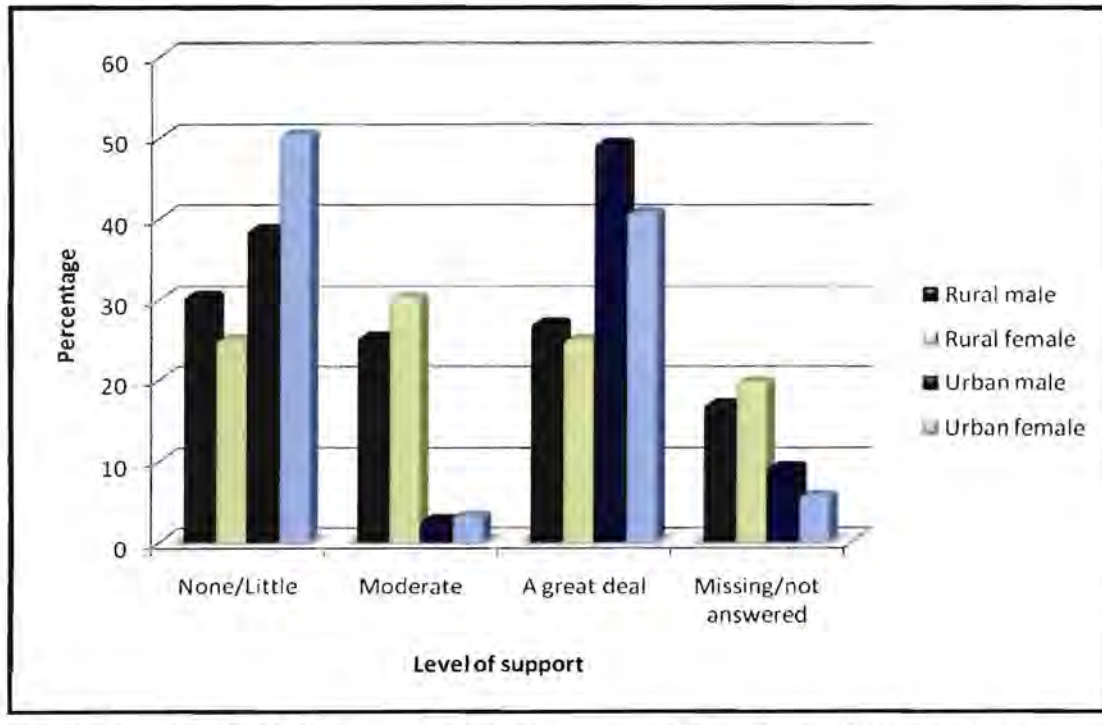


Figure 2.8: Level of total support the older persons receive from religious groups

An overwhelming number of older men (71.1%) and women (75%) from the rural area said that they belong to a religious organisation (see figure 2.8)

while 26.7% of urban men and 52% of the urban women indicated that they belong to a religious group. It is thus notable that larger numbers of older persons in the rural area belong to religious groups than their counterparts in the urban area.

An interesting observation that can be made from the results is that 44.6% of older persons in the urban area indicate that they receive none or little support from the religious groups in their area and 24% says that they receive either moderate or a great deal of support. This could be the reason why smaller numbers of older persons in the urban area (39.4%) belong to religious groups. In the rural area though, only 27.8% of the older persons indicate that they do receive none or little support and 27% that they do receive moderate to a great deal of support.

2.4.2.5 Discussion on the socio-economical data and the health of the older person

The vast majority of older persons had no schooling (40%) with the education level notable lower in the rural area (56.3%) than in urban area (30.5%). A census done in 2001 by Statistics South Africa indicates that 45.2% of persons older than 60 years had no education and they were mostly Africans (Joubert & Bradshaw, 2001:152-153). The older persons in both the rural and the urban area count to an average of 42.6% that were educated on primary level. The researcher noted during the fieldwork (the pre-and post-counselling sessions), that the older persons had trouble to participate in discussions and that they rather kept quite. This truth can handicap health promotion strategies like basic health education and other health care programmes. It also has implications for the older persons that need information on basic care of not only the AIDS-ill person at home but also basic care and help to their grandchildren. Literacy is the ability to read with understanding and to write simple sentences, an ability that individuals need to participate in programs of development (Imhabekhai, 2003:579).

An area of concern is that over 80% of all older persons in developing countries, including South Africa, have no income other than their social pension (Burns *et al.*, 2005:105; HAI, 2007:6). 15.4% of the older persons included in this study had

no income. The highly destructive and damaging effect of HIV/AIDS on the working-age population add to the financial strain in the older persons' household and has thereby placed the social pension at the centre of a survival strategy in many, if not all the older persons' households and are according to Burns *et al.* (2005:105) the following:

- grant for the aged, paid to women 60 years of age and men 65 years of age (this is now changing in South Africa, men are also going to qualify for pension at age of 60 years);
- war veterans' grant, paid to those older than 60 years and served in the South African army during the world wars;
- grant for disability, paid to those older than 18 years of age with a disability;
- care dependency grant, paid for children who are severely disabled and may need special care;
- child support grant, paid to primary care giver under certain circumstances;
- foster child grant, paid to foster parents in respect of children placed in their care through court order, and
- grant in aid, paid to an individual taking care of another person in need of full-time attention.

Social pensions contribute positively on household incomes with notable changes to child health and educational status. On the other hand is it evident that unemployed persons (children, grandchildren and/or other siblings) try to attach themselves to the older persons in order to get hold of the pension (Burns *et al.,* 2005:110). One can add to this reality in reference to Hosegood and Timaeus's (2005:431) study that revealed that illness and deaths of HIV/AIDS have short and long-term economic consequences for households and their surviving members (the older persons) and often result in reduced economic status.

The overall picture demonstrates that there are more households in the rural area with more than six people, than in the urban area. The reason could be that the majority of African households in the rural areas continue to live in multi-generational family structures with less visible changes than in the family

structures of their urban counterparts because of modernisation and globalisation. In addition to this one should take into account that care and financial security for the older persons included in this sample are important and therefore co-residence are to their advantage (Freeman & Nkomo, 2006:308; May, 2003:18). Apart from the unemployed persons that attach themselves to older persons with or without the wrong intentions as mentioned before, the extended family is the traditional social security system and the members thereof are responsible for the protection of the vulnerable. With the HIV/AIDS epidemic, it seems that this social security system, a long established practice in African communities is in jeopardy. Freeman and Nkomo (2006:303) wonder if the traditionally extended family structures are still realistic and sufficient to absorb the full social, economical and psychological strain that HIV/AIDS imposes on the older persons' household.

The older person's part of the community as a system in this study consists of a certain level of wellness and problem-solving capabilities to manage their situation. The community consists of functional regulatory sub-systems, namely health-, agriculture-, housing- and environmental departments in both the rural and urban areas where the older persons live in their households under different conditions. Although the majority of houses in both areas were formal with solid roofs and dispose of electricity and water, the results highlighted some alarming factors (see paragraph 2.4.2.2). A large group of older persons in the rural area and not so far behind in the urban area use wood and open fires for cooking and heating purposes. Open fires causes air pollution and burns; it is also dangerous to the health of the older persons and can cause different lung diseases. Previous results on the sources of income, the financial responsibilities and literature thereof leave the researcher with the opinion that the older persons use electricity sparingly in their households to save money. The same count for the older persons that should collect clean water from a community well or the borehole outside their homes (66% in the rural area) that can poses practical concerns such as the physical efforts to curry the water that is heavy over uneven surfaces that can lead to falls (Joubert and Bradshaw, 2001:154). Against the progress made by the government in both areas regarding household conditions, the older persons are prone to difficulties in their household conditions that can weaken their orderly way of functioning as a sub-system in the community as a system and can also

lead to conflict between the older persons and the sub-systems indicated in figure 2.2.

Social relationships can have health-promoting or health-damaging effects (Ostir *et al.*, 2002:355-356) and continued involvement in social activities and relationships contribute to the well-being of the older persons (Drewnowski *et al.*, 2003:300). A group of friendly people that share similar problems and challenges can have a powerful advantage (Jenkins, 2005:139). Unfortunately, only one older man and no older women in the rural area seem to belong or are involved in any social support and/or self-help groups. This troublesome reality correlates to the large number older persons (21.7%) in the rural area that said they received no support in their area of residence. In the urban area, however 22.4% of the older persons that participated in the study admitted that they belong or are involved in social support and/or self-help groups and nobody said that they do not receive support. It seems that support to the older persons in the rural area are mostly, but little, from their community members whereas the support that the urban older persons receive are from their families and children but also from the community members. Clark (2008:509) underlines the finding that older persons look for social support most often from family members. Against the support received from the children, family and community members, an alarming majority (average of 65%) from rural and urban areas said they do not receive any support from civic organisations in the community. In this study civic organisations refer to NGO's, CBO's and FBO's. If the older persons belong to a social group they not only receive, but also have opportunities to give support. One should ask questions regarding the negativism against civic organisations, for the researcher from her experience as a community nurse, are of opinion that civic organisations are indispensable components in community-based collaboration to support the older person in the world of HIV/AIDS.

