CHAPTER 3

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

"We are dwellers, we are namers, we are lovers, we make homes and search for our histories. And when we look for the history of our sensibilities...it is to...the stable element, the land itself that we must look for continuity". ---Seamus Heaney--- (in Brady, 2005:979)

Figure 3.1: Schematic layout of the chapters in relation to the different phases and the steps of the research project
3.1 INTRODUCTION

Chapter 2 offered a health profile of the older person, discussed in terms of the different themes of phase one. **Step two and step three** of the same phase (see figure 3.1), the research design thereof, the use of the Mmogo-method™ for data collection, data analysis, reporting the findings and the final conclusions form the focus of chapter 3. The second and third objectives apply, namely:

- **to explore and describe the needs and expectations of the older person infected and/or affected by HIV/AIDS;**

- **to explore and describe the facilitating and impeding factors experienced by the older person infected with and/or affected by HIV/AIDS.**

HIV/AIDS places an added burden on the aged population in South Africa (WHO, 2002:2), which has the largest number of HIV-infection rate in the world because of various reasons, as the findings revealed in chapter 2, paragraph 2.4.6. The study was conducted within the contextual reality of an increasing aging population in South Africa (Aboderin, 2005:4; Mohatle & Agyarko, 1999:6-7) of whom 67% is black (Redelinghuys & Van Rensburg, 2004:270) and 4% of all HIV-infections are found in adults aged 60 and older (South Africa, 2007:9, 24, 29). During the survey of the PURE-SA study 4.8% of the older persons test positive for the HI-virus (see 2.4.5.1). The burden of HIV/AIDS has had devastating economic, social, health and psychological impacts on the older persons. Drewnowski et al. (2003:300) agrees and notes that needs and expectations of the older persons are integrated with the maintenance of their physical and psychological functions, as well as their continued involvement in social activities and relationships. Little is known about the real impact of HIV/AIDS on the older persons in Africa, their health needs, their role in care and the responses of health and other social systems to their situation (WHO, 2002:2).

It is therefore imperative to explore the needs and expectations, the facilitating and the impeding factors experienced by the older person infected and/or affected by HIV/AIDS in their communities in order to gain a better understanding of the problem.
In order to do so, one should be sensitive and acknowledging with regard to the older persons’ social, cultural, temporal and geographical context (Holloway, 2005:275). A matter as sensitive as the older person in the world of HIV/AIDS, compels a consideration of the time, culture and history of the older persons involved. Born between sixty to eighty-five years ago, these individuals have seen and experienced numerous events and developments, such as the rise of HIV/AIDS. Older persons, (central in the study) as the fastest growing group, form part of the vulnerable population groups in the North-West Province of South Africa and as found in a Soweto study, some are infected, but they are mostly affected by HIV/AIDS, which yields them vulnerable due to social, economical, physical, psychological and political factors (Gilbert & Soskolne, 2003:105).

The research design and –methods for **step two and step three** follows hereafter.

### 3.2 RESEARCH DESIGN

Qualitative research makes use of an "emergent design", meaning that the research in a study has the potential to emerge during the research process, which implies that the study is not rigid and can change (Polit & Beck, 2006:59). The research design is subsequently discussed and includes its qualitative nature. It is explorative, descriptive and interpretive, as well as contextual. For consistency, the reader should refer to chapter 1, paragraph 1.6.1, on the research design of the total study.

#### 3.2.1 QUALITATIVE

The lived world, referred to by Banks (2007:ix) as "the world out there", in this study includes the needs and expectations in the older person’s household, as well as the facilitating- and impeding factors experienced in the socio-cultural context. In order to explore the needs and expectations, the researcher visited the older persons in their homes and had personal conversations with them to understand the lived daily world from their perspective (Kvale, 1996:27). It was especially important to conduct data collection in the natural setting where the older person lives and where the
phenomena occur (Streubert Speziale & Carpenter, 2003:23; Kelly, 2006:287). As the older persons talked about and shared their needs and expectations, the truth unfolded. The resultant perception and understanding of the older persons’ situation and experiences partly provided evidence to conceptualise community-based collaboration as a solution to support the older person in the world of HIV/AIDS.

3.2.2 EXPLORATIVE, DESCRIPTIVE AND INTERPRETATIVE

Describing and interpreting findings explored from the world of the participants through qualitative data collection methods means that an act of collaboration is taking place between the older persons as participants who share and describe their real life story (emic nature) and the researcher who interprets the story (etic nature). This part of the study aims to interpret the stories of the older persons. It could call for re-presenting of these stories and it reflects the older person’s ideas (Holloway, 2005:274). The researcher entered the world of the older person infected with and/or by HIV/AIDS to discover their practical wisdom, possibilities on how to manage their needs and expectations and to understand the facilitating and impeding aspects they experience in their households (refer to Polit & Beck, 2006:221).

Consistent involvement during the PURE-SA study gave the opportunity for background information on the reality of the participants, and this became an advantage in the process of conducting step two and step three. The contextual aspects pertaining to this part of the study follow in paragraph 3.2.3.

3.2.3 CONTEXTUAL

In addition to the detailed discussion in chapter 1, paragraph 1.6.1.5 on the context, the reader should notice that the research was executed amongst older persons from an African socio-cultural background with a strong sense of belonging and sharing, and they believe that whatever happens to the individual happens to the whole group (Mbidi, 1990:106). Mbidi (1990:100) as theology-philosopher refers to different symbolic interactions and meanings that exist, and explains that there are “many
different people within the African context, with their own language and common culture with common customs, morals, ethics, social behaviour and material objects like musical instruments, foods and household utensils". The researcher, a community health nurse in South Africa for approximately 30 years, is familiar with the different communities in Potchefstroom where she has been living and working for the last 11 years. This familiarity with the area brings cognisance of the cultural diversity encountered in the study, and raises a sensitive awareness and respect. Results of a previous study revealed that fruitful interaction based on a trust relationship between the community health nurse and the patient, involves a mixture of knowledge, cultural beliefs, cultural rituals and value systems of the people involved in the situation (Watson, 2002:169). Within this study, not only a realisation and appreciation of the African view of man and of the African religious ontology (Mbili, 1990:2), but also the beliefs attitude of the nature of nursing that justifiably relates to the practice of nursing (Chinn & Kramer, 2004:67) could be vital to interpret and give meaning to the information gathered.

A description of the research method is provided in the following section.

3.3 RESEARCH METHOD

The research method of phase one, step two and step three, includes the population and sample, methods used for data collection, the data collection tool and the data analyses.

3.3.1 POPULATION AND SAMPLING PROCEDURE

From the 2021 participants, a sub-population of older persons (n=333) infected with and/or affected by HIV/AIDS, that participated in the PURE-SA study during 2005, were selected for the previous phase one, step one to determine and describe the health profile of the older person (see chapter 2, Figure 2.2). Hereafter an explanation for clarity to the reader on the population for phase one, step two and step three.
3.3.1.1 Population

From the of older persons (n=333), a sub-population of older persons (n=198) infected with and/or affected by HIV/AIDS were selected for phase one, **step two and step three** to explore and describe the needs and expectations and the facilitating and impeding factors experienced by the older persons. The population referred to involved only the urban area.

The researcher had discussions with the president of the Local AIDS-Council and was invited to present the intended study in a meeting with members of the CBO’s, NGO’s and FBO’s at the Department of Health (District office) in the urban area. In the subsequent group discussion the people from the community and officials from Department of Health indicated that they felt that the study is important. However, they stressed the sensitivity thereof and proposed that the researcher should focus on the population of older persons in the urban area only, as

- the researcher is a community nurse specialist actively involved in various community projects for the past eleven years with a well established trust relationship in this community and can use the known environment (urban area) to operationalise community-based collaboration to support the older person in the world of HIV/AIDS to move on to the unknown (rural area) for further operationalisation,

- the researcher’s methodological assumptions embedded in the participatory (co-operative) inquiry paradigm (Botes, 1995:11; Guba & Lincoln, 2005:197) needed the trust relationship and involvement referred to, that was not possible in the rural area,

- most qualitative (naturalistic) studies involve a relatively small group of participants (Polit & Beck, 2006:17), and the nature of the research method used (see 3.3.2.2) is an in-depth investigation with regards to a rather sensitive issue, HIV/AIDS.
3.3.1.2 Sample

The sample and the context of the participants were selected purposively as it is the intention of the researcher to understand the rather sensitive problem that involves HIV/AIDS and the questions in the research (Creswell, 2003:185). Purposive selection of participants was done in this study because it was a specific group of people in the community that was needed for their particular knowledge of a phenomenon (Streubert Speziale & Carpenter, 2003:67). The older persons infected with and/or affected by HIV/AIDS was a specific group with a unique lived experience pertaining to their needs and expectations and facilitating and impeding factors experienced in this world of HIV/AIDS. In the qualitative research, the purpose was to listen to what the older persons’ had to say, and the fieldworkers knew which of the older persons infected with and/or affected by HIV/AIDS were willing to share their lived experience.

Inclusion criteria entailed the following:

- all older persons (n=198) that lives in the urban community
- age >60 years
- infected with and/or affected by HIV/AIDS
- spoke English, Afrikaans and/or Setswana
- voluntary participation and written consent apply

From the total population of older persons (n=198) from the urban area, thirty-five older persons infected with and/or affected by HIV/AIDS were purposively invited by the fieldworkers to participate in this phase of the study. Seventeen accepted of which ten (n=10) turned up to participate in the data-collection process (see paragraph 3.3.2.3).

The researcher judged the size of the sample for phase one, step two and step three on the purpose and rationale (see figure 3.1) as well as the contextual nature
(see paragraph 3.2.3) of the study (refer to Polit & Beck, 2006:273). Data collected from older persons infected with and/or affected by HIV/AIDS through the in-depth Mmogo-method™ and a focus group (see paragraph 3.3.2.2 and 3.3.2.3) resulted in a full and rich description of the needs and expectations as well as the facilitating and impeding factors they experience. The quality of the data (Polit & Beck, 2006:273), particularly in this study, that involved the cultural sensitive Mmogo-method™ (see table 1.4 and paragraph 3.4.2.2) affected the sample size. One focus group with ten older persons were adequate for a rich description of the needs, expectations and facilitating and impeding factors experienced by the older persons in their various households.

Subsequently a layout on the data collection follows.

3.3.2 DATA-COLLECTION

After a brief explanation of the method of data-collection (referred to as the pilot study) and the outcome, a detailed layout of the final data-collection method implemented and the process of data collection follows.

3.3.2.1 Introduction

Semi-structured interviews was initially planned as an option as a data-collection tool for this step of the research because the researcher knew what should be asked, but could not predict the answers (Morse & Field, 1998:76). Unfortunately, when the interview schedule was tested in the field, it was found that the information was vague and platitudinous. It was also difficult for the older person to communicate her lived reality in relation to the context of HIV/AIDS.

Although the structure of the interview did come close to an everyday conversation and encouraged active participation (Foley & Valenzuela, 2005:223; Kahn, 2000:61), the researcher realised that although the participant was willing, there could be more than one reason for the retentive attitude, and after a one-and-a-half hour open discussion it seemed that the following aspects were problematic:
• The language proficiency of the participant, as she was a Setswana woman that understood Afrikaans and English poorly;
• Familiarity between the fieldworker and the participant. The translator who was the fieldworker led the participant in what to say;
• It was very painful for the participant to talk about her experience in her lived world, because she has a son who lives with her that is HIV-infected (it was as if the words could not flow to express her needs and expectations);
• The older person had trouble to express abstract concepts like HIV/AIDS with emotional content.

The participant and the fieldworker that are both actively involved in community work and self-help groups of the older persons in the area where the research was done, proposed to the researcher to rather use group discussions. In a group the older persons will not feel so vulnerable and the group can share the pain. Although the community knows the researcher, she is not from the same community. The reading of Mbiti’s work (1990:106) helped to shed some light on deeply embedded cultural differences between the researcher and the older persons as participants.

After reflection on the results of the mentioned “pilot study”, as well as the researcher’s sensitivity to the older persons’ feelings in the community regarding HIV/AIDS, a psychologist specialised in community psychology was consulted. The researcher was introduced to the Mmogo-method™ that will allow the older persons to construct their lived experiences in interaction with one another (Roos, 2008:2). In the following section a detailed discussion on the Mmogo-method™ as qualitative data, collection tool follows.

3.3.2.2 The Mmogo-method™

The Mmogo-method™ is a culturally sensitive technique (Roos, 2008:3), and is a form of art through which the participants can create visual images to present information, both concrete and abstract (Banks, 2001:23; Roos, Maine & Khumalo,
The older persons were able to share and co-construct their social reality about their needs and expectations as well as the facilitating and impeding factors they experience regarding support in their different worlds of HIV/AIDS in the communities they live.

As discussed previously in this research, the main purpose of the study is to conceptualise community-based collaboration to support the older person in the world of HIV/AIDS. The exploration of the variables pertaining to HIV/AIDS and their personal lives, was very personal, and although the researcher was sensitive to that, the focus was on a cognitive understanding and clarification (Kvale, 1996:29) of the participants' needs and expectations, as well as the facilitating and impeding factors experienced by the older person infected and/or affected by HIV/AIDS.

Franklin (2000:2) experienced that concrete art forms can make a difference and it has the ability to communicate reality that was previously wordless, with amazing accuracy (the researcher would like to refer the reader back to the “pilot study” as described earlier in the study in 3.3.2.1). It was important to discover the most appropriate method to answer the research questions (Streubert Speziale & Carpenter, 2003:17). The “pilot study” confirmed that an alternate method than the personal research interview should be more appropriate for this part of the study. The Mmogo-method™ as an alternate technique explored the unconscious processes of the older persons through the creation of social images (artefacts) and had the ability to trigger communication that resulted in a spontaneous sharing of symbolised social meaning (Roos, 2008; Roos, Maine & Khumalo, 2008). The older persons told stories relating to the objects (social images or artefacts) they created with familiar cultural items, such as clay, dried grass stalks, colourful beads and a cloth to work on (Roos, 2008:7). The visual forms were socially comprehensible and socially appropriate (Banks, 2001:43; Roos, 2008:8) for the older persons to be able to reflect the social processes in the community relevant to the study, and the researcher could utilise the opportunity to explore the complex and often sensitive issues pertaining to the older person in the world of HIV/AIDS.
Apart from the researcher's awareness regarding the rationale for the use of the Mmogo-method™ as a qualitative technique in the research and more specifically in this chapter, it was important to inform and plan the process of the Mmogo-method™ with the older persons purposively selected for phase one, **step two and step three** (refer to paragraph 3.3.1.1 and 3.3.1.2). The focus group discussion as technique used to compliment the Mmogo-method™ is outlined as applied to this part of the study.

### 3.3.2.3 The focus group

Babbie (2007:308) describes a focus group as "a group of people brought together in a room to engage in a guided discussion of some topic" and as Kamberelis and Dimitriadis (2005:903) say, "focus groups often produce data that are seldom produced through individual interviewing and observation and that result in especially powerful interpretive insights". The statement made explains the use of the focus group as alternate to individual interviews (refer to paragraph 3.3.2.1). There are important aspects to consider when conducting a focus group and the researcher used the following components to plan the focus group as introduced by Krueger (2003:2-5):

- **Participants:** the group were all older persons with a common concern; HIV/AIDS, and has been purposively selected by a local known fieldworker; with the sensitive topic of HIV/AIDS the groups should be small; ten older persons attended the focus group.

- **Environment:** the place where they met was comfortable, convenient and familiar to the participants, the focus group was conducted in the living room of the fieldworker and it was a welcoming location known to all of them.

- **Moderators/facilitators:** the facilitator was a specialist psychologist in community psychology and the founder of the cultural appropriate Mmogo-method™, thus the ideal choice; the fieldworker acted as a translator only
when needed because most of the older persons could speak Afrikaans or English, which solved the language problem.

- **Question design:** the questions used in a focus group should be carefully phrased, and although the specialist psychologist in community psychology planned one open-ended question (see the box indicated in paragraph 3.3.2.4), she had enough experience to ensure that the needs, expectations as well as the facilitating and impeding factors experienced by the older persons were explored. The researcher had an interview schedule at hand (see Appendix E) which the facilitator studied beforehand.

- **Analysis:** the analysis of the focus group data was systematically done as explained in paragraph 3.4.3.

The procedure applied to the Mmogo-method™, including the focus group technique, follows hereafter.

**3.3.2.4 Procedure applied using the Mmogo-method™**

From the seventeen older persons that accepted the invitation to participate in the Mmogo-method™, only ten showed up on the final day of appointment. They were welcomed and seated around a large table and the researcher and the fieldworker made sure that they were comfortable. The purpose of the study, the Mmogo-method™ and the focus group was explained to the older persons and they were given the opportunity to internalize the information as stated in the information letter before they gave written informed consent (see Appendix E) to participate in the process. They had time to ask questions and clarify any uncertainties on the study.

During the initiation phase, the researcher clarified the role of the fieldworker with the older persons and the older persons demonstrated through their social interaction that they feel comfortable with the presence of the fieldworker. The role of the fieldworker in the study was to help and support the facilitator with the understanding and interpretation of words, cultural beliefs and translation of words and parts of the
conversation that will be in the mother tongue of the older persons, namely Setswana.

A psychologist specialist in community psychology and her research assistant that was familiar with the Mmogo-method™ facilitated the process. The researcher and the fieldworker were actively involved in the process, observations and field notes were made of the whole process to capture any un-spoken body language and happenings during the process that could enrich the data in an endeavour to view the reality of HIV/AIDS from the older persons' point of view and in their natural context.

Each participant were subsequently provided with known cultural items, namely dark beige modelling clay, dry grass-stalks, colourful beads and cloths. The research facilitator asked the participants to use the clay and the other items to make a visual presentation/image following an open-ended question to obtain optimal information on their needs, expectations as well as facilitating and impeding factors experienced by them in the world of HIV/AIDS (see photo 1 for an example of the cultural items).

![Photo 1: Example of cultural items used to make visual images](image)

The open-ended question was asked as indicated below.

*Could you please make a visual presentation of any aspect of your experience of HIV/AIDS?*
The older persons were provided with an opportunity to complete their visual images (refer to Appendix H) that served as messages of inhibited thoughts and feelings originated from deep within their psyche (Franklin, 2000:20). When all participants completed their visual images, they had the opportunity to explain what they created.

The group spontaneously engaged in discussions within a relaxed environment. The discussion referred to was a "carefully planned discussion designed to obtained sensitive information on HIV/AIDS in a permissive, non-threatening environment" as Krueger (in Litosseliti, 2003:1) defined focus groups. The focus group discussion was used to obtain more information after the Mmogo-method™ was applied. The Mmogo-method™ actually stimulated and caused the open environment as referred to by Krueger (2002).

Through the process that involved the Mmogo-method™ the older persons contributed in their own unique way and shared their thoughts with each other on the needs and expectations regarding support of the older persons in the world of HIV/AIDS. The research facilitator acted to the challenge and controlled the dynamics in the group without any participant dominating the discussion. All the older persons as participants had the opportunity to share and respond to comments, ideas and perceptions (Litosselliti, 2003:1) about the visual images.

The visual presentations of the culturally embedded symbols were photographed with the necessary permission and the obvious patterns, themes or relationships pertaining to the visual presentation (Roos et al., 2008:9 & 11) discussed with the older persons, was voice recorded. Observations were made with accompanying field notes (see paragraph 3.3.2.5) that helped the researcher to a deeper understanding of the context in which events occurred (Chigeza et al., 2007:7). The older persons took an active role in the research process, from the question of interest to the outlets of findings (Guba & Lincoln, 2005:197). The researcher believed that the older persons should speak for themselves through the presentation of an artefact; the researcher looked and listened to analyse and interpret their messages on a rather sensitive issue, namely HIV/AIDS, brought to the front.
3.3.2.5 Field notes

Part of recording the data of the group discussion that accompanied the Mmogo-method™ was the taking of notes. The researcher and research assistant (Ferreira & Roós, 2008:23) took field notes during the process of the Mmogo-method™ and focus group discussion. Burns and Grove (2005:433) state that research reports often read as if all went well, but that is not always true. The researcher was aware of data-collection problems that occurred, like people-, researcher-, institutional- and event problems. The field notes helped to remind the researcher of these events. The field notes entailed the time and interview procedure (methodology notes), the behaviour of the respondent (observational notes of the older persons' facial expression, gestures and reactions) and own thoughts of the researcher (personal notes).

3.3.2.6 Transcribing the group discussion

The whole process of the Mmogo-method™ and focus group discussion was voice recorded and then transcribed verbatim afterwards (see Appendix G for an example of a part of a transcribed interview). The focus group discussion was in Setswana, Afrikaans and English, it was thus necessary to ask a translator that can speak all three languages and understand the context of the African culture to do the transcription. An African community nurse specialist and senior lecturer that did extensive community work on HIV/AIDS issues did the transcribing and were able to double check the interpretation of the fieldworker, participants and facilitator. Written instructions were given to the transcriber on how to transcribe the spoken material according to a standard format. The detailed discussions that followed on the completed visual presentations were important to gain new knowledge on the needs, expectations, facilitating and impeding factors experienced by the older persons infected with and/or affected by HIV/AIDS.

3.3.3 DATA ANALYSIS

The visual images were not studied alone as an object whose meaning was intrinsic to them, the ways in which people (the older persons) assigned meaning to them was what interested the researcher. In the particular socio-cultural environment (older
persons, mostly from a black African culture) the researcher associated certain visual images with certain meanings and considered both their content and context (Banks, 2001:9-10). Cultural explanations and patterns were inductively "discovered" within the cultural context (Morse & Field, 1998:198) and was not analysed from a specific perspective or on a prior framework or theory.

There are different approaches described by Wright (in Banks, 2001:10) in the reading or interpretation of visual presentations and they are never fixed. In this study, the researcher believed that different approaches influenced the way in which the meaning of the visual presentations was intended and interpreted. The **realist** will see and try to present visual images as accurate and true to life as possible ("looking through"), the **formalist** will be excessively concerned with the form of the visual presentation ("looking at"), rather than to see the content and an **expressionist** will try to convey a thought or feeling of the inner world of emotions ("looking beyond") rather than the external reality (Banks, 2001:10).

