Expectations, obligations, and goals: An ethnographic study of two HIV/AIDS support groups south of Durban, South Africa

By

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DECLARATION

Submitted in fulfilment / partial fulfilment of the requirements for the degree of ...Masters......... , in the Graduate Programme in

...Anthropology, University of KwaZulu-Natal, South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. I confirm that an external editor ~~was /~~ was not used (delete whichever is applicable) and that my Supervisor was informed of the identity and details of my editor. It is being submitted for the degree of ...Anthropology.......... in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

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ABSTRACT

A focus on care and support for people living with HIV/AIDS throughout the world has become a key discussion in the general HIV/AIDS discourse. This thesis provides an in-depth analysis of two HIV/AIDS support groups operating in areas south of Durban, South Africa**.** In particular, the thesis presents the readers with a description of the 1) purpose of HIV/AIDS support groups, 2) main participants involved in HIV/AIDS support groups, and 3) an overview of how the two HIV/AIDS support groups under study operate. The grounded theory approach of this study led to the emergence of two themes crucial to the understanding of the HIV/AIDS support groups under study, the existence of widespread conflict, and a system of 'negotiated' reciprocity within each support group. The thesis uses the framework of Victor Turner's social drama, and the anthropological theories of reciprocity, in order to analyze these concepts. This thesis reveals that each support group operates within an environment, in which a discrepancy of expectations, obligations, and goals amongst the support group participants exists. Additionally, the support group members and the sponsoring organization of both support groups have varying perceptions of the support group, both in its ideal and actual form. Finally, the thesis reveals the way in which each support group oscillates between a state of stability and conflict, and how conflict and negotiation, in turn, become inherent within, and synonymous with, everyday organisation and operation of the support groups

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CHAPTER ONE- INTRODUCTION

Since the early 1980s to present day, anthropological studies have attempted to grasp the multitude of factors and topics associated with the HIV/AIDS pandemic. The need for anthropological studies on HIV/AIDS remains paramount; despite a general decline in the new HIV infections rates, which in the past eight years has decreased by 17%, the global percentage for people living with HIV/AIDS remains dangerously high (UNAIDS, 2009). As of December 2008, UNAIDS estimates that 33.4 million people are living with HIV/AIDS worldwide, with approximately 2.7 million new infections during 2008. Additionally, as of the end of 2007, approximately 2.9 million people throughout the world had access to anti-retroviral treatment (UNAIDS, 2009). Sub-Saharan Africa has the highest percentage of people living with HIV/AIDS in the world; an estimated 22.4 million people were living with HIV/AIDS at the end of 2008. There were approximately 1.9 million new HIV infections throughout Sub-Saharan Africa in 2008 (UNAIDS, 2009). Within Sub-Saharan Africa, the southern African countries most affected are Swaziland, Botswana, Lesotho, South Africa, Namibia, Zimbabwe, Zambia, Mozambique, and Malawi, which have the highest HIV/AIDS prevalence rates in the world (Population Reference Bureau, 2009). In particular, South Africa has an estimated 5.7 million people living with HIV/AIDS, "the world's largest population of people living with HIV" (UNAIDS, 2009: 27). As of 2003, an estimated 800,000 people living with HIV/AIDS have access to anti-retroviral treatment in South Africa (Statistics South Africa, 2003).

Prevention efforts appear to be reducing the rate of new infections throughout the world. In addition to the focus on prevention efforts of HIV/AIDS, care and support for people living with HIV/AIDS has become a paramount objective for countries throughout the world. Focusing on aspects of care and support for people living with HIV/AIDS is shown to have positive affects on the individual, aids in the HIV prevention efforts, and assists in efforts to decrease the economic and social impact of the disease (UNAIDS, 2009). As a result, HIV/AIDS support groups, community-based groups, and home-based care efforts have developed throughout the world to assist people living with HIV/AIDS (UNAIDS, 2009). In particular, South Africa's National Strategic Plan 2007-2011 has identified a key priority is the treatment, care, and support for people living with HIV/AIDS in South Africa (South African Department of Health, 2007). On the theme of care and support, the South African Department of Health and Department of Social Development proposes the implementation of "home-and-community-based care support" (hereinafter referred to as HCBCS) for people living with HIV/AIDS. These departments define HCBCS as "care/services that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life, and creates responsibilities" (Giese & Meintjes, 2003: 44). Several models of HCBCS have been provided to aid non-governmental organizations, faith-based organizations, provincial departments, and community-based organizations with information on the implementation of HCBCS programmes (Giese & Meintjes, 2003). Several suggestions are that programmes include a team of people to assist people living with HIV/AIDS, including a professional nurse and/or senior social

worker as team leader, part-time professional nurse, a youth care worker, and HCBCS care workers (usually volunteers with stipends) (Giese & Meintjes, 2003).

This study focuses on aspects of care and support amongst people living with HIV/AIDS. Specifically, this ethnographic[1] study outlines the participants and structures of two HIV/AIDS support groups, Nawe Sondela (a pseudonym) in Ezimbokodweni, and Asibemunye (a pseudonym) in Adams Mission, KwaZulu-Natal, Durban, South Africa. This study aims to understand the roles and relationships of the various participants within both HIV/AIDS support groups, which include the support group members, and the team of the sponsoring organisation for both support groups, Isibani Hospice (a pseudonym). Additionally, the study seeks to comprehend the structural components of the support groups and sponsoring organization, and to understand the way in which both HIV/AIDS support groups operate.

A brief description of statistical information will be provided for the two wards of the eThekwini Municipality, Ward 93 and Ward 96, where both support groups operate. This information, provided within Section 1, is useful to the understanding of the support groups within this study.

[1] Ethnography refers to "the art and science of describing a group or culture". More specifically, ethnographic research aims to understand the group and/or culture through studying the member's activities and everyday experiences over a long period of time (Fetterman, 1998:1, Emerson, Fretz & Shaw, 1995).

1. INFORMATION ON RESEARCH SITES

The following statistics for Ward 93 and Ward 96 are from the Municipality Ward 93 Profile and Municipality Ward 96 Profile for 2003. Both wards are situated within the eThekwini Metropolitan Municipality. The following statistics reflect data from the 2001 South African Census, and all statistics refer to the year 2001, unless otherwise stated (Statistics for South Africa, 2003).

1.1 Ward 93, in which Nawe Sondela Support Group is situated

The Nawe Sondela support group operates within the boundaries of Ezimbokodweni, which is demarcated as a part of Ward 93 (refer to Appendix for map). Ward 93 as of 2001 had a population of 34 503; of this population 29 824 were African, 144 Coloured, 455 Indian, and 4 080 White. The previous census in 1996 revealed a population of 29 178. The top five languages (refers to first languages spoken most at home) within Ward 93 are isiZulu (29 286 people), English (3 711 people), Afrikaans (1 041 people), isiXhosa (231 people), and Sesotho (87 people). Education levels of the population over 20 years of age shows that 2 607 people received no schooling, 3 828 received some primary schooling, and 1 308 people competed a primary school education. Additionally, 4 173 people completed grade 12, and there were 1 389 people who obtatined higher education (Statistics South Africa, 2003).

The employment levels for Ward 93 were as follows—8 355 not economically active people[2], 7 725 unemployed people, and 6 021 employed. As of 1996, the total labour force was 19 328 individuals, which indicates a 28.8% decrease in the labour force as of 2001 (13 746). Similarly related, the annual household income brackets with the highest number of people included 2 013 who were receiving no income, 1 182 earning between R 4 801-R 9 600; there were 1 182 households earning between R 9601- 19 200, and 1 122 between R 19 201- 38 400 (Statistics South Africa, 2003).

The population of Ward 93 primarily live in formal dwellings[3] (4 719) followed by traditional dwellings (2 211), and informal dwellings (672), and moreover, within these dwellings 5 532 households use electricity, 1 791 households use candles, and 144 households use paraffin (top three sources of lighting within dwellings). Most households either have access to water inside their dwelling (1 446), in the yard (2 493), or use water from a community stand (1 086) (Statistics South Africa, 2003).

1.2 Ward 96 in which Asibemunye Support Group is located

The Asibemunye support group operates in Adams Mission, which is a part of Ward 96 (refer to Appendix for map). Within Ward 96, the overall population for 2001 was 25 643 with 25 600 African, 11 Coloured, 5 Indian, and 26 White. The estimated population of 1996 was 20 187. The most widely spoken languages are isiZulu (25 431),

[2] 'Not economically active' refers to the population not a part of the labour force, whereas the labour force includes the population employed and unemployed (Statistics South Africa, 2003).
[3] Formal Dwellings refer to a house of brick structure, a flat in a block of flats, town/cluster/semi-detached house, unit in retirement village, and buildings in backyard (Statistics South Africa, 2003).

isiXhosa (99), English (36), Ndebele (24), and Setswana (15). The education levels (population over 20 years-old) for the population of Ward 96 are as follows 1 953 people received no education, 2 544 received some primary schooling, 963 completed primary school, 4 728 have a secondary education, 2 778 reached grade 12, and 495 people have achieved a higher education (Statistics South Africa, 2003).

In terms of the labour force for the population of Ward 96, there are 6 114 not economically active, 7 230 unemployed, and 2 586 employed. The labour force has dropped by 20.77% (9 816 in 2001); as of 1996, there was a labour force of 12 319. The largest four income brackets within Ward 96 are 1 482 households receive no income, 1 017 earn between R 4 801- 9 600, 702 households receive between R 9 601- 19 200, and 756 earn between R 19 201- 38 400 (Statistics South Africa, 2003).

Finally, there are 2 139 households living in formal dwellings, 81 in informal dwellings, and 2 364 in traditional dwellings. Within these households, 3 267 use electricity, 1 215 use candles, and 96 households use paraffin. The majority of households have a source for water inside the yard (2 028), get water from a river/stream (1 038), or from a community stand over 200 m away from their dwellings (483) (Statistics South Africa, 2003).

These statistics highlight that the majority of the people within Ward 93 and Ward 96 are facing unemployment, and have little or no income. Additionally, although many households have running water and electricity, a large portion of the population does not

have these services. Although the majority of people in both wards have received some form of education, many have not completed schooling up to Grade 12. These statistics are important to consider in Chapter Four and Chapter Five as a comparison to the demographics of the support group members.

At this point, I will discuss how I gained access to the two HIV/AIDS support groups, Nawe Sondela and Asibemunye.

2. GAINING ACCESS TO SUPPORT GROUPS

The research for this study began in April 2008 with my involvement with the Youth Aid Association (a pseudonym) of Amanzimtoti. As a researcher, in order to establish rapport, I initially volunteered and participated in the organization's projects including attending youth group sessions, entrepreneurial classes, drama or "edutainment" sessions for students in primary school, and HIV/AIDS support group meetings. According to the "Big Net approach" described by Fetterman (1998:32-33), I mixed and mingled with everyone in the organization at first, and had a "wide-angle view of events before the microscopic study of specific interaction" began. An interest in the HIV/AIDS support group began to develop and I saw a potential to gain a greater understanding of how HIV/AIDS support groups operate. I attended Nawe Sondela and Asibemunye support group meetings on a weekly basis from mid-April 2008 until the end of May 2009. Between June-July 2008, I did not attend the support group meetings because the YAA no longer had funding for the project involving the HIV/AIDS support groups. At that

point, I decided to ask both support groups if I could attend the support group meetings on a weekly basis on my own (before I attended meetings with staff from the Youth Aid Association).

Therefore, in August 2008, I contacted a former YAA volunteer, Noxolo, who lives in the nearby community of KwaMakhutha, to assist in translation and attend both Nawe Sondela and Asibemunye support group meetings with me. Noxolo became a crucial part of the research, as she was the main form of communication between the support group members and me. The support group members of both Nawe Sondela and Asibemunye spoke Zulu at the support group meetings, although several members also understood and spoke English. Even though I have a basic knowledge of Zulu and was able to have conversations with the support group members, it was important to have a translator. Thus, Noxolo became my translator during the course of the fieldwork. Noxolo assisted in translating, took notes on the occurrences and discussions within the meetings, and this contributed to the development of rapport and relationships that both Noxolo and I formed with the support group members.

3. GAINING RAPPORT AND PROBLEMS ENCOUNTERED

Upon embarking on this study, I had several concerns about gaining acceptance and developing rapport with the support group members. The members of both support groups are living with HIV/AIDS, and membership is given only to individuals who are living with HIV/AIDS. Although I never disclosed my HIV status to the support group

members, several comments made by Noxolo made it obvious that I am an HIV negative individual. While this did not cause any problems amongst the support group members, I believe it prevented me from full membership, and at times participation within the group.

That stated, throughout the research, I managed to gain rapport with many members of each support group. At times, new members joining each group were apprehensive of my presence, but usually the older support group members would explain my presence in the meetings. The following comments provide an indication of the rapport and relationships developed.

I had missed a meeting, and the following week, a member of the Asibemunye support group came up to me and said*, "There was a car hijacked around here last week, and the car was like yours. So I was worried about you—I was worried".*

During the month of December, I was ill and upon attending a Nawe Sondela meeting in the beginning of January, a member asked where I was at the last meeting. Upon explaining, she said*, "I wish I would have known where you live, and we could have come to take care of you".*

4. ETHICAL CONSIDERATIONS

The support group members of Nawe Sondela and Asibemunye gave permission for both Noxolo and I to attend the support group meetings. From the beginning, it was established that all information I obtained and observed, along with names, would be kept confidential and anonymous. Furthermore, each group gave me permission on the basis that I would not request individual interviews; but would rather speak with the group as a whole[4]. Thus, from August 2008 until June 2009, I attended both support group meetings on a regular basis.

5. RESEARCH METHODS

Upon gaining access to the research sites, I integrated ethnographic research methods such as "mapping the scene" and "outcropping" in order to become more aware of the way in which each support group functions. "Mapping the scene" refers to the skill of observing the "arrangement of physical space… people within that space…activities and movements of people in a scene, interaction among people…words spoken and non-verbal interaction…" (Dewalt & Dewalt, 2002: 69). This technique allowed me to become more aware of how each support group functions, the norms of the group, and relationships/interactions amongst the support group members. Additionally, outcropping, which refers to the observations of the community and physical setting, and changes in the physical setting over time (Fetterman, 1998: 57-58), led to a more in-depth

[4] In the beginning, this appeared to be important, but as I gained rapport with the support group members this changed. I was able to engage in one-on-one discussions with individual group members before or after the support group meetings, but always at the meeting venue of the support groups.

observation of the communities of Ezimbokodweni and Adams Mission, and the support group meeting venues within these areas.

The nature of this anthropological study necessitated the use of participant observation in order to gain a holistic perspective of the two HIV/AIDS support groups, Nawe Sondela and Asibemunye. Additionally, I incorporated informal and unstructured interviews, and questionnaires into this study. This was done in order to discover individual views and perspectives, as well as to compile statistical data on members of the support groups.

Participant observation is often viewed as a defining method of anthropological ethnographic research (Dewalt & Dewalt, 2002: 1). Participant observation is a method in which the researcher participates in the daily activities and lives of the group of people being studied. The act of participating, observing, and recording the data provides insight into the ideas and patterns of behaviours of the group, and permits the researcher to become immersed in the culture of the group (Dewalt & Dewalt, 2002: 1-2; Fetterman, 1998: 34-36). Participant observation not only refers to the gathering of information but also the analysis of the data. I incorporated the use of jot notes, thick descriptions, and anecdotes as a means to observe and record the events of the support group meetings.

My level of participant observation throughout the year oscillated between moderate and active participant observation in the support group meetings. Dewalt & Dewalt (2002: 20) describes moderate participant observation as being “present at the scene of action” and “identifiable as a researcher, but does not actively participate or only occasionally

interacts with people in it". Active participation is a research method in which the researcher "engages in almost everything that other people are doing as a means of trying to learn the cultural rules for behaviour" (Dewalt & Dewalt, 2002: 20).

In addition to participant observation, I incorporated the qualitative method of interviews into this study, specifically informal[5] and unstructured interviews[6]. Interviews, in ethnographic research, "help classify and organize an individuals' perception of reality", and interviews have a "role to play in soliciting information" (Fetterman, 1998: 38). Although I was not able to conduct formal, structured interviews with individual support group members, Noxolo and I participated in many informal interviews and gleaned information about the members lives outside of the support groups such as information on their interests, families, and opinions of the support group.

In addition to informal interviews with support group members, I conducted unstructured interviews with key informants from the sponsoring organization of the support groups, and with a HIV/AIDS counsellor at the KwaMakhutha clinic. The format of an unstructured interview enabled me to gain information about topics of interest to the research study, and the open-ended nature of the interviews gave rise to additional conversations on topics relevant to this study.

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[5] According to Fetterman (1998), informal interviews are commonly used in ethnographic research and are akin to engaging in a casual conversation, but the researcher may "ask occasional questions to focus the topic or to clarify points that she/he does not understand" (Dewalt & Dewalt, 2002: 122).

[6] An unstructured interview refers to an interview with a plan, the questions are asked in an open-ended way and often there is little control within the interview (Dewalt & Dewalt, 94).

In order to comprehend more specific details about the support group members' lives outside of the support group meetings and to gather demographic details, I administered a questionnaire to members of both HIV/AIDS support groups. I obtained permission from members of each support group before administering the questionnaires. Fetterman (1998: 54) describes questionnaires as the "most formal and rigid of exchange in the interviewing spectrum", and that it should not be used as a primary data collection technique due to bias, poor return rate, and misunderstanding of questions by the individuals. For the purposes of this study, questionnaires proved useful in providing description of members such as details about family, employment, economic status, goals for the support group, and reasons for joining the support group.

The combination of participant observation, informal and unstructured interviews, and questionnaires provided a wealth of information and detail about the support group members and the way each support group operates.

6. CHAPTER OUTLINES

This introductory chapter has provided a brief discussion of the HIV/AIDS statistics worldwide and specifically in South Africa, and has given a glimpse into the concepts of care and support for people living with HIV/AIDS. Statistical information on the areas in which the research takes place has been given in order to provide the reader with a 'sense' of the communities from which the people in this study are drawn. Finally, a

discussion on the research endeavors, including gaining access to the research site, ethical considerations, and methodology is given.

Chapter Two: Literature Review

This chapter provides background on the concept of support, the development of HIV/AIDS support groups, and various facets of these HIV/AIDS support groups. This chapter reviews several key studies on HIV/AIDS support groups throughout the world.

Chapter Three: Isibani Hospice

The central aim of this chapter is to explain the role of the sponsoring organization for both support groups under study. The chapter also introduces the concepts of hospice and palliative care, which are fundamental to the role of the sponsoring organization.

Chapter Four: Nawe Sondela Support Group

This chapter discusses the Nawe Sondela support group in terms of membership, meeting venues/days/times, and provides an elaboration of a typical support group meeting.

Chapter Five: Asibemunye Support Group

This chapter has a very similar outline to Chapter Four. The chapter discusses the Asibemunye support group in terms of membership, meeting venues/days/times, and provides a glimpse into the lives of the support group members by giving an overview of a typical support group meeting.

Chapter Six: Support Groups, Social Dramas, and the Propensity for Conflict

The aim of this ethnographic chapter is to elaborate on various themes of conflict prevalent within each support group. Theoretical concepts of social conflict and gossip are described. Social dramas as well as ethnographic accounts provide insight into the conflict amongst support group members and with the sponsoring organization and supporting organizations.

Chapter Seven: Negotiated Reciprocity

This ethnographic chapter elaborates on a system of reciprocity existent between each support group and the sponsoring organization. A background of reciprocity and gift-exchange theory is provided. Ethnographic accounts develop the theme of negotiated reciprocity and conflict, and the way in which these two concepts merge and 'feed off' each other in the unfolding of the support group relations.

Chapter Eight: Conclusion

The final chapter of this dissertation provides a summary of the key themes developed in the thesis and makes recommendations for further research in the field of HIV/AIDS support groups.

CHAPTER TWO- LITERATURE REVIEW

This chapter explores the concept of support within HIV/AIDS support groups, and discusses the purpose of these groups. Additionally, the chapter examines the various facets involved in the functioning of HIV/AIDS support groups.

1. BASICS OF HIV/AIDS SUPPORT GROUPS

A multitude of support groups exist throughout the world; in these support groups, people share and reflect on a common concern and/or crisis affecting their lives. Support groups[7] form to provide a means for individuals to cope with issues related to life transitions, common crises, and/or chronic conditions, such as HIV/AIDS (Schopler & Galinsky, 1993).

HIV/AIDS support groups offer a range of care and support services related to individuals coping with the disease progression of HIV/AIDS (Bell, Mthembu & O'Sullivan, 2007). The nature of HIV/AIDS support groups appears to change as aspects of the epidemic change (Bell et al., 2007). Also, features of HIV/AIDS support groups vary throughout the world. Yet, these support groups tend to share a similar focus on the psychological and emotional issues of living with HIV/AIDS, offer educational support and knowledge on health-related aspects of HIV/AIDS, and provide a forum where support group members may share their personal experiences, fears, and concerns about

[7] "Support groups are groups of people with some pressing common concern coming together on a regular basis, often face-to-face, to contribute personal experiences and engage in the development of a cohesive supportive system" (Schopler & Galinsky, 1993: 65).

their lives (Hedge & Glover, 1990; Oosterhoff, Anh, Yen, Wright & Hardon, 2008; Spirig, 1998; Visser & Mundell, 2008).

There are numerous studies on HIV/AIDS support groups, which differ in terms of research design, analysis, and topics reviewed. HIV/AIDS support group literature tends to focus on research in the fields of psychology, social work, health care, nursing, and clinical notes, which have a propensity to produce quantitative data on various themes associated with HIV/AIDS support groups.

Anthropological research on HIV/AIDS support groups remains limited, but several qualitative studies (Anderson & Shaw, 1994; Jacobson, 1987; Lyttleton, 2004; Manchester, 2004; Oosterhoff, Thu Anh, Yen, Wright & Hardon, 2008a; Oosterhoff et al., 2008b; Rier, 2007; Singhanetra-Renard, Chongsatitmun, & Aggleton, 2001; Spirig, 1998; Visser & Mundell, 2008) do offer in-depth descriptions of HIV/AIDS support groups in various parts of the world. In particular, these studies describe facets of HIV/AIDS support groups including dealing with stigma, social support, dealing with discrimination, gender and empowerment, self-transformation, and sexuality from the perspective of both the support group as a whole and the individual group members. This study highlights factors of conflict and reciprocity within HIV/AIDS support groups, concepts that are mentioned but not elaborated upon in the qualitative studies on HIV/AIDS support groups discussed in this chapter.

Previous studies from the fields of psychology, social work, health care, and nursing focus on the relationship between HIV/AIDS support groups and topics of social support, coping skills, physical, emotional and mental health, psychosocial functioning, stress, behaviour change, and quality of life (Bell et al., 2007; Coleman & Harris, 1989; Friedland, Renwick & Mccoll, 1996; Green, 1993; Hedge & Glover, 1990; Kalichman & Sikkema, 1996; MacNeil, Mberesero & Kilonzo, 1999; McDowell & Serovich, 2007; Schopler & Galinsky, 1993; Serovich, Kimberly, Mosack, & Lewis, 2001; Thompson, Nanni & Levine, 1996; and Walch, Roetzer & Minnet, 2006).

2. HIV/AIDS AND THE NEED FOR SUPPORT

From the onset of an HIV positive diagnosis, people living with HIV/AIDS face a multitude of challenges such as issues with disclosure, stigma, discrimination, cultural issues associated with being HIV+, access to medical services, and physical, mental, and emotional side effects of living with the disease (Kalichman & Sikkema, 1996; McDowell & Serovich, 2007; Spirig, 1998; Thompson et al., 1996; Visser & Mundell, 2008). An individual's discovery of one's positive HIV status has been described as a "crisis moment", where the individual often goes through an "emotional rollercoaster" (Coleman & Harris, 1989:540; Manchester, 2004; Visser & Mundell, 2008). The individual may face emotional and psychological reactions to being HIV positive such as depression, isolation, anxiety, guilt, fear of rejection from family/friends/communities, and a fear of disclosure and intimacy (Coleman & Harris, 1989; Green, 1993; Hedge & Glover, 1990). In particular, studies indicate that HIV positive individuals may suffer

from higher rates of depression than the general population (Green, 1993; Serovich et al., 2001). These stress factors can be harmful to the body, possibly accelerating the disease progression of HIV/AIDS in an individual (Green, 1993; Jacobson, 1987; McDowell & Serovich, 2007; Thompson et al., 1996). Moreover, the large amounts of stress associated with an HIV positive diagnosis may possibly lead the individual to engage in unhealthy behaviours or habits as an outlet for stress relief (Thompson et al., 1996; Visser & Mundell, 2008). For instance, a study of HIV positive men in the U.S. discovered moderately high levels of individuals engaging in risky behaviours such as smoking, alcohol abuse, and unsafe sex in order to reduce the stress arising from the individuals' HIV positive status (Thompson et al., 1996).

In addition to the social, mental, and emotional challenges of living with HIV/AIDS, the physical ailments associated with the progression of the disease may require the individual to seek out support from family, friends, and additional medical services (Green, 1993). People living with HIV/AIDS (herein after referred to as PLWHA) may, however, isolate themselves from family and friends and not reach out to them for support (Hedge & Glover, 1990). Moreover, studies show HIV positive individuals tend to receive less support from their community, family, and friends due to the stigma and discrimination associated with HIV/AIDS (Green, 1993; Visser & Mundell, 2008; Uys & Cameron, 2003). Therefore, the progression of HIV/AIDS may leave an individual vulnerable and unable to find support amongst his/her family, friends and/or community in a time when support is greatly needed (Green, 1993). Thus, people living with HIV/AIDS face numerous issues in all aspects of their lives due to the complex nature of

the disease. The emergence of HIV/AIDS support groups throughout the world evolved as a means to address the challenges associated with living as an HIV positive person (Visser & Mundell, 2008).

Furthermore, HIV/AIDS support groups emerged as a form of "intervention" for people living with HIV/AIDS due to a lack of professional counseling and support outlets (Bell et al., 2007; Manchester, 2004). In the beginning of the AIDS epidemic, inadequate services existed for PLWHA, especially due to the associated stigma and discrimination. Also, inadequate services existed for countries unable to cope with the high rates of HIV/AIDS and the demand for HIV/AIDS services (Bell et al., 2007). Additionally, HIV/AIDS support groups may provide a "lifeline" for people living in poverty (Bell et al., 2007).

3. PURPOSE OF HIV/AIDS SUPPORT GROUPS

A primary purpose of support groups for PLWHA is to provide emotional and/or psychological support, information, and for members to potentially develop coping skills (Schopler & Galinsky, 1993; Spirig, 1998). Many studies agree that support groups are necessary for PLWHA due to the nature of the illness and associated factors of social stigma, isolation, living with anxiety and hopelessness, the fear of dying, living with bereavement, loss of intimacy, and changes in sexual relationships (Bell et al., 2007; Coleman & Harris, 1989; Spirig, 1998).

However, individuals may have different perceptions of what support should entail. For instance, in a psychological study by Walch et al. (2006: 285) members of an HIV/AIDS support group were uncomfortable with discussing issues of illness; some members viewed the groups as depressing; and "that attendance [of a support group] implies an inability to cope" .

3.1 SOCIAL SUPPORT AND SUPPORT NETWORKS

The concept of social support is embedded in the development of HIV/AIDS support groups. Social support is described as the feelings of being valued, esteemed, cared for, loved, and having others to count on in a time of need (Friedland et al., 1996). In particular, all three types of social support, i.e. emotional[8], informational[9], and instrumental[10], are often a facet of HIV/AIDS support groups. Several studies state that social support within the support groups should be used to promote mental and physical well being, and that social support counteracts the stress, psychosocial, and physical issues associated with HIV/AIDS (Green, 1993; Freidland et al., 1996; Jacobson, 1987; Kalichman & Sikkema, 1996; Lesserman et al, 1999; McDowell & Serovich, 2007; Serovich et al., 2001; Spirig, 1998; Visser & Mundell, 2008). Although several studies state that social support has a positive relationship in improving the physical health of an HIV positive person, the means in which social support actually affects physical health is yet to be understood (Green, 1993; Spirig, 1998; Walch et al., 2003). According to Green

[8] Emotional social support refers to "affection, comforting and encouragement" (Kalichman & Sikkema, 1996: 2).

[9] Informational social support "increases one's knowledge base" (Kalichman & Sikkema, 1996: 2).

[10] Instrumental social support refers to "practical assistance with daily living" (Kalichman & Sikkema, 1996: 2).

(1993:88) “Social support seems linked to health although no-one is quite sure how”. Social support and more specifically, the role social support plays within HIV/AIDS support groups, however, remains an “intervention strategy” throughout the world for people living with HIV/AIDS (Green, 1993; Spirig, 1998; Uys & Cameron, 2003).

HIV/AIDS support groups potentially create a mutually supportive environment where members can receive and provide support (Visser & Mundell, 2008). The joining together in the common stress factor of HIV/AIDS creates a support network among the members of the support group. According to Jacobson (1987: 46), “Support networks typically refer to a network of social relationships from which individuals draw support”. The existence of a support network within an HIV/AIDS support group potentially allows the members of the group to draw on one another for emotional support, guidance, and allows and/or permits members to develop a sense of acceptance (Jacobson 1987; Schopler & Galinsky, 1993; Visser and Mundell, 2008). Jacobson (1987), however, notes that these support networks can be supportive but, at times, may also be a source of stress for the members of the group due to personality differences, conflicts of interest, and possible breaches of confidentiality amongst the group members. This is an important, although, overlooked aspect of support groups which will be dealt with extensively in this particular study.

3.2 INFORMATION ON HEALTH AND HIV/AIDS

In addition to providing a network for HIV positive individuals, support groups can provide an ideal forum for individuals to understand facts about their health and ways to manage HIV/AIDS with information on topics such as treatment options and proper nutrition (Coleman & Harris, 1989). A lack of knowledge about the disease may lead an individual to feel desperate and hopeless (Manchester, 2004). The access to knowledge and information about living with HIV/AIDS places the individual in a "much stronger position" not only to understand what is going on within his/her body, but also to access health care, which is needed to manage the disease (Bell et al, 2007: 126). For example, Oosterhoff et al. (2008a) express that participation in HIV/AIDS support groups in Vietnam gave members the confidence to seek out and expand their access to services that would be beneficial to the members.

3.3 COPING STRATEGIES

HIV/AIDS support groups often focus on developing coping strategies for people living with HIV/AIDS, and offer a fresh perspective or way of thinking about their lives, and HIV/AIDS status (Coleman & Harris, 1989; Uys & Cameron, 2003). Group members often explore ways of managing problems that may arise from living with HIV/AIDS (Uys & Cameron, 2003). A sense of belonging and involvement within the support group may aid in a self-transformation process in which an individual develops a more positive

sense of self-identity despite the challenges of being HIV positive (Oosterhoff et al., 2008a).

HIV/AIDS support groups tend to be a place where members can share their experiences of living with HIV/AIDS and other issues affecting their lives (Visser & Mundell, 2008). Moreover, an important aspect within HIV/AIDS support groups are the relationships formed between members, who feel they are able to connect with one another due to similar circumstances (Oosterhoff et al, 2008). In addition, members may enjoy and feel relaxed, and safe in a non-judgmental environment of an HIV/AIDS support group (Uys & Cameron, 2003).

Furthermore, HIV/AIDS support groups assist in the alleviation of stress and anxiety; members may experience a renewed sense of hope and confidence in their lives, in particular, pertaining to one's HIV positive status (Visser & Mundell, 2008).

HIV/AIDS support groups may also affect the discourse of HIV/AIDS amongst communities and society in general because these support groups "in part perform the social function of allowing those with HIV/AIDS a public and symbolic space…", and to also challenge social discrimination of HIV/AIDS (Lyttleton, 2004: 12-13).

4. HIV/AIDS SUPPORT GROUP PARTICIPATION

HIV/AIDS support groups typically consist of a sponsoring organization, group leader(s), and the support group members. The formation and functioning of HIV/AIDS support groups rely on the relationships and participation amongst these three entities.

4.1 SPONSORING ORGANIZATION

HIV/AIDS support groups may be initiated and supported by a variety of sponsoring organizations such as the PLWHA themselves, local community-based organizations, non-governmental organizations, private practitioners, and/or national organizations (Bell et al., 2007; Lyttleton, 2004; Schopler & Galinsky, 1993). Uys & Cameron (2003: 82) state that support groups are "usually initiated by a professional person within a formal structure (a counselor, psychologist, nurse, social worker, etc.)". For instance, as of 2002, there were over 400 HIV/AIDS support groups in Thailand, which were formed mostly by community-based organizations, but some support groups were also formed and managed by the government, non-governmental organizations, and the people living with HIV/AIDS (Lyttleton, 2004). The sponsoring organization may advertise the existence of the support group to potential members; and they may screen potential members of the support group in order to ensure that members' goals are aligned with the goals of the support group (Schopler & Galinsky, 1993; Uys & Cameron, 2003).