"A strong religious faith can be a source of comfort and strength when life is hard" (Schott & Henley, 2002:128). Various kinds of religious support is available in both the rural and urban areas and from the results it is clear that the majority of older persons do seek comfort in religious faith, and believe that they should belong to a religious group for support. A representative 36.6% of the older population

indicated that they received a great deal of support from religious organisations. Mbiti (1990:3), a theology philosopher stated that all Africans are notorious religious; a fact that can explain the results on religious involvement.

2.4.2.6 Conclusions pertaining to the socio-economical data

- Majority of older persons in the community have no or a low level of education which makes them vulnerable to participate effectively in health promotion programs and access to information pertaining to aspects like HIV/AIDS.
- The social pension that most of the older persons receive are their only hope to make ends meet and are now challenged with extra financial burdens that HIV/AIDS put on them to support their family members with material goods.
- 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.

2.4.3 PSYCHOLOGICAL DATA

The part on psychological data focused on questions regarding events that the older persons possibly experienced as stressful. The researcher explored the experiences of the older person in their everyday life to gain more insight in their way of coping in the world of HIV/AIDS. The psychological data also entail a few questions to determine the possibility of depression that could present in physical manifestations. The perceptions of the older persons of other people in their area where they live regarding honesty, respect and help were included in the questionnaires to have a better understanding of the attitudes and values of the older persons.

2.4.3.1 Stressful events experienced during the last twelve months

The data will be summarised and presented in a simple way, namely through a frequency table for clear understanding. A chart will summarise and illustrate the

stress experienced by the older persons in both areas. The summarised illustration will focus on the type of stress and the frequency of experience by the older persons per gender and area of residence. See table 2.7 on the results regarding stressful events experienced by the older persons.

Table 2.7: Percentage of stressful events experienced by older persons

Characteristics	Rural 40.5% (n=135)				Urban 59.5% (n=198)			
	Men 43.7% (n=59)		Women 56.3% (n=76)		Men 37.9% (n=75)		Women 62.1% (n=123)	
Stress because of loss of job								
Yes	3.4	(n=2)	1.3	(n=1)	4.0	(n=3)	6.5	(n=8)
No	79.7	(n=47)	94.7	(n=72)	81.3	(n=61)	87.8	(n=108)
No response and/ or missing	16.9	(n=10)	4.0	(n=3)	14.7	(n=11)	5.7	(n=7)
Stress because of retirement								
Yes	3.4	(n=2)	1.3	(n=1)	5.3	(n=4)	9.8	(n=12)
No	78.0	(n=46)	94.7	(n=72)	81.3	(n=61)	84.6	(n=104)
No response and/ or missing	18.6	(n=11)	4.0	(n=3)	13.4	(n=10)	5.7	(n=7)
Stress of intra-family conflict								
Yes	10.2	(n=6)	2.6	(n=2)	1.3	(n=1)	2.4	(n=3)
No	83.1	(n=49)	93.4	(n=71)	82.7	(n=62)	92.7	(n=114)
No response and/ or missing	6.7	(n=4)	4.0	(n=3)	16.0	(n=12)	4.9	(n=6)
Stress because of major illness/injury								
Yes	5.1	(n=3)	3.9	(n=3)	6.7	(n=5)	9.8	(n=12)
No	78.0	(n=46)	92.1	(n=70)	77.3	(n=58)	85.4	(n=105)
No response and/ or missing	16.9	(n=10)	4.0	(n=3)	16.0	(n=12)	4.8	(n=6)
Stress because of death of spouse								
Yes	1.7	(n=1)	6.6	(n=5)	9.3	(n=7)	9.8	(n=12)
No	81.4	(n=48)	88.2	(n=67)	78.7	(n=59)	85.4	(n=105)
No response and/ or missing	16.9	(n=10)	5.2	(n=4)	12.0	(n=9)	4.8	(n=6)
Stress of unavailability of food								
Yes	30.5	(n=18)	48.7	(n=37)	41.3	(n=31)	36.6	(n=45)
No	54.2	(n=32)	44.7	(n=34)	50.7	(n=38)	55.3	(n=68)
No response and/ or missing	15.3	(n=9)	6.6	(n=5)	8.0	(n=6)	8.1	(n=10)
Levels of stress at home								
Never experience stress	10.2	(n=6)	14.5	(n=11)	30.7	(n=23)	25.2	(n=31)
Some periods of stress	39.0	(n=23)	36.8	(n=28)	33.3	(n=25)	39.0	(n=48)
Several periods of stress	6.8	(n=4)	10.5	(n=8)	20.0	(n=15)	26.0	(n=32)
Permanent stress	15.3	(n=9)	14.5	(n=11)	4.0	(n=3)	4.1	(n=5)
No response and/ or missing	28.7	(n=17)	23.7	(n=18)	12.0	(n=9)	5.7	(n=7)
Levels of financial stress								
None/Little	15.3	(n=9)	15.8	(n=12)	24.0	(n=18)	35.8	(n=44)
Moderate	28.8	(n=17)	26.3	(n=20)	26.7	(n=20)	24.4	(n=30)
High/Severe	35.6	(n=21)	43.4	(n=33)	21.3	(n=16)	16.3	(n=20)
No response and/ or missing	20.3	(n=12)	14.5	(n=11)	28.0	(n=21)	23.5	(n=29)

According to table 2.7, it is clear that the food insecurity causes the largest percentage of stress to the older persons whom are mainly the head of the household and therefore responsible for food on the table. HIV/AIDS results in rapid societal transformation in families (see paragraph 2.4.2.1), diminishing family capital and capacity and the households no longer have the resources to cope (Ferreira, 2004:30). The levels of stress regarding the finances of the older persons correspond with the unavailability of food and with the levels of stress at home. Without food older persons, their children and grandchildren are hungry. Fifty-four, that is 40% of the older persons in the rural area experience high to severe levels of stress regarding their finances against the 18.2% of the urban older persons. Not only does the older persons experience financial burden that link to food scarcity, but also other material and financial needs affected the household, like needs for clothes, bedding, and funeral as well as schooling expenses for grandchildren. A heart braking reality is that the older person, particularly the women, will sell off their assets and belongings to try to care for their families (Ferreira, 2004:28).

The percentage older persons that never experienced stress at home are higher for the urban than the rural areas (27.7% and 12.6% respectively). Most of the older persons experience some periods of stress at home, it is more or less the same for all the older persons, (37.8% for the rural and 36.9% for the urban area). Although the percentage distribution for stress experience is not alarmingly high, it is clear from the results that the older persons do experience stress, some even permanently (average of 9.4%) regarding their situation at home (see table 2.7).

2.4.3.2 Risk factors that can point to possible depression

This section pertain data gathered from the adult questionnaire on psychological risk factors that can be indicators and warning signs that the older persons are or can become depressed. The data is from all older persons (n=333) included in the study and included factors regarding their feelings, thoughts and experiences over the past two weeks prior to the completion of the questionnaire. The questions asked were whether the older persons felt sad or blue, if they lose interest in most things, if they felt tired or low in energy, if they gain or lose weight, if they had trouble falling asleep, if they had trouble concentrating, if they think a lot about

death, if they felt worthless. The researcher will only focus on the percentage of older persons that said yes to the questions applicable on risks for depression. The questions focused on the two week prior to the day of participation. The results are summarised and illustrated by means of a line chart, to determine risk factors for possible depression in manageable proportions for discussion.