The researcher believes that a little of each approach applied in the manner she looked at the visual presentations, and was concerned with the social rather than the individual construction of meaning which reflected the African ontology of "togetherness" (see paragraph 3.2.3). The Mmogo-method™ complimented the symbolic interactions framework where social life is studied through exploration and inspection (Roos, 2008:11).

The researcher and a co-analyst that is the founder of the Mmogo-method™ analysed the data (photo of the visual presentation, the transcribed spoken words and the field notes). The method of data analysis is subsequently presented for the reader.

**3.3.3.1 Method of data-analysis regarding visual and textual data**

Semiotics, the science of signs or objects was used to analyse the data because of its systematic analysis nature of symbolic systems (Manning & Cullum-Swan,
The visual images created by the older persons through the culturally focused Mmogo-method™ presented meaningful data constructed through their senses, embedded in their minds to understand their changing circumstances influenced by the historical socio-cultural changes (Brady, 2005:1006). The visual data analysis was done on two levels and four steps, namely the explicit analysis and the implicit social-cultural analysis as adopted from Roos (2008:12).

An outlay of the process used in the data analysis of the Mmogo-method™ in table 3.1 and the compliant photo follows. The photo (photo 2) of the visual image that was made by the participant follows hereafter and then the continuing outlay of the process. The participants granted permission to use and publish the photos taken of the images they made.

**Photo 2: Table decorated with beads**

The participant explained that the table made with clay was too heavy and fell down through the straw sticks.
Table 3.1: Data analysis process pertaining to the Mmogo-method™ (adapted from Roos, 2008:12)

<table>
<thead>
<tr>
<th>Level 1: Explicit analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The visual images made by the older persons consist of a number of components that implies that the researcher must understand the physical objects made. It is the content of the images, the internal narrative or the story that the images tell (Banks, 2001:11; Roos, 2008:12).</strong></td>
</tr>
</tbody>
</table>

| Step 1 | Ask the participants about each visual object/artefact that was made, including the activity, gender and surroundings | The older persons responded with enthusiasm and gave a full explanation about each object. "...this is a table with four legs where all the people gather to eat....it is everyone, women, men and children..." |

| Step 2 | Determine the relationships between the different objects in the visual presentation | This was sometimes difficult for the older persons to understand, but with clarification and with the help of the fieldworker, they could manage. "...the table is in the house...part of the house...and it is for everyone to join in (all the colours of the beads mean all eat together..." |

| Step 3 | Apply the visual presentation to the initial research question | The research facilitator probed the older women and asked: "Tell me what does the table mean then for the understanding of HIV/AIDS?" |

<table>
<thead>
<tr>
<th>Level 2: Implicit social-cultural analysis</th>
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<tbody>
<tr>
<td><strong>Analysis on this level means that the researcher should have insight into the social practices and cultural context that explains the meanings attached to the physical objects. Banks (2001:11) refers to this as the external narrative, when the researcher looks beyond the visual image for information about the world.</strong></td>
</tr>
</tbody>
</table>

| Step 4 | Explore the contextual meanings that are manifested in the symbolic use of the objects | When the older persons completed their artefacts, the research facilitator explored their thoughts beyond the object that they made and discussed the emerging themes and relationships thereof. This was where the older person and the researcher act as an expressionist and tried to convey thoughts or feelings of the inner world of emotions. The research facilitator respond further to the table as object: "Yes, we should come together...that is what we have been saying...now I want to understand...can you help me to understand?" |
3.3.3.2 Method of data-analysis regarding the textual data

The spontaneous group discussions that emerged between the older persons as group members and the facilitator during the data-collection process were transcribed into text with multiple underlying meanings. The interpretation of the data existing from a hermeneutic intention is valuable to unveil possible concealed meanings in the phenomena, a deeper understanding of the lived experience of the older persons in the world of HIV/AIDS. The researcher used the interpretive content analysis approach of Paul Ricoeur as explained in Streubert Speziale & Carpenter (2003:63), which consists of a series of analytical steps proceeding “from a naïve understanding to an explicit understanding that emerges from explanation of data interpretation”. The applicability of this approach finds its value for the researcher in this study that is contextual of nature, as it acknowledge the connectedness between epistemology (interpretation of the data captured through the focus group discussion of black African older persons) and ontology (interpreter that is the researcher with own world view). The approach of Paul Ricoeur (Streubert Speziale & Carpenter, 2003:63) consists of three main steps. The researcher used table 3.2 in an endeavour to explain the process of qualitative content analysis according to Paul Ricoeur’s approach, the steps and accompanying activities thereof.

The analyses of the visual images and content analysis were inseparably linked to each other and it was not possible to analyse the visual image without the richness of the spoken word of the older persons that was transcribed into text. The Mmogo-method™ was not a purpose on its own, but rather a valuable aid that helped the older persons to create their thoughts in a tangible visual image. What the researcher observed during the group session was that the Mmogo-method™ created a relaxed environment for the older persons. The explanation of the visual image and spontaneous conversation that followed resulted in easiness during the intercourse of the discussion on a sensitive matter, namely the devastating HIV/AIDS. This gave an in-depth understanding and meaning to the study and helped the researcher to interpret and describe the data with a correctness and honesty.
Table 3.2: The Paul Ricoeur approach in the content analysis (adapted from Streubert, Speziale & Carpenter, 2003:63)

<table>
<thead>
<tr>
<th>Step 1: Naïve reading that focus on manifest (the visible or obvious) content as well as latent (the underlying meaning) content. Unit of analysis also apply here for naïve reading refer to the reading of all words and phrases written in the transcript.</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The researcher read the text without any critique as a whole just to become familiar with the text (gain a sense of the whole text)</td>
<td></td>
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<tr>
<td>• The researcher starts to formulate thoughts</td>
<td></td>
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<tr>
<td>• The first impressions of the text were documented on the right hand column of transcript</td>
<td></td>
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<tr>
<td>• The researcher and the research facilitator of the Mmogo-method™ discuss their first impression on the whole text</td>
<td></td>
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</tbody>
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<table>
<thead>
<tr>
<th>Step 2: Structural analysis focus on a meaning unit (pattern of words or statements that relate to the same central meaning, also referred to as a content unit, coding unit, idea unit or textual unit). Condensation (process of shortening while still preserving the core) and abstraction (descriptions and interpretations on a higher logical level)</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Researcher identified patterns of meaningful connection by dividing the text into meaning units through condensation and abstraction (it was done through reading, underlining and writing)</td>
<td></td>
</tr>
<tr>
<td>• The written text from the focus group is condensed by the researcher in such a manner that the core meaning of what was said is preserved</td>
<td></td>
</tr>
<tr>
<td>• The researcher creates labels for every transformed meaning unit that is coding, categorising and theming of the content units through abstraction. Categories can include a number of sub-categories and sub-sub-categories</td>
<td></td>
</tr>
<tr>
<td>• The researcher and the research facilitator of Mmogo-method™ discuss the shortened meaning units that are grouped together under different codes, categories and themes</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step 3: Interpretation of the whole involve the latent content and abstraction.</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The researcher reflects on the whole process of reading of the text, labelling of meaning units as coding units, categories and themes to make sure that she have a clear understanding of the findings</td>
<td></td>
</tr>
<tr>
<td>• The researcher read several times through the interpreted findings and descriptions and made notes on the right hand column of the transcript</td>
<td></td>
</tr>
<tr>
<td>• The researcher and the research facilitator of the Mmogo-method™ had a final consensus discussion on the results</td>
<td></td>
</tr>
<tr>
<td>• The researcher made final adjustments to the results and start with documentation, which also involve literature control</td>
<td></td>
</tr>
</tbody>
</table>
3.3.4 LITERATURE CONTROL AND THE MMOGO-METHOD™

After the results from the visual images, the textual data and field notes made during the process of Mmogo-method™, was finalised and consensus reached on the themes and sub-themes of the results, literature was used as an aid to substantiate or contrast the findings. The use of the literature at this stage was appropriate due to the inductive nature (Creswell, 2003:33) of the qualitative Mmogo-method™. A scientific basis was provided through literature control to elaborate on the themes and sub-themes and where literature was not found on a finding, it was interpreted as a unique finding and was indicated as such. The conclusions drawn from the findings and the existing literature were used to conceptualise a framework for community-based collaboration to support the older persons in the world of HIV/AIDS.

Literature was drawn from the following data bases: Academic Search Premier, AIDSearch, ArticleFirst, A-Z e-article list of the NWU, Cinahl, Google Scholar, Health Source: Nursing/Academic edition, Medline, Nexus, PsycInfo, Thesis and dissertations (NWU), Repertoire of South African Journal articles, NWU library, Inter-library loans, Sabinet, SACat, ScienceDirect, WebFeat.

3.3.5. RIGOUR AND THE MMOGO-METHOD™

Rigour in research ensures that it is reliable and valid; otherwise, it can be argued that the research is worthless, represent fiction and has no use (Morse et al., 2002:2). As discussed in chapter one, the researcher's methodological assumptions are embedded in the participatory inquiry paradigm (Heron, 1996; Heron & Reason, 1997:289-290 as referred to by Guba & Lincoln, 2005:197). The participatory inquiry paradigm includes hermeneutic elaboration 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). The researcher, with her own personal prejudice and hermeneutic intentions, tries to make sense, understand, interpret and
construct the needs and expectations of the older persons in their lived world of HIV/AIDS by observing, listening and talking.

Challenges arise in the methodology with its qualitative nature to ensure trustworthiness applicable to the study. The researcher decided to use Guba's model for trustworthiness as discussed by Krefting (1991:215) and Morse et al. (2002:5) that contains four criteria, namely credibility, transferability, dependability and confirmability.

3.3.5.1 Credibility

Deals with the focus of the study and refers to confidence in how well data and processes of analysis address the intended focus (Graneheim & Lundman, 2004) and how true the findings gathered from the participants' lived experiences in a specific context are. The prolonged involvement, selection of the participants, interview technique, triangulation and reflexivity as strategies were used (Krefting, 1991:215).

- **Prolonged and varied field experience**

  The researcher was actively involved (twelve weeks) in the PURE-SA study (see chapter 1, paragraph 1.1, page 8-10 and table 2.1) in the research process on a daily basis, responsible for the HIV-rapid testing that included pre-and post-counselling, home visits, referral management and training of fieldworkers.

- **Selection of participants**

  The entire population of older persons from the urban area that were involved in the PURE-SA study was invited to participate in the Mmogo-method™ and focus group. Two of the fieldworkers responsible for home visits invited the older persons in their various areas. The participants had lived experience, they were infected with and/or affected by HIV/AIDS, they were from different age groups older than 60 years, men and women, and decided on their own
that they want to contribute and take part. As participants the older persons were the best sources of information regarding the needs and expectations for community-based collaboration to support the older person in their world of HIV/AIDS.

• Interview technique

A pilot study was executed (see 3.3.2.1) and the researcher consulted with some of the older persons, the fieldworkers and a psychologist specialist in community psychology regarding the best way to collect data in the context of HIV/AIDS, which seemed extremely sensitive to the black African older persons. It was then decided on the culturally sensitive Mmogo-method™ and it resulted in the most appropriate method for data collection within the given context. The researcher is known to the community and the participants were part of the whole process that was facilitated by an expert in the field, which ensured a balance and prevented over-involvement, and it rather inspired them to open up and discuss sensitive matters.

• Triangulation

Different perspectives and methods were used throughout the complete research project to contribute to integrated conclusion for community-based collaboration to support the older persons in the world of HIV/AIDS. Refer to chapter 1, table 1.2 regarding the layout of the whole study, the quantitative survey that was done in chapter 2 (health profile on PURE-SA data), the Mmogo-method™ with a focus group in chapter 3 (needs, expectations, facilitating and impeding factors of the older persons) and the qualitative individual interviews in chapter 4 (perceptions of the stakeholders).

Literature substantiated results in the study, consensus discussions held with a community psychologist, study leaders as research specialists, other PhD students and Tswana colleagues confirmed the questions and cultural context of the study.
**Reflexivity**

The researcher reflected on her multiple roles during the study on a regular basis. These roles included being a community nurse specialist with clinical responsibilities (see chapter 2, table 2.1) and a researcher that played an active role in the whole research process. Reflection on questions, problems and frustrations concerning the whole research process raised awareness to the researcher’s own biases and preconceived assumptions.

### 3.3.5.2 Transferability

Transferability refers to the extent to which findings can be transferred to other settings or groups (Graneheim & Lundman, 2004; Krefting, 1991:216), in other words do the findings of this study apply to a context outside the context of this study.

- The researcher does not assume that the results and the conceptual framework will be applicable to another context, but the reader of the study can decide if there is an aspect of the study that is useful.

- The researcher believes that the method (Mmogo-method™) used for data collection is so unique and culturally sensitive that it could be transferable to similar situations where readers may experience the same difficulty with a culturally embedded context.

- The research process consists of rich and dense descriptions that allow the reader to decide if it is useful in other settings.

### 3.3.5.3 Dependability

It refers to consistency, whether the results of this study will be the same if repeated with the same respondents in the same context. It is the uniqueness of the lived experience of the respondents that is important in qualitative research rather than
repetition and therefore one can expect variability. Krefting (1991:216) states that dependability implies variability that can link to identified sources.

- The context in which the study was done changes from day to day because of the enormity of the HIV/AIDS related problems. The researcher had no intention to repeat the study with the same respondents in the same context and can therefore not claim that the results will be the same if repeated. The study helps the research community and the respondents to understand the problem under investigation for future planning.

- The researcher was aware that there could be more instability resulting in methodological changes and could account for it (Rodwell & Byers, 1997). The pilot study resulted in data collection decisions that had to be altered (see 3.3.2.1).

- During the whole research process, the researcher learned much from the respondents and a variety of sources: through field notes of all encounters with respondents, follow-up home visits, base-line data available on the older persons and changed situations like newly HIV-infected older persons.

- Audibility was ensured in that the decision trail used by the researcher was clear and easy to follow by another researcher, if any description was not clear the co-coder, the study leader and co-leader would clarify and ask for corrections.

### 3.3.5.4 Confirmability

It is necessary to ensure freedom from bias in the research procedures and results. Neutrality was achieved when truth-value and applicability were established (Krefting, 1991:221), the results of the study should link to the data themselves (Rodwell & Byers, 1997).
• The research was conducted through multiple methods (survey with descriptive statistics), visual research method (cultural sensitive Mmogo-method™), focus groups, personal research interviews, statistical analysis, explicit analysis and implicit social-cultural analysis of visual images, interpretive content analysis and content analysis through cognitive mapping.

• All base-line data was on the SPSS data base, raw data was systematically filed since fieldwork when PURE-SA started in 2005, all other data (photographs, field notes and text of Mmogo-method™ group sessions), electronic voice recordings are saved on the hard disk of a computer as well as on a CD as back-up together with all the transcribed text.

• The researcher gave a clear and dense description of the research process for possible auditing by other researchers to strengthen rigour.

3.3.6 ETHICAL CONSIDERATIONS AND THE MMOGO-METHOD™

Although ethical issues regarding the study were dealt with in chapter 1, a layout of special ethical issues that could manifest in this part of the study follow hereafter. The researcher was sensitive to it and aware of what is right and what is wrong in any given situation (Babbie et al., 2004:520), in other words do good to the participant and avoid harm (Streubert Speziale & Carpenter, 2003:311). Ethical issues may arise in the researcher's interaction with the older person infected and/or affected with HIV/AIDS. The aim of special care concerning confidentiality when HIV/AIDS issues are involved is because stigmatisation can be extremely harmful to the older person as part of vulnerable groups (Hewitt, 2007:1152), their households 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 experiences 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). The ethical considerations and the key elements pertaining specifically to the Mmogo-method™ will subsequently be accounted for in the discussion that follows.

3.3.6.1 Voluntary participation

The qualitative design and methodology should honour the principle of voluntary participation and try not to intrude into people’s lives (Babbie, 2007:27).

- To reach the objectives in this part of the study, namely to explore the needs, expectations and desires of the older persons in the world of HIV/AIDS, the culturally sensitive Mmogo-method™ was chosen to explore the lived world of the older persons. The process was explained to the participants who engaged voluntary in the process after they had signed the consent form. Participants were also informed that they could withdraw at any stage.

- The researcher had the opportunity to engage the older persons in the community through meetings and follow-up home visits, which enhanced their involvement (Roos, 2008:9) in conducting of the study. The researcher's presence among the group of older persons on a regular basis in the community resulted in formal (research permission from Department of Health) and informal (establishing trust) social negotiations (Banks, 2001:119).

3.3.6.2 No harm to the participants

The revelation of information should not embarrass the participants or influence their lives in their households, neighbourhood and community amongst their family and friends (Babbie, 2007:63). Some research populations are vulnerable and need special protection, this vulnerability could refer to participants because of the sensitivity of the topic and the social context (Hewitt, 2007:1152). Qualitative
researchers should take special care when analysing words and images of participants (Morse, 2007:1005) regarding the promise of confidentiality in the consent forms.

- The researcher and the research facilitator were aware of the sensitivity of HIV/AIDS and the vulnerability of the older persons, who come from a different cultural context than the research team. The researcher, as a specialist community nurse, was familiar with the community's social composition, the geographical area, as well as most of the cultural customs and beliefs (Roos, 2008:9).

- Before the onset of data collection, aspects pertaining to anonymity, confidentiality and privacy were discussed and it was explained how the researcher will organise and manage the photographs of the visual images made by the participants, as well as the discussion that was voice-recorded. The process of data analysis was explained and the transcribers involved signed a vote of confidentiality contract.

- The researcher complies with the Declaration of Helsinki regarding vulnerability (Hewitt, 2007:1152) of the older persons, and special care was taken to accommodate the older persons that had problems to attend the group session because of physical impairment and no transport.

3.3.6.3 Representation of participants' visual images and accompanying words within social contexts

Qualitative research is concerned with exploration, descriptions and interpretations of participants' experiences of HIV/AIDS related to the visual images, and one should be careful of distorted interpretation, which means that the inductive nature of the research should not be tampered with (Hewitt, 2007:1153; Roos, 2008:9).

- The research facilitator, as a community psychologist, is an expert in communication techniques and through the use of clarification,
paraphrasing, reflection and summarising, the research facilitator ensured that distorted interpretations were eliminated. The researcher will give feedback to the participants regarding the results and ensure that the participants stay in control of their visual images with their personal meaning in order not to lose control over self-identity (Hewitt, 2007:1153).

- The researcher worked in the field with a manageable number of older persons, marked by a trust relation (Banks, 2001:129), and the research facilitator and research assistant managed the Mmogo-method™ in such a relaxed “down-to-earth” manner that their professional backgrounds had minimal influence (Hewitt, 2007:1151) on the process of the group session and the participation of the older persons.

- The social constructivist nature of the study forced the research facilitator to recognise different versions of realities given by the older persons with more than one potential world of meaning. The “need for self-reflection and empowerment” of the older persons as participants “without researcher-driven agendas” (Hewitt, 2007:1150) was the intention during the Mmogo-method™.

3.4 RESULTS AND DISCUSSION

The findings indicated in this chapter form part of a larger research project, as explained earlier in the study (see chapter 1, table 1.2 and figure 3.1). The discussion of the results that follows hereafter is an integrated discussion of the visual and textual data. The biographical data of the ten (n=10) older persons that participated in the Mmogo-method™ is included for the sake of background information.
3.4.1 BIOGRAPHICAL DETAILS OF PARTICIPANTS

Before the findings are proposed to the reader, a brief outlay of the biographical details of the participants follows in table 3.3.

Table 3.3: Biographical data of older persons (n=10) that participated in the Mmogo-method™

<table>
<thead>
<tr>
<th>Age</th>
<th>All participants were older than 60 (inclusion criteria for older persons in sample), five were in age group 60-64 years, two in the age group 65-73 years, while three presented the age group 74-83 years.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Only two males attended the session, the other eight were females.</td>
</tr>
<tr>
<td>Marital status</td>
<td>Six of the participants were widowed, four were currently married, either rightfully or by common law according to traditional beliefs.</td>
</tr>
<tr>
<td>Education</td>
<td>The education levels of the vast majority of older persons, in both genders and the rural and urban area are low, and this is reflected in the group of older persons also. Three (3) of them had no education, five (5) had education on primary level and only two (2) had education on secondary level.</td>
</tr>
<tr>
<td>Place of residence</td>
<td>Eight (8) older persons that attended the group session live in their own houses and are the head of their household. The other two (2) females live with their extended families and are not the household heads.</td>
</tr>
<tr>
<td>Health</td>
<td>The older persons that attended the session were all able to walk (one female had trouble and walked very slow). They said that their general health was good. All the participants looked relaxed, one female was very quiet.</td>
</tr>
<tr>
<td>HIV/AIDS infected and/or affected</td>
<td>One of the older persons, a woman, was infected with HIV, and they all agreed that they are affected by the disease, some more than others.</td>
</tr>
</tbody>
</table>

3.4.2 DISCUSSION OF VISUAL IMAGES AND TEXTUAL DATA

The visual images presented and explained by each participant with instigated discussions in the focus group that was voice recorded, produced rich data. The visual data and transcribed textual data were organised into main themes and sub-themes, as indicated in the discussion.

The question asked by the research facilitator spontaneously resulted in the three main phenomena that the researcher wished to explore, and they are presented in that order.
• Needs and expectations of the older persons infected with and/or by HIV/AIDS

• Facilitating factors experienced by the older person infected with and/or by HIV/AIDS;

• Impeding factors experienced by the older person infected with and/or by HIV/AIDS.

Through the process of inductive reasoning (Babbie, 2007:22) the researcher reduced the identified sub-themes (twenty-six) to three main themes integrated from all three phenomena as indicated in table 3.4. The numbers of the sub-themes that apply to the main theme were indicated after each main theme.