4.2 GROUP LEADERSHIP

Although a support group usually has a sponsoring organization, the facilitation and leadership of the group varies between professionals, volunteers, and sometimes members, who can be trained or untrained, and may/may not have personal experience in the group member's common concern of living with HIV/AIDS (Schopler & Galinsky, 1993; Visser & Mundell, 2008). For example, in a South African study, eight master students from the University of Pretoria attempted to implement four support groups by liaising with local clinics. In some instances, the master students facilitated the group meetings and discussions, and in other groups, the associated clinic sister (nurse) would facilitate the HIV/AIDS support group meetings (Visser & Mundell, 2008).

Alternatively, the group leaders may be elected by other group members (Oosterhoff et al, 2008). Leaders and group members must have a sense of trust in one another considering the nature of the support group, illness, and possible stigma associated with HIV/AIDS (Uys & Cameron, 2003). For instance, the Sunflower support group in Vietnam found their first group leader using the leadership position for "personal gain", thus resulting in an abuse of trust (Oosterhoff et al., 2008:165). The sponsoring organization and group members took leadership elections more seriously in the future to ensure that there was a successful leader for the group (Oosterhoff et al, 2008).

Group leaders and the sponsoring organizations have a responsibility to "prepare each group member for the group experience"; to help the members understand the "nature

and process of the group", through explaining details about the structure, format and rules of that particular support group (Uys & Cameron, 2003:88). Leadership of the support group also involves ensuring that the specific needs of members are met (Uys & Cameron, 2003). In a pilot study by Schopler & Galinsky (1993), the planning, guiding, and maintaining of the groups was the responsibility of the professional leaders of the group. Although there is a need to support leaders of support groups with information, basic resources, and training on topics, Uys & Cameron (2003: 86) cites it "is essential but is often neglected".

4.3 GROUP MEMBERSHIP

Even though the sponsoring organization and leadership of the group are important and integral aspects of a functioning HIV/AIDS support group, the members are the core of the support group. Often the sponsoring organizations and leaders will offer approaches and guidelines for the group and also facilitate the support group (Schopler & Galinksy, 1993). But often the group members decide what approach best fits the specific needs and goals of the support group (Uys & Cameron, 2003). An important aspect of group membership is that potential and existing members must be aware of the group's focus (refer to Section 5.4), as each individual expects to gain certain things from being a member of that HIV/AIDS support group (Uys & Cameron, 2003). Moreover, when member expectations and/or goals for the group are not met, the individual may describe and experience the group as "less supportive" (Kalichman & Sikkema, 1996; Schopler & Galinsky 1993; Spirig, 1998; Uys & Cameron, 2003:84).

HIV/AIDS support groups membership criteria can vary in terms of gender and sexual orientation (Bell et al., 2007; Hedge & Glover, 1990; Lyttleton, 2004; Visser & Mundell, 2008). Several studies also promote the idea that support groups for people living with HIV/AIDS should be subpopulation specific, i.e. gay, lesbian, women, drug users, etc., due to the different needs of each subpopulation (Spirig, 1998). Several examples of support groups specifically for "subpopulations" of PLWHA include the La Shanti support group in North America developed specifically for homosexual, HIV positive men (Martin et al., 2001). In addition, a support group in London maintains very specific criteria for becoming a member, including the individual must be "(i) HIV seropositive, symptomatic, asymptomatic, (ii) the male partner of an HIV seropositive man, or (iii) the bereaved male partner of a man who had died from an HIV-related illness" (Hedge & Glover, 1990).

Amongst the different types of groups based on gender, there are mixed groups, men only, and women only groups. There tend to be fewer men only groups (Bell et al., 2007; Manchester, 2004). Support groups may decide to specify group membership due to cultural issues of gender and/or sexuality within that particular society (Spirig, 1998). A Vietnamese support group known as the Sunflower Group was originally open only to HIV positive Vietnamese women (Oosterhoff et al., 2008a). In the beginning, the support group members were hesitant to include males into the group. According to Vietnamese society, the women in the Sunflower group were viewed as unsuitable mothers because of their HIV positive status, and therefore, faced gender discrimination and social stigma from being HIV positive (Oosterhoff et al., 2008a). Eventually the

group members accepted male members, in particular widowed men, and family members of HIV positive individuals, yet male involvement still remained limited (Oosterhoff et al., 2008a). Similarly, in Thailand, notions of masculinity and ideals held by Thai society tend to keep men from joining HIV/AIDS support groups as it appears to be contradictory to the values and roles men are supposed to uphold in Thai society. As proof, women members outnumber men in Thai support groups (Lyttleton, 2004).

Support group members may be at various stages of their disease, e.g. recently diagnosed or living with HIV/AIDS for numerous years, HIV seropositive: asymptomatic or symptomatic (Hedge & Glover, 1990; Martin et al., 2001). For example, a counseling service in the USA believes there is a need to create different support groups for individuals at different stages of the virus because some long term members in the on-going support groups did not like disruptions from new members being introduced (Coleman & Harris, 1989). Some members may fear mixing with other members at different stages of the disease; in particular, an HIV seropositive member may fear being in a group with someone diagnosed with AIDS because they fear the "sickness towards which they might be moving" (Hedge & Glover, 1990). A study by Hedge & Glover (1990: 7) found, though, that members in a mixed group valued a "variety of perspectives" on how members coped at different stages of the disease.

The suggested number of members per support groups varies. A specific number of members may be necessary depending on the particular focus of a support group (Uys & Cameron, 2003). For instance, a group focusing on interpersonal discussion may need to

limit membership from five to ten based on the notion, “more members, the less time” for each member to participate in the group discussion (Uys & Cameron, 2003: 88). Some groups prefer to keep the membership between 8-12 individuals (Martin et al., 2001). Schopler & Galinsky (1993) state that the more members in a group, the more need there is for group leadership, whereas in a smaller group, members may facilitate the meetings. Literature cites that support groups tend to have problems with irregular attendance, and premature departure of members. Additionally, members within support groups may have personality differences, i.e. “disruptive or controlling members”, and the support group as a whole, may lack focus/direction (Schopler & Galinsky, 1993: 9).

5. STRUCTURE OF HIV/AIDS SUPPORT GROUPS

HIV/AIDS support groups do not necessarily follow specific guidelines (Kalichman & Sikemma, 1996; Visser & Mundell, 2008). Guidelines concerning the format and structure of the groups are often dependent on the principles and structures put in place by the supporting organizations, group leaders, and members of the support group (Schopler & Galinsky, 1993). The structure of HIV/AIDS support groups can refer to the “roles and bonds, norms and culture, group operating procedures, and the meeting format” (Schopler & Galinsky, 1993:7). As stated previously, the involvement of support group members’ remains paramount on decisions concerning various facets of the functioning of the support group including open or closed groups, the number of sessions, group design, group discussions, and group rules (Uys & Cameron, 2003).

5.1 <u>OPEN VS. CLOSED GROUPS</u>

An important aspect of HIV/AIDS support group structure is whether a group is open or closed (Coleman & Harris, 1989; Uys & Cameron, 2003; Visser & Mundell, 2008). A closed support group, for example, only allows people living with HIV/AIDS to join the group. An open support group, alternatively, allows any individual affected by HIV/AIDS to join the group, which includes family members, partners, and friends of an individual living with HIV/AIDS (Hedge & Glover, 1990; Kalichman & Sikkema, 1996; Visser & Mundell, 2008). In a study by Hedge & Glover (1990), the members expressed that in a closed group they felt able to speak freely, but some members felt they were unable to introduce friends, who were affected by their association with someone living with HIV/AIDS, to the group.

5.2 <u>SUPPORT GROUP MEETINGS: NUMBER OF SESSIONS, DURATION, AND VENUES</u>

The lifespan of a support group may vary from an unlimited number of meetings to a specific number of meetings (Hedge & Glover, 1990; Lyttleton, 2004; Schopler & Galinsky, 1993; Visser & Mundell, 2008). For instance, in a study by Coleman & Harris (1989) a counseling service in the USA offered a psycho-educational group for HIV/AIDS patients that lasted for eight weeks, and simultaneously offered ongoing support groups, and group counseling with an unlimited number of sessions. A clinic in

England offers 12 week HIV/AIDS support group sessions, which last two hours each (Hedge & Glover, 1990).

Similarly, the time duration of each session may vary and often depends on the focus of the group (Uys & Cameron, 2003). One study states that two hours is an ideal time limit for support group meetings focusing on interpersonal discussion (Uys & Cameron, 2003). The time of the meetings and duration of the particular session may not allow for certain individuals to join the support group; for instance, if an individual can only attend support groups after work, a support group meeting taking place during the daytime is inaccessible (Uys & Cameron, 2003).

In addition to the duration of the group sessions, the venue for HIV/AIDS support groups varies depending on the sponsoring organization and group members. The venue, though, ideally should be "secure and safe", i.e. "free from interruption or exposure to non-group members" (Uys & Cameron, 2003:89). Members or individuals interested in joining a support group may be unable to attend meetings due to lack of available transport or money to pay for transport (Uys & Cameron, 2003)

5.3 SUPPORT GROUP DESIGN

HIV/AIDS support groups have different approaches in the organization and design of the meetings. Some HIV/AIDS support groups use specific models and/or practices for support groups. Groups might be more structured or unstructured, ranging from "informal

get-togethers" to "formalized training sessions" (Lyttleton, 2004: 13; Schopler & Galinsky, 1993).

The basic plan for HIV/AIDS support groups begins with the involvement of a sponsoring organization, described previously, the introduction of members and leaders to the group, and a discussion of how the involved parties want the support group to operate in order to meet the specific needs and goals of the support group (Schopler & Galinsky, 1993; Uys & Cameron, 2003). Often the norms and culture within a group may influence the way in which a group is structured (Schopler & Galinsky, 1993). Norms of a group can deal with factors such as participation, confidentiality among group members, disclosure, and attendance rates (Schopler & Galinsky, 1993).

A variety of designs are incorporated into HIV/AIDS support group meetings including the use of guided/focus group discussions, films and videos, close interpersonal discussions, questionnaires, guest speakers, drama group presentations, problem solving exercises, meetings and seminars, role plays, and home visits (Schopler & Galinsky, 1993; Uys & Cameron, 2003).

In addition, the format of the actual meeting varies between support groups. For instance in clinical notes by Coleman & Harris (1989), the support groups had a guest speaker at the meeting for the first hour, a ten minute break, and then the second hour was a discussion amongst the group members on concerns, issues, or fears affecting the members' lives.

Schopler & Galinsky (1993) advocate a model for HIV/AIDS support groups that focuses on a variety of components, which in theory affects the structure, development, and goals of the groups. The components include consideration of the environmental conditions of a support group, which are the potential members, sponsoring organizations, a meeting place, and funding. Another component is participant characteristics of the group that comprise the size of the group and composition of the group including the ethnicity, gender, culture, social class, coping behaviours, and behavioral attributes of the members. Lastly, the technology of the group, and the knowledge and experience of the leaders are an integral component of the model. Schopler & Galinsky (1993) suggest that the use of this model will lead to an understanding of the numerous factors, which mediate the operation and success of HIV/AIDS support groups.

5.4 GROUP DISCUSSIONS

Group discussions largely depend on the group design and structure and focus on various aspects associated with HIV/AIDS (Uys & Cameron, 2003). Discussions may be planned in advance by the sponsoring organizations such as an eight-week HIV/AIDS support group model discussed in a study by Coleman & Harris (1989), by the group leaders, or by suggestions from members of the group on a weekly basis (Schopler & Galinsky, 1993). A group can focus on a variety of subjects and activities such as topics related to health and HIV/AIDS, for e.g., therapeutic strategies, nutritional aspects of HIV infection, medical aspects of disease, and healing processes. In addition to health topics, discussions may focus on gaining access to HIV/AIDS treatment, legal aspects of living

with HIV/AIDS, income-generating projects (such as gardening schemes or micro-credit loans), and gaining access to HIV service organizations. Furthermore, support groups may discuss the physical and emotional effects living with HIV/AIDS has on relationships (lovers, friends, families, and co-workers), safer sex options, and sexuality (Coleman & Harris, 1989; Hedge & Glover, 1990; Lyttleton, 2004; Oosterhoff et al., 2008; Visser & Mundell, 2008). Some support groups focus on obtaining access to medical services and treatments, in addition to emotional and practical support;(Oosterhoff et al., 2008) while others support groups have a purely psychological orientation and centre exclusively on coming to terms with an HIV positive diagnosis, emotional support, discussing disclosure, and sharing strategies of coping with the disease. Support groups, though, may have more than one focus (Bell et al., 2007; Manchester, 2004; Oosterhoff et al., 2008).

5.5 GROUP RULES AND CONFIDENTIALITY

HIV/AIDS support groups may or may not have group rules (Schopler & Galinsky, 1993). Most support groups, though, choose basic guidelines for the organization, leaders, and members to follow (Uys & Cameron, 2003). Inevitably, the group members as a collective must decide on what rules are important for the functioning and success of their group, including agreements on structural issues such as times, venues, attendance, and admittance of new members (Uys & Cameron, 2003). For instance, the Sunflower group of Vietnam originally had a rule that only HIV positive women who tested negative for drugs would be allowed into the group. The rule changed once members

began to gain a greater awareness of the cultural and structural constraints that existed within the community (Oosterhoff et al., 2008a). An assortment of rules collected from interviews with support group leaders in a study by Schopler & Galinsky, (1993: 11) included the "freedom to leave the group during the meeting, permission to remain silent…rules against smoking, bad language or violent actions, and the need to give everyone a chance to speak". An important rule for support group members includes being respectful of other group members (Uys & Cameron, 2003).

An important feature of HIV/AIDS support groups is confidentiality within a support group, which for the most part appears to be an understood characteristic or "rule" (Schopler & Galinsky, 1993). More specifically, due to the nature of the disease and associated stigma and discrimination, confidentiality is valued due to the fact that the individuals are disclosing their status (Schopler & Galinsky, 1993; Uys & Cameron, 2003). A breach in confidentiality may affect a support group member's relationship with family, friends, and community members; the individual may face stigma from his/her community, and possibly be a victim of discrimination and/or violence (Uys & Cameron, 2003). In order for members to discuss openly and freely, an environment of respect and confidentiality must be applied to support groups (Visser & Mundell, 2008). Moreover, support group members have the choice to reveal as much information about themselves as they choose and should not be pressured by other group members (Hedge & Glover, 1990).

6. KEY STUDIES ON HIV/AIDS SUPPORT GROUPS

Spirig (1998) formulated a literature review based on 15 studies of support groups for people living with HIV/AIDS. The studies are separated into different conceptual frameworks of support group. The different frameworks include stress, or the effect of stress on the individuals' physical well-being, and empowerment, which focuses on personal growth and development, such as making decisions and taking action in his/her life. In addition, the concepts of social support, i.e. the need for emotional, informational, and instrumental support, and group support, i.e. intervention from professionals and/or peers over a period of time, are frameworks used to discuss the various studies done on HIV/AIDS support groups. Finally, the review focuses on the concept of quality of life, which is the belief that the way an individual manages their disease leads to a positive outlook on his/her life (Spirig, 1998). The variety in support groups focus and designs suggest that these variations "meet the needs of the different subgroups of PLWAS [people living with AIDS]", and that support groups tend to be viewed as effective for support group members in relation to the concepts of quality of life, coping skills, and social support (Spirig, 1998: 54).

A quantitative study by Hedge & Glover (1990) focuses on support groups and psychosocial issues. The questionnaire-based study attempts to understand the psychosocial needs of 14 homosexual men with HIV/AID and/or their partners living in London. The study aims to understand if joining twelve information sessions and discussing topics including diet, general health, dealing with stress, medical treatment,

social services, and safer sex, would lead to a decrease in the need for individual counseling. The study was inconclusive, but did suggest that there was no significant effect on the amount of individual counseling needed by the participants (Hedge & Glover, 1990).

An article based on social work field notes expresses a different aspect of HIV/AIDS support groups by discussing the formation of a support group for families and partners of people living with HIV/AIDS. Findings indicate that the group was constantly conscious of the social stigma surrounding HIV/AIDS and made every effort to keep the group secure and confidential (Anderson & Shaw, 1994).

An anthropological study by Rier (2007) discusses the emergence of internet HIV/AIDS support groups that differ from the face-to-face interaction normally associated with support groups. These internet support groups have become popular amongst individuals suffering from chronic illness including HIV/AIDS. The characteristics, structure, and format of HIV/AIDS internet support groups differ greatly from those described above, although the discussions may or may not differ from the general discourse in HIV/AIDS support groups (Rier, 2007).

A qualitative dissertation by eight Psychology master students from the University of Pretoria discusses the trials of attempting to implement four HIV/AIDS support groups in South Africa. Three out of the four support groups failed for various reasons. The authors state that one reason for failure centres on the fact that the "primary needs of the

women were not addressed", and in order for higher needs to be fulfilled, the basic needs must be satisfied first (Visser & Mundell, 2008:70). This sentiment is supported by an in-depth qualitative study conducted in Vietnam by Oosterhoff et al. (2008a), which likewise states that when women had access to services, and their immediate needs were taken care of, the members had time to reflect on other issues within the support groups.

This study further explores the way in which HIV positive mothers in Vietnam navigated their position in society, their HIV positive status, and their attempts to access treatment and support. The author states that the group "reshaped a negative HIV positive identity" (Oosterhoff et al., 2008a:167); members grew in confidence; some members completed a personal development plan, and helped others to receive access to treatment and services. The group members, although active in their community, were afraid to expose themselves to the public due to fear of discrimination and social stigma (Oosterhoff et al., 2008a).

Another qualitative study by Oosterhoff et al., (2008b) on the same support group in Vietnam described above, focuses on aspects and implementation of a micro-credit loan program for women in HIV/AIDS support groups. The study examines the effects of micro-credit loans in relation to empowerment, health, and economic status of Vietnamese women in HIV/AIDS support groups, (Oosterhoff et al., 2008b).

In an anthropological study of support groups in Thailand, Lyttleton (2004) focused on creating a narrative framework for being HIV positive and discusses socio-cultural

notions associated with the support groups and HIV/AIDS, stigma and discrimination, and the development of a social and group identity. The author believes that the support groups have mirrored phases and perceptions of HIV/AIDS over time throughout the country. Also, the study focuses on the social normalization of being HIV positive, including the self-transformation of publicly acknowledging one's HIV status, thus combating commonly held notions of people living with HIV/AIDS and the associated social stigma and discrimination (Lyttleton 2004).

7. CRITICISMS AND LIMITATIONS ON RESEARCH OF HIV/AIDS SUPPORT GROUPS

Criticism of support group research cites a lack of literature and theory on HIV/AIDS support group implementation and evaluative studies on the practice of HIV/AIDS support groups (Schopler & Galinsky, 1993; Spirig, 1998). Sprig (1998: 55) comments that "Because support groups offer considerable promise for meeting the complex psychosocial needs of PLWAs [People Living with AIDS], research is urgently needed to address process, content, and outcome of support groups".

Literature cites that HIV/AIDS support group studies tend to focus on the positive feedback of support groups, and do not focus on the negative aspects of the support groups or sponsoring organizations. Negative aspects amongst members may include issues of conformity, obligations, inadequacy, and embarrassment, and additionally, sponsoring organizations may face issues of unproductiveness amongst staff and

resources, and the possibility of “group failure” (Schopler, Galinsky, 1993: 9; Spirig, 1998). This particular study addresses several themes associated with “negative aspects” amongst support group participants.

Limitations on HIV/AIDS support group studies include small sample sizes and a lack of qualitative, in particularly, anthropological studies (Spirig, 1998; Singhanetra-Renard et al., 2001; Kalichman & Sikkema, 1996; Martin et al., 2001). There is also a need to study HIV/AIDS support groups within the particular cultural context of the communities and societies, in which the support group operates (Jacobson, 1987).

The topics addressed within this chapter are integral to the comprehension of concepts and descriptions of both HIV/AIDS support groups under study, the sponsoring organization, structural components of the support groups, and interactions amongst the support group members and with the sponsoring organization; all these concepts will be elaborated upon throughout this thesis. The subsequent chapter describes the concept of hospice and palliative care, as well as describing the role of the sponsoring organization, Isibani Hospice.

CHAPTER THREE- ISIBANI HOSPICE

As discussed within Chapter Two, HIV/AIDS support groups usually have a sponsoring organization. The support groups under study, Nawe Sondela and Asibemunye, had the same sponsoring organization, Isibani Hospice. This chapter provides an overview of hospice and palliative care, as well as an understanding of the organization, Isibani Hospice. Moreover, the chapter discusses Isibani Hospice's roles and functions within the HIV/AIDS support groups, as well as support provided to each support group by additional organizations.

1. CONCEPT OF HOSPICE AND PALLIATIVE CARE

The concept of hospice has developed over the centuries, since, as Forman et al. (2003: 1) states, "the care of suffering and dying patients is a part of human history". Beginning in the early 19th century, institutions throughout Europe and North America saw a need to care for the dying in a humane way (Forman et al., 2003: 4). The formation of the modern hospice, common throughout the world today, has roots in the research and work carried out by Dame Cicely Saunders, who opened the first modern hospice outside of London in 1967 called the St. Christopher's Hospice (Forman et al., 2003). In addition, the research and writings on death and dying by psychiatrist, Elisabeth Kubler Ross, strengthened the development of the hospice movement, in particular throughout Europe and North America (Forman et al., 2003). Hospice care provides support to terminally ill patients and their family members in an attempt to improve the quality of life for those

nearing death, and traditionally was a free service for needy patients (Forman et al., 2003).

Hospice care may be carried out in a hospital setting, within an in-patient unit at a hospice centre, and/or within the patient's private home (Hospice Palliative Care Association of South Africa, 2009).

Figure 1 provides an overview of the different types of services traditionally provided by Hospice Care, including who provides the care, to whom, and where the service is provided (Hospice Palliative Care Association of South Africa, 2009).

Figure 1- Different services provided by Hospice Care

Hospice Home Based Care	Hospice Community Centres	Hospice In Patient Units
• Provided by professionally trained caregivers	• Facilitated by doctors, nurses, social workers and variety of professionals	•24 hour professionals trained in palliative care
• Home-bound patients	• Mobile patients, reasonably good health	•Patients must meet specific criteria i.e. no support systems at home
• Service provided at patient's home	• Patients meet as a group usually in a community centre	•Service provided within hospice centre (In Patient unit)

Hospice care utilizes the therapy known as palliative care (Forman et al., 2003; Hospice Palliative Care Association of South Africa, 2009). This term palliative care, first used by the Canadian doctor Balfour Mont, focuses on a holistic approach in providing quality

of life, including the emotional, psychological, spiritual, and physical needs of a person approaching death (Forman et al., 2003; UNAIDS, 2009). Specifically, palliative care aids in symptom relief and the control of pain including administering strong painkillers to terminally ill patients (UNAIDS, 2009). The World Health Organization, additionally states that palliative care “affirms life and regards dying as a normal process”; creates a support system for both patients and their families; offers bereavement support; and “enhances the quality of life, and may positively influence the course of illness” (WHO, 2009). Palliative care must be administered by a trained specialist (UNAIDS, 2009; Hospice Palliative Care Association of South Africa, 2009). According to UNAIDS, palliative care is “one of the most neglected aspects of health care”, since there are ethical issues in countries throughout the world concerning the use of strong painkillers and morphine (2009).

Hospice and palliative care may be used to treat patients suffering from a wide range of terminal illnesses. With millions of people living with HIV/AIDS throughout the world, an interest and understanding of the role hospice and palliative care may offer to people suffering from HIV/AIDS has become a priority amongst many nations and worldwide organizations such as WHO and UNAIDS (Foundation for Hospices in Sub-Saharan Africa, 2009). In addition, since the advent of the hospice movement and the use of palliative care, numerous organizations and associations advocating and explaining the use of hospice and palliative care have developed worldwide. The International Association for Hospice and Palliative Care believes that the hospice and palliative care

models should be developed in accordance with the needs, experiences, and resources of each country (Hospice Palliative Care Association of South Africa, 2009).

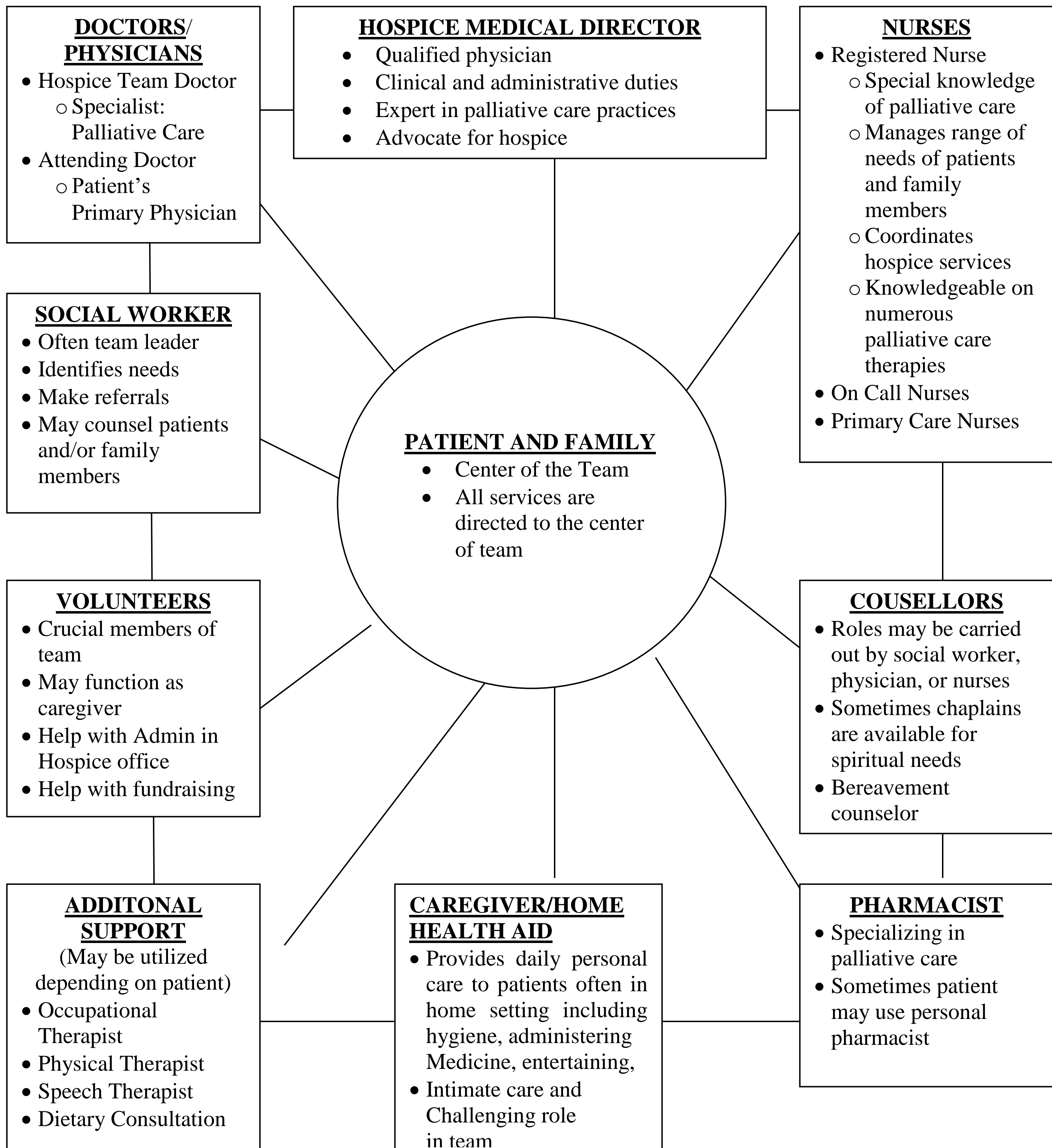
The Foundation for Hospices in Sub-Saharan Africa has a partnership initiative, which partners an American hospice organization with a health organization/ hospice within Sub-Saharan Africa. This partnership aims to provide a sharing of knowledge and experiences, and often entails a monetary donation (from the American partner) (Foundation for Hospices in Sub-Saharan Africa, 2009). Additionally, the Hospice Palliative Care Association of South Africa (hereinafter referred to as HPCA) and the Council for Health Service Accreditation of South Africa (hereinafter referred to as COHSASA) monitor hospice and palliative care and offer accreditation to quality providers, offer training and advice, provide a membership base for hospice and palliative care providers throughout the country, and also operate as a form of advocacy (Hospice Palliative Care Association of South Africa, 2009; Council for Health Service Accreditation of South Africa, 2009). The mission statement of HPCA is to "promote quality in life, dignity in death, and support in bereavement for all living with life-threatening illnesses by supporting members' hospices and partner organizations" (Hospice Palliative Care Association of South Africa, 2009). In 2009, HPCA launched a media campaign, to enlighten the South African public of the changing role that hospice has taken on in recent years, with the following slogan, "Have you been touched by Hospice? I have" (Hospice Palliative Care Association of South Africa, 2009). Often members of the general public associate hospice with death, yet HPCA and hospices throughout South Africa are attempting to change that perception of hospice, which

includes caring for the dying, but also “quality of life” (Hospice Palliative Care Association of South Africa, 2009).

Hospice and palliative care centres on the premise that an interdisciplinary team should be involved to provide the patient with a holistic range of tools, in order to improve quality of life and end-of-life care (Forman et al., 2003). Forman et al., describes hospice work as “inherently difficult and emotionally draining”, expanding on this theme by stating that each person working for a hospice should develop his/her own coping strategies for dealing with death on a regular basis (2003: 14). The following model developed by the United States Medicare Hospice plan describes the interdisciplinary team and core services of a hospice set-up. The centre of the team is the patient and family, and core services provided within this framework include nursing, physicians, counseling, and medical social services (Forman et al., 2003). The hospice team assesses the patient’s needs, although not every patient necessarily utilizes all services provided by hospice (Forman et al., 2003). In addition to the services provided, hospice programs function under the operation of a Hospice manager and office staff (Forman et al., 2003). Figure 2 (overleaf) provides a diagram of the Hospice interdisciplinary team and core services.

A brief history and description of hospice and palliative care enables a greater understanding of the structures and roles within Isibani Hospice, the sponsoring organization of both the HIV/AIDS support groups, Nawe Sondela and Asibemunye, which form the focus of this dissertation.

Figure 2: Core Services and Supporting Services Provided to Patients and Families



2. HISTORY OF ISIBANI

The sponsoring organization for the support groups under study, Isibani Hospice, began with a public meeting in Scottburgh Town Hall in 1985 to discuss the possibility of forming a hospice to care for the terminally ill and their families. The newly formed hospice, originally named Sunshine Hospice Association (also a pseudonym), purchased land, and functioned through the support of local volunteers. In 1988, Isibani opened an in-patient care unit with four beds; with this addition, the hospice saw the need to hire part-time paid staff and eventually shifted to full-time paid staff. In 1990, an administrator was appointed full time, and the hospice was caring for the terminally ill and their families as far south as Mtwalume, north of Athlone Park, and inland to Braemar. The hospice acquired its first vehicle and a Home Care sister was appointed to Isibani in 1996. Originally, Isibani mainly catered to terminally ill cancer patients, similarly the hospice movement in its early days also largely cared for terminally ill cancer patients. However, as the HIV/AIDS epidemic worsened throughout KwaZulu-Natal, the hospice correspondingly expanded its efforts to care for terminally ill patients suffering from HIV/AIDS. In 2001, Isibani Hospice amalgamated with a newly formed hospice organization in Amanzimtoti. The two hospice organizations amalgamated due to the fear that neither organization would be sufficiently supported by the local community with two hospices operating in the same vicinity. The Hospice board ran a public competition to decide on a new name for the combined hospice, thus, the present name of the hospice was decided.

2.1 FINANCIAL HISTORY OF ISIBANI

Isibani provides a service free of charge to all of their patients, and the hospice does not receive funding from the government. In 2001, Isibani became a Section 21 Non-Profit Organization (hereinafter referred to as an NPO). Isibani operates on public donations and fundraising, and the organization has faced financial troubles several times throughout the hospice's existence. In 2002, the hospice, due to financial constraints, closed down the in-patient unit, but at the same time, restructured the services offered; the hospice increased the home based care program and developed an outreach program. In 2007, the hospice became a Public Benefit Organization (known as a PBO), under Section 10F of the Income Tax Act, which provides donors with a tax exemption certificate. Isibani also received funding from the Global Fund, as well as the United States President's Emergency Plan for AIDS Relief (known as PEPFAR). Specifically, in 2007, PEPFAR awarded the Hospice and Palliative Care Association of South Africa with $5, 020,000 U.S. dollars. This money was then distributed to 38 hospices throughout South Africa to be used in programs targeting orphans and vulnerable children, and palliative care for basic health care and support. Towards the end of 2008, Isibani decided to restructure several services offered to patients, due to financial constraints. The current C.E.O. (as of 2009) of Isibani Hospice states that the "*Organization has improved according to the needs, the only thing we worry at all about is funding*".[11]

[11] Quotations throughout this chapter were acquired through personal correspondence and/or interviews.