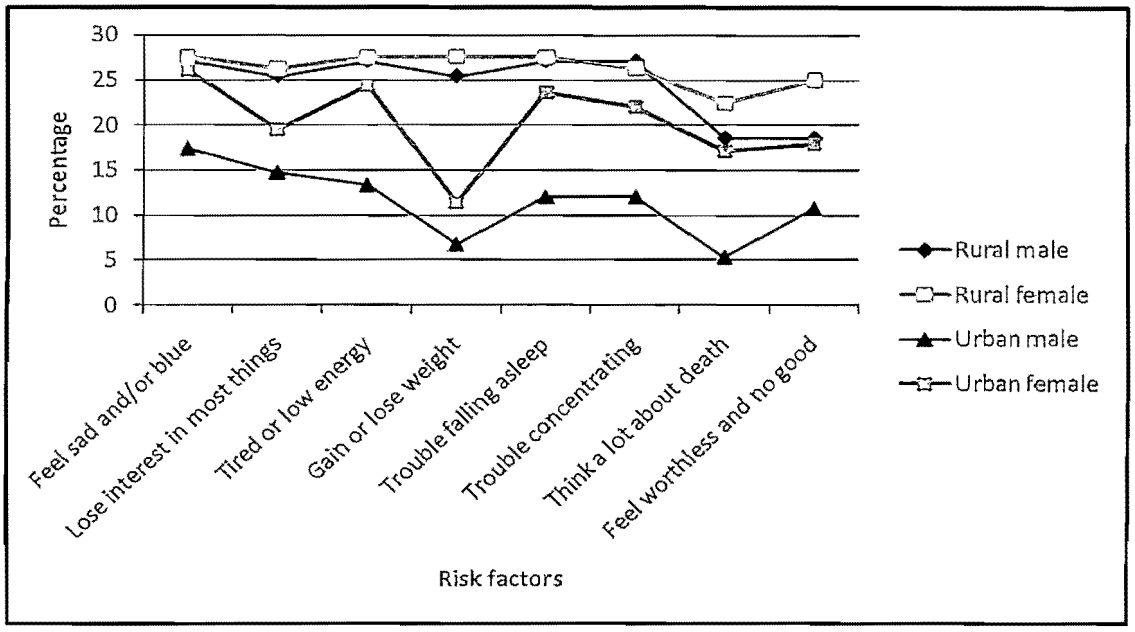


Figure 2.9: Older persons with feelings, thoughts and experiences of risk factors of possible depression

More than 25% of all the older men and women from the rural area said yes to all the questions pertaining to risk factors for depression. The average older men and women from the urban area that indicated risk factors for depression count for 16.9%. It is also notable that the percentage "yes" responses to the risk factors is more or less the same for the older men and women from the rural area. The average percentage yes for rural men is 24.6% and 26.3% for the women. The percentage "yes" responses to the risk factors for depression show a clear difference between the urban men and women older persons, the men count for 11.5% against that of the women of 20,2%.

From the results, it is evident that the risk factors that point to depression are present for 20.5% of all 333 older participants. Although the group of older persons in the rural area raise concern regarding possible depression, the older women from the urban area also count for concern.

2.4.3.3 Perceptions of older persons regarding honesty, respect and help from other people

The older persons had to respond to two statements. The first one refer to whether they (older persons, n=333) agree that people are generally honest and the second refer to whether they (older persons, n=333) agree that if they (older persons, n=333) do nice things to others, others will respect them and treat them (older persons, n=333) the same. The results to the two statements will be summarised and illustrated by means of a column chart, to gather a clear picture on the older persons' view on mutual trust between themselves and the people in their area of residence. The people referred to can be in their own household, neighbourhood and from the community.

The results on the perceptions of the older persons' whether people are generally honest and want to help others shows that 25.9% of them from both areas strongly agree, 25.5% somewhat agree, against 15.7% that somewhat disagree and 25.9% that strongly disagree. For further discussions, refer to figure 2.10 below.

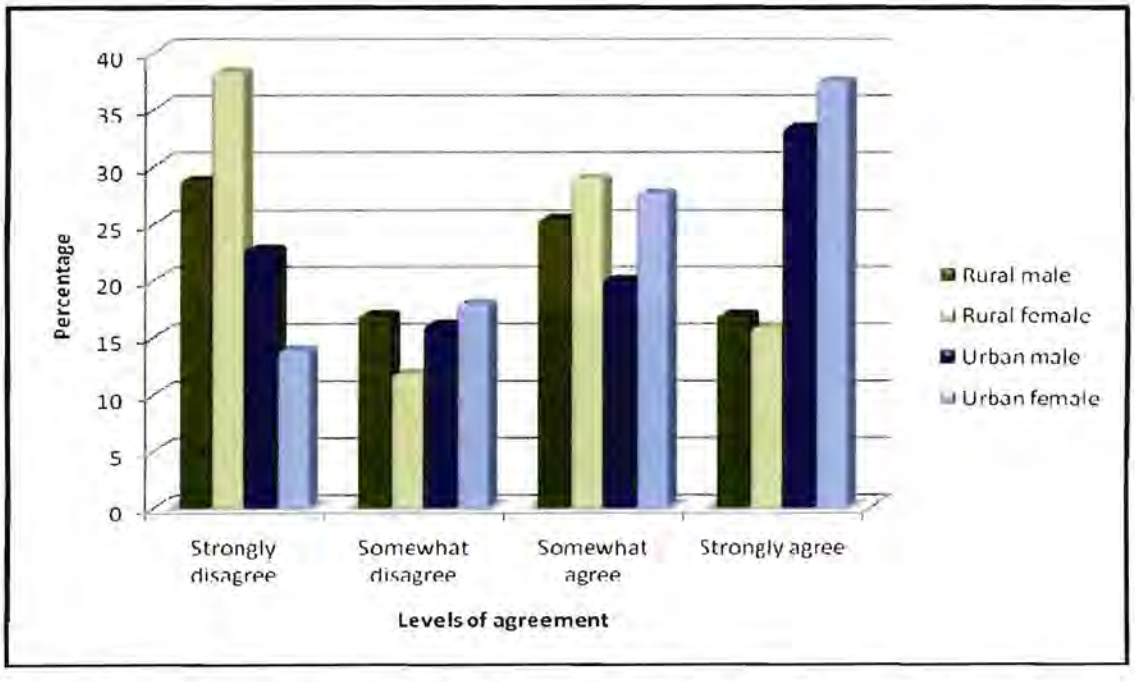


Figure 2.10: Percentage agreement of older persons on honesty from others in their area

In figure 2.10, the results demonstrate that the urban men (33.3%) and women (37.4%) older participants perceive other people in their area of residence as honest and helpful against the rural men (16.9%) and women (15.8%) respectively. Another interesting observation made when looking at figure 2.10 is the notable opposite views between the rural and urban women when it comes to their perceptions on trust and honesty of other people. Twenty-nine (38.2%) of the older women in the rural area strongly disagree that people are honest and can be trust against the smaller group of older women in the urban area (13.8%) that disagree that people are honest and helpful.

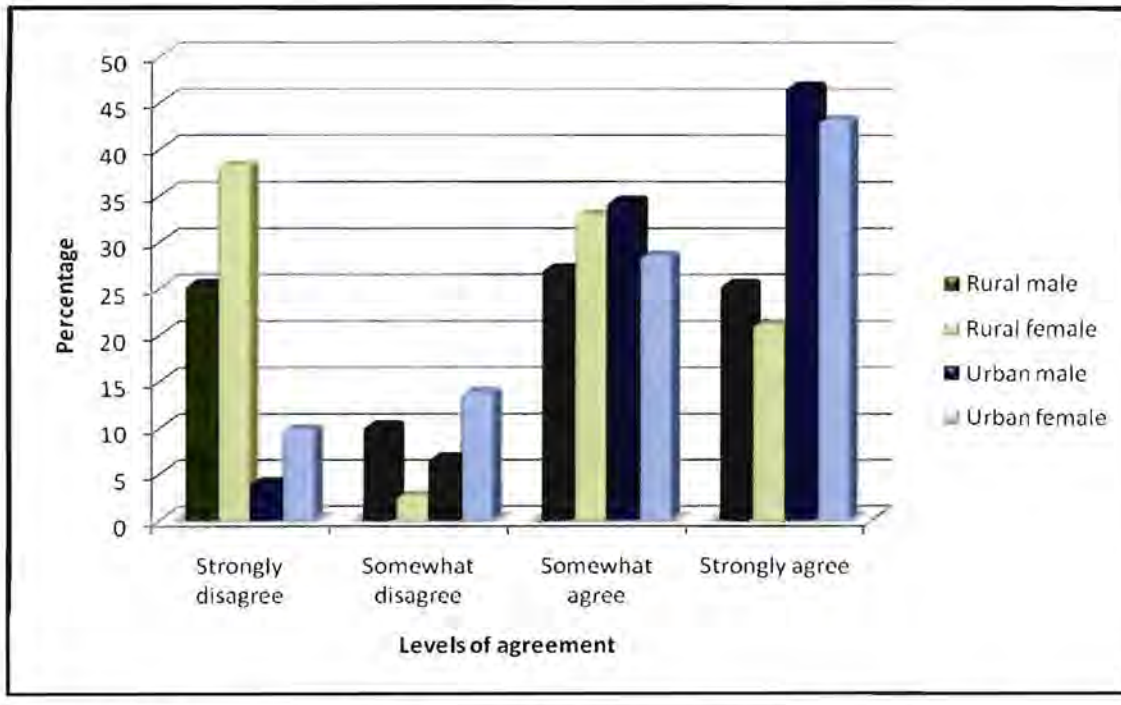


Figure 2.11: Perceptions of older persons that if they do nice things to others, they will be respected and be treated well.

In the bar chart (figure 2.11) the older persons indicated that if they do nice things for someone, they can anticipate that they will be respected and be treated just as well as they treated the other person. The result are very much the same as the perceptions on honesty (see figure 2.10) that confirmed to the researcher that the older persons, both men and women in the urban area have a higher level of trust in other people than of that of their counterparts in the rural area.