An integrated discussion of the themes and the sub-themes supported by relevant literature gives clarity and insight into the results and findings. The findings from phase 1, step 1, step 2 and step 3 were integrated with the findings from phase 2, step 4 and 5 in phase 3 (see chapter 5) to conceptualise and formulate guidelines to operationalise community-based collaboration to support the older person in the world of HIV/AIDS.
Table 3.4: Sub-themes and themes regarding the needs, expectations, facilitating and impeding factors experienced by the older persons

<table>
<thead>
<tr>
<th>Sub-Themes</th>
<th>Main-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Needs and expectations of the older persons</strong></td>
<td></td>
</tr>
<tr>
<td>1. Community participation and support</td>
<td>1. Community participation within the social-cultural context of HIV/AIDS (1, 2, 7, 8, 9, 10;13)</td>
</tr>
<tr>
<td>2. Community development and advocacy</td>
<td>2. Knowledge generation and skills development (4)</td>
</tr>
<tr>
<td>3. Communication in the context of HIV/AIDS</td>
<td>3. Collective relationship between community members, family members and the older persons based on cohesion (3, 5, 6, 11, 12, 14)</td>
</tr>
<tr>
<td>4. Health information and education to develop their knowledge and skills</td>
<td></td>
</tr>
<tr>
<td>5. Community members unite and stand together</td>
<td></td>
</tr>
<tr>
<td>6. Relationship between children and older persons</td>
<td></td>
</tr>
<tr>
<td>7. Community-based home care</td>
<td></td>
</tr>
<tr>
<td>8. Central community functional system</td>
<td></td>
</tr>
<tr>
<td>9. Stakeholders should work together and coordinate</td>
<td></td>
</tr>
<tr>
<td><strong>Impeding factors experienced by the older persons</strong></td>
<td></td>
</tr>
<tr>
<td>10. Stigmatisation is a reality</td>
<td></td>
</tr>
<tr>
<td><strong>Facilitating factors experienced by the older persons</strong></td>
<td></td>
</tr>
<tr>
<td>11. Strong religious value system</td>
<td></td>
</tr>
<tr>
<td>12. Extended family important support and security system</td>
<td></td>
</tr>
<tr>
<td>13. Behaviour and socio-cultural structures</td>
<td></td>
</tr>
<tr>
<td>14. Coping abilities</td>
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</tbody>
</table>

Community participation within the social-cultural context of HIV/AIDS; knowledge generation and skill development; collective relationship between community members, family members and the older persons based on cohesion as the main themes will now be presented in a discussion together with the sub-themes.
3.4.2.1 Community participation within a social-cultural context of HIV/AIDS

The older person viewed as a dignified social being, should visibly participate in society with values like sharing, respect, solidarity, loyalty and rights central to Ubuntu. Ubuntu is an African view of life and represents African humanism, a collective consciousness that refers to the phrase "a person is a person through other people". Human interaction is characterised by harmonious participation and cooperation, internalised in the extended family as a closely-knit social web (De Villiers & Herselman, 2004:19).

When people participate, they become part of the decision-making and planning of a project in the community, in this case, the older persons infected with and/or affected by HIV/AIDS as the main partner in the endeavour to conceptualise a community-based collaboration framework that can be operationalise in the community to support them.

- Community participation and support

Human beings function in groups and within the context of HIV/AIDS, support in the mentioned groups could be vital for the older person's health and wellness. Groups can refer to the family of the older person, to their neighbours, friends and other groups in the community, like groups in the church. Based on the results it is obvious that the older persons not only need support, but also have an urge to give support to others in need. Participation does not imply that the older persons and other stakeholders, especially the volunteers should, be "used" to fulfil certain tasks. Community participation refers in this context to the older persons that are involved in the decision making process with regard to the identification of needs, planning to meet the needs and personal contributions in solving the needs (Dennill et al., 1999:93; Swanepoel & De Beer, 2006:28-29).
The older persons referred to different people, groups and organisations that should "take part" in support of the older person in the context of HIV/AIDS as indicated below.

"I am sitting along the river so that I can heal. I am waiting for somebody to help me get in. I need to be healed...he cannot go in by himself, they are asking for help"

"There are other people that can help the girl, like the sister, the nurse and the family of the mother that is ill...also the NGO's...there are so many community NGO's that can take part to help"

"The community can form the committee that will visit the people to talk to them. It will help a lot"

The older persons put a high value on neighbourly care and support. They view the neighbours as whole persons and consider their physical environment, their basic needs like air, water, food, as well as the socio-psychological aspects. The following quotation gives clarity:

"Yes Yes it means that if someone knock, and come in the house, then they can see that the person is alone. If they are sympathetic, they will look around. And if he says that I am tired of sleeping, then they can take him out of bed on to the chair. And if he asks for water then they can give him. Then if he asks for something to eat, then they can give him bread and milk".

"I notice that the house is closed, the windows are not opened and that is why I knocked. I wonder where are the people of the house because I know that he is alone. He stays alone.. Then I say let me see what is going on here"

"When you wake up in the morning, we usually see each other and greet...how are you?" If you don't see you neighbour, then you get worried...it is part of our culture...involvement"

Community participation held certain promises and advantages for the older persons and others who become involved in community participation, namely to become more self-reliant, self-sufficient, self-confident and independent. They will become part of decision-making processes and will be able to
advocate and exercise their voice as older persons with a rich life experience and wisdom.

- **Community development and advocacy**

In the reality of HIV/AIDS it is difficult to grasp the picture of "hope for the future" and "changing social and economic" situations through development for the better. However, the same authors explain that perceptions of development depend on the socio-economic as well as the cultural context of the people. Whatever the case, the people (the older persons) need to have a dream - some goal, some promise (Barnett & Whiteside, 2006:24). In the context of this study, community development held a more general description, and it promotes group action and provides a voice in decision making for disadvantage groups (Clark, 2008:299). The older persons expressed their need for somebody that can act in an advocacy role to help them to gain a voice in their community. The following quotation refers to the expressions of the older persons:

"Should send someone to help...from government specially to the community, the community must stand together...talk and trust"

"Need someone to help those who are illiterate, they don't have information, they do not know what to ask...someone should do that for them...we need a voice"

Many older persons' have decision-making taken out of their control and as the older person said when they discussed photo 2 (see Appendix H), they need to "stand up and fight" tell that they are motivated to act and regain their voices.

- **Community-based home care**

Community-based home care is defined as care given to the sick people in their homes (Ncama, 2005:34) and it aims at community empowerment that is congruent with the "Ubuntu" principles (De Villiers & Herselman, 2004:20). The older persons and their families are directly involved in this type of care and
support to the person as a whole that needs biophysical, psychological, social, environmental and spiritual care.

The older woman that made the visual image (see photo 8, Appendix H) of a man alone at home, ill with HIV/AIDS in a bed explained that he has nobody to care for and support him. They explained during the Mmogo-method™ several aspects of how they perceive care to people in their homes; they also refer to what they will need to do home-based care, like equipment and transport. See the following quotations.

"In that bag, they get cotton wool, dettol, ointments, and napkins" (on question what does she put in bag).

"We do not have transport, we walk to do home visits...now I have to walk from here to Sonderwater to wash that old lady or that child and I have to walk back...by 1 o'clock I am already tired and I have washed only two people"

Some of the older persons referred to their own experience of the health services and the impact that the shortage of personnel have on them and others during the discussion. They sketched the situation and the need for them to help because of the shortage, and also said that home-based care should be effectively co-ordinated, as can be seen in the next citation:

"We need to help...The clinic if you go at 10 or 11 then it is full. 4'o clock you leave the clinic and you have not received your treatment. You were sitting on the queue without even a slice of bread for the day. Then they tell you they are closing they are going home. Then you go home without medications, without food and you do not know what is going to happen to you at night. If you do not have an appointment for the doctor, you will not see him. They will give you for the following month even when you are sick now. You have to wait for the next month"

"The NGO's that passes by usually make a turn and when they hear that the patient is back they go and check her...not good communication...the NGO's try to find out and need to be told if there is anybody sick at home..."

"To help in the community...nurses are very few. The NGO's try, but because people are scattered, then you can only visit two people per day"

"Help with medication...some places there is other none...we need more doctors, more nurses..."
As explained above, the older persons also revealed what they do during home-based care in the community. Louw (2001:1) explains “ubuntu” as taken from the 1997 South African Government White Paper on Social Welfare as the “principle of caring for each other’s well-being...and a spirit of mutual support...” Most of the older persons that participated in the discussion did home visits in their community as volunteers without any financial support. The following quotations apply:

“I made someone who does not have people. He stays alone at home; there is nobody to take care of him. He always stays in bed, nobody gives him water, bread for energy....He also need somebody because when he is tired to stay in bed, he will help to sit him down in the chair”

“You can come and chat to them....you help with bathing, chat to them so that they don’t feel lonely, you give them love....”

“This is a chair next to the wall. The patient is on the bed...If he is tired then he can get out of bed and sit there on the chair...”

The overall relationship between older persons and the community members refer to dependency on each other for help. Compassion and social responsibility are expressed in caring for each other, and this refers to an “Ubuntu” principle (De Villiers & Herselman, 2004:20). The sense of belonging is deeply rooted in the African culture and finds its expression in the neighbours that are looking after each other and will help if they found someone that cannot help him and who is lonely. As the one participant verbalised:

“In the African culture the people involve themselves, go into the house and look for the ill person...”

- Central community functional system/structure

One of the older women enthusiastically told the group that she built a house as visual image to explain the need for a day-care centre (see photo 3, Appendix H). The other older persons actively commented on this aspect and it was clear that they identified this as a real need in the community to support
the older persons infected with and/or by HIV/AIDS. People expressed their feelings as follows:

"I have built this house because of the people who are sick. Some have difficult lives, their parents have left them in the zinc houses in their backyard. If we can have drop-in center or day-care centre...we can collect them from their homes and they spend the whole day here...we can wash them, give them food"

"When they are clean and have eaten, they are here together, they can talk to each other...and the disease will become better and they will enjoy..."

"We don't have day care center, we don't have a children's home..."

"I made this veranda at the hospital where people sit if they want to get some air..."

Older persons have a complex range of needs, and within this context it is even more complex because of HIV/AIDS. It does not only refer to their own needs, but as discussed earlier in the results, also to that of their extended family members that most probable include their children and grandchildren. The Government of South Africa share the vision of the older persons that existing buildings can be used as day-care centres, and at the same time be utilised as a place where programmes to promote inter-generational integration can realise (Strydom, 2008:107).

According to Dennill et al. (1999:91-92) a day-care centre or a drop-in centre, as expressed by the older participants, should comply with certain expectations:

- it should be seen as a project according to a need identified and should at least be able to satisfy identified needs,
- contribute to quality of life,
- develop a sense of ownership amongst the older persons as community members,
- promote community involvement,
- be done in co-operation with the older persons,
o involve excellent planning and
o ensure sustainability.

The day-care centre visually presented by the older female in photo 3 (see Appendix H) symbolises a place where people can be together, share their problems and help each other.

"So that we can take care of them in one place....for the people with HIV, the children should be together with their parents...now the children loiter in the streets...you don't know what happens between 2 and 4 to those girls. alone at home...."

Moreover, the older persons can be active in the day-care centre and start with a programme to encourage and mentor their grandchildren and other teenagers in the community to be aware of HIV/AIDS and prevent risky behavior (Dodge & Khiewrord, 2005:14). This can have a positive influence on the relationship between older persons and the younger generation for mutual understanding and building of a trust relationship and "bridge the gap".

- Stakeholders should work together and co-ordinate

The older participants referred to the stakeholders in their community as the different NGO's, the FBO's (churches), Government (health facilities and ward councillors), and the university and existing day-care centres. The participants mentioned that they have already started with discussions in the community regarding a central centre for the older persons. The discussions they have started with in the community imply possible partnerships and collaboration that should take place. It can however, never be isolated from politics or institutional structures like the Department of Health or the University. There will always be shared responsibilities, the outcomes of the discussions is often unpredictable, democracy always needs leadership, no two persons have the same expertise, there should be no struggle to take over, participation is crucial, and one should understand how it is created and how to sustain it (Ashford et al., 2006:58-70). Here follows some citations from the older
persons' opinion on different stakeholders that should work together and co-ordinate their services:

"And also clinic porridge that we bring, they have to eat before they drink medication...also get it from the NGO's"

"So if we together with you...from the university...the NGO's, together with everybody who is involved with HIV...look maybe if we begin with these words (referring to the graffiti) to kill this thing, maybe we can get somewhere..."

"...to get a cure medication for HIV (with reference to research by the university)"

"Let the Government not be so slow, they must help if we cry for help for these people, they should send someone to help"

Some authors use the concept of co-ordination to refer to collaboration, in the context of HIV/AIDS it refers to a framework for collective action to manage the phenomena under discussion (Swanepoel & De Beer, 2006:21). Working together and co-ordinating means that the stakeholders should understand and respect how other disciplines approach social problems, understand the context and complexity of the community and understand community links (Mitchell & Crittenden, 2000:2). It is important to include all or most stakeholders as partners from the beginning to work together. The development of an organisational "culture of ownership and accountability" will be the ideal. Boessenkool and Schutte (2005) delivered a paper at the 2nd South African AIDS Conference where they argued that the presupposed causality between organisational structure and culture of ownership regarding HIV/AIDS prevention in the North-West Province of South Africa has no theoretical base. They based their results on data gathered from 2002 to 2005. Some of the main findings with regard to the Local AIDS Council (LAC) apply in the context of this research and includes aspects like there is much frustration about dysfunctional meetings, culture of ownership is missing and organisations and individuals are leaving the LAC. LAC's are powerless bodies and capacity building on grassroots level is crucial for sustainability. The outcomes of the research of Boessenkool and Schutte (2005) showed that it is imperative to start any project from a sound foundation, keeping in mind the failures of the past to be the challenges of tomorrow. The UNAIDS Best Practices
Guidelines (2006:39) refer to some aspects that should be taken into account when projects with different stakeholders in the community are considered:

- interpersonal skills of staff involved in partnership;
- mutual goodwill between organisations plays an important role;
- similar goals and objectives;
- a decentralised, participatory approach, that is with involvement of all sectors, is the only way to get wider coverage and enable programmes to reach all those who are hard to reach, especially at the grass-roots level;
- recognition of the administrative challenges, the capacity of the institution, like management structures and the administrative infrastructure;
- slow, out-of-date bureaucratic procedures that choke initiative and reduce effectiveness;
- lack of procedural transparency, allowing inefficiency and corruption to 'eat' scarce resources; and
- lack of follow-up, either because short-term political priorities 'hijack' carefully planned programmes or because monitoring and evaluation are not built into planning cycles.

An important group that needs to be included in any partnership regarding HIV/AIDS is the traditional healers. The participants as a group had strong feelings about the traditional healers and their medicine. Some feel positive and some do not believe in them and confirm that there are different thoughts on the two health systems, namely the Western medicine and the traditional healers. Effective interaction and co-ordination would benefit both systems and referrals can be made from the one to the other when limits have been reached (Tjale, 2004:6). Some of the quotations that captured the thoughts of the older persons include:
"The other thing... we know about the illness, but we do not do what the doctor says. If I get my person out of the hospital after discharge, I take her to the traditional doctor. I leave the medication from the hospital. And what is it that is going to happen to the people? They deteriorate. They become more sick... our people believe too much on the traditional doctor or 'muti' or tradition"

"Yes we go to the traditional healer... yes it is like that, we use the Traditional healers but they also help. They help with AIDS, they give us medication"

"But the traditional healer lies... they say their medication takes out the disease, but they say so... they say the other doctor's medication don't take the illness out..."

"I believe in the case of a Sangoma and a medical doctor... if they work together to help someone, then it is OK. But otherwise, if you get treatment from hospital that is specific to the illness, then you should keep to it. Otherwise from one doctor to another, qualified or not, I think you are taking chances with your life. So I think the people should keep to treatment. If they go to a Sangoma, it is another story. Because that doctor has done tests and he knows what is the problem, and he had given the right medication... what I mean they must work together"

However, co-ordination cannot be enforced and promise to demonstrate several difficult challenges for the older person in the world of HIV/AIDS (Swanepoel & De Beer, 2006:21).

• Stigmatisation is a reality

Stigma can be seen as "prejudice, discounting, discrediting and discrimination" directed at people perceived to have HIV/AIDS (Holzemer et al., 2007:1002). According to Barnett & Whiteside (2006:72) stigma can be seen as a social process, an element of social relations that can reflect tension, conflict and silence (see photo 6, Appendix H). The colourful beads that can be seen around the table (see photo 1, Appendix H), refer to the different people that should all be inclusive, no matter if you have HIV/AIDS. Unfortunately, an undertone of discrimination surfaces in the family, community and churches. The HIV/AIDS patients are often cared for in isolation in cultures where the sick are traditionally cared for by families and communities (Airhihenbuwa & Webster, 2004:5). Stigma continues to affect people living with and affected by HIV/AIDS (Holzemer et al., 2007:1002). The reality is that the people in the
community is hiding from the truth and living in isolation, as they fear rejection as they express in the following citations:

"...we older persons, we still hide them...isolate them, we don't talk the truth..."

"The family is there, but they just look at him, they are not interested, now he goes to eat with the pigs...It is not that the family is not interested but they have tried and tried but the child would not listen. So they sit him on the side, there is nothing they can do...wasted everything that his parents had, like the riches and all the money. He wasted everything with his friends now he has nothing and no one..."

"The people are still there that say: you are HIV. They isolate them...there are still people that isolate the HIV people...or if you sit at the table, they don't want to sit with you"

• Behaviour and socio-cultural structures

The older persons in the study feel that they should play an important role to influence the behaviour of the younger generation, but because of Western influences and the need for their children to work outside their homes, the older persons have lost their influence. Culture is the foundation on which health behaviour is built and HIV/AIDS in the African population should be understood within this social-cultural context. See photo 5 (Appendix H) on the relationship between the pig food and the son that symbolises that pigs eat everything, the pig food relate to HIV/AIDS, although HIV/AIDS is not seen as "dirty", some people with it display the same behaviour of ignorance than the pigs. Pigs do not care what they eat and that is what happened to the child, he did not listen and that is brought into relation with his behaviour that followed his ignorance.

However, it seems that the traditional culture is contradicting to that of the mainstream practices with reference to condom use. One of the older persons said during the group discussion:

"But the condoms...also are not good..."
In this case culture refers to beliefs and values regarding sexuality, which explains the often contradictory “condom use in South Africa” (Airhihenbuwa & Webster, 2004:5).

The results showed that conflicting interest also exists between the traditional healers/sangomas and mainstream medical care. The older persons as participants agreed that the traditional healers can have a positive contribution to HIV/AIDS and the well-being of the people in the community, but only if they work hand-in-hand with the mainstream health services, as the participants said during their discussion:

"I believe in the case of a Sangoma and a medical doctor...if they work together, to help someone, then it is OK...but if you get treatment from hospital or the doctor that is specific for the illness, you should keep to it" : "After discharge from the hospital, I take my sick person to the traditional doctor, I leave the medicine from the hospital...and they deteriorate. They become sicker. They believe...our people believe too much on the traditional doctor or muti or tradition...."

From the results and literature, it is clear that there is a need for health care professionals to integrate traditional healing with Western practices. It also links to other studies which found that up to 80% of the African population use mostly traditional healing (Sukati et al., 2005:191).

3.4.2.2 Conclusions on community participation within a social-cultural context of HIV/AIDS

- Older persons infected with and/or affected by HIV/AIDS as stakeholders need to take part in decision-making processes in the community where all other stakeholders like the university, Department of Health, NGO’s and FBO’s should work together and co-ordinate their services.

- Older persons with extended experiences and wisdom gain confidence through community participation and take the responsibility to “stand up and fight”, advocate, and develop a dream for a better future despite HIV/AIDS.
• The older persons that render community-based home care, as a volunteer are aware of stigmatisation, have caring attitudes to the community with their different dimensional needs and they need equipment and transport.

• The needs of older persons infected with and/or by HIV/AIDS within a socio-cultural context refer from personal health needs to coping skills in a multi-generational household and a well-defined need for interaction and co-ordination between the Western medicine and the traditional healers.

• A day-care centre is a high priority and functional as a central structure in the community for the older persons to be together, share their problems, give care and support to each other with a positive influence on the relationship between the older person and the younger generation with special inter-generational programmes in mind.

3.4.2.3 Knowledge generation and skill development

The older persons need to be enabled to take control over their lives and their environment within the socio-cultural context of their household and the reality of HIV/AIDS. If enabled to acquire knowledge and skill people can make informed decisions and be empowered (Clark, 2008:260). The results in chapter 2 showed that the majority of older persons in the community have no or a low level of education that makes them vulnerable to participate effectively in health promotion programmes and access to information pertaining to aspects like HIV/AIDS. Some of the remarks made by the older persons clearly state how they feel about their own knowledge:

"The old people are not literate, and our children know what their problem is but they do not tell their parents. In addition, the poor old woman will do your wounds with her hands and wash you without using hand gloves; she is going to do everything. Tomorrow she goes to hospital, to the doctor, and they tell her you have HIV. Now the old woman knows she does not have...that her old man is long dead...."

"Need to learn about the medication, these people are illiterate and they don't have information...need people who can teach them"
There exists a great need for more knowledge in this regard and this need should be carefully considered in context with an African-based cultural strategy. It was noticed in the visual presentations and the discussions with the older persons that they have some basic knowledge on what a person sick with HIV/AIDS needs as one woman presented (see photo 8, Appendix H).

"I made someone who stays alone at home.........I made a cup of water, a plate of porridge, bread, fruits, apples and tomatoes...."

On the other hand, it was made clear that they need knowledge on managing and basic treatment of the symptoms that came with HIV/AIDS, especially when they care for someone at home. In South Africa, those who are infected face the challenge of managing their symptoms to decrease discomfort and enhance their quality of life (Sukati et al., 2005:185 & 191).