3. DESCRIPTION OF ISIBANI

The mission statement of Isibani is "to provide palliative care to the terminally ill and support for their families". The current CEO of Isibani states that the hospice "*would just like to reach as many people as possible, you know that's our goal. It's a very nebulous sort of goal. It's nothing you could put a number on, but it is to help as many people as possible within the budgetary constraints".* Isibani's creed states, "You matter because you are. You matter until the last minute of your life and we [Isibani] will do all that we can not only to help you die in peace and with dignity, but also to live as fully as possible until you do". Additionally, Isibani aims to serve all communities and to provide its services to patients of all color, creed, religion, and race. In the past, Isibani Hospice participated in the Foundation for Hospices in Sub-Saharan Africa's Partner Initiative, and was paired with a hospice organization in American, the VITAS Innovative Hospice Care based in Florida (Chestnut Hill Local, 2007). In addition, Isibani has received accreditation from COHSASA, which lasts for two years from 2008-2010. Also, Isibani is a fully accredited member of the HPCA.

3.1 ISIBANI HOSPICE TEAM

At present, Isibani's team includes one CEO, two Administrative Assistants, one Administrative Clerk, and two part-time Domestic Staff, who operate out of the Isibani office. Also the Isibani team, which implements services on-site, i.e. Home Based Care and support groups, includes one Nursing Manager (Sister Joyce Sithole, a pseudonym),

four Professional Nurses (including Sister Ngcobo, a pseudonym, who worked with Nawe Sondela support group), one Psycho-social Coordinator (Rosheni, a pseudonym), one Support Group Coordinator (Bongiwe, a pseudonym), and nine Caregivers (including Hlengiwe, a pseudonym, who works with Asibemunye, and Lungi and Nombali, both pseudonyms, who work with Nawe Sondela). The support group members and the Isibani team refer to all nurses as "sisters". Additionally, there are four Shop Keepers that operate the Isibani Charity Shops, which are located throughout the South Coast. Since the organization's inception, Isibani has relied extensively on the support of volunteers and continues to do so. Volunteers, who will be working directly with patients, are required to take a caregiver's course prior to working with patients. The majority of the caregivers at Isibani are volunteers. Volunteers, also, take on roles with the office administration, charity shops, and fundraising efforts. All staff receives education and training upon employment with Isibani, and different courses are offered to gain and update knowledge depending on which aspect of care is the team member focus. HPCA also offers courses and workshops on hospice and palliative care to member hospices and their employees. Additionally, there is a great deal of literature and guidelines provided by the various hospice and palliative care associations throughout South Africa, for example, HPCA has developed clinical and caregiver guideline booklets (Hospice Palliative Care Association of South Africa, 2009).

There are three different teams at Isibani consisting of a Professional Nurse and three to four caregivers per team, who go out to visit and care for home bound patients from Monday to Thursday. Additionally, these teams often accompany the support group

coordinator to the support group meetings that take place throughout the week between Monday and Thursday. The social worker accompanies the teams to visit a patient when necessary and also occasionally attends support group meetings. Friday is a mandatory office day for all team members. The team members are required to fill out outstanding paper work for any of the patients seen throughout the week, discuss issues, problems, and suggestions, and debrief about the week's events. The Professional Nurses and Support Group Coordinator report any issues/needs/concerns and events of the past week to the Nursing Manager. The role of the support group coordinator will be discussed in detail in Section 4.

3.2 ISIBANI PATIENTS AND SERVICES OFFERED

Isibani offers a range of hospice and palliative care services to patients suffering from terminal illnesses. The majority of Isibani's patients are suffering from HIV/AIDS. The estimated figure of patients in mid-May 2009 was 100 category 1 patients, 80 category 2 patients, and 50 category 3 patients [Categories elaborated below]. People become patients through referrals by the patient, the patient's doctor, or their family. The clinics within the areas Isibani operates such as Adams Mission, Ezimbokodweni, and KwaMakhutha Clinics refer patients to Isibani. Knowledge of Isibani throughout the communities also spreads by word of mouth. The support group coordinator, Bongiwe explains that, *"When we [Isibani Hospice] first started, we went to the local clinics, the schools, the inkosis (kings,) and indunas (chiefs) and introduced ourselves and told them that we were here and told them to contact us."* The patient must give consent and be

willing to be placed under the care of Isibani. After a referral to Isibani, the patient is assessed in order to decide what form of care Isibani will be able to offer the individual. In order to assess the patient, the nurses and caregivers must have specific information about the individual, such as medical history, health, lifestyle, personal situation, i.e. living, social, and economic situation.

Isibani then categorizes the patient into different categories: 1, 2, and 3. The different categories essentially differentiate the patient's level of health, thus forming the basis for the type of care each patient receives. Category 1 patients are mobile, active, relatively healthy, in that the individual may be HIV positive, but are capable of daily life routines (i.e. working, cleaning, cooking, and taking care of children). Category 2 patients are also mobile but less active. The Category 2 patient's health has begun to decline, and the individual may experience more sicknesses associated with HIV/AIDS and/or side effects of anti-retroviral treatment (hereinafter referred to as ARV or ARVs). Every Category 2 patient is not necessarily receiving ARVs. Category 3 patients are immobile, often bed ridden or confined to home. The patient is no longer able to care for himself/herself without assistance and requires additional support from the professional nurses, caregivers, and family members. In terms of patients with HIV/AIDS, this category of patients often have a low CD4 count and are suffering from AIDS.

Figure 3 provides an overview of services offered by Isibani Hospice, the patients that receive the services, and by whom the service is provided.

Figure 3: Isibani Hospice Services

Services:	**Traditional Home Care Service**	**HIV/AIDS Support Group Meetings**	**Bereavement Support**	**Orphans and Vulnerable Children**
Patients:	Category 3 Patients	Category 1 Patients, Category 2 Patients (as of 2009)	Category 1 Patients, Category 2 Patients, Category 3 Patients	Children of Category 1, 2, and 3 Patients
Services provided by:	Professional Nurse; Trained Caregivers; if needed Doctors & Social Worker	Support Group Coordinator; Trained Caregivers; if needed, Social Worker	Professional Nurse; Trained Caregivers; if needed, Social Worker	Support is provided by Isibani team depending on needs of children

Isibani provides a Traditional Home-Based Care Service to category 3 patients. This service is provided by a professional nurse and trained caregivers, who drive Isibani vehicles to the patient's home. Additionally, if needed, Isibani consults and provides medical doctors to patients, as well as loans medical equipment to patients and their families. The holistic approach of a palliative care service, such as that offered by Isibani, means that the team also addresses issues or problems the patient's family may be experiencing. For instance, Bongiwe explains that with category 3 patients, Isibani works *"to educate the family on how to care for them [the patient], and we show them, so*

maybe if they are bedridden, how to turn them, when to turn them, how to wash them, and feed them".

Before the beginning of 2009, Category 2 patients were seen by a professional nurse and caregivers at the patient's home. Category 2 patients were seen on a weekly basis and for those not receiving a grant, such as child support or a disability grant, were given (including his /her family) a food parcel, and sometimes donated clothes. Since 2009, though, Isibani restructured their services offered to Category 2 patients. The management decided, *"We had been working in a non-cost effective way, our professional nurses have been going around with the teams seeing categories 1, 2, and 3 [patients]".* Now, Category 2 patients must attend the weekly HIV/AIDS support group meetings. The CEO, in relation to the restructuring said, *"It is change. Of course, change is not usually comfortable, but we'll work through it. We have come through a lot of change over the years already, so, I think it's going to be beneficial especially to the people who really need us [Category 3 Patients]".*

Category 1 patients attend weekly HIV/AIDS support group meetings, which are facilitated by one of the Isibani teams. As of mid-2009, Isibani was not formally accepting any more individuals referred to the support group. New individuals are still welcome to attend the support group meetings, but due to budgetary constraints, the individual would not be considered an official patient (Category 1) of Isibani. More details concerning the support groups will be explained in Section 4, as it is necessary to

elaborate on the support groups in order to understand the latter chapters within this study.

Additionally, Isibani encourages category 1 and 2 patients to check their CD4 count on a regular basis, and for the patients to inform the Isibani caregivers and support group coordinator of a patient's CD4 results. Isibani keeps track of a patient's CD4 results, in the case a patient's CD4 count drops below 200. If this happens, a professional nurse from Isibani then writes a referral for the patient to go to the nearest ARV site (usually at a clinic and/or hospital) in order to begin ARV treatment. The trained caregivers, also provide counseling if requested by the patient. Isibani also provides category 1 and 2 patients with vitamins on a monthly basis. At the beginning of each month, patients are given 30 tablets of the following: Multivitamin, B Complex Vitamin, Vitamin C, and Folic Acid. Panado, a tablet for mild pain relief, is also provided to the patients once a month. Some members request additional Panado tablets from Isibani throughout the month, and are usually given the extra tablets. Sister Joyce Sithole, the nursing manager, states, *"Folic acid is very good for people taking ARVs because it helps ARVs and all the medicine to be absorbed".* Patients on ARVs do not always receive vitamins from Isibani because many ARV sites, in addition to providing the antiretroviral treatment, also provide vitamins to the individual. The category 1 and 2 patients are also weighed on a monthly basis; the results are kept in each patient's file. Isibani will do a blood pressure reading on Category 1 and 2 patients, if needed. If there is a serious health concern or question that a caregiver or the support group coordinator is unable to address,

the coordinator then liaises with the professional nurses and nursing manager to provide an answer or help for the patient.

3.3 <u>FUNDING AND DONATIONS</u>

As stated previously, a main concern for the organization is funding. Isibani has received funding from international and national donors, and local donations from community members and businesses, service groups, and faith-based organizations. At the end of the 2008 financial year, the cost of providing services was R 2.25 million. The CEO states that the biggest constraint on management is *"Funds. It's the number one priority really. We ran at an operating deficit of R 500,000. It takes a lot to keep it going. So we will just pray a bit harder this year".* Additionally, the CEO believes that the government of South Africa takes an interest in home-based care initiatives, but does not take into account that many hospices provide a palliative care service, which is different from the regular Home-Based Care, due to the incorporation of professional nurses. In order to increase awareness and promote hospice and palliative care, the CEO states that the HPCA on the national level corresponds with the Department of Health, at the provincial level with the KwaZulu-Natal Department of Health, and locally, the Isibani's professional nurses network and engage with local and primary health care givers. Yet, the CEO does not think the government *is "planning to give us money any time soon. In fact they really should support us because the work that our sisters [professional nurses] are doing in the field is actually preventing or stopping people from abusing and overusing the state hospitals".*

The local community supports Isibani through donating clothes to the four different Isibani Charity shops in Amanzimtoti, Scottburgh, Umkomass, and Port Shepstone. Isibani makes a profit on the sales of clothing donated to stores by the general public. At the same time, any clothes that have been donated by the public but are unable to be resold, e.g. torn clothes, missing buttons, or holes, are packed into black bin bags every week. These clothes are then given out to patients in the home-based care service, support groups, and children. In addition, the clothes are given to general members of the communities in which Isibani operates.

Isibani receives food items for the numerous food parcels given out to all three categories of patients, through donations from local grocery stores. UNAIDS believes that nutrition and access to food, i.e. "nutrition support", while an individual is taking ARVs is paramount in order for the individual to benefit from the ARVs (UNAIDS, 2009). Isibani receives loaves of bread from Checkers-Umkomass throughout the month. Also in 2009, the Anglican Parish of Umkomass with Scottburgh began the Impilo Food Parcel Project, which takes place on a monthly basis. The food parcels contain staple food items, which are purchased and packed by the church members. Eighty parcels per month are given to Isibani. Isibani passes these food parcels out to all three categories of patients throughout the month. Bongiwe, the Isibani Hospice support group coordinator, mentioned that the Impilo Food Parcel Project is *"fantastic because we [Isibani Hospice] know we will be receiving 80 parcels a month"*, but eventually the Impilo project will end. Thus, Isibani will need to find more donations from local community members and businesses.

Additionally, the previous social worker, Rosheni, managed to get four sewing machines donated to the support groups (refer to Chapter Four and Chapter Five for a discussion of group projects).

An outline of the sponsoring organization has been provided, and now the attention will focus on the functioning of Isibani and the HIV/AIDS support groups.

4. ISIBANI HOSPICE AND SUPPORT GROUPS

As noted in Chapter Two, HIV/AIDS support groups often have a sponsoring organization (refer to Bell et al., 2007; Lyttleton, 2004; Schopler & Galinsky, 1993), which in the case of the two support groups under study is Isibani. Isibani works with five different support groups throughout the South Coast region, primarily in the areas of Ezimbokodweni, Adams Mission, KwaMakhutha, and surrounding areas. This study focuses on the Nawe Sondela support group in Ezimbokodweni and the Asibemunye support group in Adams Mission. As mentioned previously, individuals who are members of the support groups are patients of Isibani Hospice. Category 1 and Category 2 patients attend the HIV/AIDS support group meetings. Bongiwe, the support group coordinator usually visits Nawe Sondela and Asibemunye at two meetings per month, alternating between the two groups. At times, Bongiwe visits both groups in one week, but there is a conflict in time as both meet on Tuesdays with Asibemunye meetings beginning at 11 a.m. and lasting between one to two and a half hours, and Nawe Sondela meetings beginning at 12 p.m. An Isibani caregiver, Hlengiwe, facilitates the Asibemunye meetings when Bongiwe is absent; similarly, Lungi tends to facilitate the

Nawe Sondela meetings. Before 2009, Sister Joyce Sithole was the facilitator for Asibemunye, and Sister Ngcobo was the facilitator for Nawe Sondela.

The formal structures, or way in which the support groups operate from the viewpoint of Isibani Hospice, is elaborated below through Isibani's definition of a support group, the formation of support groups under study, Isibani's role with the support groups, and goals and challenges faced by Isibani and the support groups, Nawe Sondela and Asibemunye.

Firstly, it is important to identify how Isibani defines and conceptualizes an HIV/AIDS support group. Bongiwe, previously mentioned, became the newly appointed support group coordinator for all support groups working with Isibani. This position was created by the management at the beginning of 2009, in order to alleviate the time spent by the professional nurses in attending to the matters of the support groups. The position also requires Bongiwe to liaise with the sisters on medical advice, or to consult them, if a patient has a specific problem that needs to be addressed by a professional nurse.

Bongiwe says, "*A support group, for us [Isibani], is a group of people who are living under the same circumstances, like people who are all HIV positive, to come in together and to support each other. Even if maybe you have disclosed your status at home, when you speak to them about something, maybe problems you are encountering, they don't actually really understand what you are going through. So to have— to be with people who are also in the same situation as you, it's easier to talk, you know. Just to come in talk, joke, laugh, with people who understand what you are going through.*" Similarly,

the Nursing Manager, Sister Joyce Sithole states that a support group is created with the hopes that its members *"equip each other in any way, either by skills, knitting, sewing, and even information".*

A second important factor for Isibani is the formation of the support group. Several members of the Isibani team state that many of the support groups were formed by Isibani Hospice, through various means such as the Isibani team recruiting members from clinics, through word of mouth. Some of the groups were started by individuals coming together on their own initiative to discuss issues in their lives and issues pertaining to HIV/AIDS. Thus, these groups of people were "informal get-togethers" (refer to Lyttleton, 2004; Schopler & Galinksy, 1993). In terms of Nawe Sondela and Asibemunye, it was only after the establishment of these informal meetings that Isibani was then contacted by one of the individuals. At that point, Isibani became the sponsoring organization for the group, and the group members became Category 1 or Category 2 patients of Isibani. There are different opinions, amongst members of both groups and the Isibani team, on origin of each support group, which will be elaborated upon in Chapter 6.

Isibani, headed by the efforts of the nursing manager, would like to continue setting up more HIV/AIDS support groups. Moreover, Sister Joyce Sithole has begun to work with other support groups operating in the same vicinity as the Isibani support groups. Joyce explains that at times you will find support groups meeting, *"who are funded by the government, but they don't have trained sisters to work with the support groups. It's*

easy for us [Isibani] to go there, work with them [the support groups], and where there is condition—to follow them [continue to help the support groups]". Thus, support groups are formed by both the PLWHA themselves and also Isibani Hospice.

Isibani provides vitamins, medical advice, some food parcels and second hand clothing to the support group members as described in Section 3.3, and additionally, an Isibani caregiver or the support group coordinator facilitates an educational session during the weekly meeting (in actuality, the educational session does not take place every week). Bongiwe explains that she or a caregiver will ask the support group members what they would like to learn or achieve. Then, Bongiwe finds relevant information on the topic, sometimes utilizing pamphlets or magazines such as Soul City (which focuses on health and HIV/AIDS); or asks for additional information and clarity on the topic from the nursing manager, sisters, and nearby clinics. Several topics facilitated by Bongiwe throughout the year included information on pap smears, a discussion on gender-based violence, and discussion of ARV treatment.

In 2009, Isibani also began providing a small lunch to the members attending the meetings. Each member receives one to two sandwiches consisting of two pieces of bread, butter, and polony, as well as juice made from concentrate and water. Bongiwe explains that Isibani began providing a small lunch to the members because some members *"complain that they have to come from far and by the time maybe by twelve, they are hungry and need something [to eat]. So…they know when they come to support group they have something to eat. They won't just sit there and go hungry".*

4.1 <u>ISIBANI'S GOALS AND CHALLENGES WITH SUPPORT GROUPS</u>

Sister Joyce Sithole expressed that Isibani Hospice would like to extend services, such as providing a volunteer doctor, psychologist, or physiotherapist to the patients. Bongiwe believes that Isibani's vision for the support groups would be possible if the support group members were *"able to do things for themselves because most of them are unemployed. We would like them to have skills like sewing, gardening—things that can generate an income for them"*.

At the same time, Isibani faces several challenges in the operation of the support groups such as instances of conflict amongst the support group members, and between the support group members and Isibani team (refer to Chapter Six and Chapter Seven). One particular challenge for some of the support groups, including Nawe Sondela and Asibemunye, is the need to find a suitable meeting place for the group. For instance transportation and money for those living far from the meeting venue became a challenge, as well as the fact that many of the members express the wish for their own place (refer to Uys & Cameron, 2003). The members of both Nawe Sondela and Asibemunye would like a building solely for use by the support group members; both current meeting venues are used by the communities for community purposes, i.e. church services, meetings. Sister Joyce Sithole believes an ideal meeting venues for the support groups is to use a large house (either a member of the support group or community) and if there is a need for bigger accommodation that the groups can always plan to meet in community centres and/or halls such as the hall in Ezimbokodweni clinic.

Additionally, Sister Joyce Sithole, at times, faces issues with other support groups operating in the same vicinity as support groups under Isibani. Sister Joyce Sithole would like to work together with these support groups (and has successfully done so, as described previously), but has become frustrated when groups, *"start taking our patients. I contacted one of them because it wasn't fair".*

Other organizations have been involved in the past (and continue to) with the support groups such as, the Youth Aid Association (hereinafter referred to as YAA), members of the Treatment Action Campaign (hereinafter referred to as TAC), and the National Association of People Living with AIDS (hereinafter referred to as NAPWA).

In terms of challenges faced by the support group members within their local communities, Isibani states stigma is a major issue. Stigma of people living with HIV/AIDS exists amongst the communities that Isibani operates in. Isibani believes that some individuals do not come to the support groups, or do not become patients of Isibani due to the fear of stigma. Sister Joyce Sithole thinks, *"60% [of people] don't care about PLWHA, but there is still that 40% which do".* Furthermore, Sithole explains, *"Some they [patients] do want us to help them, they don't want Isibani there. They ask us [Isibani] when we come to visit them in their homes to leave the car there—farther away from their [the patient's] home".*

Another main concern for the communities is poverty, and many of the members of the support groups face poverty on a daily basis. Thus, Isibani feels there is a need to provide food parcels to the support group members.

The support groups under study, Nawe Sondela and Asibemunye, receive support from the sponsoring organization, Isibani Hospice, and additionally, at this time, a description of the YAA's involvement with the support groups will be described, as well as local clinics and hospitals that work the support groups.

5. INVOLVEMENT OF YOUTH AID ASSOCIATION

In addition to the support and services that Isibani provides to the support groups under study, several organizations were and continue to be involved with the groups. My fieldwork began with volunteering at the YAA in Amanzimtoti. The YAA is a non-profit organization, which runs several projects throughout the communities of Illovo, KwaMakhutha, Nsinmbisi, Adams Mission, Ezimbokodweni, and Folweni. The YAA has no affiliation with Isibani Hospice, except that both organizations worked with the support groups under study. The YAA became involved with the support groups, which stemmed from their own organization's initiatives and projects. Not all of the projects at YAA will be discussed, except for the Masibambane Project due to its connection with the support groups. My entry into the support groups began with my involvement at YAA, and my impression from these two months with the organization was that the YAA was in charge of the support groups under study. The ideas surrounding the origin of the

support groups as well as the ownership of the support groups will be discussed in relation to the YAA in Chapter Six.

The YAA Masibambane project focused on various aspects of improving lives of PLHWA, one of which was the facilitation of HIV/AIDS support groups. The project began in 2006 and aimed to finish by June 2008. The project received funding from Oxfam Australia, the South African National Lottery, local companies, faith-based organizations, and individual donations. One objective stated in the YAA operational plan for July 2007 to June 2008 was to “formalize support groups as a community-based organization and build capacity to ensure sustainability [of the group] beyond 2008”. The specific objectives, which began in July 2007, were first to “assess the support groups’ readiness for a formal structure”. The YAA administered questionnaires to the support group members, in attempts to assess their ‘readinesses'. The second objective was to “register the support groups with the relevant bodies” [forming constitutions, and registering group as a NPO]; the YAA aimed to have this completed by October 2007. Other objectives set out the need to help the support groups build capacity, implement projects (specifically business oriented), and assist in monitoring and evaluation of groups from September 2007 to May 2008. Additionally, the YAA planned to facilitate weekly meetings in the hopes of building capacity in the groups. The YAA Support Group Facilitator (Sandile), Masibambane Project Coordinator (Nelly), the Support Group Executive Committee, and the Manager were involved with the planning of the objectives, and more specifically, the Support Group Facilitator was involved with the

implementation of the objectives. The YAA attended and worked with five different support groups including Asibemunye and Nawe Sondela.

The YAA experienced financial constraints in May 2008, and as a result stopped regularly attending support group meetings. According to the operational plan, the YAA planned to complete the Masibambane Project in June 2008. Nelly explained that although the YAA was not going to be regularly involved with the support groups anymore, that YAA did not *"want to close the door. The door is always there".* Moreover, Sandile explained that YAA would still be involved with the groups in the form of mentorship, training, and information.

5.1 YAA AND SUPPORT GROUPS

Support groups, in the context of the Masibambane Project, were described by the Project Coordinator, Nelly, as a group for those affected by or infected with HIV/AIDS. The people within the communities came together and "*began to talk with each other, counsel each other. At the end of the day, they didn't just talk about HIV/AIDS. They wanted to deal with other issues [as well]".* The Support Group Facilitator, Sandile, believes that "*You can't define a support group for them [the support group members]. The group has to come to an understanding on their own about what they are to do".* Sandile also, states that *"to know about HIV you have to know about everything else affecting [the support group members). People in these groups need to be in control of their lives, and then they can begin to address HIV/AIDS".*

The YAA, specifically Sandile, and a YAA staff member, Nokwazi, attended the support group meetings on a weekly basis, although some weeks they were unable to attend due to YAA transport problems. The facilitators would often bring pamphlets, flip charts, and diagrams, discussing issues on the physical and social aspects of HIV/AIDS, particularly HIV/AIDS and gender. In addition, the YAA provided transport for the support groups under study to participate in an exchange visit with two different HIV/AIDS support groups on the South Coast. Nawe Sondela and Asibemunye (on separate occasions) visited two different HIV/AIDS support groups on the South Coast in order to share information about the groups, and to learn about the groups income-generating projects (candle making, gardening, and beading). Additionally, the YAA provided R 200 to each support group every month. The support groups had autonomy over the money given to them by YAA, and according to Nelly and Sandile, the support groups generally spent the money on buying coffee/tea and biscuits for the meetings.

In accordance with the objectives of YAA, as outlined above, Sandile encouraged the support groups to write constitutions for their groups, although Sandile primarily wrote the constitutions for Asibemunye and Nawe Sondela (refer to Chapter Four). Sandile stated, *"Support groups need to run in a particular framework—to maintain a high level of discipline and conduct…in the daily functioning of the support groups you need to look to the constitution"*. Moreover, Sandile's main aim was for the support groups to become a NPO. The hope for YAA and Sandile was that if the support groups became an NPO, the groups would be on their way to becoming sustainable organizations, with the ability to source funding and donations on their own via grants.

The YAA encouraged the support group members to develop income-generating projects. However, Sandile acknowledged that the groups (particularly referring to Asibemunye) needed more training and simple bookkeeping skills to learn how to develop and run an income-generating project.

The YAA faced several challenges in implementing their objectives for the support groups. Sandile expressed frustrations with the support groups because he did not believe that support group members joined because they were personally committed to making the group a success. Sandile says, *"When I came in, they were strong and promising. During the times, though, they are showing signs of disillusionment, lack of focus, and dependency syndrome. Some [support group members] do not understand what the constitution stands for in meaning"*. Additionally, Sandile and Nokwazi viewed instances of conflict arising out of personality differences amongst the group members (refer to Chapter Six).

6. SUPPORT FROM LOCAL CLINICS AND HOSPITALS

The support groups, Asibemunye and Nawe Sondela, have also received support from the local clinics and hospitals within their respective communities, Adams Mission and Ezimbokodweni, in addition to the support the groups receive from Isibani Hospice. The Charles James Hospital in Ezimbokodweni provides Nawe Sondela with support including providing a venue for the children's Christmas party, as well as running a long-term gardening project with the support group and Isibani. Nawe Sondela also

participated in a march for awareness of HIV/AIDS and gender/domestic violence organized by Charles James Hospital (discussed in detail in Chapter Four). Charles James Hospital, established in 1966, began as an institution for tuberculosis patients. In addition, the hospital also provides services for HIV/AIDS and sexually transmitted infections (STIs), The Siyalulama clinic, which opened in the beginning of 2008, provide voluntary counseling and testing, and ARV treatment to the surrounding communities.

Nawe Sondela also receives support from the Ezimbokodweni Clinic. The clinic provides the support group with a meeting venue (refer to Chapter Four). Ezimbokodweni Clinic operates from Wednesday to Friday.

Asibemunye receives community support from the Adams Mission Clinic. This clinic was developed in conjunction with Zoë Life, a non-profit organization, and McCord Hospital in Durban. The clinic provides access to healthcare for the nearby community members, who previously had to travel to clinics in other communities. Adams Mission Clinic provides basic healthcare and is in the process of also having a dentist on the premises. Additionally, the clinic provides voluntary counseling and testing and ARV treatment. The patients at Adams Mission clinic pay a minimal fee in order to receive a consultation and medicine. Adams Mission Clinic has agreed to the erection of a vegetable tunnel on their land for use by Asibemunye support group. The clinic is also considering the idea of allowing the support group to meet within their premises.

Thus, it is clear that the support groups, Asibemunye and Nawe Sondela, receive support and a wide range of services from organizations and community facilities, in addition to the services provided by Isibani.

The background provided within this chapter allows for a greater understanding of the sponsoring organization, Isibani Hospice, in relation to the functioning of the support group. This chapter proves useful to understanding the relationships and interactions between the support group members and members of the Isibani Team described in the remaining chapters of this thesis. Now, descriptions of the support group members and specifics pertaining to the Nawe Sondela support group will be elaborated upon in Chapter Four.

CHAPTER FOUR-NAWE SONDELA SUPPORT GROUP

The aim of this chapter is to provide a description of the Nawe Sondela support group and information on the members of the group. Additionally, the structures of this support group are elaborated upon including the meeting venue, days and times, group projects/events, and an account of a typical Nawe Sondela support group meeting.

1. INTRODUCTION TO NAWE SONDELA

The name of the support group, Nawe Sondela, is a Zulu phrase that translates into "You Can Come Close". Both Isibani and the members define the Nawe Sondela support group, as a group specifically for people living with HIV and/or AIDS. This is known as a "closed group" (refer to Coleman & Harris, 1989; Uys & Cameron, 2003; Visser & Mundell, 2008). According to questionnaires administered by the YAA, members of the group prefer to be a "closed" group due to *"negative experiences that we [the support group members] have encountered [referring to mixing group with HIV positive and HIV negative members]"*. The decision to be a "closed" group is linked to issues of confidentiality within the group, and the possibility of stigma and discrimination against the members (see Schopler & Galinsky, 1993; Uys & Cameron, 2003). Because concerns about stigma are important to many of the support group members, the Isibani team regularly reminds the group about the need to keep group matters confidential, and to respect one another. Moreover, the Isibani team tells the group, and at times reprimands

individuals in the group for "being talkative", i.e. gossiping about group members (refer to Chapter Six for a discussion on gossip within each support group).

The Nawe Sondela support group operates within the boundaries of Ezimbokodweni (See Section 1.1 in Chapter One for statistical data), and the majority of support group members are residents of Ezimbokodweni, although members also live in KwaMakhutha and Eplagweni. The members living in Ezimbokodweni walk to the support group venues, which have taken place in several locations throughout Ezimbokodweni. The members living outside of Ezimbokodweni take kombis (taxi vans) or walk.

An introduction to the Nawe Sondela members and discussion on the roles of members, and reasons for joining the support group provide a sense of understanding of the group composition and a background to the relationships and organizational culture, which has formed within the support group since its inception. The norms and culture of a group are often influenced by the group membership and sponsoring organization, and moreover, all of these factors relate to the way in which the group is structured and functions (refer to Schopler & Galinksy, 1993). Additionally, a description of the members allows for a clearer understanding of conflict amongst members elaborated upon in Chapter Six and Chapter Seven.

2. NAWE SONDELA MEMBERSHIP

Nawe Sondela members are a diverse group of people varying in terms of age, gender, interests, goals, and group involvement. This variation tends to be typical of support groups and is evident in many support group studies (see for e.g. Bell et al., 2007; Hedge & Glover, 1990; Lyttleton, 2004; Visser & Mundell, 2008). Despite the numerous differences that exist between the group members, overall, members face similar circumstances, in terms of his/her health, HIV status, economic position, living situation, and employment status. Every member of the support group is living with HIV and/or AIDS, although the specifics of an individual's stage of their disease, i.e. how long the individual has been HIV positive, an individual's CD4 count, the treatment (ARVs) an individual is receiving are rarely discussed in detail during the meetings. This is synonymous with discussions found within support group studies by Hedge & Glover (1990) and Martin et al. (2001).

The majority of members within Nawe Sondela are women, which is frequently the case in support groups (see for e.g. Bell et al., 2007; Lyttleton, 2004; Manchester, 2004). Throughout the course of the year, 92.8 percent of the members attending Nawe Sondela meetings (45 meetings) were women, and 7.2 percent of the attendees were men. Additionally, the average age of the group for both men and women is 33.9 years, but members range in age between 20 and 50 years old.

Towards the end of the field research (in the 10th month), a questionnaire was administered to fifteen members of the support group.. Although not indicative of every support group member's circumstances, the following figure, Figure 4 (overleaf), presents several results of the questionnaire, specifically on education, family, employment, and social grants. Additional results from questionnaires will be discussed in Section 4.

2.1 <u>MEMBERSHIP ROLES</u>

Before describing several of the support group members in detail, I will briefly explain the various roles a member can have within the support group. The roles of members are defined through a support group constitution created by the YAA. Thus, these defined roles were standardized only when the YAA became involved in 2007. At times, the members adhere to the YAA recommended structure, and the Isibani team tends to follow suit by referring to the various positions of group members. The Nawe Sondela constitution, written in English and Zulu, in addition to stating the various roles of support group members such as governance, also discusses the group's mission, objectives, meeting structure, elections, decision-making, rules, and finances. The management committee is to be elected by the group (according to quorum 50% +1) at the annual general meeting, elections are a common practice of support groups (refer to Oosterhoff et al., 2008). The management committee consists of five office bearers and one additional member, all of whom (in theory) should meet once a month to review the

Figure 4- Information on Nawe Sondela Members

Education: Grade Completed	Number of Members
Grade 1-Grade 5	1
Grade 6-Grade 8	8
Grade 9-Grade 12	6

Employment	Number of Members
Yes	2 *
No	13

* Temporary Jobs*

Member survive via*	Number of Members
Child Grant	8
Disability Grant	2
Pensioner Grant	2
Family and Friends	2
Isibani Hospice	2
Piece Jobs	3

*Some members responded with multiple answers,
Ex: receiving both disability and child support grant*

Number of Children	Members Have
None	1
One	4
Two	5
Three	3
More than Three	2

For those children attending school, they pay via:	
Child Grant	12
Help from Family	1
Pensioner Grant	1
Piece Jobs	1

progress of the group and share various group reports. An important consideration concerning the constitution is that very few of the structures described were ever implemented into the daily functioning and structure of the group. Thus, the constitution symbolizes the hopes of a supporting organization, the YAA, for the support group to have a particular structure. Yet, the support group members, although attempting at times, for the most part, choose not to adhere to the suggested structure, and, as result, the reality of the group differs greatly from the constitution. Although Nawe Sondela members do not adhere exactly to the YAA's proposed structures, the group has adapted the management committee in order to fit their needs and ideas of how the support group should operate.