2.4.3.4 Discussion on the psychological data and the health profile of the older persons

Lower incomes have been associated with stress and psychological distress and may have negative impact on the older person's health (Drewnowksi *et al.*, 2003:304; Orner, 2006:236). The results reveal that the older persons in both rural and urban areas experience moderate (26.6% of the sample) to severe (29.2% of the sample) financial stress and it is no surprise because "older persons are consistently among the poorest of the poor" (Ferreira & Kowal, 2006:20).

HIV/AIDS not only places financial pressure on the older persons (Population Reference Bureau, 2007:1), but also causes severe changes in the household of the infected with and/or affected by HIV/AIDS older persons and result often in family structure changes with diminished kin support for older persons and associated stress in the household. The majority of older persons that participated in the study said that they experienced some periods, several periods and even permanent stress at home. Other factors that cause stress to the older persons are more or less the same for both rural and urban men and women. The older respondents refer to the loss of job, retirement, intra-family conflict, major illness/injury and death of a spouse as some of the factors that caused stress. The unavailability of food caused an average of 39.3% of the older persons to experience stress. Money buys food and money is a scarcity in the older person's household. The food parcels that are given by different community organisations to households are mostly for assumption by the HIV/AIDS persons in the household only. Stress occurs because all the people in the household experience food scarcity (Ferreira, 2004:30 & 34). The same author as well as Hosegood and Timaeus (2005:433) stated that the strain of care giving, coping with death of children and grandchildren, uncertainty about the future as well as their own personal health can lead to a series of emotional reactions, such as fear, anger, hurt, a lack of understanding, confusion, deprivation and also possible abandonment. Anxiety over the illness or death of loved ones (Population Reference Bureau, 2007:1) and stressful events in households can be harmful to the older persons' health and can result in discouragement (Ferreira, 2004:28).

A phenomenon that raises concern from the results is that the older persons from both the rural and the urban area experience feelings and thoughts that refer to risks for possible depression. Although the older persons from the rural area experienced by far higher percentages of the risk-of-depression feelings and thoughts during the two weeks prior participation than their counterparts, the older women from the urban area did not lack far behind. More than 25% of the older persons was from the rural area that indicated that they felt sad and blue, they lost interest, they feel tired, gained weight, had trouble falling asleep at night, they felt worthless, think a lot about death, feel worthless and no good and have trouble to concentrate. Lack of concentration and altered sleep patterns are often characteristics of depression in the older person (Drewnowksi *et al.*, 2003:303).

How the older persons perceive other peoples' honesty, respect and payback treatment, refer to the older persons' perception regarding trust towards other people in their area of residence. To "trust" someone means to have a firm belief in someone or to be a believer in the reliability, truth, ability or strength of other people (South African Concise Oxford Dictionary, 2002:1261). Older persons, both the men and women in the urban area exhibit a notable higher view on trust towards other people in their community (35.9%* and 45.4%#) than their counterparts' exhibit in the rural area (16.3%*and 23%#). There is a remarkable resemblance between how the older persons in the rural area perceive "trust" from other community members, the low percentage that belong to support groups, support they receive from their children, other family- and community members as well as support from civic organisations (refer to paragraph 2.4.2.4).

(* *refer to people are honest and want to help others and* # *refer to if I do nice things, people will respect and treat me the same*).

2.4.3.5 Conclusions pertaining to the psychological data

- The older persons infected with and/or affected by HIV/AIDS do experience stress because of different reasons:
    - they give material support to their family members and cannot make ends meet with their money that furthermore result in food scarcity and more stress,
    - 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.

- A large number of older persons experience the feelings and thoughts that refer to risks for possible depression.
- Older persons perceive honesty, respect and payback treatment as important values pertaining to trust in their homes and the community. The majority however do not experience mutual trust pertaining to their relationship with the different organisations in their neighbourhood and community.
- The ontology of older persons is rooted in religion and they experience a great deal of support from religious groups in the community.

2.4.4 BEHAVIOUR/LIFESTYLE DATA AND THE HEALTH OF THE OLDER PERSONS

How the older person live and behave contribute much to their health and the aspects that the researcher can explore for description are data obtained from the adult questionnaire that refer to the tobacco and alcohol use as well as the sleep and rest pattern of the older persons.

2.4.4.1 History on tobacco and alcohol use

The results that refer to the tobacco and alcohol use by the older persons in the rural and urban areas are illustrated and discussed in the following section and focused only on the older persons that currently use the products.

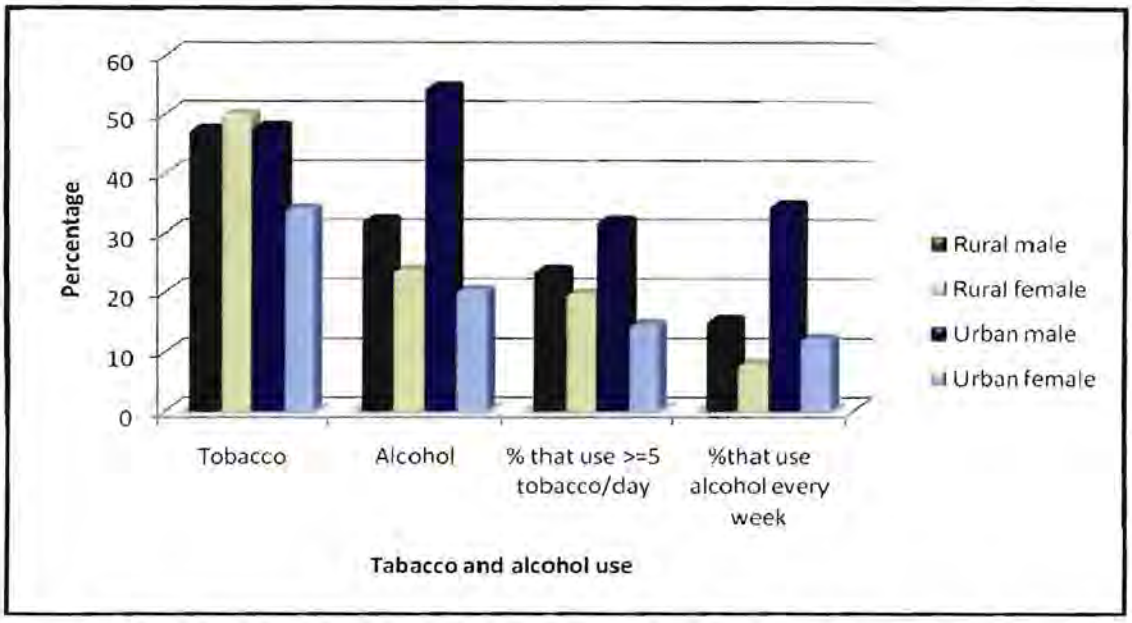


Figure 2.12: Percentage tobacco and alcohol use of older persons

From all the older persons that responded 47.5% men from the rural area and 48.0% men from the urban area indicated that they currently use tobacco. It is notable that older women from the rural area use slightly more tobacco products (50%) than the older men (47.5%) in the same area, but definitely more than the urban women (34.1%). The men from the urban area are the highest percentage tobacco consumers of the two genders and areas, 32% of them smoke more than five tobacco products per day.

It is striking that the older men from the urban area demonstrate the largest consumption of alcohol (54.7%) against the 32.2% of the older men in the rural area. The older men in the urban area further more demonstrate the highest percentage regular use of alcohol, 34.7% of them use alcohol on a weekly base. From the results it seems that 38.8% of all older persons included in the study (n=333) engage themselves in unhealthy behaviour, like either tobacco use (average of 44.9%) or alcohol use (average of 32.7%).

2.4.4.2 Rest and sleep pattern of the older person

In the adult questionnaire the older persons was asked what time they normally go to bed at night and what time they normally wake up in the morning. The results

indicated that most of the older persons go to bed between eight and ten o'clock at night (74.5%) and wake up between five and seven o'clock in the morning (76.9%). It seems thus that the larger number of the older persons both from the rural and urban area sleeps more than seven hours per night. When asked if the older persons take a nap during the day the results showed that one-hundred-and fourteen older persons (34.2%) take a nap each day that last between thirty to sixty minutes.

2.4.4.3 Discussion on behavioural-, lifestyle data, and the health of the older person

In South Africa, there is a strong link between tobacco use and diseases like tuberculoses, chronic obstructive airway disease, lung cancer and heart diseases and the incidence of cancer of the cervix is high amongst women who smoke and increase the risk of coronary heart disease, stroke, thrombi, pulmonary embolism, and circulatory disease, raised blood pressure and cholesterol levels (Stellenberg & Bruce, 2007:992-993). The same literature stated that tobacco reduce stress and anxiety and replace it with relaxation. In the context of this study, one can ask if this could be the reason why nearly 50% of all the older persons, both men and women from the rural and urban area, use tobacco products. However, is it important to note that tobacco kills a third to a half of all those who use it. On average, every user of tobacco loses 15 years of life (WHO, 2008a:18).