"Yes they have HIV, and then it goes into AIDS. Some have TB and you can see that they have a lot of pain, they complain, they moan and they say itchy...itchy..."

"We don't know what to do. We just have sympathy for them. Sometimes we make the salt and sugar water...we need someone to learn us what to do"

"The other can't hear well...Some cannot eat, if they eat they vomit. Then you should know that their condition is not good if they vomit..."

It is also important to empower the older persons with knowledge and skill to teach their children on sexual behaviour, within cultural boundaries (see Photo 5, Appendix H). Health education often misses the purpose to educate people for free choice or for empowerment. It should rather focus on life skills education that enables individuals to become more empowered (Coulson et al., 1998:78). The older persons not only expressed their worry and need for information regarding general precaution aspects when caring for children or community members that have the HIV-virus.
They also expressed their need for information and general knowledge on how to communicate general aspects pertaining HIV/AIDS and sexuality and said:

“If we all can teach our children…..we must try”

“...the old people, us we need more information regarding HIV and training. We need to know more so that we can help many people especially the children. More information and training...For instance, I am the old person living with the child, and I see that he is sick, he has the virus but he will not go for test. What should I do as an older person?”

“Our children listen to their peer group because they say we don’t understand. Even if it is important, they see you as someone who don’t know anything because we did not go to school, who are stupid so they ignore us”

“We want teaching of old people. Old people are the ones who look after the children. The young children do not talk. They do not say to their parents “you should handle me this way”. They don’t talk...”

Health education can result in behavioural change necessary to influence the value, belief and attitudes systems if the education has a broader focus to enable the older person through life skills to act assertively in their household, they may feel empowered to deal effectively with issues around relationships, childcare and HIV/AIDS. The primary purpose of health education is to assist the older person to make health-related decisions about self-care, the use of health resources and decisions about societal health issues and imply that the older person infected with and/or by HIV/AIDS

- should participate in health decision making,
- develop increased potential to comply with health recommendations,
- develop self-care skills,
- improve self and family coping with HIV/AIDS,
- increase participation in continuing care for persons with HIV/AIDS, and
- adopt to healthier lifestyle Clark (2008:262).

3.4.2.4 Conclusions on knowledge generation and skill development

- The older persons at risk or already infected with and/or affected by HIV/AIDS have a low educational level and/or are illiterate with
subsequently **inadequate health-related knowledge** that refers to HIV/AIDS.

- **To participate** effectively in **continuing care** for persons with HIV/AIDS the older person **needs health information** and **education** on matters like **self-managing and basic treatment** of HIV/AIDS symptoms.

- The older persons are the **caregivers** challenged by multi-generational households that need knowledge and skill on **conveying messages** to family members, young and old pertaining to **HIV/AIDS prevention** matters to improve family coping with HIV/AIDS and need **life skills education** to make own choices through **empowerment**.

- The older persons need support through knowledge on **general precaution aspects when caring for persons infected with HIV**.

### 3.4.2.5 Collective relationship between community members, family members and the older persons based on cohesion

Collective relationship firstly refers to the interrelationship between the older persons themselves as a group that share a common problem, HIV/AIDS. The collective relationship further refers to activities planned by the group of older persons to deal with human problems and needs that is in the context of HIV/AIDS. All activities in the relationship refer to voluntary actions with a need to work together (Swanepoel & de Beer, 2006:36-37) as a group and relate in a collective manner to other groups and members that could be their families, neighbours and the community at large. If based on cohesion, it means that the actions that the older persons take should bring them together as a whole or "unite them as a whole" (SACOD, 2002:224).

- **Communication in the context of HIV/AIDS**

  To "share problems and to talk", was a regular phrase used by the older persons during the Mmogo-method™, that refer to communication. Communication is the exchange of messages and the creation of meaning (Andrews & Boyle, 2003:21) or to "share our ideas and feelings" (Parry,
2004:107). The context of HIV/AIDS place new challenges on communication and more so on communication between the older persons and the other members of the family and the rest of the community like other stakeholders involved with HIV/AIDS matters. In photo 2 (see Appendix H) the participant refers to the fact that although everybody hears and reads messages on television and in the newspapers respectively regarding the fact that South Africa has the highest HIV/AIDS prevalence rate in the world, people are still dying in the thousands. The government chooses to communicate the message of HIV/AIDS to the community on a cognitive level and want to reach as many people as possible, but maybe qualitative reasoning underlies the message that the participant wants to convey through his visual image and calls on the need for a collective fight against the disease. As the participant said:

"It is just to talk, to talk these through...we can talk to the people, give them strength and not be scared and talk...we must stop to blame the government...the only thing that is left for us now is in a manner to stand up and fight".

The older persons agreed that communication should be open and honest. Interaction between family and group members is only possible if there is an open system that allows free flow of information and ideas and includes qualities of wholeness, interdependence, hierarchy, balance, change and adaptability (Parry, 2004:126). The environment of the older person in the family with the changing roles is under tremendous pressure because of HIV/AIDS, however, the family as a system is constantly adapting to the challenges of HIV/AIDS and the older persons feel that open communication can help to manage the situation and maintain some balance in their households:

"If I talk I can get help, but how can I get help if I keep quiet, how can I get help? I won't get help...they will know I need help...but they hide this illness, we don't talk."

"We can talk to the people ...to the children, make plans, if we talk we can give them strength"
Although the older person acknowledge that open communication is necessary, it seems that it is still difficult for them as well as for other members in the family to openly discuss HIV/AIDS matters. HIV/AIDS opened a completely new form of word that means that members of a family should talk about formerly taboo and secretive aspects like penetrative sex, safer sex and condoms (Schott & Henley, 2002:228), as the older respondent revealed in the first citation: “...we don’t talk”

- **Community members unite and stand together**

To unite means to come together for a common purpose (South African Concise Oxford Dictionary, 2002:1285). The older persons revealed that they want to take responsibility and act. Development involves changes in the awareness and motivation of individuals and in the relationship between individuals as well as between groups in the community. These changes must come from within the individual and cannot be imposed from the outside (Davids et al., 2005:156). The older persons felt strong during the focus group discussion that they want to join as a group (unite) and fight HIV/AIDS in their community (common purpose), as the following quotations (also see Appendix H on photo 2) explain:

"*We as the older persons must stand up and fight...*"

Further discussions lead to agreement amongst the participants that everybody should be included in the fight against HIV/AIDS, and that it should exclude neither individual nor any groups, respectable of the disease they have or their color (see Appendix H on photo 1). The image referred to in photo 1 present interaction between people in a group that refers to interconnectedness and symbolises the African culture regarding sharing with the community. The table with colourful beads symbolises that everybody should feel welcome and that it is better to deal with problems together as on their own. "*...we should come together...*" was an expression heard throughout the
whole Mmogo-method™ group discussion, they said that people should share their problems and talk about it,

"He did that so that people can sit around the table...all the colors means everybody is there and we do it together..."

"We must come out of that room. We must come to this table...if we share and talk these things through you are going to get healthy..."

HIV/AIDS placed a strong need amongst the older persons to stand together and fight as visible in the above citations. They should act collectively because of the need, crises and urgency (Swanepoel & De Beer, 2006:37) placed upon their families, neighbourhood and community by HIV/AIDS.

- **Strong religion value system**

"Humans are spiritual beings and they are aware of a higher power with a sense of connectedness to a bigger reality in relation with a higher power, themselves and their environment" (Watson, 2007:77). Some authors refer to spirituality and religion as the same concept, others say they differ, but what is important in the context of this study is to note that Mbiti (1990:1) writes that religion cannot be isolated. It is present in life and runs like a golden threat in the African worldview. He also says that "Africans are notorious religious" and in the following saying of a participant it is clear what the author meant when he wrote that everyone has its own religious system with a set of beliefs and practices. African religion goes back to the religious practices of the Khoi-San and one of the oldest forms of religion in Southern Africa and demonstrates a process of cross-fertilisation between the African ethos and Christianity (Lubbe, 2004:81). In the following remark of the participants' religion refers to traditional beliefs as well as Christianity.

"The water can clean you...the traditional healers also say so...water is also like the word of God..."

"Water has great healing power...the water at the river...even Jesus at the cross asked for water...water is like medicine...if you drink water it give you energy..."
From a clear Christian frame of reference, the older persons had a lively discussion and agreed that the symbolic use of the table (see photo 1 in Appendix H) told a story of people sharing around the table as a symbol of the love Jesus had for His disciples irrespective of whom and what they were.

In photo 9, (see Appendix H) the older person created an image of a man that is reading the Bible at the table. The person that is reading the Bible is ill with HIV/AIDS and is alone. More than one strength are illustrated through this presentation like hope, coping abilities, social support and the implicit faith in God's Word can be heard in the participants' citations:

"Yes this person has HIV, now he is asking God to take away the pain...he is reading from the Bible...God will hear him and take away the pain...."

"We can pray that the Lord help us to give the people light and understand and give acceptance when they have the disease...they should not lose hope"

"We should be like Jesus, sit around the table with His disciples and share...share that piece of bread"

"Yes we talk at church...this Sunday is candle light for HIV/AIDS"

• Coping abilities

It is important to understand why some older persons can thrive amidst miserable circumstances, stress and the onslaughts of life. Where does this strength come from? This perspective is called the fortogenic perspective that relates to resilience, strengths or protective factors (Wissing, 2008:14). Which strengths contribute to the fact that an HIV-positive person can still enjoy life?

Typical strengths may be hope, optimism, sense of coherence, vitality, a healthy outlook on life, experience and (giving) social support, ability to forgive, problem-solving skills, constructive coping abilities, sources of information, assistance and support, seeing problems as challenges, and healthy lifestyles (Wissing, 2008:14).
Uys (2003:278) put it short, but with an element of reality in it when she stated that the health workers in hospital and clinics expressed the same views that "AIDS is a hopeless disease". Photo 6 (see Appendix H) could tell the story of hopelessness, but then hope emerged in the form of "healing water". In the study that Uys (2003:278) performed, a nurse remarked what link to the next thought that one should not lose hope, God can perform miracles and a cure might be found on day. During the Mmogo-method™ group session, the researcher heard the following from an old man:

"We can pray that the Lord help us to give the people light...they should not lose hope."

One of the outstanding coping strategies that could be seen and heard during the Mmogo-method™ and group discussion was the religious element as a reality of hope in the world of the older participants infected and/or affected with HIV.

- **Family as support and security system**

The family is a social system with patterns recognised by different roles, status and power assigned to the members of the family or group (Andrews & Boyle, 2003:510) and is the most important resource available for meeting the needs of older persons (Strydom, 2008:110). Social relations according to "Ubuntu" are internalised in the extended family and the relations form a closely-knit social web that promotes solidarity among people (Tjale & De Villiers, 2004:20). The family in this study refers to the extended family within the context of HIV/AIDS, with broad kinship structures, where the older person is the decision maker. 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 social nature when a person voluntary visits someone in the community that is in distress or housebound" (Brooker, 2006:234-235). Social support in the family is a valuable contributor within the socio-cultural reality of the older person and often the only support available to
the infected with and/or affected by HIV/AIDS (Pequegnat & Szapocznik, 2000:3). Support can be focused on structure (existence and quantity of social relationships that is family, friends, and neighbours) and functions (perceptions of the availability of support in form of love, practical assistance, self-evaluation, advice and spending time with others).

Social cohesion in a family means that the family or group work together to unite as a whole and is one of the shared objectives that was clearly expressed by the older persons in the group and it refers to different features like norms and trust to act together to ensure social cohesion amongst themselves, their families and the community (Gilbert & Soskolne, 2003:113). The philosophy of togetherness implies in this situation that the older person from a collective approach involve themselves as part of a societal group where each one of them should find their place within the structure (Tjale, 2004:207) with the responsibility to promote individual and social well-being (Louw, 2001:1). The older persons made it clear during the discussion that they see the family and themselves as part thereof as a support system, structural and functional. The following quotations apply:

"I bought the bag for my medications, because I am a patient myself, I am sick...No I help myself, if I can't help myself anymore...My aunt will help me. She and I stay near, I send the kids to call her"

"The women in the hospital (refer back to the visual image of women in hospital ) when she goes home it becomes the responsibility of the family"

"We will never send our children away...we love them. That bonding with your children. Who will look after your child if you send him away? Who will help if you cannot help your own child? Even if it is not your own. I worked at W..., you get so attached to these people. For those whose families are far and they are lonely. The same with the sick people. The love of our children even though they do nothing for you. That is love"

Older persons in an African context strongly believe in caring for and supporting people in need, they can share whatever they have to share. Social support within the family is important with regards to the HIV/AIDS infected and/or affected older persons and refer to the "availability of people whom the
individual can trust, on whom he can rely, make him feel cared for and valued as a person” (Westaway et al., 2005:74).

- **Older persons and the younger generation**

Although the family is the main source of care and support for people living with HIV/AIDS in most developing countries, negative responses from the same family are common (Parker & Aggleton, 2002:8). In addition to this, it should be noted that older persons often carry the burden of three generations when HIV/AIDS strikes. They carry the burden for “themselves”, without support from their children that might be sick; their “sons and daughters”, who they must now care for; as well as their “grandchildren”, who become their responsibility when their parents are too ill to look after them or have died of HIV/AIDS (Dodge & Khiewword, 2005:3). The results indicate that the older persons are always willing to share whatever they have and do themselves short to look after their children and grandchildren. The older persons engaged in the discussion furthermore explain (refer to photo 4, Appendix H), that they feel worried about the children that are loosing their parents to HIV/AIDS and feel that they should do something:

"This girl (refer to herself as the caregiver watching the mother and child) is trying to help this woman and she feels pity for this child looking at her mother who is sick with HIV. Now if this girl can get help to assist this poor old woman to get the child to live well in this world"

"This is somebody who is sick with HIV (in hospital). The child is heartbroken that her mother is sleeping there and sick..."

"This poor child is not going to learn when she gets back from school because she has to make food, feed the mother, give her water, try to make tea...she is going to be hopeless, but she is going to try. When the mother is discharge from the hospital the doctor will explain to the child how to give mother’s medication...the child takes responsible herself if there is nobody in the family..."

However, while the older persons expressed their worries and concern for the younger family members and other children, they are just the same worried about the fact that they have trouble to understand the younger ones.
"Worry about children's behavior and children that don't want to listen, they know what will happen, but children do not listen to older persons anymore. These children does not listen...the TV talks to the children...we don't know what to do..."

The interaction between the children and the older persons are recognised by some interplay between the forces of the older person that is known as the wise and respected one and that of a younger generation exposed to Western culture and development. The one participant refers to the influence of the television on the children of today and that they as parents do not understand these influences (see photo 1, Appendix H). Their relationship leaves the older persons more than often desperate with recognised gaps in their communication with each other and trust towards each other. The older persons feel secure in their ontology of culture and religion while the younger ones feel rebellion towards their outdated ideas and cultural practices carried from one generation to the other. Mpofu, (2001:344) give clarity against this reality and explain that modern African communities are under the strain of the competition between Western and indigenous African value systems.

Older persons are respected in their community because of their knowledge, experiences, personal influences and power, they are thus regarded as being more of a person than the younger ones (De Villiers & Herselman, 2004:20). Many older persons share their homes with children and grandchildren (Bohman et al., 2007:331), which could result in opportunities for conflicting interest. The older persons are desperate to understand their younger family members that are “forced to live in two half cultures which do not unite to form a single culture” (Mbiti, 1990:216). A study done by HelpAge (Dodge & Khiewword, 2005:3) confirmed the finding in this that the older persons complained that the generation gap affected their relationships and many viewed their grandchildren as disobedient and disrespectful.
3.4.2.6 Conclusions on collective relationship between community members, family members and the older persons based on cohesion

- Older persons infected with and/or affected by HIV/AIDS share HIV/AIDS as a common phenomenon in the community and act together as a whole to manage the needs of their families, friends and neighbours.

- HIV/AIDS put new challenges to older persons that function as a whole system through open and honest communication and collective actions to maintain balance in the community.

- The older persons' needs and expectations are reflected in their sense of Ubuntu, characterised by a need for collectiveness and traditional values.

- The strong religion systems of the older persons contribute positively towards the ability to cope amidst HIV/AIDS.

- The older person is not only responsible, but also willing to share material goods and give emotional support.

- The older persons infected with and/or by HIV/AIDS are central to the multi-generational or extended family system of the community as a whole, are voluntary stakeholders that need and expect to participate and co-ordinate with other stakeholders in decision-making processes involving care and support of all the older persons.

- Care and support of older persons aim at community-empowerment and involve a functional structure in the community where comprehensive care and support is delivered to the older persons including enhancement of their knowledge regarding health-, social-, cultural-, economical- and educational issues.
3.5 CHAPTER SUMMARY

In the preceding part, the results on the needs and expectations as well as the facilitating and impeding aspects experienced by the older persons in the world of HIV/AIDS were outlined with an accompanied discussions integrated with literature as theoretical base. The conclusions are based on this.

The conclusion drawn in chapter 3 served as triangulation of the findings and conclusions from chapter 2 on the health profile of the older persons, and added to a comprehensive picture on the health of the older person within the socio-cultural context of the study. The needs and expectations as well as the facilitating and impeding aspects experienced by the older person contributed to the final needed evidence from the empirical world to conceptualise community-based collaboration to support the older person in the world of HIV/AIDS.

Phase 2, step 4 and step 5 of the study pertaining to the existing networks and support programs available in the urban community, as well as older persons' perceptions regarding community-based collaboration to support the older person in the world of HIV/AIDS are provided in the following chapter.
Chapter 4 focuses on phase two, step four and step five as indicated in the schematic outlay (see figure 4.1) that indicates the chapter in relation to the phases, steps and the objectives of the research project. It furthermore entails the research design used, personal interviewing as data collection, transcribing of the interviews, data analysis with literature control, verification of the interview findings and reporting to communicate the findings.

Figure 4.1: Schematic layout of the chapters in relation to the different phases and the steps of the research project
The fourth and fifth objectives apply, namely

- to identify and describe the existing networks and support programs available in the urban community;
- to explore and describe the perceptions regarding community-based collaboration of the stakeholders and role players involved in the mentioned networks and support programs.

4.1 INTRODUCTION

The results in chapter 2 and chapter 3 introduced the reader to a rather bleak picture of the older persons regarding their health, needs and expectations, as well as the facilitating and impeding factors they experience in the world of HIV/AIDS. However, despite the unfortunate situation of the majority of older persons in South Africa, they have been recognised as the group who can make a difference and can contribute to development and support in their various communities. They are the people who meet financial and material needs in households, take responsibility for the upbringing and nurturing of grandchildren, provide care to the sick household members, to name but a few (Joubert & Bradshaw, 2006). These contributions older persons make are often ignored and development processes tend to exclude them (Baiya & Peachey, 2003). The different decision makers, stakeholders and role players should change their negative attitudes and strive to value old age, seek to understand the needs of older persons and treat them as equal partners in the community. It has become a great necessity that all communities and organisations at local level initiate planned action towards forming close partnerships within the community (Dorrington et al., 2004:2; Lindsey et al., 2001:829; WHO, 2004:43) and not only look at the Department of Health at National, Provincial, District and Local level for solutions. The government, non-governmental organisations (NGO's), community-based organisations (CBO's), faith-based organisations (FBO's), private sector and the people living with HIV/AIDS (including the 4.8% older persons in this study) should make a joint effort and be involved at all levels of this Strategic Plan (Ncama, 2005:33-34; Pelser et al., 2004:308-309).
Collaboration in the context of this study (see chapter 1, table 1.1 as adapted from Winge \textit{et al.}, 2005:5) refers to the stakeholders and role players in the urban area referred to in the study. They are the older persons (≥60 years) infected with and/or affected by HIV/AIDS, their families, friends, neighbours, government health care, local political leaders, NGO's, CBO's, FBO's and people from the private sector. The question that comes to mind is whether collaboration can assist the stakeholders in the health services and the community under discussion to work together in an effective and efficient manner to strengthen the older person's support regarding the effect of HIV/AIDS on their lives (EICP, 2005:1). There should be a partnership-relationship between the older people in the community as key stakeholders and the other stakeholders who aim to generate a suitable climate (in this case to support the older person through group discussions, policies, education, etc.) where the older person's point of view is valued with the negotiation of key decisions (Mash & Allen, 2004:21).

Considering the results of the health profile of the older persons in the study (see chapter 2) as well as their experiences regarding HIV/AIDS (see chapter 3), community-based collaboration is clearly required to support the older person who faces tremendous challenges in their households and communities. The new empirical knowledge explored in this chapter will add to the quest for answers for community-based collaboration to support the older person in the world of HIV/AIDS.

The outlay and discussion on the research design and method follows hereafter.

4.2 RESEARCH DESIGN

Chapter 1 provides a detailed layout (see paragraph 1.6.1 and table 1.4) of the research design for the whole study. The description of the design with specific reference to phase two, \textbf{step four and step five} is of special importance to this chapter. It will be proposed with reference to the qualitative, explorative, descriptive, interpretive as well as contextual aspects.
4.2.1 QUALITATIVE

A qualitative approach made it possible to discover richer definitions of the problem, to gain more insight into the processes between the role players in the community, and to gather accurate in-depth information from the empirical world regarding community-based collaboration to support the older person (WHO: 2002: 3). The different people involved in the formal and informal organisations in this research, the stakeholders and role players, brought meaning and understanding about their lived world and experiences in the community. This helped with an understanding of how they perceive collaboration in the community as they know it through their involvement in the formal and informal organisations as partners applicable in the study (Liehr & Lobiondo-Wood, 2006: 149; Sullivan, 1998: 310).

4.2.2 EXPLORATIVE, DESCRIPTIVE AND INTERPRETATIVE

The exploration and description in phase two, step four and step five is unique, with a separate plan of what and how to collect data from the stakeholders to explore their perceptions on community-based collaboration. It was a challenging task to make sense of what has been learned in the field, to put it into textual format and present a clear picture. Denzin (1998:313) calls this process “the art of interpretation”. The information collected from the stakeholders is not necessarily adequate to make interpretations that apply to other communities. No one can claim a single social reality, as different perspectives will influence it, in this case the perspective of the reader, the researcher and the participants (Holloway, 2005:272). The reader should note that the statements and conclusions drawn from the data in this part of the study apply to the context of the urban area as described below.