The office bearers and their specific duties as per the constitution are outlined in Figure 5 (overleaf). This figure shows the members responsible for the positions up to October 2008. Due to conflict within the group, the position of deputy chairperson, secretary, and deputy secretary changed before the end of 2008. Subsequently, the management committee changed three times from January 2009 to August 2009, largely as a result from conflict and resignations of members.

2.2 DISCUSSION OF MEMBERS

Every member of Nawe Sondela has a unique personality and history, and reason for being a member of Nawe Sondela. This section includes descriptions of seven members who were at some point involved (or continue to be involved) with the support

Figure 5 – Nawe Sondela Management Committee

Position	Duties	Member (as of October 2008)
Chairperson	• Presides over meetings • Represents group at other functions/meetings • Authorized signatories of group bank account	Mfundo
Deputy Chairperson	• Presides over meetings (when Chairperson unavailable) • "second in command"	Phangela
Secretary	• Write and circulate minutes of meetings • Keep all records of group • Also representative of group	Mandla
Deputy of Secretary	• Fulfills duties of secretary (if unavailable)	Patience
Treasurer	• Keeps groups financial records • One of authorized signatories for bank account • Prepares financial reports for AGM • Head of Fundraising sub-committee • Member of Financial sub-committee	Buhle
Additional Member	• Roles not specified in constitution	Goodness

group. There are many more members in the support group, thus many more descriptions of each individual's personality and stories are possible, but this section aims to provide a glimpse into the membership composition of Nawe Sondela. Additional members of the support group will feature throughout this ethnographic study.

The support group members function as one identity, the Nawe Sondela support group, but according to Slindile, there are many groups within the support group. Slindile, said,

"It's not just one group". Moreover, certain people tend to talk and associate with specific individuals before, during, and after the meetings. Some members are friends outside of the support group setting, and there are family members within the group. During conflict, certain members tend to take sides with their "groups", but this element of group dynamics will be mentioned in Chapter Six.

2.2.1 MANDLA

Mandla, a man in his early thirties, has a vibrant personality and a huge smile. Mandla was the "unsaid" leader for the singing group within Nawe Sondela. Mandla has a clear and robust voice and enjoys poetry. In addition to singing, Mandla has an interest in photography and filming. He attended several functions held by the YAA, including an entrepreneurial class, and expressed he would like to open a photography business one day. Mandla was the secretary of the group at the time I began fieldwork. He stopped attending meetings in October 2008. Mandla told the group he had found a job.

2.2.2 SLINDILE

Slindile, a 36-year-old woman, has a very small body frame, and is very thin. She has been a member of the group since 2007. She has four sisters, Mbali, Londeka, Noluthando, and Phumie, who are members of the group. (Several times within this study, they are referred to as the "Hlengwa" sisters). Slindile and her family live in Ezimbokodweni, but she also has family in Port Shepstone. Slindile has a grade seven

education, is unemployed, but receives a disability grant. She has one child, a son in his late teens; his education is paid for with a child support grant. Although soft-spoken and often quiet during the meetings, Slindile is one of the most active members in the group's gardening project; she also became the treasurer of the group in November 2008. When it comes to getting information concerning the group or what is going on with the group, Noxolo and I tend to ask Slindile for the details, and she willingly obliges and explains the stories and/or situations to us. We also phone Slindile when we have questions pertaining to the meeting venue or to explain our absence from the meetings, i.e., Slindile was a key informant.

2.2.3 MFUNDO

Mfundo, a man in his thirties, was chairperson of the support group from the time my research commenced until April 2009. The support group meetings for the majority of the year were held on his property. Mfundo is a trained herbalist and traditional healer and operates a business out of his home. In addition to the traditional healing business, Mfundo offers a transport service for children going to school in nearby areas, and uses his white bakkie (truck) to this end. The other members respect Mfundo, and often members would ask for Mfundo's advice about a particular issue facing the support group. Mfundo was involved with a large conflict in the support group, which will be discussed in Chapter Six.

2.2.4 BUHLE

Buhle, a 26-year-old woman, has three children all of whom attend school. She pays the school fees with a child support grant. Buhle has a grade six education and is unemployed. Her youngest son occasionally comes to the support group meetings with her. Buhle is a large woman and has a loud, booming voice when she speaks. She is outspoken, laughs a lot, and is often making jokes (several have been made at my expense but in good humour) during the meetings. Buhle is also attends gardening sessions, but not as regularly as Slindile. She was treasurer of the group until she resigned at the end of October 2008. Buhle was living in a home with her boyfriend and children up the road from Mfundo’s house. Buhle’s partner became ill in January 2009 and subsequently died six months later. Goodness (another member) stated that Buhle’s partner’s family has been spreading rumours about Buhle, saying she “killed her man”.

2.2.5 LEE

Lee, a woman in her early forties, has an eight-year-old daughter. Lee likes to sew and makes items from beadwork such as necklaces, Zulu skirts, and bracelets. She often wears a T-shirt to the meetings, in which she has used green beads to spell out Nawe Sondela across the front of the shirt. Lee has a shy personality and is often quiet during the meetings. She is active in the gardening sessions. Lee and Noxolo have become firm friends throughout this research process. They often talk after the meetings, and Lee tends to sit next to Noxolo and me at the meetings.

2.2.6 PHIWE

Phiwe, a woman in her mid-twenties, is a member of the support group, but also works with the Treatment Action Campaign. She does not regularly attend meetings. She speaks with a loud and commanding voice, and at times speaks over other members during the meetings. Phiwe helped facilitate a Treatment Action Campaign session on HIV/AIDS, health, and the mind for the support group members.

2.2.7 ANDISWA

Andiswa is a woman in her mid-forties and is the aunt of the Hlengwa sisters. She attended the meetings from April to June 2009. During this time, she was active in the gardening sessions. She is an outspoken woman, who reprimanded members on several occasions for not attending gardening sessions. At one point, she was named chairperson of the group following a conflict, which is described in Chapter Six. Andiswa no longer attends the meetings because she lives in Pietermaritzburg.

2.3 MEMBER'S REASONS FOR JOINING NAWE SONDELA

Every member of Nawe Sondela has their own reasons for joining the support group. As stated in Chapter Two, individuals often experience a mixture of emotions and reactions upon the discovery of being HIV positive (Coleman & Harris, 1989; Manchester, 2004; Visser & Mundell; 2008). One member, Noluthando, explains that when she discovered

she was HIV positive, *"I wanted to kill myself"*. Another member, Phangela, wrote a letter to her family stating, *"I am going to die soon"*. This "emotional rollercoaster" (Coleman & Harris, 1989; Manchester, 2004; Visser & Mundell; 2008) and uncertainty about being HIV positive led many of the individuals to join Nawe Sondela.

Individuals found out about Nawe Sondela directly from Isibani caregivers working in the communities, from local clinics, their friends, and neighbors. Individuals also joined Nawe Sondela because they knew an already existing member of the group.

Nawe Sondela members stated they joined the group for a variety of reasons, and the reasons cited tend to closely mirror reasons discovered in similar studies on HIV/AIDS support groups. Reasons cited include—

1) To have hope for their lives (refer to Visser & Mundell, 2008),
2) To be together with other people & talk with others (refer to Oosterhoff et al., 2008; Schopler & Galinsky, 1993; Visser & Mundell, 2008),
3) To get help with their lives, i.e. through support (refer to Green, 1993; Visser & Mundell, 2008),
4) To receive and share information, including discussions on their HIV status and disclosure (refer to Bell et al., 2007; Coleman & Harris, 1989; Manchester, 2004; Oosterhoff et al., 2008),
5) To solve problems in their lives (refer to Coleman & Harris, 1989; Uys & Cameron, 2003),

6) To relieve stress (refer to Green, 1993; Freidland et al., 1996; Jacobson, 1987; Kalichman & Sikkema, 1996; Lesserman et al., 1999; McDowell & Serovich, 2007; Serovich et al., 2001; Spirig, 1998; Visser & Mundell, 2008), and
7) To be happy.

Thus, the members of Nawe Sondela have a variety of reasons for becoming a member of the support group. The majority of members had told their family (14 people out of 15) and friends (11 people out of 15) about their involvement with the support group (also referred to as disclosure[12]). Reasons for not telling their friends (3 responses) included a lack of friends, not wanting to share every detail about the group, and not wanting to discuss the issues with friends who had never been for an HIV/AIDS test. One individual did not discuss Nawe Sondela due to a bad relationship with her family. Although the majority of members discussed their membership in Nawe Sondela with family and friends, stigma[13] exists throughout Ezimbokodweni and was mentioned by members during meetings and discussions. For example, Lee told a story to the group about stigma in her family and community, *"I was cooking and cut my finger with a knife, and my daughter said, 'Mom, don't give me HIV'. My daughter did not eat any food I made that day, and she told my neighbors that I am HIV positive".* Thus, the support group members must negotiate their desire to be a part of Nawe Sondela with the possibility of

[12] Disclosure refers to "the revelation of information that was previously kept secret" (Encarta, 2009). People living with HIV/AIDS may face discrimination and/or stigma if the individuals HIV status become public knowledge, thus disclosure is a common topic discussed with regards to HIV/AIDS (UNAIDS, 2009).

[13] People living with HIV/AIDS often face stigma and discrimination due to the behaviours associated with the disease, thus many people view those with HIV as "socially unacceptable" (UNAIDS, 2009).

facing discrimination and stigma from their families, friends, and the wider community of Ezimbokodweni. Hence, a need for confidentiality within the group remains paramount for the members and Isibani and corresponds to the groups' desire to cater only to people living with HIV/AIDS.

2.4 MEMBERSHIP ATTENDANCE

Over the course of the year, membership attendance at meetings varied, including several resignations from the group and new members joining. Of the 45 meetings I attended, the average membership attendance at a meeting was 11.7 (a mixture of both men and women). Despite the average of 11.7, attendance ranged from 2-24 members. In addition, the women group members often brought their young children with them to the meetings. The children would either sit with their parents and/or relatives during the meetings or play outside (depending on the venue) with each other.

I observed different "types" of members at Nawe Sondela. The "core members" attend the majority of the meetings and gardening sessions. The core members range from 7 to 9 individuals (several described in Section 2.2). Some members came to meetings once per month, and some individuals only attend meetings every other month. Members are absent from meetings for a variety of reasons, including personal illness, illness in family, traveling, caring for children, and receiving temporary jobs, similar reasons for absences were given in a study by Schopler & Galinsky (1993). Meetings, at times, are sparsely attended because the members are involved with other organizations and/or workshops.

For example, Nawe Sondela members attended a YAA youth committee meeting and a home-based care meeting, both of which took place during the regular Tuesday meeting time.

Although new members joined the group throughout the year, in particular two men and two women joined in May and June 2009, two members resigned from the group, and one member left the group because she moved to another area.

Now that a description of Nawe Sondela, in the context of membership, roles, reasons for joining and attendance have been given, I will briefly outline details concerning the meeting venues, meeting days and times, group projects and events, followed by a depiction of a typical Nawe Sondela support group meeting.

3. MEETING VENUES

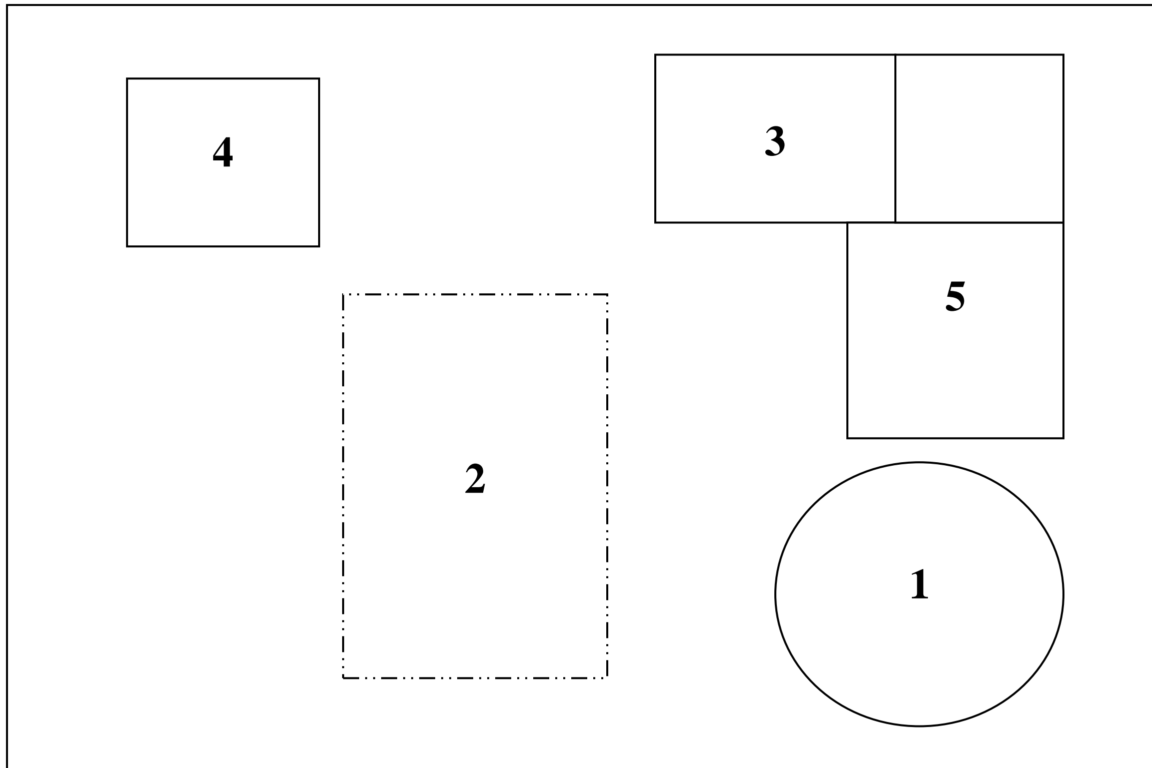
Nawe Sondela, in the past year, met in seven different venues, and throughout the year, meeting venues became a constant topic of conversation amongst the support group members often with conflicting views amongst the members and Isibani team. The group changed venues for several reasons due to weather, conflict within the group, and funding. As described in Chapter Three, Isibani, the sponsoring organization, often made the decisions concerning where the support group held their meetings, as is typical within support groups (see for e.g. Uys & Cameron, 2003).

A brief description of the support group meeting venues allows for a greater understanding of ethnographic examples discussed in Chapter Six, thus Figure 6 provides an overview of the meeting venues, all of which are in Ezimbokodweni. Additionally, Figure 7 (overleaf) provides a layout of the meeting venues on Mfundo's land.

Figure 6- Nawe Sondela Meeting Venues

Description	Owner	Reason for Change	Time Span
Rondavel mud building; also used for church services	Mfundo	Large storm damaged building, which began to collapse	Approx. 2 years
Outside in open area, no cover, on same property	Mfundo	No place to meet due to previous building collapsing	2 months
Sitting room in Mfundo's house, on same property	Mfundo	Hot summer months, difficult for members to stay outside in sun	1 month
Makeshift building (metal & tin), on same property	Mfundo	Construction, Mfundo redoing home, adding more rooms	1 month
Sitting room in Hlengwa sister's home, up the road from previous venue	Hlengwa sister's mother	Conflict amongst group, in particularly with Mfundo	1 meeting
Mfundo's sitting room in newly built concrete brick home	Mfundo	Conflict resolved, Isibani told group to meet at Mfundo's	2 months
Entrance room/area in Ezimbokodweni Clinic	KwaZulu-Natal Dept. of Health	Members wanted to leave Mfundo's place	Current (as of June 2009)

Figure 7- Layout of Meeting Venues on Mfundo's Land



Key:

1- Rondavel Mud building
2- Outside, open area, no building
3- Sitting room in Mfundo's home
4- Makeshift building (metal & tin)
5- Sitting room in renovated home

4. MEETING DAYS AND TIMES

Nawe Sondela meets on Tuesdays at 12 o'clock p.m. The meetings usually last between one and two hours, a common time period for support groups (refer to Uys & Cameron, 2003). The group does not hold meetings for two weeks out of the year, which are the last week of December and the first week of January, because Isibani staff is on leave.

The group, in the first two months of my fieldwork, also held meetings on Thursdays. The purpose for the Thursday meeting at 12 o'clock p.m. was for the group to practice singing and drama. The duration of these singing sessions was between thirty minutes to one hour. By the end of 2009, the group no longer met on Thursdays because the group member, Mandla, who was most active in singing and drama, no longer attended meetings.

Additionally, the group meeting days also include working at the vegetable garden on a plot of land in Charles James Hospital. In theory, and according to the members and Isibani, the group should meet at the gardens everyday to water and be at the gardens at 8 a.m. on Monday, Wednesday, and Friday, in order to work in the garden. The gardening days were considered part of the weekly group activities, and at times, Isibani would combine a garden session and meeting on a Tuesday. The reality, though, is that members do not meet on the specified days to work in the garden, and, as result, vegetables have been planted at two different times throughout the year and have subsequently died. The group also has plowed the entire plot of land three times, due to an overgrowth of weeds (group gardening elaborated in Section 5, and also Chapter Seven).

5. GROUP PROJECTS AND EVENTS

The Nawe Sondela members participated in several group projects and events within the community of Ezimbokodweni throughout the year. Group projects included singing and

gardening. In terms of events, the group participated in a march and ARV launch hosted by Charles James Hospital.

5.1 PROJECTS

For two months, group members participated in singing sessions held on Thursdays. The Thursday meetings consisted of a recap of the discussions from the Tuesday meeting, and then the group would sing between three to five songs. In addition to the singing, several songs were accompanied by dancing and clapping. The songs were about the members' involvement with the support group, the fight against HIV/AIDS within the community, and spreading awareness about HIV/AIDS. Mandla exclaimed that, *"They [the members] express themselves. They want other people to know that HIV positive people can do something with their lives".* As mentioned previously, the group no longer sings.

In addition to singing, Nawe Sondela members participate in a gardening project. Charles James Hospital allows the group to use a large plot of land (approximately 100 square meters). There is also a garden plot (approximately 150 square meters) to the right of Nawe Sondela's plot, which is used by another group from the community. Thembiso, a staff member at Charles James Hospital, is in charge of liaising with members of Nawe Sondela, concerning the gardening. Additionally, the hospital has agreed to buy any vegetables grown by Nawe Sondela. The support group earned R 41.00 from the sale of vegetables to the hospital; the vegetables were grown over a period of three months. Jayshree, who accompanies Isibani to Nawe Sondela meetings

once a month, donated the seedlings. Jayshree, a volunteer and nursing sister (not employed by Isibani), also brings sweets and chips for the children of support group members, and donates bread and food parcels once a month to the group. As stated earlier on, the members have faced constant challenges in making the vegetable garden successful.

5.2 EVENTS

In addition to projects, Nawe Sondela members were involved in the launch of Siyalulama clinic at Charles James Hospital and a community march, which focused on encouraging men's involvement with HIV/AIDS. Numerous organizations participated in both the launch of Siyalulama Clinic and the march, including the KwaZulu-Natal Department of Health, NAPWA, the Mandela Foundation, YAA, Ethekwini Municipality, local indunas (chiefs), counselors, and many local organizations. The march began at the community sports grounds in KwaMakhutha, with participants walking through Ezimbokodweni and ending up at the entrance of Charles James Hospital. Following the march, the hospital celebrated the launch of the Siyalulama Clinic with singing, dancing, speeches, and food/drinks for the community members. Nawe Sondela members were disappointed because the group was supposed to sing at the ceremony, but due to time constraints and miscommunication between the group and coordinators, they did not sing at the event.

Charles James Hospital also assisted Isibani through hosting a children's Christmas party. Children of Nawe Sondela members, as well as children from nearby communities attended the function, which entailed music, clowns, balloons, face painting, and Christmas presents. Additionally, the hospital also provided a venue for the annual Nawe Sondela Christmas party that was held one week before Christmas and attended by 24 members (including past members). Jayshree provided the group with food, drinks, sweets, and toys for the support group members' children. The Isibani nursing sisters, nursing manager, caregivers, and social worker attended the party as well.

The Isibani team suggested that the support group members participate in a World AIDS Day event (2008), and although the group members discussed the possibility of doing something, nothing materialized.

6. TYPICAL SUPPORT GROUP MEETING

Sitting amongst the members of Nawe Sondela on a Tuesday afternoon, one will hear laughter, women and some men chatting and relaxing together, children playing and laughing, and at times, one will hear voices rising in anger and volume in attempts to get a point across during an argument or fight. The meeting informally begins once the members start arriving at the meeting venue, and members are often seen talking with each other about things going on in their lives. Before and during the meetings, some members such as Goodness and Nomula are seen sewing and/or knitting hats for personal use or to sell, and Lee does beading. Although the meeting officially starts as 12 p.m.,

the actual start time depends on when most of the members and Isibani arrives. The group sometimes begins before Isibani arrives, although with the current meeting venue at Ezimbokodweni Clinic, the Isibani staff have the keys to the clinic, thus the meetings commence when Isibani arrives.

The seating arrangement within the group varied throughout the year depending on the meeting venue, but usually certain people sits next to each other each week. For instance, Lendi and Buhle usually sit next to each other, and Buhle regularly took care of Lendi's baby during the meetings. Buhle and Lendi live in the same house up the road from Mfundo's home. Additionally, the five Hlengwa sisters often sit in close proximity to one another. Isibani support group coordinator, caregivers, and nursing sisters usually sit wherever there is an available space, and often one or two caregivers are seen standing to the side of the room (depending on venue) or towards the periphery of the group.

Once the group members take their seats, a member sometimes initiates a prayer; often Noluthando volunteers to say the prayer. The prayer often brings a halt to any lingering conversations occurring between the members. The group does not always pray before meetings and not everyone participates in the prayer. The prayer is usually said very softly, almost to the point that it is inaudible, and at a fast pace. The meeting may have already started and the group will stop their discussion to pray. A member of the group may also say a prayer at the close of the meeting. On some occasions, Bongiwe or one of the caregivers from Isibani will initiate the prayer or suggest that someone in the group says a prayer. A song sometimes accompanies the prayer, and one or two members

(usually Buhle or Goodness) will begin singing and most of the group subsequently joins. The group, though, does not sing at every meeting.

Typically, during a meeting, members talk and whisper to each other at the same time as other members of the group are talking; the side conversations may be private discussions, but also tend to be a diversion from the topic at hand. Moreover, both support group members and the Isibani team tend to change the direction of conversation without warning, sometimes leaving the previous discussion to be taken up at a later point in time. The atmosphere within the group during discussions is often lively, with members talking loudly. Although, when a member of the Isibani team begins a conversation, members tend to lower their volume.

In the first few months of fieldwork, once the prayer and song were completed, Phangela (who was Deputy Chairperson at that time) read the minutes from the previous week to the group, recapping discussions and upcoming plans and/or events. According to the group, the secretary should be in charge of writing the minutes; Mandla was the official secretary at the time. In 2009, Goodness became secretary of the group, but did not take minutes of the meeting because she said, *"I don't know how to write"*.

In a similar light, keeping track of attendance does not occur regularly at the meetings. Phangela and/or Mandla (in 2008) kept track of attendance at the meetings in a group notebook. Isibani caregivers and/or the support group coordinator also keep track of attendance in a diary. Bongiwe stresses to the group that taking minutes, and attendance

is important to the functioning of the support group, and members should take the task seriously.

The next stage of the meeting depends on what Isibani, or more specifically Bongiwe (the support group coordinator), has planned for that day, as occurs frequently in support groups (refer to Uys & Cameron, 2003). Bongiwe or a caregiver (in the absence of Bongiwe) often begins the discussion by asking members how they are feeling and if the members have any problems they would like to discuss. Responses from members range from issues of health and illness, sexual matters, relationships, to problems with money and food. Not every member participates in the discussions or responds to Isibani's enquires. However, Nombali, an Isibani caregiver, explains to the group that every member should tell Isibani about any problems or illnesses they are experiencing, so that if needed Isibani can give recommendations or advise the member. In response, one member, Nomula, stated she is *"tired of complaining about my problems because I have many. He's [her partner] the one who gave me AIDS. And he still goes with young girls around where I am staying".* Likewise, Noluthando also explained, *"I got stress myself. My boyfriend is in prison. He was drinking and driving and was without a license. That is stressing me so much".*

In addition to discussions about the members' wellbeing, Bongiwe asks the support group members if there are any particular issues or topics they would like to discuss. Bongiwe and Sister Ngcobo also initiate discussions on a variety of topics that have been planned in advance; this is a common practice of sponsoring organizations (see for e.g. Coleman

& Harris, 1993; Hedge & Glover, 1990; Lyttleton, 2004; Oosterhoff et al., 2008; Schopler & Galinsky, 1993; Visser & Mundell, 2008). Sister Ngcobo on numerous occasions has stressed to the members that positive living, good hygiene, and using condoms are important to the member's wellbeing. Additionally, Sister Ngcobo emphasizes that members should test for tuberculosis every six months, should take ARVs correctly, and check their CD4 count regularly. Moreover, Sister Ngcobo warns the members that if an individual is taking ARVs and his/her CD4 count is high, the individual can never stop taking the medication. She also states that members should seek support because *"When a person's CD4 count drops, people worry, and they should find someone to talk to. If you accept it, you can live".*

Bongiwe facilitated a discussion on gender abuse and violence. Group members began to engage in a conversation on different types of abuse the members may have experienced, as well as issues of violence. The members made statements about the topic, such as Phumie, who exclaimed, *"Men always say we abuse them, but they are the most abusive people in the world".* The only male member in attendance that day, Andile, maintains that men *"also do get abuse from women".* Andiswa stated that, *"I don't have a problem with my man, but I don't like to have sex. I don't feel like it anymore. That is the only fight I have with my man. And now I decided to stay as I am because doing what you don't like is also abuse".*

The group does not have many guest speakers at their meetings, which tends to be a feature of support groups in the global arena (refer to Coleman & Harris, 1989).

Although Mandla with approval from the group, invited the Treatment Action Campaign to share information on HIV/AIDS, health and the mind. Two members from the TAC, Sbonelo, and Phiwe, who is also a member of Nawe Sondela, facilitated discussions over the course of three weeks.

In addition to the various discussions at the support group meetings, once a month, a caregiver brings a scale to the meeting, and each member takes turns to be weighed. The caregiver begins weighing members at any time during the meeting, as there is not a set time/place during the meeting for the weighing to take place. The caregiver writes the weight for each member in a diary. Additionally, once a month the members receive vitamins from Isibani (as discussed in Chapter Three).

At varying stages of the meeting, the caregivers, sister, and members of the group bring donations from the Isibani truck into the meeting venue. The donations (mentioned in Chapter Three) consist of food items, clothing, and occasionally, condoms, and toilet paper. Nawe Sondela receives some type of donation (usually food items) every week. Isibani tends to bring a large amount of food parcels and bread to the group.

Towards the end of the meeting, Bongiwe, caregivers, and the members help pass around sandwiches and juice (described in Chapter Three) to the group members. Some members and their children eat the sandwiches before they leave, and other members wrap the lunch in plastic bags, pieces of newspaper ,and/or paper to take home. The

group may or may not continue with a discussion once lunch is served. The tendency appears to be that serving lunch signifies an informal closing of the meeting.

The formal closing of the meeting occurs either when a support group member initiates a closing prayer and or song, or when Isibani prepares to leave the room. The members of the group for the most part, do not rush out of the meeting, but usually talk and socialize as they prepare to leave the support groups, sometimes sorting through the donated clothes, or trading food items with another. Then, the members begin their journey's home, often by foot and a few by taxis, to carry on with their lives outside of the support group meetings.

This chapter provided descriptions of the members and the structural components of how the support group operates. Moreover, several of the topics discussed within this chapter will be explored in the ethnographic chapters of this study, Chapter Six and Chapter Seven. The following Chapter, Chapter Five, has a similar layout to Chapter Four because both groups have the same sponsoring organization, thus the operation and structures are alike in both groups.

CHAPTER FIVE- ASIBEMUNYE SUPPORT GROUP

The layout of this chapter, similar to Chapter Four, provides information on membership of the Asibemunye support group including attendance, reasons for joining the group, and roles of the members. Furthermore, the meeting venues, days and times, as well as a typical support group meeting are described.

1. INTRODUCTION TO ASIBEMUNYE

The support group Asibemunye means, "Let us be one", when translated from Zulu to English. Asibemunye, like Nawe Sondela, is a "closed" HIV/AIDS support group. Thus, members of the group must be people living with HIV/AIDS. Asibemunye operates within Adams Mission, Ward 96 (refer to Section 1.2, Chapter One for statistical data). The majority of members live in Adams Mission; several members live within the boundaries of Adams Mission, but far from where the support group meets. These members live in Enkangala, Emsahweni, and Esiqunquma. The majority of the members walk to the support group meeting venue, and occasionally, the Isibani team, working with Asibemunye, transports two of the members living in Emsahweni, due to the long distance. Several members have suggested forming new support groups closer to their homes, though, new support groups in these areas have not been formed. The Isibani team and the support group members fear that stigma within areas of Adams Mission may prevent people from opting to join a HIV/AIDS support group. For instance, one member explained, *"The people I live next to are afraid to join a support group. They*

[the people] are afraid of the community—that they [the community] will see the people are HIV positive". Although members attending Asibemunye meetings face discrimination and stigma from their communities, they attend meetings on a weekly basis. Similarly a study by Lyttleton (2004), suggests that HIV/AIDS support groups and their members challenge the "social discrimination of HIV/AIDS".

This chapter will now delve into a discussion of the membership including member roles, reasons for joining the group, attendance, and an overview of seven members. A snapshot view of the members of Asibemunye provides a backdrop for understanding situations and concepts discussed in the subsequent chapters within this study.

2. <u>ASIBEMUNYE MEMBERSHIP</u>

As stated previously, a large amount of diversity exists amongst members of HIV/AIDS support groups, and this holds true for members of Asibemunye support group. Although, the group is diverse, the nature of a closed support group indicates that every member of Asibemunye is living with HIV and/or AIDS and may be at varying stages of the disease.

The majority of members attending Asibemunye meetings are women, specifically, 72.8% of members attending over the course of the year were women, and 27.3% of those attending were men. The average age for the support group members (including men and women) is 35.9 years, and the members range in age from 18 to 43 years old.

Asibemunye members participated in a questionnaire administered by Noxolo and myself in the seventh month of fieldwork. Specifically, eleven members participated in the questionnaire. The following figure, Figure 8 (overleaf), shows details concerning members' education, employment, family, and social grants.

2.1 MEMBERSHIP ROLES

The membership roles within Asibemunye are identical to the membership roles for the Nawe Sondela support group described in Chapter Four. Both Asibemunye and Nawe Sondela have the same governance structure, i.e. chairperson, deputy chairperson, secretary, deputy secretary, treasurer, and additional member. The reason for this similarity is due to the fact that Sandile from the YAA created the support group constitutions and despite several slight differences in wording between the Asibemunye and Nawe Sondela's constitutions, the descriptions of the governance and management committee are the same. Thus, similar to Nawe Sondela, the YAA had hopes for Asibemunye to utilize the constitution in the structure and operation of the support group. Yet the reality is that Asibemunye rarely consults or follows the guidelines prescribed within the constitution. The group, though, does acknowledge the different membership roles described above, and have utilized aspects of these roles within the support group meetings. Occasionally Isibani also refers to these various roles.

Figure 8: Information on Asibemunye Members

Education: Grade Completed	Number of Members
Grade 1-Grade 5	0
Grade 6-Grade 8	4
Grade 9-Grade 12	6
Schooling beyond Matric	1

Employment	Number of Members
Yes	3 *
No	8

Temporary Jobs at times

Member survive via*	Number of Members
Child Grant	5
Disability Grant	1
Pensioner Grant	0
Family and Friends	2
Isibani Hospice	0
Piece Jobs	2

Some members responded with multiple answers, Ex: receiving both disability and child support grant

Number of Children	Members Have
None	2
One	3
Two	3
Three	0
More than Three	3

For those children attending school, they pay via:	
Child Grant	4
Help from Family	1
Pensioner Grant	0
Piece Jobs	5

The following figure, Figure 9, shows the management committee in terms of the position and member in charge up until August 2008. The management committee changed throughout the year of fieldwork due to members resigning from the group or not attending meetings on a regular basis.

Figure 9: Asibemunye Management Committee

Position	Member (as of August 2008)
Chairperson	Nokuhle
Deputy Chairperson	Nolwazi
Secretary	Phindile
Deputy of Secretary	Fanele
Treasurer	Ayanda
Additional Member	No member listed

2.2 DISCUSSION OF MEMBERS

This section briefly describes several members and former members of Asibemunye. These descriptions provide a snapshot into an understanding of the members' personalities, histories, involvement in the group, and lives outside of the support group. Although not every member of the group is described below, these additional members will be referred to throughout the study. The majority of members listed below would be considered core members, i.e. regularly attending meetings.