The Social Learning Theory of Lucas and Lloyd (2005:112) indicated that poor coping resources, the presence of perceived signals to drink and the belief that alcohol will have a positive outcome, contribute to excessive drinking. Earlier results in this study gave enough evidence that the older persons have many difficulties and hardships within their world of HIV/AIDS. If not infected with HIV/AIDS they or their households are affected by the devastating disease and experience depression and stress for different reasons, like household conflict, financial shortfalls, food insecurity and lack of support. The older persons may use alcohol for different reasons and may think that the consumption thereof can help them to handle their situation. Although men are worldwide larger alcohol consumers than women (Jenkins, 2005:167), it is noted by Clark (2008:513) that more than one third of the women population start with alcohol misuse after 60

years of age. The older men of the urban area are the largest users of alcohol (54.7%) against the older men in the rural area (32.2%).

The majority of older persons both from the rural and urban area indicate that they sleep more than seven hours per night and 34.2% of the sample of 333 older persons take a nap each day that last between thirty to sixty minutes. Clark (2008:525) states that it is healthier for the older persons to limit their daily naps to 30 minutes or less, because it can result in insomnia and tiredness at the end.

2.4.4.4 Conclusions pertaining to behavioural- and lifestyle data, and the health of the older person

- The older persons experienced 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.

2.4.5 BIO-PHYSICAL DATA ON THE HEALTH OF THE OLDER PERSONS

The results hereafter on the bio-physical data of the older persons will give a bird's eye view into yet another dimension of their health. Apart from the physical frailness of the older persons, that is part of the normal course of development throughout man's lifespan; HIV/AIDS result in extra strain on the human body of the older person and exact an enormous toll on them, especially on the women (Ferreira, 2004:26). The bio-physical data refer to in this section of the study entails results on the HIV status of the older persons, physical ability and impairment, diseases diagnosed with, use of medication, signs related to lung diseases (not diagnosed) and older persons included in the study that died since January 2006 and the reason for the death.

2.4.5.1 HIV status of the older persons included in the study

The HIV status of the older persons is one of the bio-physical factors of central importance in this study, because the study in its totality investigate the empirical world of the older person that could be infected with HIV/AIDS, not only affected. Method of blood samples obtained, testing and management of the older persons

together with all the other participants in the PURE-SA study were described in paragraph 2.3.3.2. It was not possible to obtain a blood sample from two of the 333 older persons and the blood sample of one older person was spoiled. The results of the HIV/AIDS rapid test that was done revealed the following status amongst the older persons that participated in the PURE-SA study, see table below.

Table 2.8: Frequency table on the HIV status of the older persons

Characteristics	Rural 40.5% (n=135)				Urban 59.5% (n=198)			
	Men 43.7% (n=59)		Women 56.3% (n=76)		Men 37.9% (n=75)		Women 62.1% (n=123)	
Age in years	N	Percent +HIV	N	Percent +HIV	N	Percent +HIV	N	Percent +HIV
60-64	27	3.7 (n=1)	39	7.7 (n=3)	39	7.7 (n=3)	45	4.5 (n=2)
65-73	26	11.5 (n=3)	25	4.0 (n=1)	27	3.7 (n=1)	60	1.7 (n=1)
74-83	5	0.0 (n=0)	10	0.0 (n=0)	8	0.0 (n=0)	15	6.7 (n=1)
>84	1	0.0 (n=0)	2	0.0 (n=0)	1	0.0 (n=0)	3	0.0 (n=0)
Total (N=333)	59	6.8 (n=4)	76	5.3 (n=4)	75	5.3 (n=4)	123	3.3 (n=4)

From the sample of three hundred-and-thirty three (n=333) older persons in the rural and urban area 95.2 % tested negative (n=317) for HIV and sixteen older persons (4.8%) tested positive for the HI-virus and were referred to the health centre of their choice for further follow-up management. In the age group 60-64, four men and five women tested positive, in the age group 65-73, four men and two women tested positive and in the age group 74-83 one woman tested positive for the HI-virus. A summarised illustration was included for the reader, see figure 2.13.

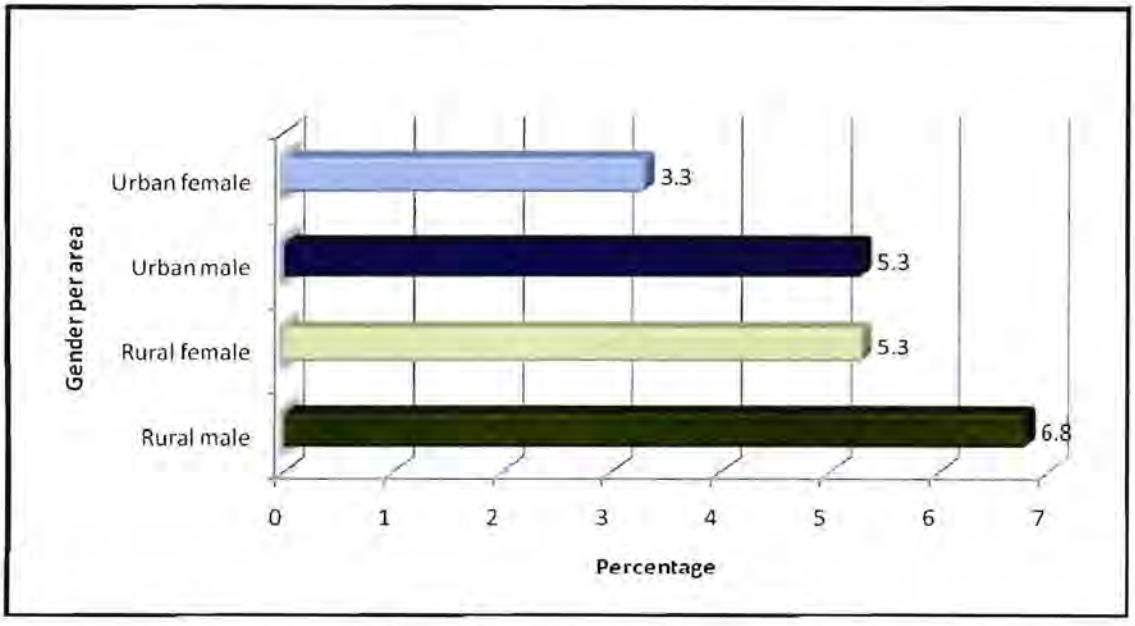


Figure 2.13: Percentage older persons (≥60) tested positive for HI-virus per gender and area of residence

In figure 2.13, it is noted that the older men from the rural area present with the highest HIV positive prevalence rate of 6.8% of the total older persons' population included in the study. It is interesting to find that the HIV positive older persons are mainly, with the exemption of one, from the age group 60 to 73. The one person referred to is a 79-year-old women and she was not aware of her status before the study. Her reaction to the researcher during post-counselling was, "No, this can't be possible...I am an old woman...it does not happen to us..." The result prove that the older persons referred to in this study is not only affected by HIV, but also infected with the virus.

2.4.5.2 Tuberculosis and/or other lung diseases of the older persons

Tuberculoses is a bacterial disease caused by Mycobacterium tuberculoses and usually attacks the lungs (UNAIDS, 2006). It is an airborne infectious disease that is preventable and curable. People ill with tuberculosis bacteria in their lungs can infect others when they cough (WHO:2007). Although the results revealed that only two of the total older persons' population reported that they were told by a health professional that they currently have tuberculosis, the following table on the self-reported symptoms of tuberculosis or other lung diseases gives a picture of

concerns regarding the older persons' health. Table 2.9 summarise the data gathered through the adult questionnaire.