4.2.3 CONTEXTUAL

The stakeholders and/or role players live and work in the urban area included in the study where they witness the hardship of HIV/AIDS and the problems that come with it through home-based care and other support programs. The stakeholders and role
players come from the same geographical context as the older persons described in chapters 2 and 3. Although they are not all from the same socio-cultural and temporal context, the stakeholders were purposively chosen because they are familiar with the community and the setting of the older persons, who are the main stakeholders and role players concerned with HIV/AIDS. Refer to chapter 1, paragraph 1.6.1.5 on the contextual nature of this study.

A detailed explanation of the research method is provided in the following section.

4.3 RESEARCH METHOD

The research method in the discussion of chapter 4, which concerns phase two, step four and five, includes the population and sample, methods used for data collection, the data collection tool and the data analysis. In September 2006 the researcher was invited to a meeting between the Department of Health on District level, different NGO's, FBO's and CBO's and given the opportunity do a presentation and explain the purpose of the study. The researcher had the opportunity to clarify any questions, and the meeting constituted the initial contact made with the different stakeholders in the community.

4.3.1 POPULATION AND SAMPLING

The data gathered on the perceptions of the stakeholders and role players on community-based collaboration to support the older person in the world of HIV/AIDS, will include a sample with reference to the urban context included in the study (refer to paragraph 1.6.1.5 and 4.2.3 on the context of the study).

4.3.1.1 Population

For the purpose of the study all the stakeholders and role players actively involved in HIV/AIDS, social support of older persons, home-based care, observed treatment, education and palliative care were included as the population. Participants from the public sector (Department of Health on District level), NGO's, CBO's and FBO's
(national and international), political role players (counsellors involved in health matters and social support) and private stakeholders (active involvement in time or material donation) were invited.

4.3.1.2 Sample

The researcher selected the sample based on knowledge of the population and the purpose of the study, and therefore it was a **purposive sample** (Babbie, 2007:184). The choice of purposive sampling allowed the researcher to gain true understanding of the problem and questions in the research (Creswell, 2003:185) regarding how the different formal and informal organisations perceive community-based collaboration to support the older persons in the world of HIV/AIDS. Local responses through purposively chosen participants are important because each community, within its own context, has its own way of responding to HIV/AIDS. The urban area that apply in this study includes formally and informally formed “indigenous organisations” (Campbell *et al.*, 2008:509; Patel, s.a.:8) known to and involved in the older persons’ every day lives, and the researcher took cognisance of this.

A meeting was scheduled with three key informants known as leaders in the field of community-based work (the co-ordinator of NGO’s responsible for HIV/AIDS, the AIDS co-ordinator for peer education and a supervisor of selected PHC clinics) and they were interviewed in the initiation phase. They assisted the researcher to identify the most active and relevant stakeholders and role players involved in community-based care and support regarding HIV/AIDS and provided the contact details. The stakeholders and/or role players had to comply with the following **inclusive criteria**:

- active involvement in HIV/AIDS issues in the community (also social support to older persons, home-based care, observed treatment, education and palliative care),
- be involved and responsible for the urban area included in the study,
- be able to speak English and/or Afrikaans,
be involved with the organisation for at least one year,

- the focus of the organisation should be on community-based care and/or support; and
- written informed consent to voluntary participation.

The researcher compiled an informational guide before starting to phone the stakeholders to capture all information that may be needed to do follow-up appointments for the final interview. Interviews were subsequently scheduled with the identified stakeholders and role players (N=26) for participation in the research at the setting of their choice after the purpose of the research was briefly explained over the telephone, and they agreed to the interview. Table 4.1 gives a layout to classify the organisations as well as the different stakeholders identified for participation, their level of functioning and their focuses.

**Size of the sample** will depend on the point of saturation and when little new knowledge is generated through further interviews (Kvale, 1996:102). Data collection continued until enough stakeholders and role players were interviewed for a full and rich description of their perceptions on community-based collaboration to support the older person in the world of HIV/AIDS. From the twenty-six stakeholders and/or role players (N=26) identified for participation, eighteen (N=18) were interviewed.

Subsequently follows an layout of the data collection with reference to phase one, **step four** and **step five** (see chapter 1, table 1.2).
<table>
<thead>
<tr>
<th>International Non Governmental Organisations (INGO)</th>
<th></th>
<th></th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>INGO (That's It)</td>
<td>Treatment and monitoring of HIV/AIDS</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>INGO (EU)</td>
<td>Tuberculosis monitoring and treatment at community-based level</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Department of Health (DOH)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DOH, Local Authority (Clinics)</td>
<td>Work together with District Health on PHC services and supervision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DOH, District Office (Clinics)</td>
<td>Responsible for management of HIV in PHC clinics, coordinate home-based care by volunteers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DOH, District Office (Community-based)</td>
<td>Coordination of all the NGO's responsible for HIV/AIDS matters, education, home-based care and support</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>DOH, District Office (Head office)</td>
<td>Health Research in the district coordination and monitoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DOH (DOTS)</td>
<td>Treatment of TB on home-based care level</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Non Governmental Organisations (NGO's)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NGO (Promosa Service Centre for the aged)</td>
<td>Service centre for the aged, home-based care with registered nurse in their service, screening and follow-up on hypertension and diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NGO (HOSPICE)</td>
<td>Home-based care, palliative care</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>NGO (Women with a Soft Spot)</td>
<td>Home-based care and support, health education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NGO (HOSPICE)</td>
<td>Day care centre for children infected and/or affected by HIV/AIDS and coordination of social support for all</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Community-based Organisations (CBO's)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CBO (Kageng Day care centre)</td>
<td>Day care centre for the aged, food gardens, needlework, home-based care, help to trace down and manage orphans</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Political</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Street committee member</td>
<td>Responsible for health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counsellor</td>
<td>Responsible for health</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>National President of NGO organisations</td>
<td>National coordinator of community-based organisations</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Academic Institutions</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NWU (AIDS peer educator)</td>
<td>Responsible for peer education at the university and collaboration on community-based level</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>NWU (AUTHeR)</td>
<td>Research and community project leader</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NWU (PURE-SA)</td>
<td>Research fieldworker and active in community projects</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Faith-based Organisations (FBO's)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UPC Church</td>
<td>Involved in the care and support of people living with HIV/AIDS in the community</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>BCC</td>
<td>Responsible for food parcel distribution, home-based care and day care centre for children (orphans)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Private organisations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical doctor</td>
<td>Private practice</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Chubby Chick</td>
<td>Private poultry farmer involved in community charity</td>
<td></td>
<td>N=26</td>
</tr>
</tbody>
</table>
4.3.2 DATA-COLLECTION

After a brief explanation in the introduction regarding the research plan, the researcher gave a detailed outlay of the final data-collection and the process of data collection.

4.3.2.1 Introduction

A psychiatric nurse specialist with a PhD conducted all the research interviews and the researcher, who is familiar with the community and most of the participants, organised and accompanied the interviewer to all the research interviews. The researcher introduced the participant and the interviewer to each other and after small talk, she left the interview setting. A relaxed atmosphere was ensured and the research interviewer not familiar with the role players ensured that bias be excluded. Consistent communication techniques and styles of probing during all interviews were also adhered to (Sullivan, 1998:310).

Before the research interviewer commenced with the interview schedule, she and the researcher ensured that both understood the main aspects or elements involved in the research interview. They had a discussion during which the interview schedule was evaluated on all possible misunderstandings that could occur. A work schedule was drawn up to fit both the researcher and the research interviewer over a period of two weeks in June 2008, and the researcher was responsible for making and/or confirming appointments with the stakeholders.

Hereafter the brief explanation of how permission for data collection was obtained from the participants.
4.3.2.2 Permission for data collection

See chapter 1, paragraph 1.6.4 on permission obtained from the Ethical Committee of the North-West University, Potchefstroom Campus, as well as the permission obtained from the Department of Health, North-West Province. During the first telephonic discussion with the stakeholder, the researcher explained the purpose of the research and the type of interview and questions that will be asked. The researcher explained that the interview would be electronically voice recorded and that confidentiality will be maintained. All the participants gave provisional permission for participation telephonically. An appointment was scheduled to suit the role players in the setting of their choice. The interviewer discussed the objectives of the research with the role players as participants; explained the procedure of the interview; and obtained written informed voluntary consent before data-collection and the interview started.

In the subsequent section, a discussion on the research interview as qualitative data collection tool follows.

4.3.2.3 Research interview as data collection tool

A semi-structured research interview was selected as data-collection tool (Morse & Field, 1998:76). Although the structure of the interview came close to an everyday conversation to encourage active participation (Foley & Valenzuela, 2005:223; Kahn, 2000:61), it was neither an open conversation, nor a highly structured questionnaire. The interviews were electronically recorded and field notes were made during and after the interview, and together this formed the empirical data. Interpretation and subsequently description followed to give meaning to what the stakeholders and role players said. The researcher utilised the elements of qualitative research interviews as outlined by Kvale (1996:30-31).

An interview guide (see table 4.2) focused on certain themes (Kvale, 1996:27) necessary for the conceptualisation of a community-based collaboration to support the older person in the world of HIV/AIDS. It furthermore consisted of an open question on
each theme and it was introduced like a request to the participants to make their views known. The questions guided the research interviewer and controlled the interview to obtain optimal information (Morse & Field, 1998:76) in the search for themes necessary. The interviewer knew what questions to ask to reach the purpose of the study and ensured before the interview started that the participants (stakeholders and role players) understood the context and the concepts applicable to the questions. The researcher developed the interview schedule according to the content and purpose of the research (see chapter 1, paragraph 1.5 on the central theoretical statement of the researcher). After consultation with a psychiatric nurse specialist to pre-test the questions in the interview schedule, the researcher made alterations and the interview schedule for implementation was compiled. Before the actual collection of data started, an interview was conducted to test the interview schedule in the field (Polit & Beck, 2006:56) and after consultation with the research interviewer, the questions were rearranged and after final adoptions were made, the researcher was satisfied to begin with the data collection.

The quality of the study and its results relied on the quality of the questions (Morse & Field, 1998:77). However, it is not only the quality of the questions that directs the success of the study, but also the qualities of the interviewer. The role of the research interviewer is outlined below.

4.3.2.4 Role of the research interviewer

The research interviewer is familiar with the context in which the research interviews were conducted because of her involvement in the community as a researcher. Kvale (1996:96) states that it is not only through literature and theoretical studies that the researchers familiarize themselves with the content of an investigation, but through involvement. The researcher maintained a high level of involvement in the community through involvement in community projects and service-learning of the community nursing science learners. The researcher also serves on different community committees and assisted the research interviewer where necessary. Gaining trust is
essential to the success of the interviews (Fontana & Frey, 2005:708). In this study this applies to the interviewer, researcher and the stakeholders and role players.

Table 4.2:  Interview guide: Stakeholders and/or role players

<table>
<thead>
<tr>
<th>Section A</th>
<th>(Phase two, step four): To identify the different stakeholders and/or role players involved in community-based HIV/AIDS care and support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Identify and describe the different stakeholders and role players</strong></td>
<td>The researcher consulted key role players in the marked community, and twenty-two stakeholder and role players that satisfied the inclusion criteria were identified. The following questions were posed in order to clarify the role and purpose of the organisation:</td>
</tr>
<tr>
<td></td>
<td>What is the aim of your organisation? What do you do in the community?</td>
</tr>
<tr>
<td></td>
<td>Do you work as a volunteer or do you receive salary/stipend?</td>
</tr>
<tr>
<td></td>
<td>What support programs do you offer in the community?</td>
</tr>
<tr>
<td></td>
<td>Does your organisation receive money on a regular basis from international/national donors?</td>
</tr>
<tr>
<td></td>
<td>Can you please tell me of any other support programs known to you.</td>
</tr>
<tr>
<td></td>
<td>How do they contribute to the support of the older person in the world of HIV/AIDS?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section B</th>
<th>(Phase two, step five): To explore and describe the perceptions of the stakeholders and role players regarding community-based collaboration to support the older person in the world of HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Explore the perceptions of the stakeholders and role players regarding community-based collaboration to support the older person in the world of HIV/AIDS</strong></td>
<td>Do you work together with other organisations in the community?</td>
</tr>
<tr>
<td></td>
<td>If yes, what is the reason for your organisation to work with other organisations?</td>
</tr>
<tr>
<td></td>
<td>And how do you work together?</td>
</tr>
<tr>
<td></td>
<td>Can you tell me how you view community-based collaboration to support the older person in the world of HIV/AIDS?</td>
</tr>
</tbody>
</table>
The research interviewer and the researcher worked hand in hand during data collection and the researcher accompanied the interviewer to all the interviews. The interviewer and the researcher were sensitive to the following:

- recognising problems in the interview schedule in order to improve the quality of the original interview by reflecting back on the main purpose of the study throughout the interviewing process (Kvale, 1996:100),
- learning throughout the data collection process, and in so doing they became wiser on new and unexpected aspects of the themes,
- observing the stakeholders and role players in their work situation, their empirical world, and in the homes of some of the NGO role players. This added valuable data to the voice recorder's spoken words, and
- the principles of community involvement and the research team's personal involvement gave them the opportunity to be cautious when entering the work settings and homes of the stakeholders and role players to minimise the risk of harm caused by stigmatisation.

The researcher of the study took note of the hints outlined by Morse and Field (1996:77-78), Kvale (1996:128-129) and Holloway and Wheeler (2002:84) regarding a good interview, which is only possible if the interviewer complies with certain criteria. The interviewer

- posed clear, simple, easy questions on the stakeholders' and role players' levels of understanding,
- knew when and how to use different types of questions, like introducing-, follow-up-, probing-, specifying-, direct-, indirect-, structuring-, silence- and interpreting questions
• used communication techniques like eye contact, open at ease posture and non-judgmental attitude,

• was gentle and sensitive, listened to what the stakeholders and role players had to tell about their life world experience, let them proceed at their own rate of thinking and speaking as this can be more important than the specific mastery of questioning techniques,

• did not rush the stakeholders and role players or lead them in their answers, but played an active and supportive role to let them talk,

• clarified the meanings of the stakeholders’ and role players’ statements to confirm or disconfirm,

• checked each recorded and transcribed interview to comment on her interview style and improved throughout the interviewing process.

All the interviews took place in the work setting, offices and homes of the stakeholders and role players included in the sample. Appointments with the stakeholders and role players were scheduled with the aim to execute the research interviews on days and times suitable to them and the research interviewer. The researcher made suggestions regarding privacy, but the stakeholders and role players made the final decision and the interviewer adapted to that without any objections. The stakeholders and role players were in their own domains and at ease and comfortable during the interviews.

4.3.2.5 Conducting of interviews

When the interview was conducted, the initiation as well as the length of the interview was taken into consideration. As explained, the interviewer created an atmosphere in which the participants felt safe and at ease. In the study, the challenge was to gain and construct knowledge from the stakeholders and role players with different cultures and norms than the interviewer and researcher. The interviewer avoided the interview
turning into a therapeutic session; especially in this study on HIV/AIDS. The interviewer and the researcher were extra cautious to keep a balance between cognitive knowledge seeking and the ethical aspects of human interaction (Kvale, 1996:125-127).

The length of the interviews varied between twenty-five minutes to one hour and eighteen interviews were conducted over a period of two weeks.

4.3.2.6 Recording interview data

The interviewer used a digital voice recorder. It was explained to the stakeholders and role players and only after permission was obtained to record all that they say, the voice recorders were switched on. The whole conversation was recorded to preserve the stakeholders’ and role players’ words and saved on a computer as spoken text under a file name with a back-up of the interviews on a memory stick.

Part of recording interview data is note-taking and the interviewer made field notes immediately after each interview. The researcher was not present during the interview and therefore the field notes gave her insight into what occurred during the interview, or something that the interviewer observed in the environment of the participant. Burns and Grove (2005:433) state that research reports often read as if all went well, but that is not always true.

However, the interviewer gave clear and precise field notes (see Appendix I for an example of field notes taken) to the researcher each day after the interviews were conducted and the researcher were allerted of data-collection problems that occurred, like people-, researcher-, institutional- and event problems. The field notes served as a reminder to the researcher of these events and included the time and interview procedure (methodology notes), the behaviour of the respondent (observational notes of the stakeholders’ and role players’ facial expression, gestures and reactions) and the interviewer’s own thoughts (personal notes).
4.3.2.7 Transcribing the interview

The spoken words of the stakeholders and role players captured by the digital voice recorder were transcribed verbatim as eighteen different interviews by transcribers. The researcher listened to the transcribed data to check the quality and if it was true to the spoken word. This gave a clear picture and overview of the data to the researcher (Kvale, 1996:168). Instructions were given to the transcribers on how to transcribe the interviews according to a standard format. All reactions like sighing, laughter, pauses or silence was indicated as discussed with the transcribers (see Appendix J for a part of a transcribed interview).

4.3.3 DATA ANALYSIS

One should never ask the question of how to analyse transcripts only after all the interviews have been conducted, therefore the researcher decided before the onset of data collection to use concept mapping to analyse the data (Kvale, 1996:176). According to Johnsen et al. (2000:67) concept mapping is a "structured process for translating complex qualitative data into a pictorial form that display the interrelationships" between the themes.

The researcher knew before the onset of the interviews that it was necessary to explore the views of the stakeholders and role players regarding community-based collaboration to support the older person in the world of HIV/AIDS. This factor influence the decision to use concept mapping as a tool to assist the researcher in this study to interpret and describe the large amount of data collected during the research interviews in order to give meaning and understand the social reality as perceived by the stakeholders and role players.

As already discussed in chapter 1, the researcher was involved during the inquiry with the focus on the activity of the exploration and interpretation of meaning made possible by the study through interaction and discourse. This was done to reach consensus on more than one construct that could result in a conceptual framework. The stakeholders
and role players took an active role in the research process, from the question of interest to the outlets of findings (Guba & Lincoln, 2005:197).

4.3.3.1 Method of data-analysis

Typed field notes made by the research interviewer were taken into account during the data analysis process. The transcribed data was further analysed in themes through the procedure based on concept mapping, as indicated by Burns and Grove (2005:552), and the result was a single page with all the main themes and sub-themes in relation to each other. "Thematic" refers to a "body of topics for a study or discussion" (SACOD, 2002:1216) and therefore the researcher refers to thematic mapping in this study as a technique to organise the data from the voice recorder and transcriptions into a map to visualize the relationships among different themes, to stimulate the generation of ideas and to communicate them as related themes. Although thematic mapping includes the transcription of the data first, it includes the process of coding, categorisation into main themes, sub-themes and sub-sub-themes and interpretation of data into one activity (Burns & Grove, 2005:552). The whole process was done with the help of a software program Mindjet® MindManager® 6 to transform and bring together diverse views and values of the stakeholders and role players to conceptualise and represent complex constructs in a clear and systematic manner (Sutherland & Katz, 2005:257). This program helped the researcher to capture and organise large amounts of spoken and transcribed information into a visual presentation that offers a clear understanding of the themes with their links to each other.

A detailed discussion of the process that the researcher followed to analyse the data of the eighteen research interviews is now offered, including the guidelines for concept mapping as outlined by Burns and Grove (2005). The general approach of Trochim (in Cousins & MacDonald, 1998:336) that refers to generating, structuring and representing of a conceptual domain was also used, as well as that of other authors as indicated to perform thematic mapping in this study:
• Field notes generated immediately after the interviews were available for the thematic mapping to compliment what was said.

• The researcher listened to each voice recorded interview while reading through the applicable transcribed interview before starting with the mapping process in order to check the exactness of the information collected during the interviews (Pinosa et al., 2004:529).

• The researcher used a mapping program (Mindjet® MindManager® 6) to order the themes of each interview in a visual map with preliminary main themes and sub-themes. The help of a consultant was called in to use the program to its best potential.

• The researcher listened repeatedly to the voice recorder while reading the series of interviews to ensure that the map accurately reflects the participants' ideas.

• The data of each interview was considered "cognitively". This process also required the formulation of codes, generation of ideas, subsequent sorting, establishing relationships, and recording of nonverbal data. The researcher had to take breaks to allow time for thought.

• Verbatim quotes were indicated where they apply on the map and a call-out balloon indicated outstanding ideas generated by the participants that the researcher should mention and discuss.

• Annotations were made on the map to indicate connections and participants or the researcher's input.

• After all eighteen interviews were mapped, the researcher started with a second-level analysis in order to develop an integrated map that combines content from all the individual thematic maps. During this process, the themes were structured and at this stage the researcher consulted with the co-analyst, who was also the research interviewer, to represent the integrated map.
• At this stage, the researcher listened to and read the transcript of an interview conducted with the research interviewer by an independent interviewer to capture her thoughts on the two-week interview process and to share her experiences. The aim of the interview was twofold, namely to give the research interviewer an opportunity to debrief and for the researcher to use the information as triangulation of own data.

• The integrated thematic map resulted in five main themes with subsequent sub-themes and a few more themes on which the co-analyst agreed (see Appendix K for an example on the integrated map).

• The integrated thematic map was converted into a word document through the Mindjet® MindManager® 6 for discussion purposes.

• The researcher plans to use the results from the thematic mapping, which was constructed from the information obtained as perceptions from the individuals within their social context (Kelly et al., 2007:284), to contribute partly to what a community-based collaboration conceptual framework to support the older person in the world of HIV/AIDS should entail.

A discussion of the final integrated main themes and sub-themes generated and structured from the data subsequently follows.

### 4.3.4 LITERATURE CONTROL

As in phase 1, step 2 and step 3, a literature control was conducted throughout the discussions of the findings in order to confirm the data obtained by the empirical investigation. The researcher used the literature to strengthen the findings once patterns have been identified (Creswell, 2003:31). Refer to chapter 3, paragraph 3.3.4.