2.2.1 NOLU

Nolu, a 41 year old woman, has been a member of Asibemunye since 2005 (more or less since the start of the group). She reached grade eleven in her studies, has no job, but receives a disability grant. Her one daughter currently is attending a university in Durban. Nolu says she is proud of her daughter. Nolu feels, though, that her daughter does not understand the financial limitations of their family. Nolu has a boyfriend who lives in KwaMakhutha, and she often asks me for a lift to KwaMakhutha at the end of the meetings. Nolu has been chairperson of the group since October 2008. She speaks in a quiet tone at the meetings, but often voices her opinion. Nolu has acknowledged she thinks other members "gossip" about her. Noxolo and I would call Nolu for information about special events and for information throughout the research, i.e. Nolu was a key informant.

2.2.2 THOBEKA

Thobeka is a 38-year-old woman and was a member of Asibemunye from 2008 until March 2009. She does not have any children and lives in the same area as Nolu. Thobeka completed some form of tertiary education, but did not explain what type and/or level of tertiary education she received. Thobeka expressed great interest to both the group and me about starting her own business; in particular, she wanted to raise chickens. She commented on several occasions that the group should be more motivated to do things such as the chicken business she suggested. She was outspoken at the meetings, often joking and laughing as well. Thobeka suggested two guest speakers for the year. In mid-

March 2009, Thobeka stopped attending meetings. Although questioned by Isibani and Noxolo, no one seems to know why Thobeka stopped attending. Nolu says that Thobeka stays in her home and does not ask about the support group.

2.2.3 AYANDA

Ayanda is a 41-year-old man, with a very small frame and is exceptionally thin. He reached grade ten in his schooling, and has been attending the meetings since 2006. Ayanda has one daughter, who has completed school. Ayanda worked as a gardener to pay for his daughter's school fees, but at present does not have a permanent job. He has, however, managed to obtain a few temporary jobs in the past couple of years. He states though that, *"I am struggling. I even sleep without food because I am not working".* Sister Joyce Sithole states that Ayanda does not have a lot of food at his home. He received a disability grant in the past, which lasted 6 months. Ayanda is the treasurer for the group, and takes pride in his involvement with the support group. He is quiet during the meetings, often writing in his notebook.

2.2.4 NJABULO

Njabulo, a 35-year-old man, has a similar body frame to Ayanda but is even thinner. He started attending Asibemunye meetings in 2007. He lives close to Ayanda in Emsahweni. Njabulo has one child, who is presently at school. He pays for the school fees through finding temporary "piece jobs", but does not have a permanent job. Njabulo is always

watching members of the group while they talk. He is often smiling, laughing, and discussing with others his passion for drama. He also likes to joke with other members. Njabulo would like to open a support group in the community where he lives.

2.2.5 FANELE

Fanele is a 34-year-old woman with two children. She has attended the support group since 2005. She does not have a job but receives a child support grant, which helps her pay for her one child in school. Fanele likes to sew and make pillow cases. Although quiet throughout most of the meetings, when she speaks it is with a deep and loud voice. Fanele is the secretary of the group, but does not like to take minutes of the meetings. Fanele, who walks to and from the support groups, was horrifically raped one afternoon on her way home from the support group. She told Noxolo and myself, but did not want to discuss it with her husband because he might tell her to stop attending the support group meetings.

2.2.6 FLORA

Flora, a 43-year-old woman, began attending the support group meetings in October 2008 and stopped attending in January 2009. Flora has a standard five level of education. She has 7 children, 6 of whom are in school. She pays the school fees with the child support grants she receives. Flora was an outspoken member while involved with the group. She often voiced her opinion, at times speaking over members who were a part of the

discussion. Nolu named Flora the secretary of the group, despite Flora explaining she had no desire to be secretary. Flora believed that the group should be more active and participate in group projects. Members felt that Flora was talking behind their backs when she decided to leave the group.

2.2.7 SBONISILE

Sbonisile is a 25-year-old woman with two children. She joined the support group in February 2009. Her two children are attending school, which is paid for by a child support grant. Sbonisile has a standard eight education. Since Sbonisile began attending meetings, there is more laughter throughout the meetings than before. Every meeting I attended when Sbonisile was there included at some point during the meeting, Sbonisile giggling or laughing. At times she began to laugh so much, she would fall on the floor with laughter. She enjoys the company of Nomsa and Nolwazi, who also enjoy laughing. Sbonisile likes to sing and participate in drama. She wishes the group would have singing sessions.

2.3 MEMBER'S REASONS FOR JOINING GROUP

Throughout the fieldwork, the members of Asibemunye openly discussed their reasons for joining the support group with the Isibani team and with new members joining the support group.

On several occasions, the existing members of Asibemunye introduced themselves and explained to new members what they felt was the purpose of the support group. The following members expressed to Zanele, a new member, why they were members of Asibemunye. Nolu explained, *"The support group is where we come to share problems that we come across at home and in the community".* Additionally, Ayanda expressed to the new member Zanele, *"We [the support group members] are helping each other in different ways, and as we are here it doesn't mean that we are sick. We are not. It's just that we are HIV positive. We help each other in such a way that we become brothers and sisters. If someone doesn't have money to collect the medications [ARV medicine], we all collect money to give to that person".* Moreover, Fanele explained to Zanele that, *"At home, we find it very hard to talk about our status [HIV/AIDS], but here we [the support group members] are able to tell someone that we got problems. But you have to find someone you trust to talk to".* Njabulo revealed to the group, *"As I am here, I find the peace of mind. It's where I feel happy. And I wish I can stay here for the rest of my life. And I understand that you [Zanele] are still new here, but you will get used to us".* Furthermore, Sbonisile amidst giggles told Zanele, *"I came here when I was very desperate but today I can laugh. I feel at home, free, and I am able to solve my problems".* Nolwazi also stated, *"Here we [the support group members] are stress free, and we give each other hope. We trust each other. And if you always laugh like we [Sbonisile and Nomsa] do, the stress is gone."* The group members also visit each other in their homes outside of the support group meetings. For instance when Flora joined Asibemunye, Thobeka and Nolu invited her to their homes.

In addition to the reasons stated above, according to questionnaires done by both YAA and myself, the members stated they joined the group for a variety of reasons. The explanations are similar to both the reasons given by Nawe Sondela support group members, and those stated in similar studies on HIV/AIDS support groups.

The reasons mentioned include:

1. To learn more about HIV/AIDS and share knowledge with one another (refer to Bell et al., 2007; Coleman & Harris, 1989; Manchester, 2004; Oosterhoff et al., 2008),
2. To live positively (refer to Freidland et al., 1996; Kalichman & Sikkema, 1996),
3. To relieve stress (refer to Green, 1993; Freidland et al., 1996; Jacobson, 1987; Kalichman & Sikkema, 1996; Lesserman et al., 1999; McDowell & Serovich, 2007; Serovich et al., 2001; Spirig, 1998; Visser & Mundell, 2008),
4. To meet with other people facing similar problems as themselves, i.e. HIV/AIDS; to talk with others (refer to Coleman & Harris, 1989; Oosterhoff et al., 2008; Schopler & Galinksy, 1993; Visser & Mundell, 2008; Uys & Cameron, 2003),
5. To receive support, i.e. tablets and food parcels (refer to Green, 1993; Visser & Mundell, 2008),

6. To discuss problems facing their lives and within the community (refer to Coleman & Harris, 1989; Uys & Cameron, 2003),
7. To have hope (refer to Visser & Mundell, 2008),
8. To build a new life (refer to Coleman & Harris, 1989; Uys & Cameron, 2003), and
9. To learn skills such as beading.

The members of Asibemunye found out about the existence of the support group primarily from friends, who were already existing members, and Isibani caregivers. Individuals also learned about Asibemunye from referrals by clinics and family members.

Similarly, to members of Nawe Sondela, the majority of Asibemunye members had discussed the support group with their family and friends. According to the questionnaires, which I conducted, 10 out of the 11 members had told their family members about being members of Asibemunye. The individual who did not tell their family expressed that the time was not right. Additionally, 9 out of 11 members had discussed their involvement in Asibemunye with their friends. The additional two individuals had disclosed their involvement to some of their friends, but not all of their friends, citing that it was difficult to discuss the support group with friends who had little knowledge of HIV/AIDS.

2.4 <u>MEMBERSHIP ATTENDANCE</u>

Asibemunye membership fluctuated throughout the year, including four resignations from the group and 6 new members joining the group (only four of these new members attended regularly). Of the 32 meetings I attended, there was an average of 7.6 members attending the meetings (both men and women). The attendance ranged from 3 to 11 members. Occasionally, children would accompany their mother and/or grandmothers to the meetings.

The "core members" of Asibemunye ranged from 6-8 individuals, correlating to the average attendance at the meetings. On two occasions, the support group was sparsely attended because the YAA invited the Asibemunye members to a "youth committee" meeting. For the most part, members regularly attended the meetings, and absences from meetings were not an issue for the group. A few members, though, had temporary jobs throughout the year including, Ayanda and Nokuhle, which affected attendance.

Before the end of 2008, 3 new members joined the support group simultaneously. Of these three members, 2 attended meetings for a few months and then stopped coming. The third member, Flora (described previously), resigned from the group because, according to Nolu, *"She [Flora] could not see the progress of the group, so saw no use to keep on coming here [to the meetings]".*

An understanding of the Asibemunye membership has been provided, thus now the attention will turn to the operation of the group in terms of meeting venues, meeting day and time, group projects and events, and a typical Asibemunye support group meeting.

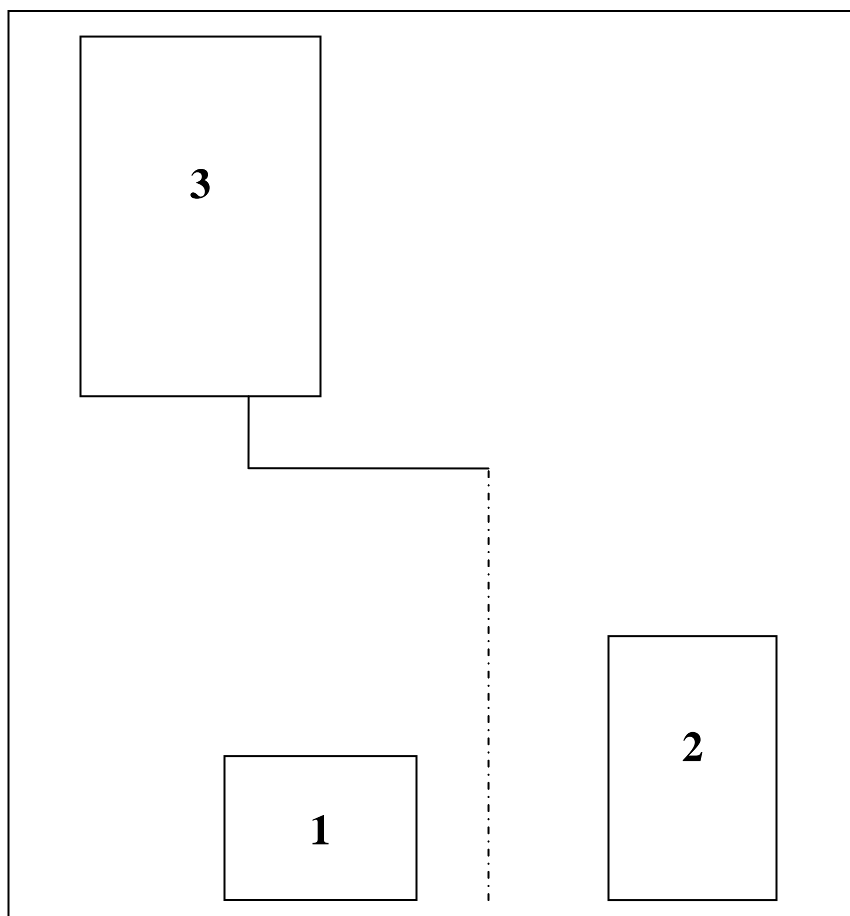
3. MEETING VENUES

Since my fieldwork commenced, Asibemunye met in three different venues throughout the year. The group discussed amongst themselves and with Isibani, the hope to have a venue specifically for use by the support group.

The support group originally met in a room attached to several buildings, which are known as the Madikane Child Support Centre. Then Asibemunye moved across the small dirt road from Madikane Child Support Centre to a small building, which functions as a church for the nearby community. The group met in this venue for the duration of the year, except for one meeting, which took place at a support group member's home. Sister Joyce Sithole requested that the support group meet on a Thursday at Phindile's house. Several of the members live in the same area as Phindile, but other members had to travel far to meet at this venue.

Figure 10 provides a layout of the support group's current meeting venue, Madikane Child Support Centre, and the nearby clinic, Adams Mission Clinic.

Figure 10- Layout of Meeting Venues



KEY:

1- Current Meeting Venue
2- Madikane Child Support Centre
3- Adams Mission Clinic
Dash Line refers to a dirt road
Bold Line refers to a paved road

4. MEETING DAYS AND TIMES

Asibemunye meets on Tuesdays at 11 o'clock a.m. Similar to Nawe Sondela meetings, the meetings tend to last between one to two hours, usually the latter. Isibani did not

attend the support group meetings from the last week of December until the first week of January, the group held their annual Christmas Party on the 23rd of December.

As mentioned in Section 3, Sister Joyce Sithole suggested to the group that they meet on a different day due to a conflict in the Asibemunye support group meeting time for the Isibani team. The Isibani team attending to Asibemunye support group attends a support group at KwaMakhutha Clinic on Tuesday as well. The group agreed to change their meetings to 11 a.m. on Thursday. Additionally, Sister Joyce Sithole told the group, *"We have nice things to give you [the group] on Thursday and no one to give them to".* The group met on Thursday at Phindile's house (discussed previously), but the distance was too far to travel for some of the members. Thus, Sister Joyce Sithole asked the groups' opinion about the new arrangements, and the group decided to return to the previous venue, day, and time.

5. GROUP PROJECTS AND EVENVTS

Asibemunye support group worked on group projects and participated in several events throughout the year. The projects include an on-going sewing project, drama and singing, and beading. The group participated in an event to bring awareness to the nearby community on World AIDS Day, a group Christmas party, and participation in an event celebrating Hospice Month. The Isibani team organized all events, and members of Asibemunye gave input and made decisions regarding all three events.

5.1 PROJECTS

The core members of the support group have mentioned on many occasions the fact that, although the members expressed interest in projects, the members do not follow through on their intentions. Additionally, the Isibani team has commented on a lack of commitment from the group with regards to group projects. This topic will be elaborated upon in Chapter Seven.

Although the group projects falter at times, approximately four of the members participate in individual income-generating projects outside of the support group meetings (but with aide from Isibani). Isibani, as mentioned previously, provides the group on a weekly basis with clothes and material. In addition to the material, Isibani was given four sewing machines, which in turn, Isibani gave to Asibemunye. Fanele makes standard and continental pillowcases with one of the four sewing machines given to the support group by Isibani. Fanele sells the standard pillowcase for R 20.00 and the continental pillowcase for R 30.00. She uses material that Isibani gives the group to make the pillowcases, but explains she does not have the filling for many of the pillowcases she makes. Several members of the group feel that Fanele should put the money for pillowcase sales into a group bank account, but Fanele keeps the profits of the pillowcases. In addition to Fanele, Ayanda used one of the sewing machines to make bags, which hold pegs for washing. He sells these bags for R20.00 and keeps the profits from his sales. Not all of the members have an interest in sewing, and some members complain they do not know how to operate a sewing machine. Conflict exists amongst

the group members because not every one has access to the machines. Additionally, a member broke one of the machines, and to this day it has not been fixed. The Isibani team did not provide training for the sewing machine, although several members know how to use the sewing machines. Flora also offered to teach sewing at her home to other members of the group.

In addition to sewing, several members expressed interest in beading. Members on several occasion stated they would like to start a beading project. In May 2009, I provided the group with the materials needed to start a beading project and taught the members how to bead simple earrings and bracelets. Only one member of the group, after the initial day of learning how to bead, kept interest in the project and created several different pieces including necklaces, earrings, bracelets, and rings. As of November 2009, Njabulo has not sold any of the jewelry, stating, *"I need more string to make things before I can sell the jewelry".*

Besides the sewing and beading, the group began practicing songs and participated in dramas. Originally, the singing and drama began when the Isibani team requested the group perform at the Hospice Month celebration. In addition to the encouragement of the Isibani team to sing and practice drams, two members, Njabulo and Sbonisile, on numerous occasions have encouraged the group to sing and perform. The group performed one "play" created by Njabulo at a meeting. Additionally, the group held several singing sessions two months prior to the Hospice month, although the group no longer sings on a regular basis. Sbonisile and Fanele led the group in song. The song

described people being scared of AIDS and not wanting to fight the disease, but tells the people, they must stop the spread of the disease. *"We don't need AIDS anymore."* One songs states, *"We come from Asibemunye and we brought condoms. AIDS will see where we stand because we have condoms"*.

At one point during 2007, the group with the help of YAA secured a plot of land in close proximity to the current meeting venue. According to Nolu, the group worked on the land to create a garden, but members stopped going to the garden and another group took over their plot of land. Despite this occurrence, the group was keen to participate in a vegetable tunnel project sponsored by a Rotary Club in Durban. As of November 2009, preparations are being made to erect a vegetable tunnel on land belonging to Adams Mission Clinic.

5.2 EVENTS

The group, with the assistance of the Isibani team, planned an event to bring awareness of HIV/AIDS to the community on World AIDS Day. The group had the event on December 2, 2008. The Isibani team brought several boxes of Choice condoms and brochures about HIV/AIDS. Sister Joyce Sithole and the caregivers set up a table with brochures, Soul City magazines, and a candle with the universal red symbol for HIV/AIDS on the candle. Every member was wearing black pants/skirts, and a white shirt, with a HIV/AIDS ribbon pinned to the shirts. The group members, Isibani team, Noxolo, and I handed out condoms and brochures to cars and pedestrians passing along

the street outside the meeting venue. One pedestrian walking along the sidewalks explained that he could not take any of the condoms with him because *"when I get home my wife will ask 'Where are these from? What are these for...?' "*

That same month, on December 23rd, the group held their annual Christmas party. Group members began planning for the party in early November. The party took place at the meeting venue and the group had a braai (barbeque). The group used money saved from the YAA (refer to Chapter Three). Isibani also helped the support group fund the party.

In April 2009, the group began singing in preparation for the celebration of Hospice Week, from the 3rd- 9th of May. The purpose of Hospice Week is to promote and discuss hospice and palliative care throughout the country of South Africa. The event took place on May 4th at the KwaMakhutha Resource Centre. Although, Asibemunye was meant to perform at the event, the group arrived late and was unable to sing. The members, though, said they enjoyed the event and had a good time.

6. TYPICAL SUPPORT GROUP MEETING

Upon entering the building, in which Asibemunye meets on a Tuesday morning, you rarely hear a lot of noise or people loudly chatting together; rather the members of Asibemunye often sit or converse quietly with other members in the room. Sometimes you will hear the clucking of baby chickens walking outside the door of the building, or the taxis, which stop on the road directly across from the building, hooting. The meetings

are characteristically quiet, although at times members do speak loudly for emphasis, in particular Fanele and Flora. For the most part, the members wait for the Isibani team to arrive in order for the meeting to formally begin. Even if Isibani arrives late, the group does not usually begin their meeting. The meeting officially starts at 11 a.m., but usually begins fifteen to thirty minutes later.

The members of the group often sit next to the same people each week. For instance Nolwazi, Sbonisile, Nomsa, and Zanele sit next to each other. Nolwazi, Sbonisile and Nomsa are often giggling and laughing with each other throughout the whole meeting. Nolu tends to sit near Thobeka or Flora (when they were both attending). Ayanda and Njabulo are usually in close proximity to each other. The Isibani team sits on the benches next to the support group members. Sometimes the caregivers stay in the truck parked outside the building, until they must bring in the donations for the group. Additionally, Sister Joyce Sithole, who facilitated the meetings until January 2009, usually waits in the Isibani truck parked outside of the building.

Now, when the Isibani team arrives to Asibemunye meetings it is usually Bongiwe, the support group coordinator, or Hlengiwe, a caregiver, who facilitate discussions in the meetings. The group sometimes says a prayer and/or sings at the onset of the meeting. At the end of 2008, Sister Joyce Sithole suggested that the support group members, *"should pray so that God will help you [the members] to get all the things you want. Even on Tuesdays, you should start with a prayer".* Nolu explained that Albertina (a former

member) used to open the meetings with prayer. In 2009, the prayer and singing was usually initiated by Fanele, Nolu, or Nolwazi.

As stated previously, although the meeting is typically quiet, members of the group are often seen joking together, laughing, and/or whispering with each other during the meeting. On a few occasions, Bongiwe and/or Hlengiwe have reprimanded Sbonisile for laughing during a discussion. The group members like to joke and playfully tease one another. For example Cebo (former member) told Thobeka (former member) that she had a real womanly body, and would make a perfect wife. The two members and the rest of the group joked about a pending marriage between Thobeka and Cebo for several weeks. Similarly, Ayanda often told me at the end of meetings, that his *"heart is sore"* because he wants to take Noxolo on a date.

Occasionally, members of the group including Ayanda, Nolu, and Fanele can be seen writing in notebooks. Ayanda tends to write about discussions and plans taking place during the meetings, and sometimes takes attendance. Fanele, also, sporadically takes attendance at the meetings, although, Fanele has stated she does not like to write.

After the members and Isibani have greeted one another, the discussion portion of the meeting begins. Similar to Nawe Sondela meetings, often Bongiwe or Hlengiwe (in the case of Asibemunye) have planned discussions for that day, but first begin by asking the members how they are feeling. Asibemunye members are quite vocal in expressing any problems they many have including health issues, problems with family/friends, or financial difficulties. For example, Thobeka inquired if taking ARVs could be the reason

why her body is always itchy. Another member asked for advice because her mother yelled at the member for disciplining her child. Along with the Isibani team offering advice to the members' problems, frequently other members of the group offer advice or suggestions to one another. The group is likely to spend over a quarter of an hour discussing issues or problems members may be having.

Then the facilitation of a topic by the Isibani team usually begins; although at some meetings the group members and Isibani team continue with general discussions prompted by issues brought up by members. The discussions facilitated by Bongiwe and/or Hlengiwe are centered on topics found in many of the Soul City magazines. Over the course of the year, topics discussed included information on ARV treatment, pap smears, sexually transmitted infections (STIs), the use of condoms, and tuberculosis. The Isibani team often hands out Soul City magazines to the members. Hlengiwe and Bongiwe encourage the members to read sections from the magazine and to ask questions. In particular, arising from the discussion on STIs, at one particular meeting the group began arguing with one member, Flora, over what causes AIDS.

A brief dialog will illustrate the discussion amongst the members.

> Flora asks Thobeka, *"Why are you always talking about sex?"* Thobeka responds, *"Because sex causes problems!"* Flora feels that *"talking about sex does not take us anywhere. But let us talk about something else, what ever we can think of."* Flora goes on to explain that she discovered her HIV positive status, when she

found wounds in her private parts. Flora states, *"That's why I don't believe that sex causes AIDS. The problem is my husband never tested positive."*

In addition to discussions facilitated by the Isibani team and/or discussions amongst the group members, Asibemunye had several guest speakers throughout the year. Thobeka invited a nutritional company called Herbal Life to come to a meeting. Herbal Life presented a variety of vitamins and supplements to the group, and invited members to become a part of the Herbal Life team and sell the products. Thobeka signed up to be a part of Herbal Life team. In addition, Thobeka heard about a company called Clean Vision Products on the radio, and asked if I could contact the company to make a presentation to the group. The Clean Vision Products has a non-profit organization within the company that encourages groups such as HIV/AIDS support groups, to sell chemical products, such as household cleaners. A member of the Rotary Club of Durban Berea also attended a meeting to discuss the possibility of the support group having their own vegetable tunnel.

At some point during every meeting, Ayanda and Njabulo leave the room in order to receive a small snack (for e.g. 'vetkoek') out of the Isibani truck. Sister Joyce Sithole believes that Ayanda and Njabulo travel far that they need some food before they make their journey back home.

The Isibani team also weighs the members once a month, recording the numbers in a diary, and sometimes saying the weight of a member aloud. An Isibani caregiver stated

Nolu's weight aloud, and Nolu exclaimed, *"What! I used to weigh four kgs less!"* Additionally, the members receive vitamins (described previously) on a monthly basis.

Once the discussions appear to be coming to an end, caregivers bring in large bin size bags full of used clothing into the meeting venue. The group receives clothing and material on a weekly basis. The Asibemunye members rarely received food parcels from the time I began fieldwork in August 2008 until January 2009. However, in 2009, the group began receiving a variety of food items such as 5 kg of mealie meal and bread rolls (largely as a result of the partnership between Isibani Hospice and The Impilo Food Project discussed in Chapter Three).

In addition to donations, as of 2009, the group now receives lunch at the end of the meetings. The group members usually eat their sandwiches while the meeting is coming to a close, and members help pass around cups and pour juice for one another. Towards the end of the meeting, the members may also begin sorting through the donations of clothes and/or begin passing out food donations.

The meeting does not have a formal closing with a song and prayer, rather once the discussions come to an end, and the lunch has been provided, the Isibani team usually packs up to leave. The Isibani team often leaves the group while they are sorting through donations or talking with one another.

The descriptions of the membership composition, insight in the members' views on the support group, and relationships/interactions between Asibemunye members, as well as the way in which the support group operates provides an understanding for the remaining chapters within this study. At this point, several themes prevalent within both support groups will be discussed, beginning with a discussion on conflict within both support groups.

CHAPTER SIX- SUPPORT GROUPS, SOCIAL DRAMAS, AND THE PROPENSITY TOWARDS CONFLICT

The previous chapters within this study describe the purpose, structures, and main actors of both HIV/AIDS support groups, Nawe Sondela and Asibemunye, and the sponsoring organization, Isibani Hospice. The aim of this chapter is to explore the theme of conflict within each support group. The analysis of conflict will take form through ethnographic accounts framed within the theoretical contexts of gossip, social conflict, and social dramas.

Although Chapter Six deals specifically with conflict, there are cross-cutting themes between Chapter Six and Chapter Seven. Chapter Seven will delve into the notion of reciprocity within each support group, and conflict is an important aspect in the discussion of this reciprocity. Thus, it is necessary to relate concepts discussed in Chapter Six with Chapter Seven and vice versa, as the two chapters are integrally linked.

The development of themes and theoretical frameworks within the ethnographic chapters, Chapter Six and Chapter Seven, stem from the use of grounded theory as a starting point for the process of fieldwork and analysis. Grounded theory[14], developed by Glaser and Strauss, provides an approach for the researcher to begin a study with general concepts and build upon ideas or impressions discovered during the actual fieldwork

[14] Grounded theory aims to build theory through identifying a phenomenon, systematic data collection, and analysis. The data collection process, analysis, and theory occur interchangeably. The inductive theory follows a set of procedures that endures the test of scientific validity, and at the same time, allows for creativity in analysis and theory building. (Strauss & Corbin, 1990).

(Charmaz, 2006). Similarly, I began fieldwork with the HIV/AIDS support groups, Nawe Sondela and Asibemunye, with a broad research objective—mainly, to discover how these support groups operate and to gain an overview of discussions which took place within the meetings. Despite the broadly framed goal at the onset of fieldwork, a series of particular themes, specifically conflict and reciprocity, began to emerge within both HIV/AIDS support groups. Thus, although "a potential problem with ethnographic studies is seeing data everywhere and nowhere, gathering everything and nothing" (Charmaz, 2006: 23), themes emerged from the data within this study through the use of grounded theory.

In order to address the theme of conflict within this chapter, it is now necessary to outline the theoretical background of gossip, social conflict, and social dramas. The subsequent analysis and ethnographic examples of conflict will incorporate these theoretical concepts.

1. CHARACTERISTICS OF GOSSIP

The analysis of gossip is inherent in many of the early anthropological accounts of groups and societies throughout the world, i.e. work by Paul Radin, Melville J. Herskovits, and James West. In particular, Max Gluckman[15] attributes a great deal to the comprehension of gossip as well as scandals within societies, stating these concepts are "among the most

[15] Max Gluckman, a British social anthropologist, was a part of the structural functional school of thought. He analyzed the concepts of ritual rebellion, and conflict in, mainly, African societies (McGee & Warms, 2004). Max Gluckman became head of the department of Social Anthropology at the University of Manchester, the department, anthropologists and theories became known as the Manchester School of Thought (Schmidt, n.d.)

important societal and cultural phenomenon we [anthropologists] are called upon to analyze" (Gluckman, 1963: 1). Max Gluckman comes from the structural-functionalist[16] line of anthropological thought, thus for Gluckman, gossip and scandal were integrally linked to the maintenance of social groups and society as described in his article "Gossip and Scandal" (Bleek, 1976; Gluckman, 1963; Paine, 1967; Wilson, 1974).

According to Gluckman, gossip has specific characteristics and social functions. Gossip, a "culturally determined process" plays a role in the maintenance of group values, morals, unity, and aids in reinforcing group norms (Bleek, 1973; Gluckman, 1963). Gossip is a more prevalent feature in exclusive groups such as kinship related, criteria based membership, and minority groups. Gossip may be exchanged privately between members of a group or expressed publicly, and in some instances, to be gossiped about indicates social importance, i.e. the individual is worthy to be gossiped about (Bleek, 1973: Gluckman; 1963).

Gluckman (1963: 313) states that gossip and scandal have the ability to "unite a group within the larger society" by 1) providing a past history (e.g. group scandals) for other members to relate to and, 2) regulating individual and clique's "struggles for power and prestige" within a group. Furthermore, an individual must gain the right to gossip about other members in a group via learning the scandals and history of the group and its members, thus gossip may be considered a "hallmark of membership" (Gluckman, 1963:

[16] Structural-functionalism, an anthropological school of thought, is commonly associated with A.R. Radcliffe Brown. The school of thought looked at the "underlying structures of society" (similar to Durkheim's work) in attempts to discover universal social laws (McGee & Warms, 2004:154).

313). An important note is gossip and scandal will aid in the uniting of a group when the group is aligned with common, collective goals; thus, if a group fails to uphold its goals, gossip and scandal may aid in and "accelerate the process of disintegration" of the group (Gluckman, 1963: 314).

In response to Gluckman's perspective on gossip, Ayanda Paine states in his article, "Alternative Hypothesis to Gossip", that gossip should be viewed as a process of information-management and from a transactionalist[17] point of view (Paine, 1967). Paine disagrees with Gluckman's notion that gossip performs a role of unifying groups; rather, Paine advocates gossip as a means for "individuals to forward their own interests" within a group (Bleek, 1976: 527; Paine, 1967). Moreover, the key to understanding gossip is through analyzing individuals opposed to Gluckman's focus on gossip within social networks and groups (Paine, 1967; Gluckman; 1968).

The hypotheses on gossip and scandal reach far wider than the dialogue amongst Gluckman and Paine. In the past fifty years, these concepts have been utilized, changed, and developed by anthropologists from various anthropological schools of thought (refer to Abrahams, 1970; Arno, 1980; Besmer, 1993; Brennan, 2004; Wilson, 1974).

Examples of gossip are widespread within the HIV/AIDS support groups, and also a vital component to the nature of conflict in each group.

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[17] Transactionalism refers to an approach led by Fredrick Barth, a student of the Manchester School of Thought, which discusses dyadic ties, which "link individuals to one another in relations of dominance and submission" and the concepts of political organization (Seymour-Smith, 1986:280).

2. ASPECTS OF SOCIAL CONFLICT

Numerous definitions of conflict exist from the perspective of various disciplines such as psychology, sociology, and anthropology. One explanation of conflict, is "a struggle over values and claims to scarce status, power, and resources, a struggle in which the aims of opponents are to neutralize, injure, or eliminate their rivals". Similarly, another definition is "conflict means perceived divergence of interests, or a belief that parties' current aspirations cannot be achieved simultaneously" (Fry & Bjorkqvist, 1997: 10&25).