Table 2.9: Older persons with self-reported symptoms of tuberculosis and/or other lung diseases

Characteristics	Rural 40.5% (n=135)				Urban 59.5% (n=198)			
	Men 43.7% (n=59)		Women 56.3% (n=76)		Men 37.9% (n=75)		Women 62.1% (n=123)	
Cough for at least two weeks								
Not answered/missing	10.2	(n=6)	2.6	(n=2)	8.0	(n=6)	2.4	(n=3)
Yes	44.1	(n=26)	32.9	(n=25)	18.7	(n=14)	13.0	(n=16)
No	45.7	(n=27)	64.5	(n=49)	73.3	(n=55)	84.6	(n=104)
Have any sputum while coughing								
Not answered/missing	10.2	(n=6)	2.6	(n=2)	8.0	(n=6)	3.3	(n=4)
Yes	35.6	(n=21)	15.8	(n=12)	22.7	(n=17)	8.1	(n=10)
No	54.2	(n=32)	81.6	(n=62)	69.3	(n=52)	88.6	(n=109)
There is blood in the sputum								
Not answered/missing	11.9	(n=7)	2.6	(n=2)	9.3	(n=7)	3.3	(n=4)
Yes	18.6	(n=11)	4.0	(n=3)	2.7	(n=2)	1.6	(n=2)
No	69.5	(n=41)	93.4	(n=71)	88.0	(n=66)	95.1	(n=117)
Has loss of appetite								
Not answered/missing	10.2	(n=6)	4.0	(n=3)	8.0	(n=6)	6.5	(n=8)
Yes	33.9	(n=20)	35.5	(n=27)	13.3	(n=10)	7.3	(n=9)
No	55.9	(n=33)	60.5	(n=46)	78.8	(n=59)	86.2	(n=106)
Had involuntary weight loss of >3kg								
Not answered/missing	10.2	(n=6)	5.2	(n=4)	9.3	(n=7)	7.3	(n=9)
Yes	25.4	(n=15)	14.5	(n=11)	8.0	(n=6)	4.1	(n=5)
No	64.4	(n=38)	80.3	(n=61)	82.7	(n=62)	88.6	(n=109)

The most frequent symptoms of pulmonary tuberculosis are cough for two to three weeks or more, sputum production that may be bloodstained, loss of appetite, tiredness, night sweat, general feeling of malaise, and shortness of breath and chest pain. If any three of the symptoms is present, the person should be seen as a "tuberculosis suspect" (Enarson *et al.*, 2000:6). Any person that reports a cough for two weeks or more could have tuberculosis and call for a complete clinical history (see paragraph 2.4.5.6 on the discussion of tuberculosis as a result pertaining to the health of the older persons). Older persons are more vulnerable than their younger members and therefore more susceptible for any lung disease. More of the older persons from the rural area, men and women present with one or more of the symptoms (see table 2.9) of either tuberculosis and/or other lung

diseases. Although the results do not reveal a frequency per person and symptom, it indicates that the leading symptoms are present to raise concern regarding the overall presence of lung diseases amongst the older persons.

One of the most common symptoms namely "cough for two weeks" was present in 44.1% and 32.9% of the rural men and women respectively. Against this reality 18.7% of older men in the urban area and 13% of older women in the urban area present with the symptom, "cough for two weeks". Although strikingly lower than that of their rural counterparts, it is present and therefore raises concern regarding the older persons' health.

2.4.5.3 Most common chronic diseases and the health of the older persons

The results demonstrated in figure 2.14 indicated the most common self-reported chronic diseases the older persons presented within the study. Hypertension seem to be the leading chronic disease, with diabetes mellitus in the second place, heart diseases in the third, arthritis in the fourth place and lastly but not the least, cancer and asthma. From the data gathered it resulted from history that 26.1% of all the older persons (n=333) in both the rural and urban area were told by a health professional that they had hypertension. Hypertension is defined in older persons when the blood pressure reading is higher than 140/90 and is often without any symptoms, referred to as the "silent killer". Factors associated with hypertension are obesity, sodium intake, alcohol, genetic factors, smoking and stress (Stellenburg & Bruce, 2007:45). The following chart, figure 2.14 reveals the summarised report regarding the history on chronic diseases known to the older persons included in the study. The use of medicine is included by the researcher in figure 2.14 as part of the most common diseases to indicate to the reader the percentage use of medicine by the older persons for chronic diseases (that is 30.6%). The percentage refers to all the older persons irrespective of gender and area of residence.

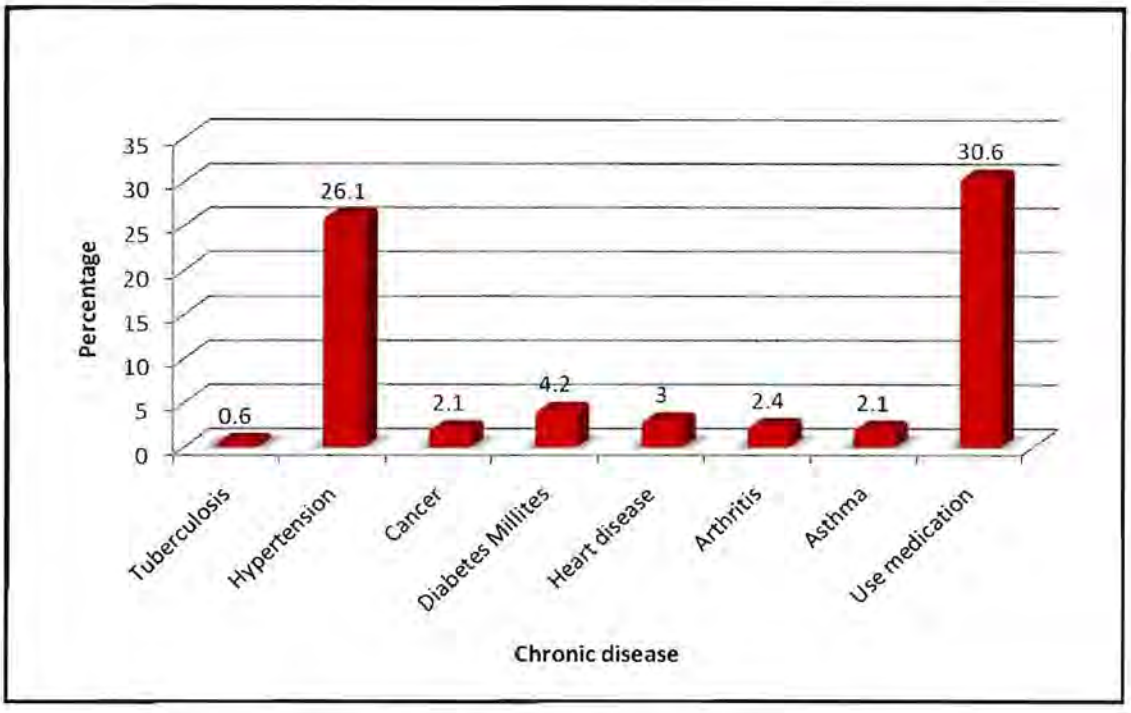


Figure 2.14: Percentage of self-reported chronic diseases by older persons (n=333)

During the time when the adult questionnaire was completed, 30.6% of the older persons in the study (n=102) said that they use some medication against the 69.6% that claimed they use no medication (n=231). The reason that only 30.6% said they use medication for chronic diseases and that so little revealed the status of their chronic diseases could be of fear of exclusion from the PURE-SA study.

2.4.5.4 Chronic diseases and deaths of older persons

Since the start of PURE-SA ten older persons (3%) died of different reasons. The death certificates revealed natural causes, hypertension, unknown causes, asthma, respiratory tract infections, and diabetes.

2.4.5.5 Physical ability and health of the older person

It is important to explore the physical ability of the older persons in the study to gain clarity on their situation and to determine if they can comply with the possible demands in the world of HIV/AIDS like care giving of the sick. In the following results, the mobility and some physical impairment of the older persons will be made available, see figure 2.15.

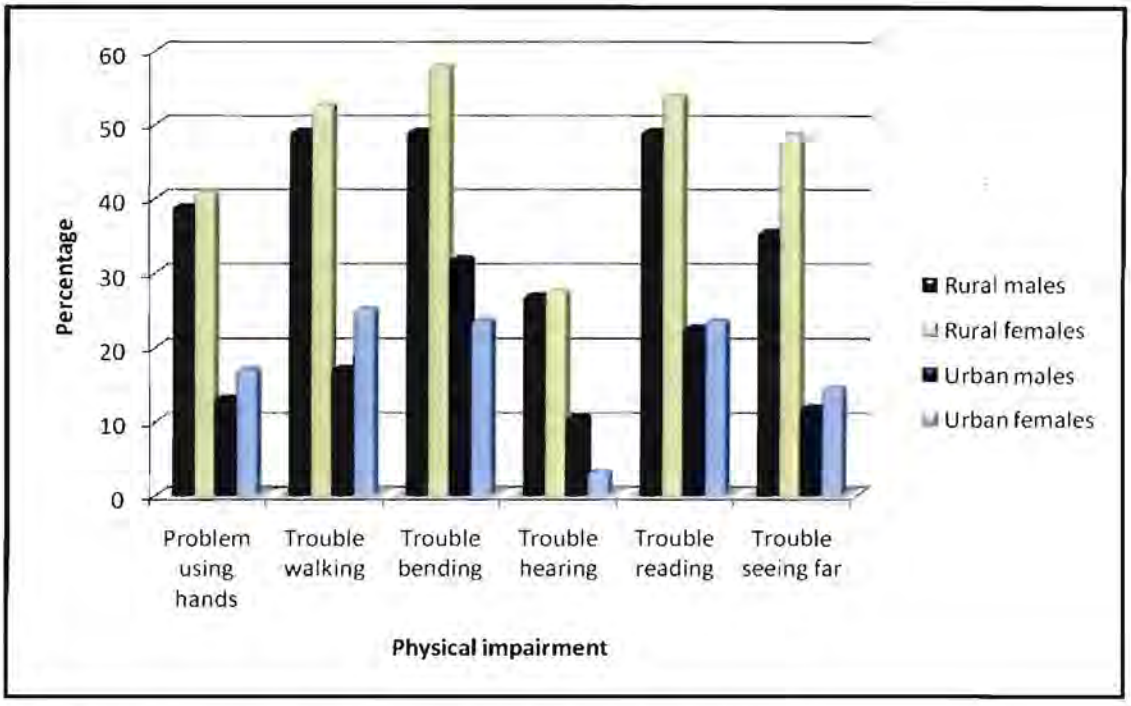


Figure 2.15: Percentage older persons with physical impairment

It is notable that the older persons in the rural area have more problems regarding physical impairment than their counterparts in the urban area. If the older persons in both the rural and urban area experience the illustrated (see figure 2.15) level of problems regarding their physical ability, it give raise for concern regarding their responsibilities, needs and expectations in the world of HIV/AIDS that will be explored in chapter 3 (phase 1, steps 2 and 3). The biggest problems seem to be with bending and walking that refer to flexibility necessary to carry out most of the responsibilities in and around the house and could be a barrier to the older person as a care giver. Problem to use their hands are also impeding regarding care giving aspects and add to the concerns.