### 4.3.5 RIGOUR

The researcher decided once more to use Guba's model for trustworthiness as discussed by Krefting (1991:215) and Morse et al. (2002:5), which contains four criteria, namely credibility, transferability, dependability and confirmability. The reader can in addition refer to chapter 3, paragraph 3.3.5 where rigour and the Mmogo-
method™ were discussed in detail. A brief discussion is furthermore proposed to the reader that specific applies to step 4 and step 5 of phase 2.

4.3.5.1 Credibility

The prolonged involvement, selection of the participants, interview technique, triangulation and reflexivity were used as strategies (Krefting, 1991:215).

- **Prolonged and varied field experience**
  
  Refer to chapter 3, paragraph 3.3.5.1, which also applies here. The researcher, as a faculty member and member of various committees in the community, is familiar to most of the systems in the community as well as the stakeholders.

- **Selection of participants**
  
  The stakeholders and role players identified from the same urban area as the older persons (see chapter 3, paragraph 3.3.5.1) were invited to participate. The participants were familiar with the community and in particular with the extent of HIV/AIDS. There was a well balanced representation of stakeholders who decided on their own that they want to contribute and take part in the study, and they are the best sources of information and input on how they see community-based collaboration to support the older person in their world of HIV/AIDS.

- **Interview technique**
  
  The researcher, who is known to the community and the participants, was part of the whole process of interviewing. An independent researcher, a psychiatric nurse specialist, ensured a balance and prevented over-involvement. The participants opened up and discussed concerns as well as sensitive matters regarding the older persons and HIV/AIDS.

- **Triangulation**
  
  The same strategies apply here as in chapter 3, paragraph 3.3.5.1.

- **Reflexivity**
  
  The same strategies apply here as in chapter 3, paragraph 3.3.5.1.
4.3.5.2 Transferability

The researcher believes that the conceptualisation of community-based collaboration as perceived by stakeholders involved with HIV/AIDS matters in the community could be transferable to similar situations where readers may experience the same difficulty or quest for answers. Also, refer to chapter 3, paragraph 3.3.5.2.

4.3.5.3 Dependability

The same strategies apply here as in chapter 3, paragraph 3.3.5.3.

4.3.5.4 Confirmability

The same strategies apply here as in chapter 3, paragraph 3.3.5.4.

4.3.6 ETHICAL CONSIDERATIONS

Cognisance was taken of different ethical issues that may occur in the interaction with the stakeholders, role players and specific organisations involved in the study. The ethical considerations and its key elements as discussed in paragraph 3.3.6 also apply in this phase of the study, step 4 and step 5.

4.4 DISCUSSION OF RESULTS

The subsequent integrated discussion of the results includes the demographic profile of the stakeholders and role players, the results generated from the data collected during the research interviews with the stakeholders and role players regarding the existing networks and support programs available in the community of Potchefstroom, as well as the perceptions regarding community-based collaboration of the stakeholders and role players involved in the mentioned networks and support programs.

4.4.1 DEMOGRAPHIC PROFILE OF STAKEHOLDERS

Eighteen stakeholders (n=18), from the urban area participated voluntarily in the research interviews. A stakeholder is for the purpose of this study a person who
represents a group or organisation with an interest in projects or initiatives and who plays a role and/or has a function in the particular situation/project/initiative. Before the findings are discussed, a brief outlay of the biographical and demographic details of the stakeholders and/or role players that participated in the study follows (refer to table 4.3).

Table 4.3: Demographic profile of stakeholders and/or role players

<table>
<thead>
<tr>
<th>Gender</th>
<th>Men = 5</th>
<th>Women = 13</th>
<th>n=18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position and frequency (n=18)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional Nurses</td>
<td>2</td>
<td>Staff Nurses</td>
<td>2</td>
</tr>
<tr>
<td>Medical doctors</td>
<td>1</td>
<td>Peer educators</td>
<td>1</td>
</tr>
<tr>
<td>Health promoters</td>
<td>1</td>
<td>Project co-ordinators</td>
<td>2</td>
</tr>
<tr>
<td>Researchers</td>
<td>2</td>
<td>Directors</td>
<td>2</td>
</tr>
<tr>
<td>Supervisors, PHC</td>
<td>1</td>
<td>Volunteers in health care</td>
<td>2</td>
</tr>
<tr>
<td>Managers</td>
<td>1</td>
<td>Ward Councillors (Politicians)</td>
<td>1</td>
</tr>
<tr>
<td>Type and frequency of organisations (n=18)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>International NGO's</td>
<td>2</td>
<td>FBO's</td>
<td>2</td>
</tr>
<tr>
<td>National NGO's</td>
<td>5</td>
<td>University (Academic)</td>
<td>3</td>
</tr>
<tr>
<td>Department of Health</td>
<td>3</td>
<td>Private sector</td>
<td>1</td>
</tr>
<tr>
<td>CBO's</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Levels of presentation (one stakeholder can be involved on more than one level)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>International</td>
<td>8</td>
<td>National</td>
<td>9</td>
</tr>
<tr>
<td>Provincial</td>
<td>9</td>
<td>District/Community</td>
<td>16</td>
</tr>
<tr>
<td>Type of service/focus and extent of involvement (one stakeholder can be involved with more than one type of service)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV/AIDS care</td>
<td>11</td>
<td>HIV/AIDS support programs</td>
<td>14</td>
</tr>
<tr>
<td>Palliative care</td>
<td>6</td>
<td>Community development</td>
<td>9</td>
</tr>
<tr>
<td>General help/household chores</td>
<td>7</td>
<td>Gender issues</td>
<td>4</td>
</tr>
<tr>
<td>Health education</td>
<td>13</td>
<td>Social issues</td>
<td>12</td>
</tr>
<tr>
<td>Religious support</td>
<td>7</td>
<td>Care for the older person</td>
<td>2</td>
</tr>
<tr>
<td>Academic lecturer and researcher</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Although only eighteen \((n=18)\) of the twenty-six stakeholders agreed to voluntary participation, the demographic profile of the stakeholders and/or role players demonstrated a well balanced representation in relation to the information needed. The women were more than the men and five men against thirteen women participated in the research interviews.

The participants are mainly involved with HIV/AIDS matters, with one political member involved with health in the community, the results revealed a presentation of members in different positions that promised perceptions from different positions (from grassroots level to management).

The type of organisations showed that the area where the research was conducted consists of a well-balanced pool of stakeholders, **formal and informal**. The formal structures refer to the Department of Health of the Southern Region with all the health facilities under it. The informal structures refer in this study to all the organisations in the community involved with HIV/AIDS on grassroots level that is community-based.

The stakeholders are involved with more than one level of service providing or support, but their focus is mainly on the younger adult and children regarding HIV/AIDS, mother and child services, palliative care, Tuberculosis treatment (Direct Observation and Treatment Strategy/DOTS program).

It seems like a reality from the results that the care and more specifically the support programs for the older person were in the minority against the other services. The reader should take note that only two of the stakeholders included in the study are linked to the care and support of the older persons in the community.

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4.4.2 CONCLUSION PERTAINING TO THE DEMOGRAPHIC PROFILE

The following conclusions flow from the preceding demographic profile of the stakeholders:

- There are different formal and informal stakeholders, but they are fragmented, duplicate services and do not focus on the older persons.
- The stakeholders hold the possibility to compliment each other and form important networks in community-based home care if co-ordinated, and the Department of Health and political structures are the policy makers with the university as a key role player.

The following integrated discussion gives clarity on the perceptions of the stakeholders on community-based collaboration to support the older person in the world of HIV/AIDS.

4.4.3 DISCUSSION OF RESULTS ON THE PERCEPTIONS OF STAKEHOLDERS

The following summary in table format (see Table 4.4 hereafter) provides an overview of the results organised through thematic mapping. All the participants granted permission to use the direct quotations from their interviews.
Table 4.4: Main themes and sub-themes generated from the research interviews with the stakeholders

<table>
<thead>
<tr>
<th>Main themes</th>
<th>Sub-themes</th>
</tr>
</thead>
</table>
| 1. Perceptions of the stakeholders regarding their role in the community | Networking role of the stakeholders (interview: 1, 2, 3, 4, 6, 7, 8, 11, 12, 13, 14, 16)  
• University as network in the community (interview: 1, 6, 8, 16, 17, 18)  
• CBO's, NGO's and FBO's as health supporting networks (interview: 2, 4, 6, 7, 8, 11, 12, 13, 14, 18)  
• Social support networks (interview: 2, 3, 6, 7, 8, 13)  
Health education role in the community (interview: 3, 5, 6, 9, 10, 12, 14, 15) |
| 2. Perceptions of the stakeholders regarding their needs in the community | Need for effective management and use of resources (interview: 2, 3, 6, 7, 14, 16)  
Transport as an imperative in community-based collaboration (interview: 2, 6)  
Need for counselling for community care workers (interview: 1, 3, 14) |
| 3. Perceptions of stakeholders regarding the role of the older person in the community | Older persons are role models in the community (interview: 1, 8, 11, 14, 17)  
Older persons are the care givers in the community (interview: 2, 5, 7, 13, 14, 15)  
Caring role of the older persons is a spiritual calling (interview: 8, 10, 11, 15) |
| 4. Perceptions of stakeholders regarding the needs of the older persons in the community | Need for community structures (interview: 1, 4, 6, 7, 8, 9, 10, 11, 15, 16, 17, 18)  
Need for knowledge empowerment (interview: 2, 3, 5, 6, 8, 9, 14, 15, 17)  
• Knowledge on prevention of infection (interview: 1, 2, 5, 14, 15, 16, 17)  
• Knowledge regarding health issues (interview: 2, 5, 6, 8, 9, 14, 15)  
• Knowledge and skills with regard to child raising (interview: 1, 3, 8, 14, 15, 17)  
• Skill to manage role changes (interview: 11, 13, 15, 17)  
Need for acceptance (interview: 4, 11, 15, 17)  
Need to be protected against socio-economical abuse (interview: 6, 7, 8, 10, 11, 15, 16)  
Health needs (7, 8, 11, 17) |
| 5. Community-based collaboration as perceived by the stakeholders | Relationships based on collectiveness and common goals (interview: 1, 2, 4, 5, 6, 7, 8, 10, 15, 16, 17)  
Community development through participation and involvement (interview: 1, 2, 5, 6, 8, 10, 13, 16)  
Identification and utilization of structures (interview: 1, 2, 6, 8, 9, 16)  
Multi-disciplinary and -sectoral networking (interview: 1, 6, 8, 10, 14)  
Sustainability (interview: 2, 6, 9, 10, 16)  
Co-ordination (interview: 2, 13, 14, 16, 18)  
The extended family in community-based collaboration (interview: 2, 3, 6, 7, 8, 12, 17) |
4.4.3.1 Perceptions of the stakeholders regarding their role in the community

In most of the interviews the stakeholders viewed their role as that of networking. The university is perceived as a vital stakeholder, the CBO’s, NGO’s and FBO’s as health supporting networks, while some thought the stakeholders to be a social support network in the community. The stakeholders, in many cases, only play a co-ordinating and advisory role and are not allowed to make binding decisions; they can, however, influence policymaking (Schiffer & Waale, 2008:1). In addition to the network role of the stakeholders, they strongly agree on the perception of their health education role in the community.

- Networking role of stakeholders

Networking means to interact with others to exchange information and develop useful contacts (SACOD, 2002:782). Many stakeholders recognised their networking role and revealed in the interviews that the University, the Department of Health, the CBO’s, NGO’s and FBO’s are the more prominent existing networks involved in some or other program regarding HIV/AIDS in the community. The main stakeholder was identified as the Department of Health as policy maker and with certain political structures in place. Networking can be effective if the stakeholders share good practices and expertise, develop organisational protocols together and gain insight into the goals and actions of each stakeholder (International Council of Nurses, s.a). Stakeholders as a network can be formal and informal, the people in the organisation (network) have certain influences or power and each organisation has its own goals, sometimes the goals of the people in one organisation can differ (Schiffer & Waale, 2008:1).

Only a few (three) stakeholders interviewed recognised the role of the Local AIDS Council (LAC) as an important structure for networking between the other organisations in the community. The LAC should function as the umbrella organisation where all the CBO’s, NGO’s and FBO’s should registered if they comply with certain criteria, like written statistical reports on what they do and on
their financial management. One of the stakeholder’s representative explained with concern that,

"...all the splinter groups...not good...should work through an umbrella organization and in Potchefstroom it is the Local AIDS Council...to co-ordinate the CBO's, the FBO's and the NGO's..."

The LAC as an organisational structure is meant to facilitate and co-ordinate the battle against HIV/AIDS in the local community, and the hope was that an organisational 'culture of ownership and accountability' develops. However, the contrary was confirmed by empirical results found in a study done and presented by Boessenkool and Schutte (2005) that argued that the "presupposed causality between organisational structure and culture ownership has no theoretical base". The authors are of meaning that a 'culture of ownership' is important for any LAC to become efficient and effective. The LAC should belong to the community they serve, not merely to the Department or Health. The results in the study show that there is plenty of room to attend to this matter and to co-ordinate the fragmentation that occurs.

As one of the role players said:

"So eh...I think it is very important that those organisations are identified so that those linkages and collaboration, it is actually there....a data base of those organisation....I'm not sure...my diary might have that....it might be outdated eh...organisation because organisation come and die....I actually told them that eh...you know we are fragmented, it's not going to help us. Tomorrow this one goes and talks to the municipality. That one goes there, the municipality are asking themselves 'Can these people organise themselves?' So that there are more people that we can talk to a few people that have got a mandate to...you know for these people. And report back..."

And another role player adds to the reality that the Local AIDS Council (LAC) does not really belong to the community and say that all other organisations in the community should rather work through the LAC:
"...look in the first place uhm, do we have an umbrella organisation in this town and in North West. In North West it is the Provincial Council on AIDS and then in this town self it is the Local Aids Council. Now at the LAC the executive major is the patron. And.. uhm, what the LAC does is in the first place to get the NGO's and FBO's and CBO's...together and register them with them...also as an organisation that look after the HIV uh...infected and affected people...to try and co-ordinate it...so that there is not such splinter groups...and to help them with...uhm..uhm...information and other uhm...support...Because what I mean is that you get churches...and I speak my mind...some churches, specially the white churches want to work in the black community...but they are not really included at the LAC...in other words they work on their own...and we do not really encourage that...we like to do a co-ordinated thing..."

Ferreira (2004:38) confirms this by stating that government, NGO’s and local communities need to work together as partners to meet the needs of the community and families. Linkages and connections among organisations and other stakeholders enable social support and the flow of information to the community. People in the community tend to model the behaviour of the people in the community with high status, reputation and prestige (Mendel et al., 2008:27) and network with them. The old saying with a new perspective regarding social networking in the community can apply here; “it's not what you know, but who you know” (Schiffer & Waale, 2008:3) with the focus on the structures in the community that interact with each other with a shared purpose to support the older person in the world of HIV/AIDS.

- University as network in the community

The community where the research was conducted is very much aware of the university and perceives the university as a network in the community vital for community-based collaboration to support the older person in the world of HIV/AIDS. The mission of the university in the context of this study is to ensure a balanced education-learning- and research environment to utilize the generated knowledge in an innovative manner in the community and the country. The
university is furthermore multi-disciplinary in nature and runs different programs with different focuses in the community, among others, research projects, developmental projects and service learning for the students with a high level of community involvement (NWU:2008:8). One of the participants said:

"...but we also have you know other institutions that we eh could link...to say there are some people here that need your intervention....What can we do? But also I think the outreach program that the University has; we also need to be looking into the university....You know to come and do base line surveys or maybe research...that could be of importance or assistance to actually the problem around....." (Name of the residential area mentioned deleted).

The university plays an enormous role with regard to research in the community. However, it is important that the university that “uses” the community and their members should utilise the knowledge and information generated through the research to give back to the community. However, the “gap” between research and practice is a growing concern in community-based settings of care, and it forced researchers to struggle with the differences between healthcare and community settings, and more specifically to come up with solutions regarding the implementation and dissemination of research findings as strategies and plans within community-based health services (Mendel et al., 2008:21). The one role player said:

“Yes, our research mainly focus on that to identify the needs in the community, and...uhm...to see what we should do with the information to develop it into an intervention program to help the community...I mean we have a moral responsibility towards the community...I feel very strongly that it is totally unethical to go into the community...to do research without giving back to the community...It is that extra mile we go...uhm...outside our direct assignment...it refers much closer to the university's community-service role...”

Research projects in the community hold the possibility to create awareness between the community members regarding important health issues, as one field worker said:
"I am a field worker...I visited my people every day and I ask them, so how did you cope...every time I go to one of my patients they tell me someone has passed away...We are starting on the 30th of this month again...we are going to weight and measure them...we get trained...I got my motivation from ..eh...it comes from inside my heart the time my child was very sick...because I also get support from X...and Y...(two researchers from the university involved in the PURE-SA project) and from all those people I am doing research with...they give me love and told me what to do...now I can help the people with uhm..like HIV/AIDS".

The PURE-SA study (refer to chapters 1 and 2) is an example of the influence a research project can have on building networks and continuous referral and communication structures between the university, PHC facilities and community members. In most of the community outreach programs initiated by the university, there is networking between different role players, namely the church, some specific disciplinary schools of the university and the health clinics. Horns et al. (2007:74) add that an academic-service partnership can work and suggest that an effective partnership includes a "clear institutional strategy, partners that bring value and assets to the partnership, mutually beneficial goals and accountability to each other" and "time and timing, tact, talent and trust are other essentials of a productive partnership".

A citation of another participant shed more light on the importance of mutual involvement in networking:

"But I mention it here, I mention it everywhere ...at public meetings or so...you will always see only black people from the community....there are no white faces...except for the ...uhh...the lecturers or those involved in research from the university...I see them at meetings...."

The need for visibility of the university in the community is clear, and although the above-mentioned citation reveals disappointment with the networking between some role players and their involvement in the community, it also confirms that partnerships are possible.
• CBO's, NGO's and FBO's as health supporting networks

There are different models on community-based care and support applicable to this study. This includes, funding, technical assistance and support programs; advocacy, and community mobilization; drop-in centres/support groups; home visiting programs and comprehensive home-based care (Ncama, 2005:34).

Although the researcher identified two CBO's, not one of the stakeholders referred to themselves as CBO's and all thought themselves to be NGO's. In literature CBO's refers to organisations that exist to provide direct hands-on services such as health care, financial assistance, housing, transportation, education and childcare services to community members in order to address a range of everyday issues that affect individual wellbeing (Day, 2007:103). One participant, also the National President of the South African National NGO Coalition (SANGOCO), made a presentation on the NGO's, CBO's and FBO's in February 2008 during the meeting of project members of the one-year project "Democracy Empowerment" (2007-2008), implemented in cooperation between the municipalities of Växjö, Sweden, and Potchefstroom, South Africa. In the presentation it came to light that that CBO's are the organizations of the poor, the leaders themselves, the volunteers, they have no or little education, are the community or grassroots' formations, are normally small organizations with limited resources and are unable to meet the requirements of the donor. They are furthermore unable to manage finances, unable to manage the organisation, cannot write funding proposals and lack the ability to report on what they accomplish in the community (Luka, 2008). A study by Russel and Schneider (2000:11) confirms that although some of the poor communities are willing to mobilise, they may not have resources or skills to come up with an effective contribution. The following quotation from this study adds to this:

"But the most thing... we used to plant vegetables for them by, by... ecosystem usually helped us to plant for our patients... eh-eh, vegetables so that... they used to eat fresh food from there. The Department of Health stopped us they said, no if... we cannot go to their patient, and then we have not been given permission by the Health...Department. That's why we, we... they said; we have to go through the
Health Department... and that... they... as they were saying, the training... maybe our training was not that......that's why I go to... to the Health... so that they must give us training... people, people from the community...now I have the help of the church group also...they help with the training from the university students..."

Another role player explained concern about the fact the CBO's are not equipped with skilled people to organise effectively:

"But the people that are running you know CBO's are actually doing that out of a passion, you know... to provide that service. They are not skilled; some of them might not be educated. They are not geared in terms of running organisation. Their management boards are sometimes dysfunctional, because the board or the management committee do not understand what their duty and responsibilities are... and the other thing is that they are also not in a position to... you know run projects, like the people are actually skilled to run a project, they not have project management skills, nor do they have financial management skill... and normally they would not be eh.... supported by funders"

Literature adds to the above citation and states that partnerships in the communities should adhere to principles as to limit the number of partners, clearly state the budget and have adequate staff to monitor the financial capacity, share resources and provide transport, have a board as system of governance, clarify the roles of partners from the beginning, allow local and community input in the planning process and establish operational guidelines to ensure correct communication (Rodney & Miller, 2003:232).

NGO's can be categorized as organizations grouping under civil society which, although complimentary to government and private agencies, has comparative advantages over government agencies and business institutions. They contribute to more than one governmental institution and private organizations, and they are normally set up by a group of members that pursue a single goal or "mission" or a coherent set of goals without a profit motive in mind (in the context of this study it could refer to the "Service Centres for the Aged" with the main focus to promote the total well-being of the older person).
The following citations refer to the network between the organisations in the community and the health services and shows that they are instrumental to health care and support:

"Yes, there is already collaboration between us and them, the NGO's...they just come and say, sister, this one doesn't go to the clinic, then we usually go and check on their ART's...take them back to the clinic...."

"...networking is needed between the district, the NGO's and the clinics...I think one should work through this...uhm...office..."

The literature adds to the role players' perspective that although limited and not always that obvious, the collaborative networks are there (Mendel et al., 2008:27) with regard to support to the health services, like identifying and reporting "defaulters".