Within the discipline of anthropology, the study of conflict has widely been recognized in studies of cultures throughout the world, but "theoretical attention to social conflict" only began to emerge in the late 1950's to early 1960s (Levine, 1961: 3; Norbeck, 1963). The theoretical discussion of social conflict, in its early days, was greatly influenced by the notions of structural-functionalism. Two schools of thought emerged on the topic of conflict centering on the views of 1) Max Gluckman and Victor Turner and 2) Bernard J. Siegel and Alan R. Beals (Levine, 1961). Gluckman and Turner viewed social conflict as a function "for the maintenance of social systems", whereas Siegel and Beals were primarily concerned with the "causes of conflict rather that its functions" (Levine, 1961: 3). Gluckman and Turner's ideas of social conflict centered primarily on the study of African societies, and although both individuals focused on the ideas of social conflict, the means and methods in which they explored this theme differed (Levine, 1961; Norbeck, 1963). For instance, Gluckman conceptualizes conflict based on his studies of

rituals of rebellion[18] in southeast Africa, and custom and conflict in Africa (Seymour-Smith, 1986). Specifically, Gluckman analyzes the processes and roles that rituals of rebellion have on the relationship between conflict and unity within society (Swartz & Jordan, 1976). Gluckman defines conflict as the term used to describe "discrepancies at the heart of the system" (Gluckman, 1965: 109), and maintains that elements and instances of conflict within a society contribute to the overall unity and/or cohesion of the society (Gluckman, 1965; Seymour-Smith, 1986). Thus, for, Gluckman, society operates and cohesion is reinforced due to the fluctuations between conflict and stability (Gluckman, 1965). These concepts are also evident in Victor Turner's conceptualization of conflict, which will be elaborated upon in Section 3. Siegel and Beals focused on developing a cross-cultural model of conflict based on their term factionalism, "a phenomenon which occurs within groups", and refers to "overt, unregulated (unresolved conflict) which interferes with the achievement of the goals of the group" (Levine, 1961:3-4; Siegel & Beals, 1960: 107).

The following description provides a contextualization of social conflict. Levine (1961) outlines several key discussions of social conflict including structures in which conflict occurs, indicators of social conflict, feelings associated with conflict, sources of conflict, and conflict resolution (primarily drawing on works by Siegel & Beals, and Gluckman & Turner).

[18] Rebellion refers to "Conflict over which individuals should hold offices or play particular roles in political processes rather than over the effectiveness or virtue of those offices or processes themselves" (Swartz & Jordan, 1976: 534).

Social conflict may exist within intrafamily, intracommunity, intercommunity, and intercultural settings, and indicators of conflict include physical aggression, public verbal dispute, covert verbal aggression (refer to Section 1), a breach of expectation (i.e. "refusal to participate in cooperative endeavors [of group]", and avoidance and separation (Levine, 1961: 6). Negative images such as unflattering thoughts of individuals within a group, and hostility are often associated with social conflict.

Although a debate exists whether conflict exists in all societies throughout the world[19], Levine (1961: 8) states, "human social life inevitably entails frustrations and incompatibilities between individuals which engender conflict in all societies". In the instances where conflict does exist, there is great variation within and across societies. Some general sources or determinants of social conflict include economic, structural, and psychological explanations. Levine (1961: 8) explains economic conflict occurs when there is "competition for scarce resources" such as land. Sources of structural conflict include the propensity for conflict to erupt amongst people who are in constant close proximity to one another and also individuals and/or groups competing over status and power roles. A psychological source of conflict cited by Levine (1961) includes environmental factors in the upbringing of children, for example a society that encourages physical aggression (Levine, 1961).

[19] Refer to book "Cultural Variation in Conflict Resolution", in which the editors and authors of several chapters, Fry & Bjorkqvist (1997), provide a list of cultures throughout the world that do not participate in expressions of conflict such as warfare.

Conflict resolution differs greatly amongst societies, in particular, depending on the societal structures that are in place to deal with conflict, i.e. formalized legal procedures, informal mediation (Levine, 1961).

Anthropologists in the past fifty years have expanded and diverged on the concepts of conflict described above, and additionally, new models and ideas on conflict have been developed. A wide range of studies (Attwood, 1979; Dirks, 1988; Fry & Bjorkqvist, 1997; Gezon, 1997; Norbeck, 1963) focusing on small scale societies, industrial societies and cross-cultural comparisons provide a wealth of ethnographic research on conflict, but it is not my intention to provide an exhaustive list of these developments.

One particular model developed to understand conflict is the social drama developed by Victor Turner.

3. VIEWING CONFLICT THROUGH SOCIAL DRAMAS

The inspiration for Turner's social drama developed out of his lifelong work involving the symbolic analysis of rituals (Turner, 1980; Turner, 1988). Victor Turner, like Gluckman, was trained in the structural-functionalism school of thought, although, he became a main contributor in the development of symbolic anthropology[20]. Primarily,

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[20] Symbolic and/or interpretive anthropology developed throughout the 1960s-1970s along two distinct trends, that of Clifford Geertz and Victor Turner. Symbolic anthropology dealt the analysis of symbols, although Geertz studies emphasized "culture as an organized collection of symbolic systems, whereas Turner focused on understanding symbols as operators within society. Turner trained at the University of Manchester, in the Department of Social Anthropology founded by Max Gluckman (McGee & Warms, 2004: 524).

Turner sought to investigate the role symbols have as "mechanisms for the maintenance of society" (McGee & Warms, 2004: 525).

Turner's conception of social dramas began in observing social relations, in particular, he states, "I saw people interacting, and, as day succeeded day, the consequences of their interactions. I then began to perceive a form in the process of social time. This form was essentially *dramatic"* (Turner, 1974: 32). Furthermore, through his studies of the Ndembu peoples of Zambia, Turner perceived that a constant aspect of social life amongst the Ndembu was a "propensity toward conflict" (Turner, 1974:33). Moreover, this conflict became observable through "public episodes of tensional irruption", thus, the term and model for social drama was born as a guide and means to interpret "human social behaviour" (Turner, 1974: 33-37). Moreover, Turner views the social drama as "a spontaneous unit of social process and a fact of everyone's experience in every human society"; Turner forms the viewpoint that social dramas or "dramas of living" are a worldwide phenomenon due to numerous cross-cultural observations and historical evidence (Turner, 1980: 149; Turner, 1988). Levine (1963: 3) in his discussion on conflict and anthropology states that Turner's social dramas provide "a case-history approach to community conflict as a method of ethnographic recording and presentation".

3.1. <u>PHASES OF SOCIAL DRAMAS</u>

Social dramas follow the path of four distinct phases—1) breach, 2) crisis, 3) redressive or remedial procedures, and 4) reintegration, or recognition and legitimation of an

irreparable schism (Turner, 1974; Turner, 1980; Turner, 1988). The social drama takes place within a group of people sharing a common history, interests, and/or values (Turner, 1980). Furthermore, Turner describes that individuals often have membership and identities linked with many social groups such as religion and family, but most individuals have a "star group". An individual (actor) is most deeply drawn to their "star group" due to loyalty and personal fulfillment that the individual experiences as a member of the group (Turner, 1980). Interestingly, a star group exists in two forms, that of the ideal paradigm, "pure and perfect image of its [the groups'] harmonious operation", and the concrete expression of the ideal "in the experience of the member" (Turner, 1988: 46).

Phase one of a social drama is the *breach* of a "norm-governed social relation", such as a rule of etiquette, custom, or law. This breach may be a public act, done covertly, or come to light due to the fact that the breach has gone against a norm or rule central to the functioning and maintenance of the group/family/community (Turner, 1974; Turner, 1980; Turner, 1988). The breach becomes a symbol of dissidence or disagreement and similarly, a "symbolic trigger of confrontation" (Turner, 1974: 38).

At this point, the social drama moves into phase 2, the *crisis*, which occurs if the breach in phase one is not sealed off or handled. Once the breach spreads and becomes a part of the larger "set of social relations", an "escalation of crisis" ensues (Turner 1974: 38). In the crisis phase, members of the group take sides, form alliances, and confront enemies, because as Turner says in relation to viewpoints of both Durkheim and Rene` Girard,

“crisis is contagious” (Turner, 1988: 34). Additionally, past conflicts may be brought up; aggression, threats, and sometimes physical violence may erupt during the crisis phase. The crisis will not disappear, and in Turner’s words this is “when a true state of affairs is revealed, when it is least easy to don masks or pretend that there is nothing rotten in the village” (Turner, 1974: 39; Turner, 1988).

In an attempt to control the expanding crisis, phase three—*redressive or remedial action* begins to unfold. A redressive “mechanism” may be an informal or formal action including mediation, advice, judicial and legal procedures. Phase three is usually initiated by members of the “disturbed social system” (Turner, 1974: 39, Turner, 1988). The redressive mechanisms provide a means for the involved social group to review the events, which led up to the crisis including actions of members and the group as a whole. Turner refers to this phase as a “process of stocktaking, of plural self-scrutiny” (Turner, 1988: 34; Turner, 1974). If the mechanisms implemented are unsuccessful, the group may re-enter into phase two, crisis (Turner, 1974; Turner, 1980).

Finally, phase four of a social drama describes two possibilities for the social group 1) *reintegration* or 2) *“legitimization of irreparable schism between the contesting parties”* (Turner, 1974; Turner, 1980; Turner; 1988). In other words, phase four is an indication that the group has come to a resolution to move on past the crisis situation, or the group has decided they no longer function as a whole and must split. At this point, the relations between members of the social group may change, for instance enemies may become allies (and vice versa), power changes may take place, and members’ status may change. Moreover previously “integrated parts” of the social group may become

"segmented" and vice versa; also, new rules and norms could be formed (Turner, 1974: 42). It is important to note that not all conflict follows through to the fourth phase of a social drama, and the conflict may revert back to previous stages of the social drama (Turner, 1974).

Now that a background on gossip and social conflict with particular reference to social dramas has been provided, the focus will shift into understanding aspects of these concepts in the analysis of conflict within Nawe Sondela and Asibemunye.

4. EXPECTATIONS

In order to fully comprehend conflict within each support group, a brief summary of several key concepts described in Chapter Two is necessary as it allows for the basis of conflict to be articulated.

The formation of an HIV/AIDS support group involves several crucial factors:
1) participation of a sponsoring organization, group leaders and/or facilitators, and the group members, specifically Isibani Hospice and teams working with each support group, members of Nawe Sondela and Asibemunye (as described by Bell et al., 2007; Lyttleton, 2004; Schopler & Galinsky, 1993; Visser & Mundell, 2008), and 2) the structure of the support group including aspects of closed versus open, meeting venues, discussions, meeting design, and group rules (refer to Coleman & Harris, 1989; Lyttleton, 2004; Schopler & Galinsky, 1993; Uys & Cameron, 2003; Visser & Mundell, 2008).

Furthermore, the interaction and roles of the participants described above largely determines how the support group will be structured (Schopler & Galinksy, 1993). In particular, the sponsoring organization and leaders/facilitators have an integral role in deciding how the support group is structured and functions; in theory, though, the members should play an equally important role in deciding how they would like the support group to operate (as described by Uys & Cameron, 2003). A specific role of the sponsoring organization and facilitators/leaders is to assist in this process of members partaking in the decision-making (Uys & Cameron, 2003). Thus, within this study, the Isibani teams working with Nawe Sondela and Asibemunye are "in theory" responsible for discussing the purposes and goals of the group, and the expectations of the individual members of the groups.

The issue of expectations is particularly important because as stated previously, if members do not feel the group is meeting their expectations and/or goals, the members will not view the group as having a supportive function in their lives (refer to Kalichman & Sikkema, 1996; Schopler & Galinsky, 1993; Uys & Cameron, 2003). This chapter argues that expectations are not being met, in general, by Isibani towards Nawe Sondela and Asibemunye, and also that the support groups are not meeting the expectations Isibani has for them. Integral to this notion of expectations is the idea that individual members' goals should be aligned with the general goals of the support groups as mentioned by Schopler & Galinsky (1993) and Uys & Cameron (2003). In addition to ensuring that new members joining the support group "fit in" with the goals of the group, it is necessary to consider if the goals of the sponsoring organization are, in fact, aligned

with the goals of the support group members, and vice versa. Additionally, the stability of the group is affected by the fact that individual members of each group may not have the same expectations and/or goals of their fellow members, which ties into Jacobson's (1987) notion that support networks, such as the support groups, provide support, yet may also be a source of stress for members due to differences in individual's personalities and interests.

This chapter argues that the discrepancy of expectations amongst the participants is a starting point for the various instances of conflict, which occur within the support group. In Chapter Seven, the concept of expectations will be elaborated upon in relation to a system of reciprocity existent within each support group.

For now, though, instances of conflict within each support group will be described in relation to several themes: 1) autonomy[21], 2) stability, and 3) loyalty[22]. Moreover, throughout the remaining sections of this chapter, it is important to consider the two factors crucial to the functioning of the support groups—the various roles, relationships and interactions between all participants, and the structures in place within each support group, because "those relations between discrepant principles and processes in the social structure… must inevitably lead to radical change in the pattern" (Gluckman, 1965: 109).

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[21] Autonomy as described by Encarta Dictionary (2009) is: "self government politics; political independence and self government, and existence as independent moral agents: philosophy personal independence and the capacity to make moral decisions and act on them".

[22] Loyalty is "a feeling of devotion, duty, or attachment, to somebody or something" (Encarta, 2009).

Conflict within Nawe Sondela will be demonstrated through Turner's concept of social dramas. Similar issues and instances of conflict exist within Asibemunye, but conflict did not reach crisis stage within Asibemunye, thus social dramas will not be utilized, rather ethnographic descriptions will illuminate the conflict within Asibemunye support group. Although only certain descriptions and situations of conflict will be elaborated upon in the remainder of this chapter, the research period was characterized by a series of social dramas and instances of conflict, in addition to the descriptions provided in the subsequent sections.

5. SUPPORT GROUP ORIGIN

There are various accounts of how Nawe Sondela and Asibemunye support groups were formed. The varying explanations are due to the fact that the support groups and Isibani Hospice conceptualize and have differing perspectives of what entails "the formation" of an HIV/AIDS support group. Additionally, Isibani Hospice and members of Asibemunye provide only a vague history for the origin of Asibemunye.

As mentioned in Chapter Three according to Isibani Hospice, support groups may originate through: 1) the Isibani team recruiting members for a group, 2) referrals from community clinics and/or organizations to individuals interested in joining a support group, and 3) individuals from the community beginning to meet informally and requesting the services of Isibani. For instance, Sister Joyce Sithole explains that in October 2008, Isibani Hospice was in the process of opening a fifth support group, she

said, *"They [individual interested in joining a support group] are there—people are there. They are ready; they just have to give me their name [for the support group]."*

According to Sister Joyce Sithole and Bongiwe from Isibani, Nawe Sondela and Asibemunye were formed by the Isibani Hospice (via number (3) described above). Sister Joyce Sithole confirmed, "We *[Isibani] were with them from the start."* Bongiwe believes that Nawe Sondela support group began in 2006 and developed due to the fact that Isibani Hospice was providing services to the five Hlengwa sisters (current members of Nawe Sondela). The Hlengwa sisters were patients of Isibani Hospice and Nawe Sondela support group stemmed from this association.

In terms of Asibemunye, Bongiwe does not remember exactly when this group began but thinks it was between 2004 and 2005 when an individual contacted Isibani about forming a support group in Adams Mission. Originally, the group met in the hall of the community library (down the road from the current meeting venue).

The support group members of Nawe Sondela and Asibemunye do not reference Isibani Hospice when discussing the formation of their support group. For instance Nolu, Ayanda, and Njabulo think that Asibemunye support group began in 2005 or 2006, but they were not original members hence, Nolu said, *"I think that those people who started the support group no longer come [to the meetings] or have passed away".* This brief description suggests that as far as current members know, individuals (like themselves) began Asibemunye and only after the group had formed, Isibani Hospice began to help

the support group. Nolu says that Isibani Hospice began coming in 2006, and that she began attending Asibemunye meetings in 2005.

Nawe Sondela's story of origin is more complex and is provided by Slindile, a member of Nawe Sondela.

"The original group was Ikuthala Support Group, and we met in the hall of Charles James Hospital. The lady [no name given] who was the chairperson and also worked with the community [Ezimbokodweni] began fighting with the management of the hospital. This lady was the one who organized for Ikuthala to meet at Charles James Hospital. The management [at the hospital] promised the group money to buy seeds, juice, biscuits, and food if we had visitors. When the management didn't do it, Ikuthala members started fighting and then the group dissolved. My sisters [Londeka, Mbali, Phumie, and Noluthando] and Lee are the ones I can remember who were with me at Ikuthala and then we became a part of the new group, Nawe Sondela, which was formed by Sindiswa. We began to meet in a house in the community, but one day we showed up and the owners had locked the doors because the owners didn't want us [the support group] to meet there anymore. Then, Sindiswa asked her father if we could meet in her house because it was a big house. Sindiswa's father agreed, but then we [the group] became so many that the space was too small, so we had to move. Mfundo joined the group at this time and offered for us to use his house [Meeting Venue Number 1, the Rondavel, described in Chapter Four, Figure Six]".

The fact that both support groups do not mention Isibani Hospice at any point when discussing the history of their group's formation insinuates that each group wants an independent identity from the sponsoring organization. The support group have a unique origin and identity (whether it the true course of events or not) that was initiated by the support group members not an "outside" organization such as Isibani Hospice. This approach provides a way for the group members to express autonomy over their participation in the HIV/AIDS support group, in a sense; allowing members to have "ownership" of their group.

An element of ambiguity exists with regards to the concept of autonomy within each support group. Several factors contribute to this element of ambiguity. The first factor is that the support groups under study strive to express and obtain autonomy in their roles and within the structures of the groups, i.e. through stories of origin, the management committee. A second factor is that Isibani Hospice also encourages an impression of autonomy and ownership amongst the members of the support groups. For instance, Isibani Hospice advocates that support group members should become involved with making decisions and developing goals for their support groups. According to Bongiwe, *"What you [Isibani team] always tell them [the support group members], the support group is not about Isibani Hospice coming in to be with them, and the support group is mainly for them [the members] to support each other".* Sister Joyce Sithole explained, "*We [Isibani team] do not always come here with something particular to talk about. We want the support group members to tell us what to talk about".* Additionally, Sister Joyce Sithole explained to Nawe Sondela members, *"If you [the members] have a*

problem with the person or people who will be visiting the group, you should not be afraid of calling the Isibani Hospice office to complain". These examples express Isibani's desire for the support group members to have an integral role in making decisions on factors such as structures, meeting design and support group discussions. Yet, as indicated throughout the previous chapters of this study, the Isibani team, for the most part, organizes the majority of structural components of both Nawe Sondela and Asibemunye support groups. Additionally, the third factor which contributes to the ambiguity surrounding autonomy is the nature and characteristics of what an HIV/AIDS support group entails; there are two essential elements—someone who gives support and someone who receives support. The support group members rely, request, and expect assistance and support from Isibani Hospice. In the same respect, one of the objectives of Isibani Hospice is to provide forms of support and services to the HIV/AIDS support groups. Thus, although the support group members do show examples of autonomy, and Isibani Hospice does encourage their own perception of autonomy within the support groups; in reality, autonomy does not exist in its true form; rather a system of interdependence between the sponsoring organization and each support group exists.

In addition to the presence of Isibani Hospice, several organizations including the YAA, NAPWA, and TAC have been and in some cases continue to be involved with Nawe Sondela and Asibemunye. This involvement adds an additional factor to the ideas of autonomy and also stability within the support groups. In some instances, the organizations, which become involved with Nawe Sondela and Asibemunye, have their own objectives (usually dictated by the organizational objectives); these objectives do not

necessarily align with the goals and objectives of 1) the members of the support group, and 2) the vision of Isibani Hospice. Furthermore, it is questionable if the support group members are always consulted by these organizations and if the organizations give an explanation of their objectives.

The subsequent section will discuss the objectives of YAA within both support groups, as well as an example of conflict between Nawe Sondela, Isibani Hospice, and NAPWA.

6. INVOLVEMENT WITH ORGANIZATIONS

In the beginning of my fieldwork, it appeared as if YAA had either 1) started the support groups under study, or 2) they were "in charge" of these support groups. The reason for my original assumption was the way in which the YAA staff discussed the support groups amongst themselves, as well as with the organization's funders. Also at the support group meetings, the YAA staff facilitated discussions on HIV/AIDS and the Isibani team remained on the peripheral, i.e. no facilitation of support group meetings.

Moreover, Sandile (the support group facilitator for YAA) expressed intense interest in making the support groups 'independent and autonomous' through implementation of a support group constitution and applications to become a Non-profit Organization (refer to Chapter Three) for both support groups. In an interview with Sandile, I asked how he knew what the support groups wanted or needed. Sandile responded, that he was *"not sure of the survey that was done [by the YAA] before I came here. Sbonelo [manager of*

YAA] introduced me to the ideas, and I helped him with this part of the operational plan [support groups becoming NPOs]." Sandile said in reference to this idea that, *"It is the first of its kind [referring to NPO applications] for the YAA. NAPWA came up with the idea of support groups, but they did not consider the ideology—'to own a support group', which is the idea I didn't like. People cannot grow if under control. They need the ability to fly, which means you need to build as much capacity as possible [within the support groups]. You need to know if you [the support group] are a growing seed or a dying seed. When sitting around, they [the support group members] know about HIV/AIDS, but what's next?"*

Thus, Sandile and the YAA staff were working towards a way for the support groups to become sustainable and independent. Although, the question does arise, did the support group members understand and agree with the YAA's objectives? Nawe Sondela and Asibemunye have support group constitutions, but as confirmed by a member of Nawe Sondela, Sandile wrote these constitutions. Additionally, the constitutions of Nawe Sondela and Asibemunye are near identical suggesting that the members of each support group did not create and/or necessarily contribute to the formation of these constitutions. Similarly, at the time I began attending the support groups meetings on my own in August 2008 (previously I had gone with the YAA to meetings), both groups had not completed nor begun filling out the NPO forms, which were Sandile's main objective for both support groups. In the end, the YAA stopped attending and consulting with both support groups in June 2008 when the funding for the Masibambane project came to an end. In the same way, all efforts (as per the YAA organization plan) to achieve

sustainability before they YAA left the support groups became non-existent. In August 2008, Noxolo and I phoned and requested Sandile to help the groups with the NPO forms as he promised both the groups and me a few months prior, but Sandile never appeared. He later resigned from the YAA due to differences of opinions he had with the manager of the YAA. In February 2009, though, Nokwazi from the YAA asked Asibemunye support group members if they would like to be involved with a Youth Committee project initiated by the YAA. Several members attend functions and meetings occasionally held by the YAA, for instance numerous members of Asibemunye attended a Youth Day function sponsored by the YAA in June 2009.

Several impressions become apparent through the description of YAA. The YAA, interestingly, was attempting to create a more autonomous system for both support groups to operate, and there were actual ideas in place that could potentially lead to the achievement of these goals. But the inactivity amongst Sandile as well as the support group members to work towards these objectives is an indication that the support group members were not consulted prior to the YAA becoming involved with the groups and/or were not committed to the objectives proposed by Sandile. Furthermore, the overall vision of Masibambane Project for the support groups in particular, presents a far-reaching set of goals for the support groups, none of which were obtained by the time YAA stopped visiting the support groups. This suggests that although with good intentions towards Nawe Sondela and Asibemunye, the YAA's first priority was to attempt to fulfill objectives pertaining to their organizational plan for the Masibambane Project, and the support groups came second in order of importance.

The YAA, both support groups, and Isibani Hospice had a peaceful coexistence, in contrast, the involvement of NAPWA with Nawe Sondela resulted in conflict, as shown in Social Drama Number 1: *A Possible Threat or Welcoming Support*? This social drama involves the following actors: Sister Ngcobo of Isibani Hospice, the Nawe Sondela Support Group members in particular Buhle, and Thandeka from NAPWA. One point of clarification is needed first, according to the restructuring by Isibani Hospice as of January 2009 (refer to Chapter Three) the nursing sisters such as Sister Ngcobo were not supposed to be attending the support group meetings, as Bongiwe, the support group coordinator, was in charge of support group facilitation. This social drama took place in October 2009. Following this ethnographic account, I will describe the social drama in relation to its four phases, 1) breach, 2) crisis, 3) redressive action, 4) reintegration or irreparable schism and will discuss several themes inherent in this conflict.

6.1 SOCIAL DRAMA:A POSSIBLE THREAT OR WELCOMING SUPPORT?

Sister Ngcobo entered the clinic where the support group members were talking. She began to speak loudly with great force and addressed the members of Nawe Sondela. *"I am not happy with the fact that NAPWA is here. I heard rumours that NAPWA is back asking the members of Nawe Sondela to attend a workshop for People living with HIV/AIDS. The last time you [the group] were involved with NAPWA, everyone ended up fighting and swearing at each other in front of the staff at Charles James Hospital. And now NAPWA is back and you are having meetings with them, arranging things with them without even telling Isibani Hospice. Whoever chooses to go with NAPWA must go, and*

who ever wants to stay must stay. I am not going to make the decision for you because you are all old enough to decide for yourselves. I want to say that Isibani and Charles James Hospital report back about this group—it even goes to the Department of Health [KwaZulu-Natal]. But what I am I going to say to them when they ask about you [Nawe Sondela]? I begged you last time not to get involved with NAPWA ever again because of what happened before. We [Isibani team] try very hard to help this support group with finding places to meet, talking with Emily to provide food for the group. And I don't want people to do things behind my back. Because last time everyone was angry and got themselves in trouble, others decided to leave the support group. I had to go to their [those who left] homes and beg them to come back to the support group."

Thandeka attempts to respond to Sister Ngcobo, but Sister Ngcobo told her, *"Let me finish first. I don't know you or where you are from."* Thandeka eventually spoke and told Sister Ngcobo, *"I am very happy that you [Sister Ngcobo] have found a place to meet. But NAPWA is an organization that helps people living with AIDS. So we [NAPWA] cannot run away from this support group. I know that Nawe Sondela has worked with YAA, NAPWA, and Isibani Hospice, but what happened before was not the aim of NAPWA. It [the conflict] was because the members always listen to whatever other people say. This group doesn't use their own rights. If the group used their rights they would be able to say no if they want to and say yes to those right things".* Thandeka explains to the group that she doesn't even remember what the previous fight was about. Noluthando tells Thandeka the fight involved Phiwe from TAC, Lungi from Isibani Hospice, and Thandeka (from NAPWA). It was primarily because NAPWA and TAC did

not get along and they ended up involving the entire group. Thandeka repeats that she doesn't think there would be a problem if some members attended the NAPWA sessions and then came back to the support group with a report of the events. Sister Ngcobo told the group once again, *"We [Isibani] have worked very hard to get you [the group] things. That is all I would like to say to you [Thandeka] and this group".*

Once the Isibani team left the meeting, the majority of members continued to discuss the issue outside of the clinic. At this time, Slindile tells me that Thandeka is a member of the support group but has a job now, so only comes every once in a while to the meetings. Slindile says that Thandeka was there since the beginning of the support group, Nawe Sondela. Thandeka begins telling members that whoever wants to stay with Isibani must stay, but she has a big house and those who want can come with her and meet there. Noxolo asks for clarification on the situation. Thandeka explains that this past week several members went to a meeting held by NAPWA and they signed an attendance register, which was passed around by Buhle. Sister Ngcobo says that Buhle forced members to sign the register and accused Buhle of causing this conflict and if she wanted to leave the group she should. At this point, Buhle begins to get upset and told the group, *"I didn't force anyone to sign the register. I told Sister Ngcobo that I wanted to learn from another organization like NAPWA because they deal with HIV/AIDS, just like us. And now, must we go if organizations invite us to things?"* The members begin discussing that maybe there will be a Nawe Sondela and an Isibani support group that meets together. Sister Ngcobo told the group she would not help or give things to those who want to be a part of NAPWA. The only male member at the meeting, Simphiwe

says that he is a patient of Isibani but doesn't know what to do. Several members tell him he must choose a group. He said, *"There is something I see here. This group does not see with 'one eye'. If you as a group can try to understand why you attend the support group, you will see what you want to do about this".* Thandeka said to the group, *"For those who don't want to be in control by Sister Ngcobo will meet in my house next week".* Mbali told Thandeka, *"We cannot go to your house because Sister Ngcobo did not say we must stop coming to the clinic. We should wait to see what happens and then decide".* Thandeka responded, *"Sister Ngcobo doesn't want other organizations to come and help us [Nawe Sondela]. She doesn't want NAPWA or YAA. But the thing is that the constitution we have as Nawe Sondela was made with the YAA".* Several group members begin discussing this fact and decide that these organizations perhaps are attempting to take the members away from Isibani Hospice. They mention, though, that Sandile from the YAA did teach the group "*so many things, attending workshops with us [the group]".* Mbali explained to the group, *"Shouting and talking won't help, we must go now".*

6.2. <u>ANALYSIS OF SOCIAL DRAMA</u>

Within this social drama, the breach consists of a break in protocol, i.e. for members of Nawe Sondela to explain to Isibani Hospice what is taking place within the support group, and also, a breach of loyalty took place as Sister Ngcobo says, people are *"doing things behind my back".* Both breaches are from the perspective of the Isibani team, in particular Sister Ngcobo. This social drama would not have taken place except that Sister Ngcobo viewed the situation with NAPWA and Thandeka as a breach and cause for

conflict within the group. This breach illustrates an expectation—that since as Sister Ngcobo stated, *"We have worked very hard to get you things",* and in return implies Nawe Sondela "should" be loyal to Isibani Hospice. This particular sentiment possibly stems from the notion that organizations (outside of Isibani Hospice) are *"taking our patients"* as expressed by the Nursing Manager, Sister Joyce Sithole, on a previous occasion.

The beginning of the dialogue above indicates the entrance into phase two, crisis. A primary reason for this conflict is that as Turner (1988: 34) states, "unresolved vendettas are revived", as Sister Ngcobo brings up the conflict (not described in great detail) that Nawe Sondela and Isibani Hospice had with NAPWA in the past. This social drama ironically comes to fruition due to the fact that Sister Ngcobo does not want conflict to erupt between members as it did in the past when NAPWA became involved with Nawe Sondela. In this phase, "taking sides" is seen through members urging Simphiwe to choose, and also Thandeka telling the group they should leave Nawe Sondela support group. Also, Sister Ngcobo accuses Buhle of causing this conflict, thus Buhle become the scapegoat as even members began to suggest and argue that perhaps this conflict was Buhle's fault.

Moreover, several important themes emerge from this conflict. The notion of autonomy and/or independence is cited by several actors within the social drama. Sister Ngcobo tells the group that they are adults and must decide what they want to do with regards to this situation. Thandeka accuses the members of being easily swayed, that members *"listen to whatever other people say"* and essentially that the group does not stand on its own i.e. *"use their own rights".* When Thandeka tells members they should meet at her

house, Mbali responds that Isibani Hospice has not told them to leave or stop coming to the clinic for meetings. Mbali's statement, though, reveals that the group, despite the atmosphere of conflict, looks for guidance and leadership from the Isibani team.

Phase three of this social drama, redressive action, begins as the members discuss the events leading up to the crisis outside of the clinic once the Isibani team has left. Simphiwe offers advice to the group, saying they should consider their motives and reasons for being a part of the group and make a decision about what to do. Secondly, Mbali effectively brings the crisis to a standstill by telling the group members they are not getting anywhere fighting about it because they must see what happens next i.e. what Isibani Hospice will do. At this stage it becomes apparent that members do not want to turn away from Isibani's support, in fact, they are afraid that Isibani Hospice may not offer them any more support.

The group decided to *"see what happens"*, and in phase four reintegration takes place. The group continues to meet at the clinic and the Isibani team continues to facilitate discussions except for one change—Sister Ngcobo no longer comes into the meeting venues as she did in the past. Now Sister Ngcobo stays in the Isibani truck while the meeting is taking place, and Bongiwe corresponds and facilitates the support group meetings. Thandeka did not come to the support group after the above incident and said that she was not trying *"to steal the support group, she was only trying to help".* Nawe Sondela effectively decides they want to remain with Isibani Hospice, although as Buhle questions should issues or conflicts exist if the group members want to learn or receive

support/help from organizations like NAPWA and YAA, who provide the group members with information on HIV/AIDS.

Several points are seen within the ethnographic examples and social drama of the supports group involvement with additional organizations. The Isibani teams and the support group members have different perceptions of loyalty concerning the relationship between the support groups and Isibani, for example a possible threat or welcoming support. Besides the differing perceptions of loyalty that evolve from the involvement of additional organizations with the support groups, the overall stability of the group is potentially affected by this involvement. For instance, the YAA became involved with the support group and expressed an interest in constitutions and NPOs, thus the support groups adopted elements of the YAA ideology. NAPWA and TAC became involved with Ikuthala Support Group, and the gossip and miscommunication between the involved parties led to the disintegration of Ikuthala support group and the emergence of Nawe Sondela. Both examples indicate that at times there are conflicting interests, which are intertwined with the concepts of autonomy, loyalty, and stability.

Even though the three themes—autonomy, stability, and loyalty are elaborated upon throughout this chapter, Section 5 and Section 6 primarily addressed the notion of autonomy and control. The subsequent section, Section Seven, delves into the concept of stability amongst the support groups with particular reference to a structural component of the groups—meeting venues.