2.4.5.6 Discussion on the bio-physical health of the older person

The report on estimated prevalence of HIV by gender and age in 2004, showed a prevalence of 5.8% for men and 0.2% for women in the age group 60-64 years, 1.0% for men in age group 65-69 years and zero prevalence in higher age groups for all gender groups (Dorrington *et al.*, 2004:9). The inferential results demonstrate that HIV infection is a reality and there are older persons suffering in a more personal way than only to be affected by the disease. The average HIV

positive rate under the older persons for both genders in the rural and the urban area is 4.8%. Because older persons are less likely to be tested for HIV (Waysdorf, 2002:49), it is believed that the prevalence of HIV/AIDS infected older persons can be larger in the rest of the older persons population in the communities of the areas where the research was conducted. As referred to earlier, the older men from the rural area present with the highest HIV positive percentage (6.8%) as well as regarding each characterised symptom for lung infections. Taken into consideration that the men in the sample show a slightly higher prevalence of HIV/AIDS as their women counterparts, it is worth mentioning that the men also account for the highest percentage that confirmed to the presence of one or more symptoms of tuberculosis and/or another lung disease.

The symptoms of tuberculosis and/or other lung diseases included in the questionnaire pertained to "cough for at least two weeks", "have any sputum while coughing", "there is blood in the sputum", "loss of appetite" and "involuntary weight loss". The results compiled from the data relied on symptoms as experienced by the older persons from the sample. According to Stellenberg and Bruce (2007:588) tuberculosis should be suspected and a detailed clinical history taken when someone presents with a cough for two weeks. All the participants that presented with a cough were therefore referred to the nearest health facility for follow-up investigation. On history, only two older persons (one man and one woman, both from the rural area) indicated that they have been diagnosed with tuberculosis at a health facility. In contrast to this, the data on questions pertaining to the symptoms, revealed an alarming picture (see paragraph 2.4.5.2 and table 2.9). The results on "productive cough" indicated a threatening possibility for infectivity (Stellenberg and Bruce (2007:590), because 35.6% and 22.7% of the men in the rural (n=21) and urban (n=17) areas respectively seem to report sputum while they cough. As discussed previously in the study, the women are also the caregivers of the ill HIV/AIDS persons (Aboderin, 2005:i). This truth can lead to greatest individual risk factor for tuberculosis in the household because tuberculosis is highly infectious through droplets and airborne. Unfortunately, the older women, the caregiver, also present with reproductive cough, 15.8% for the older women in the rural area (n=12) and 8.1% women in the urban area (n=10). Tuberculosis is the commonest infectious disease worldwide, thus also a great

threat to the health of all South Africans (Stellenburg & Bruce, 2007:588; Uys & Cameron, 2003:100), thus to the older persons included in this study. It is further more evident that there exist a link between HIV/AIDS and tuberculosis infection (Uys & Cameron, 2003:24). Although not the question in this study it comes to mind, why the older persons do not seek help when they have symptoms of lung diseases. Nyblade *et al.* (2003:43) is of opinion that people avoid or delay seeking care because tuberculosis is a HIV related disease and they could be afraid of stigmatisation. Tuberculosis was noted in the 1997 census as the 4th highest single cause of death in men and the 8th highest single cause of death in women (Joubert & Bradshaw, 2001:155). The number of new tuberculosis cases has tripled in high HIV prevalent countries in the last two decades and is the leading cause of death among people living with HIV in Africa and a major cause of death elsewhere (WHO, 2008).

Morbidity and cause of death statistics often show that chronic diseases and disability increases with advanced age (Joubert & Bradshaw, 2006a:210; Szerlip *et al.*, 2005:299). The results discussed here rely on self-reported data collected in the study through the adult questionnaire and revealed that the chronic diseases of the older persons in this sample are tuberculosis, hypertension, cancer, diabetes mellitus, heart diseases, arthritis, asthma and/or other chronic lung diseases. Although the researcher is aware that the information is not very reliable because it was self reported, it contributes greatly in the endeavour to compile a health profile of the older persons infected and/or affected with HIV/AIDS in this study. This information is supported by and corresponds with national information reported by Joubert and Bradshaw (2006a:211) that refer to hypertensive heart diseases, stroke, hyper-lipidaemia, diabetes, cancer, tuberculosis and arthritis as self-reported diseases by older persons in South Africa. The strategic priorities for the National Health System 2004-2009 give special attentions to hypertension, diabetes and cancer as chronic diseases that received greater social mobilisation (SA, 2004:10). The cause of death indicated in paragraph 2.4.5.4 correspond with the self-reported chronic diseases and it should be noted that the prevalence of the chronic diseases together with other infectious diseases like tuberculosis as well as the HIV/AIDS infection place a significant burden on the older person in the world of HIV/AIDS. The associated risk factors marked in the study refer to

hypertension, tobacco- and alcohol use and stress. Factors such as high cholesterol, obesity, underweight and diet were not reported, but could have a definite influence.

Although the specific cause of the self-reported physical impairment that is prevalent in the older persons is unknown to the researcher, the indirect evidence can be found in most of the results previously discussed with regard to the age, gender, household conditions, financial situation, social support, stress and depression, tobacco and alcohol use and chronic diseases. The older persons reported that they have trouble to use their hands, walk, bend, hear and read, some more than others. The mentioned physical limitations indicated in figure 2.15 predict that the older persons' future responsibilities will go hand-in-hand with even more hardship, especially the women that could be responsible for housekeeping chores and care giving responsibilities that could involve a range of physical activities.

2.4.5.7 Conclusions pertaining to the bio-physical health of the older person

- 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.
- 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 that add to their vulnerability.
- 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 that in itself refer to difficulty with household and self maintenance activities.

2.4.6 HIV/AIDS DATA RELATED TO THE OLDER PERSONS

This section refers to questions that relate to HIV/AIDS with a possible effect on the older persons included in the study. It is important to gain background knowledge on factors related to HIV/AIDS and the household of the older persons included in the study.

On the question if the older person knows someone with HIV/AIDS, 53.7% of the urban older women and 30.7% of the urban older men said they do know someone with HIV/AIDS. It is noteworthy that against the results from the urban area, a much smaller percentage of older persons in the rural area indicated that they know someone with HIV/AIDS, 5.1% older men and 3.9% older women' accounts for yes as an answer. Fear for stigmatisation and lack of knowledge can be the reason for this. HIV/AIDS are still a taboo subject in many African countries and remains an obstacle in many ways for the infected and affected older persons. This can even lead to the loss of community support and loneliness of the older persons and the other people in the household (Ferreira, 2004:29).

Figure 2.16 hereafter illustrate the response received on whom the people with HIV/AIDS are that the older persons know in their area of residence. Striking how many older persons chose not to respond to this question. It confirms the large number of older men and women that did not answer the previous question if they know someone with HIV/AIDS.