FBO's refer to organizations with a system of religious beliefs, based on spiritual apprehension rather than proof (SACOD, 2002:415). In South Africa the church is the strongest and most influential NGO and it is generally accepted that no other NGO can reach and influence the public (in this study the older person) more regularly and consistently than FBO's (Erasmus, 2005:139). A study done in a rural area in South-Africa adds to this and shows that the networks of various churches were the only organizations which seemed to have a real network infrastructure in place (Campbell et al., 2008:511). As one lady explained during the research interview:

"We worked together, the church, the university and NGO's...now we work only with our church...it was good when we used community workers...they know the community and all partners could gain and learn from each other..."

The same participant explained that the church where she is involved, decided to work only within their own structures in the church and that she thought that was not such a good idea because it helped them when they worked with all the organizations and with the health workers and volunteers who know the community. In addition, another role player explained:
"...uhm...yes, care workers...they identify the people and then we go out...work very well together..."

The influence of religion and the church a person attends, on health issues cannot be ignored, and is clearly shown by the following statement:

"You know every year the people goes to this church...Morea...the preacher usually said on television...please people, as the community if you come to Morea those with hypertension come with your tablets, those with HIV/AIDS come with your tablets...So if the reverend...the minister of your religion doesn't know that you are sick, how is he going to get involved..."

Mbiti (1990:3) explains this phenomenon in a nutshell in the literature when he states that each African ethnic group has its own religious system with a set of beliefs and practices. It is always with them, they carry it to the church, the school, the beer party or to the funeral ceremony.

Health management, as adapted for this study from Clark (2008:277), refers to health management as "a collaborative process that directs, links and co-ordinates with the person in need, the family, healthcare professionals, service providers and NGO’s, CBO’s, FBO’s to assess, plan, implement, advocate, co-ordinate, educate, monitor and evaluate options to support and care". It was clear from the interviews with stakeholders that the different NGO’s, CBO’s and FBO’s compliment the health services and demonstrate a health management role. One participant said that:

"...the NGO’s work at the clinic...they co-ordinate well with the clinic...they come on regular basis to the clinic and help us a lot...when they come in they will give report and tell they have been to so and so....they can tell you of the problems and why patients are defaulting...they play an important role...they actually bring the home to the clinic....and you understand the problems better..."

However, it seems that the community-based structures as referred to by the participants, do need external assistance and need to form partnerships between government and themselves. Turok (2006:9) states in her proposal that comprehensive home care should become a part of community-based services and
should be available to the older person with the necessary financial support from government. The CBO’s, NGO’s and FBO’s play an important role in **home-based care** as health-supporting networks. This came to light in most interviews with the stakeholders as the following quotations show:

"We go to their homes, talk to the older people and let them trust you..."

Family and friends often need much counselling and teaching (Uys & Cameron, 2003:4) to be able to care for someone at home with HIV/AIDS, and it is often the community care giver from one of the community-based structures referred to in the study that helps the older persons in their homes with this. The results in the study furthermore refer to the networking role of the stakeholders in the following quotations, which clearly indicates that there is a **link between the NGO’s and the service provider**, and the PHC clinic.

"They (the NGO's) come regularly to the clinic...you know...they will say...'Sister I visited so and so....' and then I will know that there is someone that is bedridden..."

The community caregivers and volunteers are more than often the ones that **find new cases** and will refer them to the PHC clinic, as the following citation highlights:

"When the older person fell ill at home, they need home-based care, we do have a kombi for that....but it is mainly for TB and HIV defaulters....they know of the elderly that need care, but they can't visit them...so it is a problem for us, the fact that we don't have a home-based care currently...."

Others do **follow-up visits** to households and in so doing help the staff at the PHC clinics and **act as extended help** to reach the people in the community that need health care and support. The following remark of the role players made it clear that although the organisations are of great help, the services do not focus on the older person. She said:

"But the NGO's support the PHC clinics...and then the PHC nurse in charge of the clinic give the names of patients that need home visits...they do the visit and will give feedback to the PHC nurse...but that is not for the elderly as such..."
The above-mentioned themes that emerge from the interviews with the role players with regard to their health supporting networks, namely health management and home-based care, are supported by literature from Uys and Cameron (2003:5-6), and seem to be a classic example of integrated home-based care. The same authors state that home-based care entails the provision of needed health care by a primary caregiver to a patient or family at home, but it should always be with the assistance of a trained community care giver. During the interviews it became clear that the larger well established NGO's linking with specific PHC clinics give feedback to the professional nurse.

• Social support networks

The different organisations in the community help with a variety of social issues and refer to the Department of Social Development where they deem fit. HelpAge International (2007:9) has set one of their targets to develop effective programs and advocacy activities through networking partners, which includes a wide range of organisations, including CBO's, NGO's, academic institutions and government agencies. In a previous community project in which the researcher was involved, it became evident during the small scale survey of all households in one of the wards that social issues like registration of births, identity documents and grant applications are problematic (Watson & Cloete, 2003). Some results from the interviews refer to the social networking in operation, as can be seen in the following quotations:

"When I visit them...look at the normal social issues...we will contact the social workers...to apply for grant or so..."

In order to apply for the grant that the participant refers to, people need relevant birth and death certificates, which they do not have (Strachan, 2000:8) and since the year 2000 when the author wrote this article, it is still applicable, as one role player explains:

"..you have a picture of what is going on at home through the NGO's and you can take it further at the clinic....give a date to the doctor to complete the form to help the patient to apply for a grant or a older person pension..." and another role player
enlighten the reader on their important role regarding social support networks, "They look after the community needs, registering them at he...helping to get them registered and getting them social grants..."

Most of the stakeholders involve themselves in a social network of different organisations in the community, as the participant explains in the following citation:

"There can be a partnership between the church, the school, the clinic, social development and the service centre in the community..."

HelpAge International endorses this statement of the stakeholder in that they acknowledge the need to strengthen collaboration between the individual partners and support the network to deliver its full potential (HelpAge International, 2007:9).

- Health education role in the community

Health education seems to be an imperative according to the stakeholders and role players that participated in the study, and it was the theme that repeated itself with each interview. Ferreira (2004:32) also refers to the urgent need that was identified in meetings with regard to policy issues in Africa regarding ageing, and to educate older persons in relation to HIV/AIDS. The need for health education is deemed necessary not only for the older persons as caregivers, but also includes the people they care for, as well as the role players themselves. HIV/AIDS prevention and education in their community remains a challenge for the NGO’s, CBO’s and FBO’s in the community because of the lack of resources and the main barriers identified in a study done by Rodney and Miller (2003:231) in collaboration with South Africa were insufficient resources, cultural differences, communication, delayed funding and unclear roles/responsibilities. However, in this sub-theme the focus will be on health education in a broader sense, but also with the focus on the older person, who could be educated by the different role players.

The older persons' education level is low and that can contribute to their lack of knowledge regarding health issues, subsequently the NGO’s takes the responsibility on them to educate these older persons. The older persons cannot read and/or write, and therefore other skills and methods are necessary to educate them. The
following citations refer to the concern of the stakeholders regarding the lack of knowledge among the older persons infected and/or affected with HIV/AIDS. One participant said:

"The older people are the ones with the problem...how can I say, they are the once that are illiterate...we must show them and give them knowledge..."

It is interesting that the role player recognise that it should be better to show them what to do. Clark (2008:270) refers to how important it is that health literacy principles and related tasks are taken into consideration when health education is considered. Aspects like written objectives should be explained clearly, the education material should be age, gender and culture appropriate, and the use of visuals that are clear and that motivate the older person to learn can be helpful.

The following remark of the participant adds to the reality that the stakeholders attempt to educate the older persons in the community:

"With the older ones...we go to the pay points...then we give something like health education".

The participants further explained in the interviews that the older persons’ themselves are explicit in their need for empowerment and to gain a voice. Way back in 1999, HelpAge International and the South African members made a commitment that education activities should be initiated by different stakeholders that focus on the rights of the older person, as well as to raise awareness of issues facing older persons at all levels through education (HelpAge International, 1999:74).

The following quotation sheds light on the need identified with regard to the fact that older persons need information on human rights also:

"And I think, in a way the classes could be extended for people around basic human rights....come talk about basic hygiene or health issues...and sometimes we just pass information...you know and at the same time empowerment...." and another role player refer the people that are educated and skilled that should participate in the training and education of the ones in need of it in the
The health education role of the stakeholders should be considered in the context of their own health literacy, and therefore the necessity to educate them, the stakeholders as well and to focus on more than just health issues. They should be educated on the rights of older persons in terms of the Older Persons Act (13/2006) (SA, 2006:10) in order to "recognize the undeniable link between human rights and public health in the context of HIV/AIDS" (Ferreira, 2004:33).

During the interview with one of the stakeholders it was made clear that training and education should rather be built on a trust relationship with the older persons according to their needs for support, and should not be forced on them, as was said:

"Mmm, and to build a trust relationship and to work accordingly to the needs of the older person...that the training must be the supportive system...ehm...not enforce....you might just touch on turning the tide...."

However, it is useless to give education and training without monitoring its success.

Needs in the community constantly changes and this should be taken into consideration when the stakeholders become involved in health education or education regarding other issues. As one participant says:

"...the education we give to the elderly should also be monitored and according to their needs...."

4.4.3.2 Conclusions pertaining to how stakeholders perceive their role in the community

- The stakeholders recognise their networking role, although fragmented, between the University, the Department of Health, the CBO's, NGO's and FBO's as the more prominent existing networks involved in different programs
regarding HIV/AIDS in the community. The main stakeholder is the Department of Health as policy maker with certain political structures in place.

- Stakeholders should establish networking systems based on a participatory-trust relationship with awareness for research projects to generate knowledge and utilise the knowledge to develop and empower both the stakeholders and the older persons in the world of HIV/AIDS.

- Knowledge and information generation through research are perceived as vital in the community and poses a huge challenge to the university as stakeholder, which is multi-disciplinary in nature. The challenge is to implement research projects on a community-based participatory basis in order to enhance community development and build trust relationships between all stakeholders that exist in the community for effective knowledge utilisation.

- The CBO's, NGO's and FBO's are health supporting networks that are important for support programs, advocacy, community mobilisation, health management that includes home-based care, lack the basic principles for effective partnership like organisational and financial management, as well as operational guidelines to ensure correct and open communication.

- Relationships between the different stakeholders are interrelated and complimentary to each other and the NGO's, CBO's and FBO's are important links in community-based home care between the household and the PHC facility.

- A partnership with a shared goal and adherence to the basic principles of effective partnership needs to be established in order to embrace the philosophy of collectiveness, culture of religion, experiences, wisdom, sense of responsibility for care giving and advocacy.
• The influence of religion on health issues cannot be ignored and should be acknowledged within the socio-cultural context of the older person infected and/or affected with HIV/AIDS.

• Most of the stakeholders involve themselves in social issues between different organisations in the community, and they often assist people in the community with issues like death registrations and grant applications.

• The conducting as well as the monitoring of health education built on a trust relationship is perceived as one of the most important roles of the stakeholders in the community, and should address illiterate- as well as older persons with low educational levels to empower them on older persons’ rights and relevant health issues like HIV/AIDS.

During the research interviews the stakeholders reported how they perceive the needs that some of the stakeholders experience in the community. The existing need for effective management and use of resources, for transport as an imperative as well as for counselling of the community care workers, will subsequently be discussed.

4.4.3.3 Perceptions of the stakeholders regarding their own needs

Although most of the CBO’s, NGO’s and FBO’s in the community have physical structures, received equipment like faxes and computers, these are often donations and are old, as mentioned by one of the participants:

"The problems we encounter...we've got a computer and we've got a fax machine...they are not up to date...I mean particular technological instruments...

In order to function well they need resources, and not only material resources. It is often more than that, and this includes skill and empowerment. Their expressed needs for effective management and use of resources, for transport and for counselling of community care workers will be discussed in the paragraphs that follow.
• Need for effective management and use of resources

Although an estimated 17% of the population in South Africa volunteers to give their time to service in different community-based organizations (Patel, s.a:16), there is currently no formal geriatric services in South Africa, and the provision of care falls mainly on NGO's, CBO's and FBO's (Turok, 2006:3). An appraisal of community-based HIV/AIDS care and support in South Africa lead to recommendations such as that 

**assistance in the developing of simple management systems** can be more beneficial than financial support (Russel & Schneider, 2000:35). One of the role players add to the authors' recommendation in the following citation:

"Remember not all of them receive financial support...it could be a lack of financial management in the NGO self...also, their businesses plans are of such nature that they do not qualify for financial support...also lack other management..."

However, according to Uys (2003:271), NGO's render service without government funding and it could lead to "patchy delivery systems". She confirmed what was said by one of the role players:

"That he...there is a plethora of you know, opportunities in the NGO sector...an empowerment and growth at the same time....but there is also a problem of lack of resources..

Whatever the case, it is clear that most NGO's are **highly motivated** and usually view hardships as a challenge rather than punishment, and these organizations are viewed in the community as “the hands that carry out the charity work" (Mohan, 2002:139).

Although volunteers work day in and day out in the community caring and watching over people dying, and often of HIV/AIDS, they are sometimes only paid a little stipend or get money for travelling costs alone, some get no material rewards for their efforts (Cullinan, 2000:3), which results in what one role player says:
"Although they (the NGO's) perform and deliver stats, e.g. their is no salary, they lose volunteers that feel disheartening and stay away...it is also a problem nobody receive the same payment and it differs from group to group"

**Transport as an imperative in community-based collaboration**

The need for transport is a reality and if the volunteers from the CBO's, NGO's and FBO's do home-based care and support they can only visit two or mostly three households per day. They walk far distances. The researcher can confirm this from personal experience when working in the community. The concern of the participants is clearly verbalised in the following phrases:

"...fact that we don't have transport to go out to their homes...we miss important aspects..."

"There are days that they do not come in for three days....then they will say: 'Sorry, we could not come...there is no money for the taxi....'...that is a great setback for the service at the clinic"

During the conducting phase of the research interviews in the community some of the older ladies that work as volunteers asked the researcher to assist them with transport to a household of two leprosy cases. The researcher measured the distance that they have to walk two times a week and it was five kilometres for ladies between the age of 71 and 75 years. This is the reality, and from this the constant cry for transport.

**Need for counselling of the community care workers**

In South Africa the focus of counselling is on before and after diagnostic testing mainly, and is not developed for the community care givers as support strategy.

"We need to talk...to off load...they promised us that they will send someone...I try to work it out for myself..."

"...the older persons need counselling...they can get counselling at the day care centre..."

"The elderly need a place where they can have support groups, to come together and talk..."
Conclusion on the findings follows.

4.4.3.4 Conclusion pertaining to how stakeholders perceive their own needs

- The stakeholders' needs included effective management and use of resources through effective skill development and empowerment strategies. The community care workers often work day in and day out without any payment or support and need counselling to cope with the demands of HIV/AIDS in the community. Effective community-based collaboration to support the older person is impossible without transport.

4.4.3.5 Perceptions of stakeholders regarding the role of the older person

The older persons are not only perceived as the role models by the stakeholders, they are also the caregivers, and this is a spiritual calling to most of them. The media should be encouraged to promote images that highlight the strengths, wisdom and contributions the older persons make to their family, community and workplace (Turok, 2006:9).

- Older persons are role models in the community

The role players view the older person as people who work hard; they are also an important link to the community, because they know the community. They have courage and are the resourceful ones, as the previous author stated. The participant agrees by saying the following:

"...yes they are very hard working...and the older people, they look well after the children...and they are an important link to the community..."

Older persons are respected in their communities because of their knowledge, experience, personal influences and power, they are thus regarded as being more of a person than the younger ones (De Villiers & Herselman, 2004:20). They are role models and are prepared to talk about HIV/AIDS issues, they participate in the community matters, are the pivots on which everything hinges, the ones that can be trusted. A role model is a person looked up to by others as an
example to be imitated (SACOD, 2002:1012) and the following citations refer to that:

"...and they are actively involved in being role models in talking about sex and HIV issues...."

"You know the extended family... and the poor granny....is the pivot on which everything hinges"

"And ehm...the elderly person is really the more trustworthy person...they are much caring..."

Social regulations of a moral nature refer among other things to respect for elders and to behave humbly towards those senior to you (Mbiti, 1990:208). The author adds to the view of the role players on the older person as role model, and one participant explained the connection in her words:

"We care; we share love, respect and honour...ne...Isn't that right? We are involved...we are here..."

- Older persons are the caregivers in the community

The theme is repeating itself in the study, and the reality is clearly stated by different stakeholders and/or role players that the older persons are the generation remaining in the community left with the responsibility to care for the children that are most probably ill and to care for the grandchildren. Whether they are infected or affected by HIV/AIDS is irrelevant.

The willingness to fulfil their parental obligations (Barnett & Whiteside, 2006:235) can clearly being heard in the following citations:

"And unfortunately, the task to care for the children that is left falls on the older person..."

"Even if they are not their real kids, they call them their kids"

"Uhm...sometimes it is family, but sometimes it is not even family...they will orphanage the children out of empathy"
Effective programs are needed to help and support the older person as caregiver in the community (Ferreira, 2004:38).

- **Caring role of the older persons is a spiritual calling**

Religion has a tremendous influence on the African people and as Mbiti (1990:2) explains, wherever the African is, there is his religion, and African people do not know how to live without religion. The primary pillar that motivates the older persons to act as volunteers in a caring role is their religious commitment to their actions (Zachariah et al., 2006:174). The literature explains the caring role, which is more than to help and support someone in need, it is rather a spiritual calling, a *religion* that the older persons take with them when they do a home visit and care for someone or when they care for their children, grandchildren or other orphans.

The following quotations of different role players shed some light on how they view the caring role of the older person in the community. The one says,

> "Yes, that's why...that's where the religion part comes in...yes...because most of us...our people are religious people..." and the *role of the church* is explained by another, "...we go from the church...from the faith perspective to support them spiritually...to give them the Word...uhm...and also to give bread...you know that you are only the sewer...it is God that let growth happen..."

The importance of the **spiritual dimension** of the older person its influence on their social and economic dimensions is supported by a study done by Nilsson et al., (2004:304). All the decisions they make, also the decision to care for others, is made on religious grounds.
4.4.3.6 Conclusions pertaining to how stakeholders perceive the role of the older person

- The older persons in the community have their own socio-cultural value system with a strong spiritual calling to fulfil the caregiver role; they are also the role models in the community, the ones with knowledge, personal influence and power, respected by the stakeholders.

The stakeholders had their own perceptions on the needs of the older person in the community that follows beneath.

4.4.3.7 Perceptions of stakeholders regarding the needs of the older persons

Older persons have been overlooked and ignored in service delivery, with very low education levels and mostly burdened with ill health (Turok, 2006:3) or physical impairment due to the aging process (see results in chapter 2, paragraph 2.4.5). HelpAge (2007:6) stipulates that it should be noted that old age brings reduced capacity to sustain a household with all the demands, and also increased difficulty to access health services. The stakeholders and role players that participated in the study explained the needs that the older person in the world of HIV/AIDS has as they view them. They perceive the older person to have a need for community-based structures that focus on the older person’s needs. They have a need for financial support, for empowerment through knowledge and health education, a need for protection and as mentioned, they have a health need. The needs of the older person in the community will subsequently be discussed.

- Need for functional community-based care and support structures

Overwhelming remarks were made by the role players that they experience and observe that the older persons in the community lack community-based structures for social support and care. This could be because the older person is not one of the priorities in health services, and that the focus is on mother-and-
child services. A study done by Baiya & Peachey (2003) in Africa, confirm this finding and states that development processes that are supposed to meet the needs for all, routinely exclude older people. One of the role players' adds that the older persons can no longer been ignored, they need care and support, more specifically in the reality of the existence of older persons in the community that are HIV/AIDS infected, and he express himself in the following words:

"No...we don't focus on the older person...maybe we are naive to think that it is only a problem for the younger ones...I saw a white man of 70 years that is HIV infected...you know, I think there exist a great need for geriatric care...and there is a lack thereof...specially for the older person infected with HIV/AIDS"

Another role player adds to this when the following was mentioned:

"From my experience...he...I think there was not much ehh...information that our organization specifically targets our elders..."

With reference to the first paragraph, it came to light that most participants view day-care centres as indispensable and consequently some quotations on the matter:

"At the day care centre they can do exercise, have nutritious food from vegetable gardens, and get moral and spiritual support..."

"...they need one central place from where they can co-ordinate...and yes refer if necessary..."

"Currently there are no services for the elderly infected and/or affected with HIV/AIDS in the community...uhm...in a more structured elderly care...co-ordinate..."

"...the older persons enjoy being together, to sit and talk...on grounds of that common experience of HIV/AIDS...to share and motivate each other..."

"Maybe a centre specific for older persons...for support...a safe haven...that I will recommend..."

The literature support the mentioned desire, and Russel and Schneider (2000:37) refer in their rapid appraisal of community-based HIV/AIDS care and support in

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South Africa that community centres are focal points where people can meet for support groups, confidential counselling, distribution of educational and information material, training of care givers and volunteers, legal advice, help with grant and disability applications, referral to other services and recourses in the community. It would be better if support services are housed in one place, a one-stop centre (HelpAge International, 1999:71).

Strydom (2008:107) adds to this and argues that service centres should serve as a place where they can obtain information, where they can be trained in different skills like how to raise a child, for income generation and a place where community sources can be mobilised.

• Need for financial support

The older persons expressed their need for financial support. Strydom (2008:83) states in an article that older persons are very worried about their financial situation, and of the Black population all received only social pension. Some of them were involved in income generating activities, but with hard work and low energy levels, they can easily turn frustrated and disheartened, but they will always have plans, as the one role player explains:

"When the money is scarce...it is the granny that will think of ways to bake 'vetkoekies' and sell them...she will make different plans to cope..."

Most of the programs visited during a study by Russel and Scheider (2000:33) confirm that income generating activities were mostly unsuccessful. However, the researcher can tell from experience and observation in the community of exceptions, as in the case where a group of older persons (mainly women) grow their own food garden, sell the food and generate money to give food to the poor and to bedridden people in the community.

However, there is a struggle with social grants, disability funding and orphanage grants. As has been discussed earlier in the study, this problem could result from
older persons that are not registered, or the red tape with regard to the application procedure.