7. MEETING VENUES: CHANGE AND CONFLICT

Support group members within both Nawe Sondela and Asibemunye expressed interest throughout the year of having their "own place" to have support group meetings and moreover that if the support groups had their "own place" they could participate in group projects. For instance, Ayanda from Asibemunye explained, *"We want to find something like a container to meet and keep our sewing material. If the group finds a place [of their own] we can keep ourselves busy Monday to Friday—practicing singing and drama, meeting, sewing, and gardening".* Andiswa similarly believed that if Nawe Sondela *"can get a place to meet we can do more things in the group. I have plans for the group. I think we should become a big centre, with a crèche and sewing project".*

7.1 ASIBEMUNYE MEETING VENUES

Asibemunye support group experienced conflict with the owners of two of the support group's meeting venues. The ethnographic account below provides the details of the conflict.

As of April 2008, Asibemunye support group was meeting in a building at the Madikane Child Support Centre. In July 2008, though, the group began meeting across the road (the current meeting venue) from the Madikane Child Support Centre. Nolu explained, *"We [the group] don't meet there anymore. Now we meet at this church. The church told us we can use this space until we find our own place. We need to find our own place".*

The reason for the group leaving was never explained in detail, but Thobeka said, *"The mother of that house [Madikane Support Centre] chased us away"*. Fanele said it is a shame because, *"there are so many rooms that they don't use in that building [Madikane Support Centre]"*. When Asibemunye stopped meeting at the Madikane Centre, they forgot to take their cups and dishes with them. Sister Joyce Sithole went to the centre and asked for these items as they belonged to the Asibemunye Support Group, but the person in charge of the Centre denied this saying *"the things belonged to us [Madikane Child Support Centre]"*.

In January 2009, Asibemunye began receiving complaints from the "owner", the pastor of the church, of the building where the support group meets. Nolu was told that the support group members were leaving the floors dirty and not cleaning the toilets. Fanele angrily responded that *"I always sweep the floors every time our meetings end. They [the pastor and church] are the ones who leave this place dirty. If he doesn't want us to meet here, he should tell us"*. The support group members began enquiring at the Counselor's office (Ward 96), if Asibemunye may have permission to use the church building for their meetings and group projects. Nolu explained, *"We don't have electricity. As I said before, sewing will be good for us, only if we can get the electricity in this room and get this place as our own permanently"*. Subsequently, Nolu went to speak with the Ward Counsellor about using the building, but the counselor was not in his office. Thobeka said she heard several stories about this building, that the building was going to become a Land Affairs office, and also rumours that the pastor had bought the land and the building. The group with the help of Bongiwe from Isibani, wrote a letter to the Ward

Counsellor requesting use of the building on a permanent basis. Asibemunye never received a response from the Ward Counsellor (as of October 2009), as Thobeka stated back in February 2009, *"The counselors always like to keep people waiting or not give any answers at all".*

As of November 2009, Asibemunye support group continues to meet in the church building described above. The conflict regarding the group meeting venue and the sentiments expressed by the group members centre around a common theme—the need for stability. The group members believe that a permanent place of their own also symbolizes several things—ownership, progress, and the ability to have group projects. The idea of 'permanence' and 'our own building' relate to the notion of ownership and autonomy. The support group members also associate the permanence of their own building with the ability to progress and flourish, possibly due to the fact that no one would be *"chasing us[the support group] away".* The support group expresses interest in projects such as becoming more involved with sewing, but often the lack of a stable place is cited as a reason for not partaking in these projects (refer to Chapter Seven for an elaboration on inactivity/activity of support groups).

7.2. NAWE SONDELA MEETING VENUES

Similarly, Nawe Sondela support group experienced conflict concerning the support group's meeting venues. Although in contrast to Asibemunye support group, the conflict centered on inter-group conflict and gossip. The following ethnographic description and

brief social drama highlights several themes associated with the constant change in meeting venues.

The search for a stable meeting venue began when a large storm destroyed the meeting place number one (refer to Figure 7 in Chapter Four) the Rondavel building owned by a member at that time, Mfundo. From this point in October 2008 until June 2009, the support group met in seven different places (several on Mfundo's land). When the Rondavel collapsed, Jayshree, who donated food to the support group and helped Isibani Hospice, offered to look for possible donations for building materials in order to build a temporary meeting venue. Similarly, at Mfundo's request, I enquired into a company called Kinosh, which supposedly donated buildings to community organizations. Both these attempts proved unsuccessful, but a social drama did develop out of a letter I wrote requesting aid to build a meeting venue for the support group. The intention was to request building sponsors. Also Mfundo was in the process of rebuilding his house. This background leads into a brief social drama within Nawe Sondela, *"There was a Report"*.

7.2.1 SOCIAL DRAMA: THERE WAS A REPORT

As Noxolo and I sat down on the ground next to Mfundo (refer to Meeting Venue 2, in Figure #), he greeted us, smiled and quietly whispered to me, *"The members think that I am using money given to the group to build my new house"*. Nolu explained to the group, *"There was a report that Mfundo's new building is from the Kinosh donation. The man [no name given] says he heard this report from Buhle."* Londeka responded that,

"Jabu [myself] came with the application last week and Mfundo's building is already being built". Buhle denied that she spread the rumours Nomula is referring to. Nomula responded, *"Mfundo wants to chase us away because the members of the support group are talking about him".* Buhle began to cry and continued to defend herself, explaining she did not say this. Noxolo spoke to the group, *"The rumours cannot be true because there is no donation. Jabu brought a letter to request sponsors for a new building. The application to Kinosh has not been sent".* Nomula tells Noxolo, *"Thank you for explaining. Everything is clear now".*

This brief social drama begins when the breach is made public via accusations and rumours supposedly spread by Buhle. The actual breach is the idea and/or possibility (suggested by the rumours) that group money is being used for a member's personal gain. The crisis phase has begun before Noxolo and I arrive at the meeting, and it appears that we were only present during the ending phase of the dialogue amongst the group members. The accusation by Nomula that Mfundo is angry with the group, heightens the sense of crisis amongst the members, in particular for Buhle, who begins to cry. The redressive action, phase three, begins when Noxolo explains the situation and contradicts the rumours. The group does not see the need to take the issue further, thus reintegration and/or the conflict comes to a completion.

The themes, which become obvious within this brief social drama are 1) the presence of gossip within the group, 2) stability, and 3) loyalty of group members. As seen within the social drama involving NAPWA, gossip (in the form of rumours) has set both social

dramas into motion, as Turner states, gossip is “almost always ‘plugged in’ to social dramas” (Turner, 1980: 149). The accusation that Buhle spread the rumours insinuates that Buhle is the cause of the conflict. The accusation itself, though, becomes an important issue amongst the group members (even though the accusation proves to be false) because the accusations imply that Mfundo is disloyal to the group. Both support groups, despite conflict of personalities and difference in opinions on the operation of the support group, in general, have a strong sense of loyalty to the group and its members, as seen in Nawe Sondela by the example that Mfundo’s alleged act led to a social drama amongst the group.

In addition, the members of Nawe Sondela had been without an official meeting venue since October 2008 and this social drama took place in April 2009. The group had been holding their meetings in the various buildings on Mfundo’s property, and the idea that Mfundo may “throw them out” due to these alleged accusations would lead to more instability within the group, and the group would not have a place to meet. As shown throughout this section, the meeting venue is integral to the way in which the support group members perceive their autonomy over the group, and the desire for a permanent meeting venue perpetuate the hopes and goals the members have for the group.

The concept of gossip, which has been referred to throughout the chapter will now be developed through ethnographic examples.

8. PREVALENCE OF GOSSIP

The aspect of gossip prevalent within Asibemunye and Nawe Sondela has been referenced in both social dramas, and now examples of gossip amongst the members will be demonstrated.

Several aspects of gossip as described by Gluckman are relevant to the discussion of gossip within both support groups. 1) Gossip functions as a means to reinforce norms of the group. Furthermore, when the boundaries of these norms are tested and/or breached, gossip is a means to express dissatisfaction with the breach, i.e. rumours are spread which either bring about conflict (social dramas) and/or keep conflict at bay. 2) Gossip is also inherent in groups where one or more cliques exist within the wider social network such as a support group. 3) Gossip may be a means to express dislike and/or disapproval of a group members' personality and/or actions. Furthermore, the themes of loyalty, stability, and autonomy/control are found in the discussion of gossip, as well as through comments from the Isibani team on gossip within both groups.

For example, in both Nawe Sondela and Asibemunye, gossip is often integral to debates within the groups over management committee positions and members' resigning from the support groups.

In October 2008, I began asking members of the Asibemunye support group about roles of the various management committee positions, as well as which members were a part of

the committee. A document (related to the NPO forms) which was filled out previously stated the office bearers of the support group (refer to Figure 8, in Chapter Five). The chairperson, Albertina, according to Nolu is no longer attended meetings. When Nolu offered to be chairperson, several members expressed reservations regarding Nolu having the position of chairperson. Nolu was aware that members gossiped about her because one day she left the meeting early to get a lift with me to KwaMakhutha, and as she opened the car door, she said, *"Maybe they [the support group members] will talk about me"*. Nolu, then, shut the door and went back into the building where the meeting was still in progress.

Next on the list of office bearers was Nokuhle, the vice chairperson, who sometimes worked in Amanzimtoti. Due to confusion, I asked several times if Nokuhle still attended meetings, until at one meeting, Nokuhle entered the room and Nolu explained to Noxolo, *"I told Nokuhle about the NPO forms, and how Jabu said she hasn't been coming to the meetings on Tuesday".* Thus, my enquiry into Nokuhle's attendance led Nolu to tell Nokuhle that people at the meetings were gossiping about her, in turn she began attending meetings more frequently.

The secretary of the group at this time was Phindile, who stopped attending the meetings in December 2009. Nolu, who lived near Phindile, explained, *"Phindile says she is too sick to come to the meetings".* Thobeka responded, *"Every Tuesday she [Phindile] is getting sick and every other day she is fine. The secretary is very important for the management of the group, to take minutes. And she is absent on Tuesdays".* A member

(at this time), Edward also added, *"We saw her with stock that she is selling from her home while she is sick. We don't understand."* Njabulo comments that Zandile must come and *"tell the group what is going on with her".*

Gossip in the accounts described above functions as a way to hold the group members who are in a position of "power" on the management committee accountable. When group members are dissatisfied or unhappy with a member on the committee, they use gossip in order to express this dissatisfaction and possibly to instigate a reaction from the "accused".

In terms of resignations, when Flora decided to resign from Asibemunye (reasons elaborated upon in Chapter Seven), Njabulo and Ayanda accused Flora of *"whispering behind our backs because she [Flora] had a chance to tell us straight in the eyes that she was resigning."* Njabulo exclaims that Flora was busy *"talking about us and then quits".* This brief account shows the importance that group members attribute to group loyalty. Njabulo and Ayanda were offended by the manner in which Flora left the group, simultaneously accusing her of gossip about the group. In the same instance, Njabulo and Ayanda are effectively gossiping about Flora's departure.

Similarly, within the Nawe Sondela support group, when Mandla stopped attending meetings, other members began talking about him turning the meeting. Phindile said, *"Mandla says he has found a job, but it's not true".* Members accused Mandla of "*running away from his problems".* The week after the group expressed these

sentiments, Mbali explains to the group that *"If you see Mandla during the day [in the community], that it is not because he isn't working, he is just off work early."* Lee responded, *"Someone from the group must have told Mandla what we were talking about on Tuesday because how else would he know to say that [referring to Mbali's statement]".* Mfundo says, *"Mandla has a lot of stress, and he is not leaving his house".* In general, the group did not approve of Mandla not attending the support group meetings because before his resignation Mandla was very active within the group. Thus, his resignation symbolizes disloyalty, and the group expresses resentment over Mandla's disloyalty and departure through engaging in gossip about Mandla.

The Isibani team on numerous occasions remarked and also reprimanded both support groups for gossiping about other group members. For example, an Isibani caregiver, Hlengiwe tells the group, *"Today I am not feeling well because people from Asibemunye are gossiping about other people. If you come here to gossip about others, you must stay home because it is a waste of time for you to come here. Do I need to tell someone to come and solve the group's problems? Please act like elders because it doesn't look good to other people and new member too [referring to gossiping about others]."* Sbongile expressed the following sentiment, which is pertinent to Hlengiwe's statement, *"People from Asibemunye are not serious [about projects]. But if you tell them to gossip, they are very good in useless things."*

For instance, Bongiwe told members of Nawe Sondela support group *"Be honest and confident. Don't talk about other people's business. We are here to help each other, not*

to discourage one another. Try to do something to help yourself, your group. Try to think about what you can do to build your lives". Additionally, Sister Joyce Sithole, at the Nawe Sondela Christmas party, told the members, *"I know that there are many talkative people in this group, but we [Isibani] have always been patient with you [the group] because we don't want to lose communication between us [Isibani Hospice and Woza Nawe]. We all know that people living with AIDS have problems and sometimes they [members] even take these problems into the group and people end up fighting because of stress and no communication. Everyone is affected with this disease, but we have to respect one another because if you don't there are no sisters from Isibani Hospice that will want to come visit you [Nawe Sondela Support Group]. Let's respect each other till next year [2009]. Please let's not come with the same attitude next year".*

The sentiments expressed by members of the Isibani team reflects—

1) Gossip is widespread in Nawe Sondela and Asibemunye.

2) The Isibani team views gossip as hostile and dangerous to the sustainability of the support groups (possibly due to the potential for gossip to erupt into conflict).

3) The Isibani team exercises control over the group via reprimanding the group members, and in the case of Nawe Sondela, a warning that if the members continue to gossip and cause conflict, the Isibani team will not want to support and help the group.

An interesting element of the existence of gossip within the support group is that although viewed negatively by the support group members and the Isibani team, it may in fact contribute to the overall unity of the groups. Gossip, as shown in examples of the

Asibemunye support group, prevent a norm from being breached, by 'putting members in their place' and reminding members of the overall structures and norms which perpetuate their involvement within the groups, thus conflict is averted. When gossip is the cause or the breach (as seen within Nawe Sondela), and sets a social drama into motion, the gossip symbolically functions as a means to reevaluate the norms and relationships amongst the support group members and Isibani, as well as the structures of the support group, thus conflict leads to a new form of unity/stability.

The final section of this chapter highlights all aspects discussed within this chapter but only centres around one of the support groups, Nawe Sondela. A comparable event did not occur within Asibemunye, and the intensity of this social drama, *Do I Still Have a Support Group?* warrants a discussion. Additionally, the section presents concepts that contribute to the understanding of reciprocity, expectations, and obligations between Nawe Sondela and Isibani Hospice, which will elaborated upon in Chapter Seven.

9. SOCIAL DRAMA: DO I STILL HAVE A SUPPORT GROUP?

This social drama involves several key actors including Nawe Sondela members, in particular Mfundo, Phiwe, and Andiswa, and the Isibani Team, in particular Sister Ngcobo and Lungi. There are elements of gossip, expectations, loyalty, stability, autonomy, and examples of reciprocity (which will become more apparent upon the completion of Chapter Seven).

Breach

Support group members sparsely attended a meeting in March 2008 because many of the members were attending a home based care workshop. A few weeks later during facilitation on gender violence by Bongiwe, a woman raised her hand and introduced herself as vice chairperson of the new committee. The majority of the members did not know what was happening, and the Isibani team was completely unaware of a new committee in Nawe Sondela. The following week, Buhle, Slindile, Andiswa, and Londeka explained to Noxolo and I that *"Mfundo has changed towards us* [the group]". The details at this point were not clear, but Mfundo had started an organization called Thembelami Health Care. Slindile found a letter in the post addressed to Mfundo and Thembelami Health Care. They read the letter, which stated that all members of Thembelami owed R 300.00 to the organization, and members' names from Nawe Sondela were listed in the letter. Andiswa said, *"Mfundo has a lot of money to help out with Thembelami, but has forgotten us [Nawe Sondela]".* The women accused Mfundo of lying to the group because *"Mfundo said he organized the training for us [the support group], but he used us [the support group] as a step in his success".* The women concluded *"We [the support group] want to move away from Mfundo and do everything for ourselves. We want a place to meet very soon, so that we won't bother Mfundo anymore. We trusted him so much. He was very helpful to us, but now he has left us—like this".*

The following week, Noxolo and I gave a ride to Patricia who proceeded to explained, *"I don't want to come to the support group anymore because there are people who are*

talking too much. These ladies with the surname Hlengwa. They like to talk too much; even Mr. Mfundo wants to leave the group because of them". At a gardening session the next day, Andiswa and Slindile explained that the main problem arising from the training session was that Mfundo was mixing HIV positive people with HIV negative people and Phiwe told Mfundo that Nawe Sondela was for HIV positive individuals only, *"it's even in our constitution".*

Andiswa then stated, *"I don't like that Sister Ngcobo is busy begging Mfundo to stay in the group even though he doesn't want to. Mfundo said he doesn't want to be in the group anymore, but if the group wants they can meet at his place".* Andiswa continued, saying Sister Ngcobo is *"taking advantage of us. The group should change and not rely on people who take advantage of them".* Slindile agreed that Isibani is not *"doing right by us in terms of the food parcels. The support group in Port Shepstone gets a lot more food than Nawe Sondela. They [Port Shepstone Support Group] get 10kg bags of Maize Meal a week and here—".* Slindile threw her hands up in the air. Andiswa began to describe her hopes for Nawe Sondela, with their own centre. Noxolo mentioned that Sister Ngcobo suggested the group begins with a container. Andiswa responded, "*Sister Ngcobo has not right to choose what is good for us [the support group]. She is here to provide us with medication and all other things we [support group members] should decide what we want".* The women want to change the committee because some members, such as Zandile are *"siding with Mfundo"*, and so far, decided that Andiswa will be the new chairperson, and Phumie, the secretary.

Crisis ensues

The following week, Sister Ngcobo tells the group she has heard rumours and *"Mfundo is very upset and he resigned from the support group yesterday because Phiwe is busy talking lies about him"*. Andiswa explained that some members wanted to talk to Mfundo before a situation occurred, such as his resignation. Sister Ngcobo requested, *"You [the members] come to us [Isibani] and inform us about situations like this. I tried to solve the problem but Mfundo does not want to talk to the group"*. Later on, Sister Ngcobo told me *"Some of what they are discussing is probably true because this lady, Phiwe, is busy destroying the support group with lots of lies"*. There are rumours (spread by Nawe Sondela members) that Phiwe has previously been kicked *"out of other support groups because she is talkative"*.

Attempts at mediation

The following week, nine members along with the Isibani team held the support group met in the Hlengwa sisters' home. The women at this meeting discussed with Bongiwe the events thus far. Londeka said, *"We [members present at meeting] don't want to talk about their issues with Mfundo because he is the one who doesn't want to talk to us. He even told us [members present at meeting] to come and get our rubbish from his house"*. Andiswa exclaimed, *"I don't beg from anyone and especially won't beg from Mfundo"*. Bongiwe replied, *"Another thing it that Phiwe is talking to you [support group members present], but she is fighting with Mfundo. If they have a fight, do not get into their problems. There are two sides to every story, so try to get [information] that is true, have a meeting with Mfundo, and forget about what Phiwe says"*. Londeka though, *"He*

[Mfundo] will not want to talk to us [support group members]". Andiswa said*, "I am not going there".* In addition, Mbali mentioned, "*He [Mfundo] says, he is not talking to us women because he is a man".* The members decided they will meet next week, but Bongiwe warned, *"Stop making Phiwe your [support group members] messenger because maybe if you talk to her she goes along to Mfundo [and tells him], and when Mfundo talks [to her] she comes to you [and tells support group members]".* Lungi, an Isibani caregiver, responded, *"I know Phiwe very well. You will do things wrong because of her. Everyone knows her. She will destroy Nawe Sondela, after that she will laugh at you. She will say Nawe Sondela is falling apart. If I am there [when support group meets with Mfundo], I will remind Phiwe to today of every time she's done something wrong. She's like that all the time and she will disappear for a long time and will come back when this thing [conflict] is over".*

Crisis escalates: "Crisis is contagious"

On the day of the meeting between Mfundo and the support group members, Noxolo, and I arrived, sat down, and Sister Ngcobo was speaking to the group. She turned to us and says, *"The members are discussing their problems".* Phiwe told the group, *"I told Mfundo that Nawe Sondela cannot be together with negative people [HIV negative] like Thembelami, while we are positive [HIV positive], it's not allowed in our constitution. Mfundo sent me a message on my phone that said, 'Just because you [Phiwe] said you don't want to mix with others [Thembelami], please come with your group [Nawe Sondela] and take all your things [belonging to support group] because I am no longer involved with Nawe Sondela. I don't think it is wrong that I told the group what this message said".* Mfundo responded, *"I wrote that message because of the rumours that*

were being said [about him], that I had received money when members attended the training at Thembelami, and those who told him these rumours said Phiwe was saying them. After I sent the message, Phiwe disappeared for a long time, so I thought the rumours were true". Phiwe says Mfundo said, *"We [support group] must take him out f the committee as chairperson. So we [support group] decided to select Andiswa as chairperson".*

Phiwe told Sister Ngcobo, *"I heard that someone from Isibani told the group, 'why do you allow Phiwe in this support group because the group knows what she did last time'".* Lungi from Isibani raised her hand and says, *"I know that you [Phiwe] know that it was me [Lungi] who said that last week Tuesday. I said that because last time you talked about one of the sisters from Isibani Hospice, you said 'how can Isibani Hospice hire that person who is drinking and you also mentioned that person's name'. We [at Isibani] did not like that. We realized that you are a talkative person because you whisper about that person to the head sister [Sister Joyce Sithole] because you wanted Isibani to fire her".* Phiwe told Lungi, *"That was a long time ago. And I can say it again, we [support group] cannot get enough help if you sisters [Isibani team] are drinking and expect us to respect you. We cannot".*

Mediation takes place

At this point, Sister Ngcobo attempted to mediate, *"I heard the entire story now, but now it is time to make things right. We are not here to fight anymore, we are solving problems here".* Noluthando raised her hand and mentions, *"Maybe we were also wrong*

by going to the Thembelami meeting when we [support group] does not know who they are [Thembelami], where they come from and what they do. We are supposed to get information about what is happening first". Sister Ngcobo thanked Noluthando for taking some blame [of conflict] for the group *"being careless".* Londeka said, *"The only problem here is that negative people were mixing with positive people [idea that Mfundo was trying to get Nawe Sondela to join in with his newly formed organization Thembelami Health Care]".* Phiwe agreed, *"No one has told me where I was wrong and what wrong I did to anyone".*

Reverts back to crisis

Andiswa told the group, "*Lungi [from Isibani] said that Mfundo should not talk too much to Phiwe because Mfundo is a man, not a woman".* Phiwe became very angry, stood up and moved towards Lungi, as if she wants to fight Lungi, and several members including Mfundo held Phiwe back, Phiwe screamed, *"Lungi is busy bad mouthing my name and you want me to leaver her, just like that".* Mfundo told Phiwe to stop, but an argument erupts between Lungi and Phiwe, who begin shouting at each other. Sister Ngcobo told everyone to calm down, and other members in the group begin talking loudly. Mfundo told Phiwe to calm down, *"I did not want to talk to you because there were rumours that you and I were lovers".* Several members confirm they also heard this rumours. Phiwe began to calm down and sat back down.

Mediation & Crisis

Sister Ngcobo told the group that Mfundo has offered for the group to still meet at his place, and told everyone to meet at Mfundo's place the following week. Mfundo was no longer a part of the support group and continued working with his new organization, Thembelami Health Care. As the argument came to an end, Andiswa said, *"Now that problem [with Thembelami] is over, there is one "snake" who pretends to be sick but is not sick".* Several members, Mbali, Thusile, and Londeka agree with Andiswa's statement". Andiswa continued, *"It's a shame because this person is very old and she asks Mfundo and Isibani Hospice for help. She has to stop. They [some members of group] heard she is a real snake, and that person is Nomula".* Andiswa told Sister Ngcobo, *"People talk too much in Nawe Sondela. They [the members] even talk about you [Sister Ngcobo]. They say they don't want you anymore, and it was better when Sister Khosi was working with the group".* Sister Ngcobo responded to Andiswa, *"People [support group] will not like everything you [Isibani] do for the people and some will hate you for no reasons. I appreciate you [Andiswa] telling me because I am always waiting for challenges like this. If people can't discuss things they see wrong with me, than I am not a good leader".* Andiswa told Sister Ngcobo, *"You [Sister Ngcobo] should know one day you will eat poison without knowing who did it because people are complaining about everything that you do".* Sister Ngcobo replied, *"You [support group members] can all say what you want, but I will always give to those who want it, no matter what they say about me and how bad it gets, she will always help them [the support group]".*

Mediation and Resolution

There was a lull in the conversation and Bongiwe asked the group, *"I was wondering if I still have a support group"*. Several members said *"Yes. You still do"*. Bongiwe said, *"I am glad because if I don't that means I don't have a job anymore, but if you say yes, I am glad. Now that you [the group] are done discussing problems we [Isibani and group] should talk about the progress of Nawe Sondela"*. A brief discussion of Hospice Day, which was taking place in two weeks, but the group, explained to Bongiwe that they had not done anything to plan for the event. Bongiwe replied, *"You [the group] should start [working on a plan for Hospice Day]. Make sure you do what is best for the group. Do not talk about helpless things"*.

Member began standing up, Isibani began handing out lunch and juice and then places several bags of clothes in the middle of everyone. The members began sorting through the clothes. Several members were engaged in conversation. Mfundo was talking with Andiswa, who was smiling and laughing. Phiwe was mingling with several members. I turned to Noxolo and asked, *"Is it [the conflict] over?"* Noxolo replied, *"I guess so"*.

The element of conflict with each support group has been illustrated throughout this chapter by analyzing the concepts of expectations, autonomy, stability, loyalty, and gossip. A particular element that manifests from the discussion of conflict within each group is the way that each support group functions in a manner reflective of Gluckman's notion that societies/groups oscillate between conflict and unity. Moreover, there is an indication that "no neat integration of norms and values" exist within each support group,

rather “often there are conflicting values and principles, as well as conflicting interest groups” (Morris, 1987: 248).

The following chapter also analyses the “norms and values” of the support group, but from a perspective of a system of reciprocity between each group and Isibani Hospice.

CHAPTER SEVEN- NEGOTIATED RECIPROCITY

The previous chapters within this study provide a framework in which to comprehend the dynamics of the participants within this study: Nawe Sondela, Asibemunye, and Isibani, and the structures of each HIV/AIDS support group, both of which contribute to the overall functioning of the support groups. Chapter Six delved into the notion that, at times, the relationships and interactions between these participants results, in instances of gossip and conflict, specifically due to a discrepancy and/or unfamiliarity of goals, expectations, and purposes among all the participants involved within this study.

Chapter Seven aims to elaborate on a vital component within each support group, a system of reciprocity[23] that becomes evident when analyzing the roles, relationships, and interactions of Isibani Hospice and each support group. The notion of reciprocity within each support group will be demonstrated through ethnographic examples and analysis of expectations, obligations, and conflict within each support group.

As stated previously, Chapter Six and Chapter Seven are integrally linked. For instance, the concepts of autonomy, stability, and loyalty are also relevant to the discussion of reciprocity. Moreover, an integral aspect of the system of reciprocity between each support group and the sponsoring organization is the element of conflict, which will be expounded upon through ethnographic accounts and the use of social drama.

[23] Reciprocity i.e. reciprocal refers to "1) given or shown by each of two sides of people to the other, 2) given or done in return for something else, and 3) something mutual that is done in return (Encarta, 2009).

First, an outline of the theoretical underpinnings of gift-exchange and reciprocity are necessary in order to understand the form of reciprocity, which exist within both HIV/AIDS support groups.

1. MAUSS AND GIFT-EXCHANGE

Anthropologists studying the theory of reciprocity within society are greatly influenced by the concepts of gift-exchange proposed by Marcel Mauss in *The Gift,* originally published in 1925 (Firth, 1967; McGee & Warms, 2004; Sahlins, 1972). Marcel Mauss[24] examined the principles of gift-exchange through a cross-comparative analysis of historical and ethnographic studies of (in the terminology of his day) "primitive or archaic types of societies" particularly in Melanesia, North-West America, and Polynesia (including Malinowski's study on the Kula). Mauss referred to the system of gift-exchange as a concept of "total prestations" (Mauss, 1969: 1-3). Prestation refers to "any thing or series of things given freely or obligatorily as a gift or in exchange; and includes services, entertainments, etc., as well as material things (Mauss, 1969: *xi).* Mauss uses examples of the "potlatch"[25] within these societies, as a means to explain various facets of gift-exchange.

[24] Marcel Mauss trained under the French sociologist, Emile Durkheim, and his work is greatly influenced by Durkheim's concept of social facts and viewing phenomena in its totality (Mauss, 1969; McGee & Warms, 2004). Mauss states, "We are concerned with the 'wholes', with systems in their entirety. … Only my making such concrete observations of social life is it possible to come upon facts such as those which out study is beginning to reveal. Nothing in our opinion is more urgent or promising than research into 'total' social phenomenon" (Mauss, 1969: 77-78).

[25] Potlatch refers to a grand 'ceremonial exchange' that usually takes place between different societies/groups. The distribution in goods allows for the host(s) to displays power, prestige, and rank within their own society and in comparison to the 'guest", who then hosts a potlatch, which in theory often aims to 'outdo' the original event. Anthropologists through the years have explained various interpretations on the function that potlatch has within society (Seymour-Smith, 1986: 229).

Throughout *The Gift*, Mauss examines the concept of prestations through several key principles including the form a gift takes, the “spirit of the thing given”, rules and motivations of gift giving, and the “three obligations: giving, receiving, repaying” (Mauss, 1969). The following excerpts from *The Gift* provide insight into how Mauss understands the notion of gift-exchange. The act of giving creates a bond between the giver and recipient, and the gift itself creates an obligation to repay because “to give something is to give a part of oneself”, and thus, one receives “a part of someone’s spiritual essence”. Concerning the theory of obligations, to give, receive, and repay, there are a “series of rights and duties” that are involved (Mauss, 1969: 10-11). The three obligations have a reciprocal and cyclical pattern, one must give because one has, in the past, received, and one is obligated to receive if given a gift, thus if one receives there is an obligation to repay. For instance Mauss (1969:11, 39-40) states, “To refuse to give, or to fail to invite, is—like refusing to accept—the equivalent of a declaration of war; it is a refusal of friendship and intercourse”, and to refuse a gift, “would show fear of having to repay and being abased in default”, and finally, when repaying a gift, a “worthy return is imperative” and in some cases of more value than the original gift. Moreover, according to Mauss, the “failure to give or receive, like failure to make return gifts, means a loss of dignity” (Mauss, 1969: 40).

There are many more principles and ideas associated with Mauss’s conception of gift-exchange. Mauss stated that the theory of gift-exchange he proposed, “is incomplete: the analysis could be pushed farther. We are really posing questions for historians and

anthropologists and offering possible lines of research for them rather than resolving a problem and laying down definite answers" (Mauss, 1969: 76).

Thus, it is necessary to review anthropological responses and elaborations on Mauss's theory of gift-exchange. In particular, the theoretical contributions and commentary on reciprocity by anthropologists Mfundo Firth[26] and Marshall Sahlins[27] prove useful to the discussions of reciprocity within this chapter, Chapter Seven.

2. GIFT-EXCHANGE FROM FIRTH'S PERSPECTIVE

Firth compares principles of Mauss's theory of gift-exchange with evidence from his study on the Tikopia society (a "primitive or archaic" Polynesian society). Firth explains the triple obligation to give, receive, and repay was existent within the Tikopia society, yet gift-exchange took place between groups and individuals, whereas Mauss viewed gift-exchange as a "total prestations", between groups and/or societies (Firth, 1967). Furthermore, Firth did not find evidence within his study of Tikopia society that giving a gift entails giving away a part of one's spirit as cited by Mauss. According to Firth, the triple obligation of gift-exchange is not as straightforward as Mauss suggests, rather, "in

[26] Raymond Firth, a British social anthropologist, was a student of Bronsilaw Malinowski, and placed importance on "linking interpretations of symbolism to social structures and social events", yet he made a "notable divergence from the prevailing orthodoxy of structural functionalist theory". In particular, Firth focused on concepts of social organization and contributed to the development of theories in economic anthropology. Victor Turner was influenced by the work of Firth (McGee & Warms, 2004: 538; Seymour-Smith, 1986: 119).

[27] Marshall Sahlins, an American anthropologist, studied under Leslie White, and originally focused attention to the theoretical concepts of cultural ecology. Sahlins contributed to the development of economic anthropology, and also looks at the interplay between history, anthropology, and culture (, Nation Master Encyclopedia, 2009).

all three fields there are significant areas of choice and uncertainty, and that in the existence of this uncertainty lie some of the most delicate problems of procedure for those engaged in the transactions" (Firth, 1967: 10). Moreover, Firth categorizes the practice of gift giving into three "sanctions" of 1) economic and political advantage, 2) social status, and 3) religious belief, and that the obligation to give falls primarily under sanction 1 and 2 (Firth, 1967). Mauss's concept of social status, prestige, and "losing face", is expounded upon by Firth, who states, "giving is an extension of the self, and hence the obligation to give is bound up with the notion of the self, its social bounds and social roles" (Firth, 1967: 10-11).