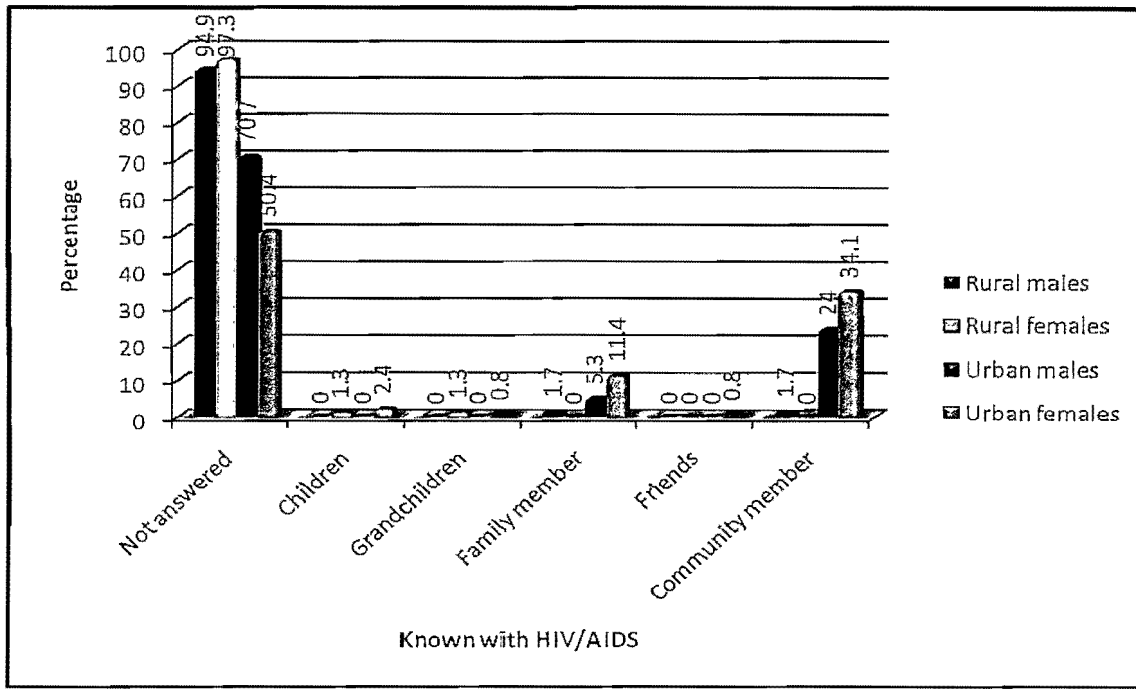


Figure 2.16: Percentage responses of older persons on whom they know with HIV/AIDS

If the older persons answered yes on the question above, and if they know people with HIV/AIDS, they were asked to indicate whether it was their children, grandchildren, spouse, family members, friends or people in the community. Note that the highest number of responses that indicated whom the people is they know with HIV/AIDS, is from the urban older persons. It is remarkable that the respondents (both genders) from the urban area indicated that they know very little people near them (children and grandchildren) against the openness to reveal that they know 24% and 34.1% respectively, community members with HIV/AIDS.

The majority of older persons chose not to answer the question of who the primary caregiver is if someone in the household is HIV positive. 75.4% of the total sample did not answer the question. From the 24.6% that answered this question, 3.65% indicated that the primary caregiver will be the spouse, 14.9% said that in their household it is the parent, whereas 2.4% indicated that a family member cares. Volunteers as primary caregivers count for 0.3%. Although the response rate was low, it gives an indication that care to the HIV/AIDS person in the rural and urban area of residence takes primarily place within the family structures. In practice what has been seen in South Africa, is that families are increasingly taking

responsibility for providing care (Orner, 2006:236-237). Refer to paragraph 2.4.1.1 regarding the gender proportion. The older women present the larger count of the total sample and in addition to this it was found in several studies that women form the bulk of caregivers in the community (HelpAge, 2007:5; Orner, 2006:240).

The question regarding the mean age the older persons consider being the age when people are ill with AIDS or die of AIDS was well answered and only 16.5% of the total older persons included in the study did not answer the question. See figure 2.17 for an illustrated summary.

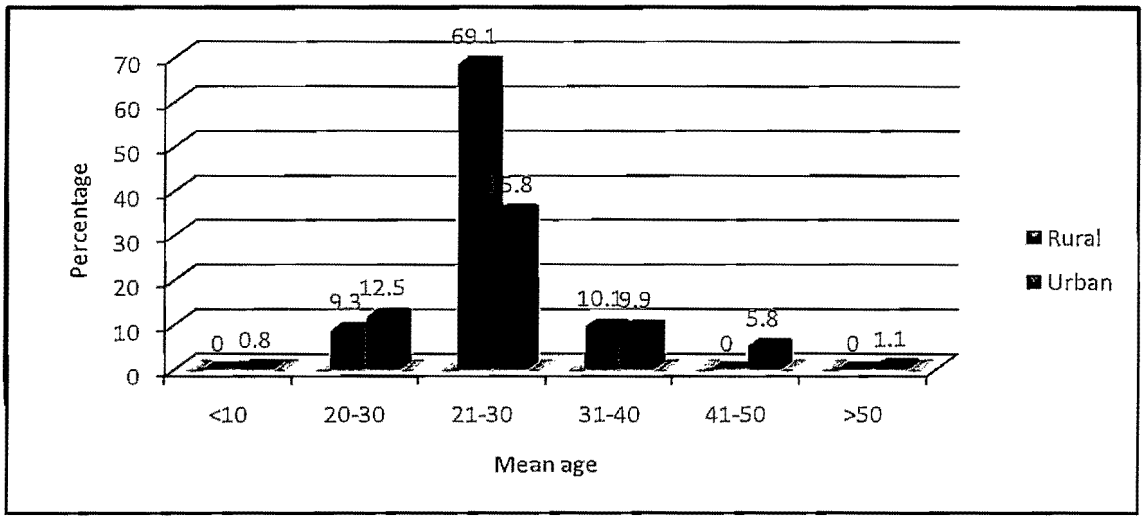


Figure 2.17: Percentage on the mean age the older persons consider being the age when people are ill with or die of AIDS

The results indicated that the majority of older persons (69.1% for the rural older persons and 35.8% for the urban older persons) consider the age between 21 – 30 years when people are ill or die of AIDS.

The last question on HIV/AIDS was whether the older persons care for any orphans in their households. Considering the vague answer given by the older persons on people they know with HIV/AIDS they surprisingly indicated that they do care for orphans in their households. Sixteen older men (27.1%) and 23% of the older women from the rural area said that they care for orphans against the 33.3% and 43.1% of urban older men and urban older women respectively. The reason for this openness could be that if a person acknowledges that they care for an orphan, they can qualify for a foster care and child support grant. The

researcher speculated that the reason for this openness could also be because an "orphan" is also not "my child" or "grandchild" and stigmatisation could not be link directly to the household. Booysen *et al.* (2004:126) add to this suspicion and stated in the final report on trends in access to social grants that considerably higher proportions of affected households have access to social grants. In HIV/AIDS affected households of older persons, this income can alleviates the financial burden of the older persons to some extend (Ferreira, 2004:27).

2.4.6.1 Discussion on the data related to general HIV/AIDS information

The reality that so little respondents answered the question regarding which they know in their area of residence with HIV/AIDS, confirms the researcher's presumption that the older persons are afraid of stigmatisation and therefore prefer to keep the secret. If one looks at the results of the rural areas, it demonstrates that they feel even more secretively about HIV/AIDS matters when it comes to their households. Only 5.1% older men and 3.9% older women respectively from the rural area acknowledged that they know someone with HIV/AIDS. Although the older persons in the urban area were open to say they know someone, they were not prepared to reveal others' in the area they live. The older persons may feel that they should prevent others in the area where they reside from knowing their own as well as the status of their family members in the household out of fear for discrediting and discrimination (Holzemer *et al.*, 2007:1002). In spite of this reality, the majority of older persons indicated that they look after orphans in their households and that the primary caregiver is either the spouse or the parent in the household.

2.4.6.2 Conclusions pertaining to general HIV/AIDS information

- Older persons are afraid of stigmatisation and only a small percentage revealed that they know someone with HIV/AIDS
- Older persons do not have a problem to look after orphans and demonstrate their willingness because they can receive a child support grant

2.5 CHAPTER SUMMARY

In the preceding part, the results on the health profile were outlined to the reader with accompanied discussions on which the researcher made final conclusions.

The HIV/AIDS epidemic gave new meaning to the successful aging of the older population in South Africa because of the added challenges whereby the aging process is complicated. Not only are they dealing with their own aging challenges that refer to the bio-physical-, social-, economical-, and psychological changes, but they need to adjust to other aspects of change, like role- and family structure changes. The older person, traditionally the receiver of support became the source of help to others regarding physical, financial and emotional support.

The women outnumbered the men; they are the caregivers of sick children, grandchildren and raise orphans with the implication of increased responsibilities and a growing need for support, bio-physical, psychological, emotional, financial, spiritual and social. Education as the gateway to development show vulnerability in the older persons' low educational level and the older persons will need supportive health education to understand and manage the magnitude of the effect of HIV/AIDS in their households.

The conclusion drawn in chapter 2, the researcher trust, might provide needed evidence about the older persons' health profile and real life situation in conceptualising the need for community-based collaboration to support the older person in the world of HIV/AIDS.

Phase 1, step 2 and step 3 of the study pertaining to the needs and expectations as well as the strengths and impediments of the older persons infected with and/or by HIV/AIDS are provided in the following chapter.