"...also find that there are older persons that are not registered...do not receive old age pension"

- **Need for knowledge empowerment**

According to the guiding principles for provision of services in terms of the Older Persons Act (13/2006), the environment of the older person should ensure access to information by education of and training of older persons (South Africa, 2006:12).

**Professional people need help and assistance to empower** the volunteers that serve the older persons as one of the vulnerable populations in the community (Hutchison & Quartaro, 1995:111), as also remarked by one of the role players:

"...uhm...we train the field workers...for example the lecturers from social work and nursing...they offer short courses to the field workers, who are in the community...so we empower them to take the task of education out to the community members..."

The need for knowledge empowerment that the stakeholders and/or role players perceive among the older persons refers to knowledge on prevention of infections, on health issues, on skills in child rising and management of role changes.

- **Knowledge on prevention of infections**

Although education is currently still one of the most effective ways to prevent HIV/AIDS, Rose (1996:141) mentions that educational efforts are not directed at older people or their service providers. Previous results mentioned in this chapter revealed that the role players acknowledge a lack of social structures for the care and support of the older person infected and or affected with HIV/AIDS in the community. The following quotations add to that, as well as the written view of the author that the educational efforts are also not directed at the older person, and that they lack knowledge,
"...look when I bath someone without gloves...if I start talking to someone and forget to wash my hands...or the sores that drain and you wash them..."

The older persons are **unsure about precautions** that they should take when caring for the sick at home, as clearly stated by a role player:

"And we talk about a granny that could be infected by looking after a HIV/AIDS person at home...we find it...often...some people raise their eyebrows on this...where is the precaution?"

"...where there are cases ... the grannies....uhm...cases that I know of where infection took place as a result of care practices...they are sexual not active and really shocked that they got infected..."

Older persons are also involved in **risk behaviour** and urgently need HIV/AIDS educational programs designed for older adults (Rose, 1996:142). This statement can clearly be linked to the statement of one participant:

"the other problem is...our older people here...they like to have sex with the younger one...they think if they are having sex with young people they will be healed...that is my experience...you see that is the problem...that is how HIV/AIDS is transmitted to the mothers..."

**Knowledge regarding health issues**

Through the findings of all the previous chapters, it has become clear that the older person is the caregiver of the sick at home, the sick in the neighbourhood as well as in the community. A collaborative study done on HIV/AIDS symptom management in Southern Africa found that effective symptom control helps people living with HIV/AIDS to maintain a better quality of life, and that when conventional Western medicine fails, they resort to their own ways and implement self-care (Sukati et al., 2005:185 & 186).
The older person can be of great support and help if they have more information regarding the diagnosis and treatment, so that they can develop effective symptom management strategies as highlighted by the following verbal responses of participants:

"And to support them and empower them with knowledge...how to manage this and that...the sick children..." as well as "The granny or the mother that have to take care of the terminally ill patient...we have to train them and make them sole responsible for caring..."

- Knowledge and skills on child rearing and role changes

The stakeholders thought the older persons to be unsure of child rearing aspects pertaining to the younger children in the family and need some knowledge. As one of the participants noted:

"...because they face challenges...they have to take the kids to the school and look after them and all that...."

The older person should therefore be helped by the organisations in the community to enhance their capacity, and to strengthen the bond between them and the other generations (Ferreira, 2004:38). The role players that participated in the study argued what Ferreira (2004) stated in the previous sentence and one responded with:

"If we can really train the older people...grannies about the children, how they can discipline, because they must educate the children and raise them...it falls upon them...",

"She raised her children...now she starts anew...you know children grow into teenagers and it causes a real problem for the elderly...the fact is that the elderly that look after the small children do not have the knowledge and skill to raise children of today...I think they need help and facilitation with that..."
The role players expressed the following view regarding the **changing role of the older person**:

"With this new role of the older person...in the community regarding HIV/AIDS...it is like a newly discovered place and role of the elderly...the value that they have in our community..."

- **Need for acceptance and social support**

**Social support** has been defined as the "availability of people whom the individual trusts, on whom they can rely, and who make them feel cared for and valued as a person" (Westaway *et al.*, 2005:74). The following spoken words by the participants tell the opposite of the given definition:

"They are often alone in a little room...uhm...lonely, weak...can't get up...they are often rejected...and-uhm...then they basically lie there viewless and wait for their death..."

The older person **feels rejected** and **discriminated against** and therefore experiences a need for acceptance. The results from the interviews with the stakeholder and role players show that **stigmatisation** is everywhere. The following explanation is an example of an experience of stigma where there is fear for contagion (Holzemer *et al.*, 2007:548). The participant experienced a case where the other members in the household behaved in a manner that showed fear of close or direct contact with a woman with HIV/AIDS:

"I can tell you about a case we had...they discriminate against the woman...she had to use her own cutlery and was not allowed to use the toilet...our older persons are scared, they need counselling..."

- **Need to be protected against socio-economical abuse**

The Older Persons Act (13/2006) states that any service to the older person should be provided in environments that promote the prevention of exploitation of older persons and promotes their respect and dignity (South Africa, 2006:12).
Abuse of the older person is either an "act of commission or omission, it may be intentional or unintentional, it may be of physical nature, it may be psychological or it may involve financial or other material maltreatment" (Krug et al., 2002:126). The following verbal response of how the role players in the community view the socio-economical abuse of the older person in the community and therefore the need of the older persons to be protected, apply:

"And sometimes you know the issue of abuse...because of them trying to...you know...make a living...we should make sure that the elderly are not abused...they don't look well after them...they take their money...".

"They receive grants, but they give nothing to keep the household going, the mother keeps them going, their material and emotional wellness...the mother is sick...she has high blood pressure and diabetes..."

The findings from the interviews with the stakeholders and/or role players discussed in various previous paragraphs refer to the generation gap, the younger generation that are disrespectful to the older person, the older person that experiences the challenge to adjust to the new roles imposed on them in their households. This made the researcher aware of their vulnerability towards socio-economic abuse. This aspect is also supported by the World Report on Violence and Health (Krug et al., 2002:132), which states that mistreatment of the older person includes a lack of respect by the younger generation, tension between traditional and new family structures as well as the restructuring of the basic support networks of the older person. The following citation explains the reality of some of the social mistreatment the older person experience in their community:

"Uhm ...there are this sort of perception in the community that ...the life of the older person is over...they are at the end of their contribution to the church and the community...but as we know this is the wrong perception, they form an integral part of the church and organizations in the community, also in the family...the extended family...they are the pillars"
• Health needs of the older person

The inferential results in chapter 2 on the health profile of the older persons, demonstrate that HIV-infection is a reality and that 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%. The stakeholders and/or role players working in the community with the older persons explain the health needs of the older person as follows:

"Some are now 60 or 65 years old...and some of them are positive...they themselves...although they come to the PHC clinic, I think they need a very well structured support system..."

"Some of the elderly are so weak, the can't even help themselves anymore...they see the food but can't prepare it or get up to get the food"

"The elderly neglect themselves and their health...they don't have time for themselves...they have a full time schedule to manage with the children...they loose their energy...."

The results in chapter 2 furthermore reveal that the older persons are vulnerable to chronic diseases. The national information report by Joubert and Bradshaw (2006:211) support the findings and refer to hypertensive heart diseases, stroke, hyper-lipidaemia, diabetes, cancer, TB and arthritis as self-reported diseases by older persons in South Africa. The older persons reported in the findings of chapter 2 that they have trouble to use their hands, walk, bend, hear and read. The mentioned physical limitations predict that the older persons' future responsibilities will go hand-in-hand with even more hardship, especially the females that could be responsible for housekeeping chores and care giving responsibilities that could involve a range of physical activities.
4.4.3.8 Conclusions pertaining to how stakeholders perceive the needs of the older persons

- The needs of the older persons in their communities are perceived by the stakeholders as a need for social structures that focus on the needs of the older persons with explicit reference to a focal point where they can meet and have support groups, generate an income and so forth. This can be accomplished in the form of a day-care centre where their need for financial support can be partly decreased.

- The stakeholders in the community know the older persons, and the health education role that such stakeholders have in the community should fulfil the need of the older person regarding empowerment through knowledge on the prevention of infection, knowledge on health issues, knowledge and skills with regard to child rearing and how to manage their role change.

- The university as academic institution should take leading role in coordination and monitoring community-based education of health issues with focus on HIV/AIDS, human rights and management skills.

- The older persons are also exposed to stigmatisation, which is still a reality in the community and has the need for acceptance and functional social support so that they are not isolated and ignored.

- The older persons are often victims of socio-economical abuse and have a need for protection against that as well as needs regarding their health.

4.4.3.9 Community-based collaboration as perceived by the stakeholders

The literature refers to different explanations of community-based collaboration. Community-based support refers to services available to the older person in the community per se, services that render care and support either through formal services (PHC clinics) and/or informal services (friends, neighbours, family members, and other
volunteers). Community-based refers to **active involvement** of community members (Penning, *et al.*, 2002:1). Some authors refer to collaboration as "a dynamic, transforming process of creating a power sharing partnership" (Sullivan, 1998:19). Collaboration means "**shared responsibility** for planning, problem-solving and evaluating with clients and others in the health care delivery system" (Leddy and Pepper *in* Hutchison & Quartaro, 1995: 112). The following discussions show clearly that the stakeholders and role players view more than one aspect, (see bulleted list below), as part of community-based collaboration:

- **Relationships in a collaboration process** should be based on **collectiveness** and a **common goal** for all **partners** to understand;
- **Community development** form an integral part of the collaboration **process** that is impossible without **community participation and involvement**;
- it is important to **identify all possible structures** and to utilize them;
- **Multi-disciplinary** and **multi-sectoral networking**;
- **Sustainability**;
- **Co-ordination** and
- the role of the **extended family** in community-based collaboration.

- **Relationships based on collectiveness and common goal**

Developing a **common goal** entails that the partners involved should be prepared to explore new options for services, and as the author of the important statement says, for this to happen a vital ingredient is needed and that is "trust" (Wildridge *et al.*, 2004:3). The results from the integrated thematic mapping show that the role players viewed the relationship between different role players in community-based collaboration as a relationship that should be **open and transparent**. As one role player said:
"And you can see my face, but my heart...no you cannot read..." and "OK...I should say there must be sincerity, respect and yes... good communication...total collaboration..." and another stakeholder agree that the organizations and community should say what can collectively be done, "Once you have them on board...say what can be done...what we as a collective can do about..."

A study done in Malawi confirms the findings and shows that there is a need to create an environment between stakeholders based on "collective responsibility", all stakeholders should take ownership of interventions, individuals attending forums where they are open to free and transparent discussions and communication, they should have an urge to collaborate (Zachariah et al., 2006:168). Collaboration require joined ownership of decisions and collective responsibility for the way forward and the activities involved in the process (Hutchison & Quartaro, 1995:112; Wildridge et al., 2004:3), and if this could realise the stakeholders can have an influence on policy. The following quotation illustrates this:

"So...if we could work together...and co-ordinate...and say OK...we have this common goal...then we will be able to do more things and have an influence on policy"

- Community participation and involvement

Community participation is an overall strategy in the development processes that also refer to involvement of the community; it should be an end in itself and motivate people to participate in more than one aspect or program (Mohamed, 2006:37).

The role players see that the older person should be empowered to participate and verbalise the following:

"Are not empowered to participate...these processes go by without them (the older persons) having an input..."

Older persons are seldom recognised in the practices of development agencies like UNAIDS (Baiya & Peachey, 2003). The stakeholders furthermore thought that all
programs for the development of different role players in the community of whom the older person is part, should go beyond planning and talk, it should focus on the end result of independence. It is not just about how the program or project in the community will be developed, but the main issue is how the delivery of services will be developed (Wildridge et al., 2004:7). The relevance of the literature to the view of the role player is clear:

"...programs should assist the community...you know...also to catch the fish, rather than be given fish" and "I would say that the secret lies in that ...I think...to help them to help themselves...to empower them in their community...to tell them where the resources are for them to take it further..."

During the interviews with the role players it became clear that some of them feel that they are not capable of interacting effectively with their local community and that they lack communication skills and self-esteem. The researcher agrees with Uys (2003:107) that supervision and support by professionals are of great importance to the community care workers and that the community care workers are very appreciative of the training and guidance they receive from the registered nurses and the social workers. The community workers from the NGO's and CBO's need someone to be an advocate for them in the community, to be their voice, and to support them in their doings:

"...we need an educated person to talk for us..."

The stakeholders from the university and larger organisations verbalised their need to assist the other organisations in the community with regard to the various skills they lack, like financial management, general management, communication, and etcetera. NGO's have become increasingly important agents of the development process in the countries of the South (Atack, 1999:855), including South Africa, and can play a large role in long-term development work or capacity building that links well with the view of the role player:

"I mean...the NGO's get money, but they do not always have the 'know how'...we can help them with that and build their capacity..."
"...nor do they have financial management skills...and normally they would not be...he...supported by funders, because they cannot account and manage those resources"

Open and clear communication is viewed as an imperative in the collaboration process for successful partnership and involvement, as the one participant explains:

“A problem might be...fear for the unknown...because they are not like ehe...well informed...they don’t understand what collaboration is ....I think that will create problems...would cause gossip...clear communication from the start...to say this is the...what....”

The participants view communication as instrumental to make information accessible and ensure involvement in the collaboration process. Wildridge et al. (2004:7) refer to the role of clear and consistent communication and to link with the partners to ensure their involvement. This can be linked to what was said during the research interviews:

"...make information accessible...communicating the problems can help" and “Help them...I think as a community we all need to be involved....as long as we are going to develop the community...”

• Identification and utilization of care and support structures

The stakeholders verbalised that they perceive the identification of different care and support structures available in the community as an imperative for effective management of HIV/AIDS in the community. The majority of organizations in response to HIV/AIDS serve the people in the community if they are ill or in need in their homes, with advice, information, education, training, referrals, counselling or support groups (Ferreira, 2004:34). However, it is important that the community knows where to find these organizations and know what they do and how they can give support, as the participant stated:
"Should know that organization...you got your researchers, IT specialists, your fund risers..." and another one added, "...as a community member and the government...the councillors...and the university with the research can work together...and support the older person..."

Hutchison & Quartaro (1995:112) confirm the suggestions of the participants through their reference to some isolated factors that contribute to successful collaborations, namely, the ethos of the structures (different organisations or volunteerism), the maturity of the collaborating organisations, the structural similarities and differences, the accreditation and standard setting requirements as well as ethical, social and legal issues of the organisation. A database should include the mentioned factors as explained by the role player:

"Start to get a database of those organizations...the level of their focus and exactly how they are working..."

Commitments for action that were made during a national research dissemination workshop held by HelpAge International in Johannesburg referred to improvement of networking by establishing databases. This implies that an audit of health and welfare's resources at district level should be conducted. Shortcomings should be identified in relation to older persons in the community, and a booklet should be produced on resources, services and contacts for older people in the community (HAI, 1999:75).

- **Multi-disciplinary and -sectoral networking**

Wildridge et al. (2004:3) support this finding by the following: "we live in a global society" and therefore we should realise that it is no longer effective to work alone. Networking between partners from different public, private, voluntary organisations and sectors apply (refer to paragraph 4.4.3.1). Based on an inter-disciplinary philosophy, collaboration refers to the "management of organisational linkages essential to mutual goal setting and shared responsibility for planning,
implementation and evaluation of patient/client outcome" (Hutchison & Quartaro, 1995: 112). The networking can also be outside the boarders of the country, as the researcher also identified (see paragraph 4.4.1 and 4.4.2).

From the results it seems that the participants view networking as linking with different stakeholders in the community, but it is only possible to link with identified structures in the community and more than one role player made it clear in the following citations:

“So if we have younger persons with HIV/AIDS we will say...’OK WIPA, you must come in...care for this woman, we will look after her mother, the older one...’”

“I think it could also help if someone from the clinic sits in at the meetings between the NGO’s and the Department of Health....to network...yes to listen to the NGO’s....”

The participants view knowledge and information regarding different stakeholders and partners in the community as empowerment, the following quotation sheds light on what was said:

“That kind of empowerment will go a long way, because this one will inform this one...this one will ask question...where you get this information. Word of mouth...even if people did not know about that institution, they will start knowing...”

“I think it should be...eh...collaboration between lots of different professionals....”

“I was involved with a family...the granny was the only person to care for the children and she was OLD...believe me...and blind, but she coped...nobody knew of her existence and situation...maybe if there is a network in the community...an awareness of the need...”

Ward committees are established in local municipalities to enhance participatory democracy and to serve as advisory bodies to councillors. This is an endeavour to enhance community participation at local government level. Unfortunately, as reported by Mohamed (2006:39), the system fails to engage all the groups and that could be the reason why the research result does not reveal views of the
participants on this system, only the following remark refer vaguely to the wards. However, it does seem that the role player views this political structure in the community as a possible support system:

“There are different wards (political system) in the community...maybe one should look at that for support systems....this could be wonderful...”

It is true that the ward committees can be a meaningful assistance to the community members in their wards; they can initiate projects to improve the lives of the people in the ward and can be a voice for the local community (Mohamed, 2006:40).

- **Sustainability**

Sustainable development means that it “meets the needs of the present without compromising the ability of future generations to meet their own need” as stipulated in Clark (2008:229). The role players in their understanding partly share the definition given by the author:

“Everything that we do stays there. It is a continuous service...”

“Sure, there is no continuity; there is no consistency...not really”

“...a dream...yes to co-ordinate, get it going, keep it going and to ensure sustainability...”

- **Co-ordination**

A statement was made in meetings to develop the African Union Policy Framework and Plan of Action on Aging 2002, that co-ordinated planning for older persons are needed (Ferreira, 2004:32) in communities to support and protect them in relation to HIV/AIDS. Some of the role players underlined this statement during the research interview:
"What I suggest...uhm...how you can support the older persons is through co-ordination...We work with any NGO in the community,...we get to know what they are doing so that we shouldn't duplicate services..."

"I actually told them...you know we are fragmented...tomorrow this one goes and talk to the municipality...that one goes there...they will ask 'can these people organize themselves?'...It's not going to help us"

"We invited all the stakeholders, Agri-AS, the NGO's, five different governmental departments...started a forum and identified projects,...somebody should co-ordinate and the university can do this..."

Collaboration requires tolerance between the different stakeholders and the ability to negotiate on all grey areas and differences that may occur (Hutchison & Quartaro, 1995:114).

"And then there is S....also a NGO, they are more focused on the counselling part...whereas the other .....They go out on daily basis...."

- The extended family in community-based collaboration

Persons with HIV/AIDS rely on the intergenerational support, in other words sick adult children and their dependent children often reside with elderly parents, there is no indication that family values and bonds are not as strong as ever and remains a central institution in African societies (Ferreira, 2004:34). It is therefore necessary to include the extended family, of which the older person is a member, in the collaboration process. As one of the role players stated the reality:

"The extended family plays an important role, they want to take responsibility, involve them..." and in addition another is of the opinion that, "right...mm...at the end of the day our older peoples need support...my personal opinion is that....it comes from each family...yes at the end of the day is it the responsibility of each family to care for their people..

Although the commitment for action was made nearly ten years ago, it is worthwhile mentioning in supporting the results of the study that already then did
HelpAge International, with the South African team, ask that family members should be included in forums, committees and Boards and be made part of networking regarding aspects referring to older persons (HelpAge, 1999:75). The following quotation adds to the view of HelpAge International:

"But it is like I said just now...in the Black families, their will always be an aunt or a niece...whoever relevant...that will look after the older person..."

Community-based collaboration to support the older person in the world of HIV/AIDS also refers to collaboration within the family and informal networking among the members of that family, which is expressed by a role player that shared her experience with a family member that is infected by HIV/AIDS:

"If the family knows, there's no work load...there's no heartbreaking...everybody is just active to participate...the grandfather knows, the brothers knows, the sisters knows, even the young ones...there is a reassurance from the whole family...there is no problem..."

A study done by Wacharasin & Homchampa (2008:395) revealed that family members are able to take up the role of the caregiver, but they do need the support from health care professionals and social networks.

Family caregivers are an important resource for patients, as demonstrated in the quotation above. It is also clear that if the family of someone with HIV/AIDS knows timeously about the infection of one of the family members, the can accept it and support the family member against stigmatization and rejection.

4.4.3.10 Conclusions pertaining to how stakeholders perceive community-based collaboration

- Relationships between different organisations in the community should be open and transparent; it should be based on collectiveness and have a common goal, which means that the stakeholders should make joint decisions with shared responsibility.
• Community participation is an overall motivational strategy in the development processes and implies involvement in the community that is not possible without effective communication and linking between the stakeholders as partners.

• Identification of structures in the community in databases is imperative to know where to find the structures and how to utilize them in the support of the older person in the world of HIV/AIDS.

• Collaboration in the community entails multi-disciplinary- as well as multi-sectoral networking, and is not possible on one's own. The different stakeholders need each other. The ward committees and the extended family on community level form an integral part.

• Community-based collaboration should be sustainable and look at the future. It should not only meet the needs of today, but also the needs of tomorrow and this is only possible through co-ordination between the different stakeholders in the community, otherwise support of the older persons can be jeopardized through fragmented services.

4.5 CHAPTER SUMMARY

In the preceding part, the results on the existing networks, support programs as well as the perceptions of the stakeholders of community-based collaboration to support the older person in the world of HIV/AIDS were outlined to the reader with accompanied discussions integrated with literature scrutinized on identified themes on which the researcher made valid conclusions.

The conclusions drawn in chapter 4 provided needed evidence about the existing networks and support programs in the urban community. It is also trusted that the way in which the stakeholders perceive community-based collaboration contributed to the final needed evidence from the empirical world to conceptualise community-based
collaboration to support the older person in the world of HIV/AIDS.

Phase 3, step 6 and step 7 of the study pertaining to the conceptualisation and operationalisation of community-based collaboration to support the older person in the world of HIV/AIDS are provided in the following chapter.