Firth analyses the act of gift-giving and reciprocity, which often takes place between the anthropologist partaking in fieldwork and the actors/friends/communities under study, as a means to highlight several key aspects of reciprocity. For instance, Firth explains Mauss conceived of gift-exchange taking place between groups of equal social status, but the involved parties may not be on par with one another and a differentiation of status may exist, i.e. differences in economic position (Firth, 1967: 13). In the case of the anthropologist and those under study, Firth cites that the Malay peasants he worked amongst viewed Firth as a source of unlimited wealth. Thus, "to ask for assistance, then, was not necessarily demeaning, indeed could seem quite reasonable in their circumstances", which "conditioned the attitude towards reciprocity" i.e. no obligation or expectation to repay existed (Firth, 1967: 13). Even if the expectation to repay no longer exists, in a sense, the recipient's repayment does not necessarily involve material goods. Rather the act of giving may be seen as "an instrument of enhancement for the giver",

thus the giver may receive “status or merit by his act” (Firth, 1967: 15). Additionally, Firth’s examination of reciprocity reveals three variations in reciprocal transactions (elaborated upon in Section 3).

A complexity and ambiguity exists amongst the three obligations, and the reality of reciprocity between societies/groups/individuals shows there “is often some degree of uncertainty as to whether to give and whether to reciprocate (Firth, 1967: 17).

In addition to Firth’s elaboration on gift-exchange, Marshall Sahlins developed a model for reciprocity, and aspects of this model prove useful in the analysis of the ethnographic accounts within this chapter.

3. SAHLINS’ “SPECTRUM OF RECIPROCITIES”

Marshall Sahlins, in *Stone Age Economics,* defines reciprocity as a “whole class of exchanges, a continuum of forms”, and furthermore Sahlins perceives that two types of economic transaction exist 1) vice-versa action “between two parties”, e.g. “reciprocity”, and 2) collection and redistribution within group, e.g. pooling (Sahlins, 1972:188). Examples of vice versa transactions may include loans/repayment, informal hospitality, sharing/counter-sharing of food. In terms of the reciprocal transactions, Sahlins developed a model—“a spectrum of reciprocities”, which describes three types of reciprocity generalized, balanced, and negative and that form of reciprocity. Sahlins additionally proposed that the type of reciprocity individuals/groups engage in is

dependent on several variables including the idea of "kinship distance", e.g. generalized reciprocity is the norm between closer the kin relations, and on the other end of the spectrum, negative reciprocity often occurs between distant kin relations[28] (Sahlins, 1972: 193). In addition to kinship distance, the relationship between reciprocity and kinship rank, wealth, and food play a role in determining the type or form reciprocity takes (generalized, balanced or negative) (Sahlins, 1972).

Generalized reciprocity involves "putatively altruistic" transactions, a transaction in which a repayment takes place only if necessary and able. This form of reciprocity is similar to Malinowski's description of a "pure gift" amongst the Trobriand islanders, which Sahlins notes is similar to a free gift, hospitality, and sharing. The obligation to repay in this scenario does not have stipulations of quantity, time, or quality; thus, the "expectation of reciprocity is indefinite" (Sahlins, 1972: 194). Opposed to a "sustained one way flow" of goods within generalized reciprocity, balanced reciprocity presents a more equal transaction between two parties, therefore when something is given, the reciprocal transaction is equal to that which was given, and often takes place immediately after the first transaction. Sahlins qualifies balanced reciprocity as a "less personal" and "more economic" transaction, whereas generalized reciprocity, according to Sahlins' theory, would often take place amongst those of close kinship relations (Sahlins, 1972: 193-194). An important observation for Sahlins is that within generalized reciprocity the "material flow is sustained by prevailing social relations" and balanced reciprocity the "social relations hinge on the material flow" (Sahlins, 1972: 195). The final form of

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[28] Refer to Appendix A, B, and C in *Stone Age Economics* for a list of societies/tribes/communities that provide ethnographic examples of the relationships between the types of reciprocity and kinship distance, kinship rank, and wealth (Sahlins, 1972).

reciprocity is negative reciprocity, referred to as the “unsociable extreme”, where one partakes in a transaction with the hopes of having to return nothing—the least personal, but possibly most economical form of transaction. Similar to generalized reciprocity, within negative reciprocity the reciprocal action of a return action/gift is conditional; as a result, a “one-way” flow of exchange may exist” (Sahlins, 1972: 195).

The particulars of Sahlins model on the concepts of kinship distance and rank will not be described at this point, but the discussion of reciprocity in relation to wealth and food prove useful to the understanding of reciprocity within the support groups under study. Similar to Firth’s example of the anthropologist’s relationship with informants in the field, a difference in economic positions may exist between those involved in a reciprocal transaction. Sahlins explains that differences in wealth, especially for the wealthier participant in the transaction, may result in a more generalized reciprocity, “a more altruistic transaction” (Sahlins, 1972: 211). Moreover, in Sahlins’ words, “the greater the wealth gap, the greater the demonstrable assistance from rich to poor is necessary just to maintain a degree of sociability” (Sahlins, 1972: 211).

Another degree within the reciprocal spectrum offered by Sahlins is the concept of food within reciprocal transactions. Sahlins states that differences exist between goods exchanged and food being exchanged, that “socially they [staple foodstuffs] are not quite like anything else” due to the necessity of food for one’s survival. Furthermore, the exchange of food, may be viewed as a “starting, a sustaining, or a destroying mechanism of sociability” and the exchange of foodstuffs tends to follow the route of generalized

reciprocity (Sahlins, 1972: 215).

Attributes of Sahlins' model of reciprocity are described within this section, but this description does not detail the intricacies of Sahlin's model. The discussion presented is sufficient in relation to understanding concepts of reciprocity within this study.

Counter arguments and discussions of reciprocity within anthropology are far reaching, and several authors will be discussed within Section 4.

4. ADDITIONAL COMMENTARY ON RECIPROCITY

In addition to the discussion of gift-exchange and reciprocity from the viewpoints of Mauss, Firth, and Sahlins, Sherry (1983) describes several factors involved with gift-exchange. Sherry (1983) states that when considering the donor and recipient of a reciprocal transaction, the intention, motivation, reaction, and status of the involved parties must be examined. Sherry asserts there is a "motivation continuum" of the donor ranging from altruistic, "maximize pleasure", to agonistic motivations, "maximize personal satisfaction" (Sherry, 1983: 160). Additionally, Schwimmer (1979: 271) focuses on the analysis of reciprocity and myths of the Orokavia society as a means to understand the structures/"world order" within the society commenting, "The principle of reciprocity is one of the structures around which men organize their thoughts" (McCormack, 1976; Schwimmer, 1979: 272).

The complexity and, at times, ambiguity surrounding the notion of reciprocity and various types of reciprocity, and the role these ideas have within anthropological studies has led to criticism of the theory of reciprocity used within studies. In particular, McCormack (1976) believes that there needs to be more understanding of and description within studies that use the terms, "reciprocity", "reciprocal", and "principles of reciprocity". Moreover, McCormack (1976: 89) states, "They ['reciprocity' and 'reciprocal'] appear to have a simple and even self-evident meaning, but any attempt to ascertain precisely what aspects of social relationships they describe proves elusive". McCormack reviews the various ways in which anthropologists (including Evans-Pritchard, Firth, Sahlins, and Mauss) have developed the concepts and use the terminology of reciprocity. With regards to Sahlins' model of reciprocity, McCormack (1976: 99) states, "It is not clear whether the model is descriptive or normative, that is whether it provides a scheme of analysis for patterns of behaviour or rules". Additionally, Lebra (1975: 559) offers a critique of Sahlins' model of reciprocity and forms an alternate view of reciprocity based on the concepts of intimacy and courtesy, object dualism, and Lebra's term the "triadization of reciprocity".

I believe due to the ambiguous nature of reciprocity and the various ways in which reciprocity may be interpreted within a particular set of social relations, anthropologists since the original discussion of Mauss's *The Gift,* and Malinowski's ideas on exchange amongst the Trobriand islanders, various "genres" or variations (as Sahlins describes) of reciprocity have developed in order to conceptualize the intricacies involved. For instance, the "norms of reciprocity" proposed by Gouldner maintain that receiving

implies the expectation to repay (outside of obligations within kinship relations), and "the norm contributes to the maintenance of social stability" through the social networks and relationships involved within the reciprocal transactions (Gouldner, 1960; McCormack, 1976: 98). Additionally, Sahlins points to Price's idea of "weak reciprocity", which refers to the "vagueness of the obligation to reciprocate" (Sahlins, 1972: 194). McCormack (1976: 95) cites that Kridge and Kridge conceived that the "ideal of reciprocity" meant kin and neighbours are always helping others within the community without expectation of a repayment. Ojong (2009) develops the notion of "forced reciprocity" through the examination of African migrants and their decisions/choices regarding making remittances to their home country.

Thus, a perusal of anthropological studies (Bird & Bird, 1997; Gouldner, 1960; Ojong, 2009; Schwimmer, 1979; Sherry, 1983) on reciprocity results in a vast diversity of focus, types, and ideas on the topic. Moreover, it becomes evident that anthropologists' theory of reciprocity may be dependent on one's affiliation with a particular school of anthropological thought, but also that the relationships, groups, and/or societies under study at times necessitate the use of "genres" or variations of reciprocity.

These concepts of reciprocity provide a framework in which to recognize the unique system of reciprocity existent within each support group and Isibani Hospice. A brief review of ideas on support, in relation to the support groups and sponsoring organizations, also presents several concepts related to this system of reciprocity.

5. SUPPORT RE-EXAMINED

The discussion of expectations in Chapter Six reiterated a theme present throughout this study, on the participants and structures of Nawe Sondela, Asibemunye, and Isibani Hospice. These factors (participation and structure) are not only integral to this study, but they are intrinsic to the entire concept of HIV/AIDS support groups, and in particular, Chapter Seven.

A summation of key concepts discussed in Chapter Two is relevant to the understanding of reciprocity within each support group. Support groups, social support, support networks— inherent in all of these concepts is the notion of support, e.g. the act of assistance, help, comfort. The act of providing support negates that one or more parties are involved within this action, 1) an individual/group/community providing the support (giver/donor), and 2) an individual/group/community receiving this support (receiver/recipient). As mentioned previously, support may take different forms. For instance, Kalichman & Sikkema (1996) describe three types of support: emotional, informational, and instrumental. These forms of support provided by Isibani Hospice to both support groups may be described as emotional support, e.g. enquiries into members' health and wellbeing, and offering advice, informational support, such as providing information on HIV/AIDS, Tuberculosis, health-related and social issues, and instrumental support, e.g. providing medicine, food parcels, lunch, clothing, sewing machines.

The purpose of HIV/AIDS support groups in its simplest form is to provide support to people living with HIV/AIDS. This support may also take the form of emotional and psychological support. Moreover, the support may assist individuals living with HIV/AIDS to develop coping skills, reduce stress, and improves quality of life (refer to Coleman & Harris, 1989; Friedland et al., 1996; Schopler & Galinsky, 1993; Spirig, 1998; Uys & Cameron, 2003). From the perspective of social support, varying perceptions of the 'act' of support may exist between the giver and receiver of support. There may be differences in motivations, perceived effects, and reactions to the act of support (Green, 1993; Jacobson, 1987; McDowell & Serovich, 2007). As Jacobson (1987: 42) states, "Different social circumstances and /or individual needs can lead to different interpretations of an action's significance". The ability to discern perceived versus actual support of donors and recipients is difficult due to the psychological and behavioral attributes associated with the giving and receiving of support (Jacobson, 1987; McDowell & Serovich, 2007).

Several key factors of support seen through the explanations above:

1) Support involves a giver and receiver, donor and recipient.
2) Support may take various forms.
3) Various motivations, reasons, and outcomes are associated with the act of support.
4) The giver and receiver of support may perceive the act differently.

The final statement, the differences in interpretation and/or perception of support, I believe, are useful as a starting point for the understanding of reciprocity with each

support group, and as a means to view facets of the relationships/interactions between Isibani Hospice and each support group from a reciprocal viewpoint.

Reasons for the varying interpretations of the support given by Isibani Hospice and received by Nawe Sondela and Asibemunye support group members, centres on different interpretations and expectations of the support group participants (Nawe Sondela, Asibemunye, and Isibani Hospice). As stated in Chapter Six, these perceptions of expectations are crucial to the development of each support group. In addition, the conceptualization of expectations by both Isibani Hospice and each support group aids in defining the purpose of the group and affects the means in which the involved parties seek to achieve this purpose. Chapter Six revealed that expectations, as well as interpersonal relationships amongst the support group members and Isibani team, at times, resulted in conflict.

The discussion of expectations within this chapter is in relation to a system of reciprocity, which I argue is inherent in the formation and functioning of both Nawe Sondela and Asibemunye support groups. According to the types of reciprocity described by Sahlins (1972), an exchange or transaction between individuals and/or groups may be balanced, generalized, or negative reciprocity. The type of reciprocity existent between Isibani and each support group does not "fit" into the types of reciprocity described above for several reasons. (An understanding of the roles, goals, and structures of Isibani, Nawe Sondela, and Asibemunye are vital to this claim; these aspects were elaborated upon in detail throughout Chapters Three-Five).

Section 6 will describe the form of reciprocity that takes place within the support groups under study. Following this description, ethnographic examples as well as social drama will illustrate this form of reciprocity within Nawe Sondela and Asibemunye.

6. CONCEPT OF NEGOTIATED RECIPROCITY

The forms of support described within Section 5 are a facet of the reciprocal transactions and/or exchanges between Isibani Hospice and each support group. The reciprocal nature of their relationship, simply stated, is Isibani provides support to the members, and the support group members, in return, participate in the support group meetings, and fulfill the role of the recipient of support. Yet, the relationship between these two entities is more complex, because the expectation of the involved parties translates into a system of obligations between each support group and Isibani, and vice versa.

Isibani Hospice aims to provide emotional, informational, and material support to Nawe Sondela and Asibemunye, but the notion of reciprocity centers on the role (giving and receiving) of material support within each support group. Isibani Hospice gives vitamins, food parcels, clothing, and provides lunch for the support group members. The support group members attend the meetings for a variety of reasons (refer to Chapter Four and Five: Reasons for Joining Support Group), but a primary aspect of attendance is based on the goods/donations support group members will receive if they attend the meetings (ethnographic examples will be provided in subsequent sections). The reciprocity existent within this transaction does not resemble balanced reciprocity, because an equal

exchange does not take place, primarily due to a differentiation of wealth. Members within each support group are faced with the effects of poverty on a daily basis, and Isibani Hospice, as an organization, has the means, e.g. donations are available; therefore, this differentiation does not make balanced reciprocity an option within these groups. The form of reciprocity within the support groups under study has aspects of both generalized and negative reciprocity. Features of generalized reciprocity exist primarily from the stance of Isibani Hospice towards the support groups, and as support group members are not in a material position to give in return (repay), the transaction reflects aspects of a free gift or hospitality. In addition, the Isibani organization is of an altruistic nature—to give to those in need, thus, similar to the idea of "putatively altruistic" (Sahlins, 1972: 194) within generalized reciprocity. Yet, unlike generalized reciprocity, Isibani Hospice has expectations for the support group members to "repay" their gift, thus the "expectation of reciprocity" is not indefinite. Additionally, aspects of negative reciprocity are evident primarily from the viewpoint of the support group members. For instance, the support group members, in some ways, partake in a transaction with Isibani Hospice in the hopes "to get something for nothing" (Sahlins, 1972: 195).

What exists between Isibani Hospice and each support group, Nawe Sondela and Asibemunye, is a form of reciprocity, which I term "negotiated reciprocity". Negotiated refers to an "attempt to come to an agreement of something through discussion and compromise" (Encarta, 2009). This term, coupled with the aspects of reciprocity described above, provides a means to explain the constant interplay and/or negotiation that takes place between the expectations and obligations that both Isibani Hospice and

the support group members have for one another. Furthermore, conflict often erupts with the support groups under study when a breach in the expectation of reciprocity is not met[29].

The following sections provide ethnographic examples and accounts of negotiated reciprocity viewed from the idea of the three obligations: to give, receive, and repay. Many more examples and situations have occurred involving the giving and receiving of food, clothing, toys, and T-shirts between Isibani, each support group, and myself. The ethnographic accounts shown here aim to highlight and provide a glimpse into the nature of reciprocity within the groups under study; additionally, these examples are indicative of similar events which occurred throughout the year.

7. THE OBLIGATION TO GIVE

7.1 THE OFFER

A reciprocal relationship most often begins with an individual and/or group entering into the transaction through the giving of a gift and/or service to another individual or group. Implicit in this gesture of a gift or service is the notion of an offer "to provide something, or make something available" (Encarta, 2009) to someone else.

[29] Refer to the Social Drama 1 in Chapter Six, which describes Sister Ngcobo's disappointment that, Isibani had upheld their end of the bargain, so to speak, by providing the support group members of Nawe Sondela with donations, and finding a meeting venue for the group, yet the support group members are "disloyal" and talking "behind my [Sister Ngcobo] back "with NAPWA.

Isibani Hospice offers their services of providing support to the support groups free of charge. Bongiwe, the support group coordinator describes the role of Isibani and these services, saying Isibani is "*providing the education that they [the support group members] basically need, maybe they would have concerns, maybe questions that they need answered. And maybe if we have things to help them like food parcels and things like that".* Interestingly, the "offer" of food parcels is mentioned last, symbolically indicating in the view of Isibani Hospice, a ranking in importance of the services offered.

When I began my fieldwork with both support groups, I felt obligated to offer my help and/or services to the support group members. The reasons for my feelings of obligation are most likely similar to many anthropologists who feel a sense of duty and/or need to repay those actors who are willing to let us [the anthropologist] participate in and observe their lives. Also, at one of the initial Asibemunye meetings I attended, Nolu asked that since I would be coming every week now, could I bring food parcels for the group. In addition to this and my own sense of obligation, I told each group, *"I can help you with things in terms of learning about grants, and income-generating projects".* This offer of help and my subsequent "gifts" were sometimes received well by the support group members, but at times, these gifts also resulted in conflict.

The reciprocity existent within these support groups begins with the offer of a gift, thus Isibani enters into a relationship with the support groups, and from this relationship stems the obligation to give. The motivations and reasons for Isibani Hospice providing/offering gifts is important to consider, as the way in which Isibani negotiates

the reciprocal relationship with each support group has its basis in the preconceived motivations of the gift.

7.2 THE REQUEST

The offer to give may or may not be preceded by a request[30] of an individual or group for another party or individual to give something. In the case of Nawe Sondela and Asibemunye, the original members of the group contacted and requested the services of Isibani Hospice, which led to Isibani Hospice becoming each support group's sponsoring organization. Additionally, the organizational culture within each support group indicates that the act of requesting is a norm within both support groups. For example, members regularly makes requests of Isibani concerning discussions and donations, and the Isibani team makes requests of the support group members to become involved in certain events or projects. The request is not only crucial to the existence of reciprocity, but requests are also involved in negotiating the terms of reciprocity.

For instance, Isibani restructured their services offered to patients and as of January 2009, the Category 2 patients began attending support group meetings with Category 1 patients; simultaneously, the Isibani teams began bringing lunch for the members at the weekly support group meetings. Bongiwe explains, *"The motive behind that [bringing lunch] was most of the patients [Category 2] we [Isibani teams] had been visiting at home complained that maybe they have to come far and by the time it is twelve, they are hungry*

[30] Request in this context means "to ask somebody for something" or "to ask somebody to do something", an "an act of asking or petitioning for something to be done or given" (Encarta, 2009).

and need something. So, that is when we started to provide food. So that they [the support group members] know when they come to the support groups they have something to eat. They won't just sit there and go hungry".

This quote from Bongiwe exemplifies the notion of "negotiated reciprocity". Isibani wanted to change the structures and/or way it provided services to Category 2 patients. The category 2 patients do not appear to be completely "on board" with Isibani's restructuring. Thus, the category 2 patients requested or complained, according to Bongiwe, that if they [the category 2 patients] were to participate in Isibani's new venture, the restructuring, the patients would like to receive lunch at the support group meetings. The Category 2 patients negotiated the terms of exchange and expectations — they will remain patients of Isibani Hospice (a mutually beneficial act, in particular for Isibani who wants and needs patients) but they want to benefit in some way, e.g. lunch. An additional factor or motivation for this negotiation is that Category 2 patients received food parcels from the Isibani teams visiting their homes, whereas membership in a support group does not necessarily entail receiving food parcels on a weekly basis.

In the realm of the "obligation to give", the components of offers and requests are relevant to the discussion of reciprocity with each support group. Furthermore, the culmination of the offers and requests of Isibani Hospice with the offers and requests from the support group members, at times, are not always compatible.
A second element in the system of negotiated reciprocity, the obligation to receive, is discussed in Section 8.

8. THE OBLIGATION TO RECEIVE

Mauss states within the theory of gift-exchange, there is an obligation to receive because a refusal would result in 'loss of face' affecting an individual or group's prestige and status (Mauss, 1969). This statement suggests gifts are scarcely refused, but Firth (1967:15) explains refusal of a gift may occur if 1) it is too much or too little, i.e. "over-generous" or "inadequate", and even then, the individual may still accept the gift in relation to ideas of status and respect of the donor.

Within this study, the obligation to receive often centers on transactions of foodstuffs. The majority of support group members in Nawe Sondela and Asibemunye are of a low economic position; thus, the support group members rarely refuse donations from Isibani such as donations of clothing and food, as well as vitamins on a monthly basis.

An element of conflict exists amongst support group members upon receiving donations, in particular foodstuffs. Conflict does not occur every time the support group members receive donations, but it is wide spread within both support groups.

8.1 CONFLICTS OVER 'GIFTS' RECIEVED

Both support groups do not receive the same type of donations, nor do they receive the same quantity of donations. For instance, Nawe Sondela support group receives some form of donation every week, most often foodstuffs. In contrast, the Asibemunye support

group receives donations around two to three times per month (sometimes less often), and the donations are usually clothes, shoes, and material for sewing as opposed to food. Sister Joyce Sithole commented that within Asibemunye support group, *"More members used to come when there was a food parcel, but now there are no food parcels, so only 11 come— the genuine ones [members]"*.

Conflicts and arguments often occur amongst the support group members when sorting through the donations Isibani has brought to the meeting. For instance, at an Asibemunye meeting, the group members began sorting through large bags full of bread and pastries. When Nolu came to take some of the donations, there were four pieces of bread left. Nolu told Cebo, *"Everyone should put all the bread back because I was not here when everyone started taking [the bread]"*. The following week, a member suggested that when receiving donations from Isibani Hospice, members "*should take one by one, and not go for the stuff at the same time"*. Several members began making motions of running and pointing at Nolu. Nolu rolls her eyes. Sister Joyce Sithole commented, *"I like what you [the member] are saying because it is not a good idea to act like kids. Fanele, what do you think because you are one of the oldest members in the group?"* Fanele responds, *"I like it because some people [members] leave the meeting without getting anything [donations]"*.

Similarly, on several occasions Sister Ngcobo made comments that members of Nawe Sondela are *"fighting about clothes"*. On one occasion, members were sorting through boxes of food (vegetables and fruit) and began arguing while sorting through the box.

Slindile told the group, "*Sister Ngcobo says we [the group] must try to give everyone [something], so that people won't get angry"*. Similarly, Lee explained that Sister Ngcobo mentioned, *"They [members] should give the old people food first"*. Goodness became angry because the members handing items from the box were supposedly "*not cutting an apple so that everyone will get some"*. Sister Ngcobo told the group, *"You [the members] must figure it out and not fight. Next time I will bring more"*.

These examples demonstrate the nature in which many of the donations are received by support group members. Additionally, comments from the Isibani team suggest that the fighting is inappropriate but also a norm within the groups, and despite the conflict, Isibani continues to provide and offer the support.

The following statements provide insight into reasons Isibani provides support despite the fact that support group members default in expectations of the Isibani team that members should not fight over the donations. Sister Ngcobo said, *"More people will come on Tuesday because we bring food"*. Similarly, members of the support groups are also aware that the donations of food are a powerful force in bringing members to the support group meetings. Slindile stated, *"People [the members] only seem to come when Isibani is here to bring food"*. Thus, there is a reciprocal relationship between membership attendance and receiving donations. Moreover, the Isibani teams are willing to negotiate goals and expectations they have for the support group members in order to sustain this reciprocal exchange.

A brief social drama will display an instance of conflict over donations. The main actors within this conflict include members of Asibemunye support group, Bongiwe and Sister Joyce Sithole of Isibani Hospice, and myself. Although I am involved with this particular instance of conflict and reciprocity, the situation described below occurred in similar instances with donations from Isibani Hospice.

8.1.2 SOCIAL DRAMA: THERE IS NOT ENOUGH

I wrote a motivation for both Nawe Sondela and Asibemunye support groups to receive food parcels from an organization that was running a food campaign. I received a total of thirty 10 kg bags of mealie meal, and ten 40kg boxes of assorted foodstuffs. I decided to divide the food parcels between both support groups—sixteen bags of mealie meal and seven boxes of foodstuff for Nawe Sondela (as there are more members in this group), and eleven bags of mealie meal and three boxes of foodstuffs for the Asibemunye support group. I arrived at the Asibemunye meeting, but I only had five bags of mealie meal on this day because I was waiting to receive more. The group decided that five members would take the mealie meal this week, and then next week the remaining 6 members would receive their bags. I explained to the group, *"Next week, I will bring 3 boxes of food. I only have three, and please do not fight over the food because everyone will have to share as there are not enough boxes for each member"*. Nolwazi arrived late to the meeting and sat down on the bench next to Sbonisile. A bag of mealie meal was in front of the bench between Nolwazi and Sbonisile, and when the meeting ended, Nolwazi picked up the bag of mealie meal and stood up to leave. Sbonisile immediately asked

Nolwazi, *"What are you doing? That is mine"*. Nolwazi returned the bag of mealie meal to Sbonisile.

The following week I was unable to come to the meeting and gave the remaining bags of mealie meal and the three boxes to Bongiwe to deliver to the group at the next meeting. The following week I attended the meeting. Bongiwe and Sister Joyce Sithole were outside of the building in the Isibani truck when I arrived. I enquired if everything went well with the donations. Bongiwe told me, *"You know the group fought over the food last week. We [Isibani team] did not want to give the food to the whole group. We wanted to split the food between Ayanda and Njabulo because they are the two, struggling the most out of the group. But when we got to the meeting, the other members were expecting the food. The members started fighting over the food because everyone wanted the same type of food, in particular the vegetable oil. Members were yelling and arguing with each other"*. Bongiwe explained that while members were arguing, *"Nolu told me [Bongiwe] that Jabu [me] told us she was bringing a box for every member"*. Bongiwe said, *"The only two members who were not fighting were Ayanda and Njabulo. Fanele eventually left the meeting and did not take any food because she was angry"*. Sister Joyce Sithole interjects Bongiwe's story, and stated, *"I think that members of this group [Asibemunye] are greedy and that some of the members are not hungry. Look at Ayanda and Njabulo—they are struggling. But other members are greedy because they are arguing over the types of food, not being grateful for the food."* I enquired to Bongiwe, *"Do you think if you [Isibani] did not bring things like food, the members would come?"* Bongiwe responds, *"I don't think that they [support group members]*

would come. I don't know what it is because it [conflict over food] is happening in the other support groups [associated with Isibani]". As I was leaving, Nolu asked me, *"Could you please bring more food?"* I respond, *"I heard you all were fighting about the donation. But you [the support group members] are always in my thoughts and if anything comes up, I will keep you in mind".*

8.1.3 ANALYSIS OF SOCIAL DRAMA

Within phase one of this social drama, the breach takes place when there is not enough food parcels for every member, thus the amount of food donated falls short of the expectations of the support group members (i.e. that every member of the group should receive the same donation—quantity and type of food). The breach in expectations is fuelled by arguments and fighting amongst the members, resulting in an escalation to crisis, phase two. Bongiwe describes the crisis phase. An important event during the crisis phase is the departure of Fanele from the meeting. As mentioned, despite the conflict involved with donations, the group members do not refuse the donations. This is the first instance I heard of throughout the year in which a member refused a donation. During the crisis, Nolu partakes in gossip and insinuates that part of the reason the group is fighting is because I told the group every member would receive a box of foodstuffs.

Bongiwe does not describe the redressive phase in detail, but the members continued to sort through the donations, in spite of the conflict and arguments. The members arrived the following week with no visible grudges or displays of lingering feelings of the conflict from the previous week (even though there were no public displays of remnant

conflict, private relationships may have been affected by this social drama). Thus, no specific resolution is reached to resolve the crisis (phase four), although Nolu does requests more boxes of food.

A similar display of dissatisfaction over the amount and distribution of mealie meal and boxes of foodstuffs took place when the remainder of the donations was given to members of the Nawe Sondela support group.

These ethnographic accounts and the use of social drama highlight the expectations members have when receiving donations, the element of conflict involved within the transaction. The widespread association of conflict with receiving donations indicates that conflict is a factor in the overall notion of reciprocity within both support groups

9. THE OBLIGATION TO REPAY

The obligation to repay centers on the way each party involved views the "gift" or in the of case of the support groups, the services and/or donations that are given. These differing perceptions effect how each party reciprocates. Moreover, in the case of each support group and Isibani, these differing perceptions of the "gift" lead to the negotiation of a repayment, for instance, what Isibani expects the support groups to "repay" may not happen true to their expectations, and vice versa. Thus, the involved parties negotiate the terms of the obligations, in order to fit what they perceive to be the best outcome for each entity (Isibani, Nawe Sondela, and Asibemunye).

The following views of several members of the Isibani team reveal an expectation for the support groups to be active by participating in group events and income-generating projects (some of which are sponsored and/or supported by Isibani). As stated previously, these views shape the way in which Isibani perceives the obligation to give, and the obligation for the support groups to repay.

9.1 VIEWS FROM ISIBANI TEAM

The goals of the Isibani Hospice were described in Chapter Three, and these additional comments from the Isibani team highlight the expectations and impressions that the Isibani team has of each support group.

Bongiwe stated, *"I would say the vision at Isibani Hospice is to see them [support group members] being able to do things for themselves because most of them are unemployed. We [Isibani team] like them [support group members] to have skills like sewing and gardening things that can generate an income for them, so that they have something to take home"*.

Sister Joyce Sithole commented on the Asibemunye support group, *"When I came here last year, I found them [members of Asibemunye] very lazy. I brought the issue up, here at our meetings [Friday in-service day at Isibani], and fortunately our manager seemed to understand the matter and helped us [Isibani team and Asibemunye]. Because after that we [Isibani team and Asibemunye] received the sewing machines and wool and all*

those things. And before they [support group members] were using money from the YAA to buy food— that's all. Yes, that is what I found when I joined them. But from then, we tried to change. I told them what the principle for forming the support group is—what support groups are for. A support group is not to come sit down, chat and eat. The support group is to equip each other in any way either by skills, knitting, sewing, everything. And even information, yes, everyday we receive new information [about HIV/AIDS]. Since then there is a big change. Asibemunye, they are working. I told them when I came here they are just passing time. I want them to do something. Some [the members] they said they can sew, some can weave, and crochet".

Similarly, Bongiwe commented that the Asibemunye support group members *are "a good bunch. They [the support group members] are quite committed, especially the members who have been there from the start, like Nolu. I think they are lazy, a bit lazy. It will be interesting to see what happens… because they have a sewing machine, which I am not sure if they are using because we haven't see anything. Apparently, the sewing machines are broken. So I don't know, once they get a proper venue, maybe we will see a change--because maybe they can come on Wednesday or whatever day they choose and come and do some sewing or gardening. Because not everyone is able or wants to sew or garden, some members might prefer one or the other".* Additionally, Bongiwe comments that her hope for Asibemunye support group is, *"I would like to see them [support group members] grow, like maybe get more members, seeing them sewing and selling things to get money. Maybe in the long run maybe get another sewing machine—just for them to grow".*

Bongiwe's outlook for Nawe Sondela is not so optimistic, mainly due to the constant conflict amongst the group members. Bongiwe stated, *"I don't know. There is too much stuff going on there [within the Nawe Sondela group]. They are all so angry. I suppose it is because they [the support group members] are from that same area and they know each other—I don't know what it could be. But from what happened with Mfundo, I don't know [referring to schism described in Chapter Six]. Hopefully, it will pass and we [Isibani team] will see them working together and see them doing things for themselves, for them to grow, and be independent. I am hoping they get past their differences".*

In addition to the expectation that group members become active and involved in projects, a particular theme arises within the statements made by Bongiwe and Sister Joyce Sithole. The Isibani team would also like to see the support groups become more independent, "doing things for themselves", which ties into the theme of autonomy described in Chapter Six. Interestingly, the support group members express a similar sentiment on the notion of inactivity and activity, and the quest for independence, yet the reality within each group is that the members themselves do not appear willing do partake in what they wish to occur. One factor for this division in the ideal and reality, centers around the reciprocal nature of the group, the act of receiving donations and support fulfills the expectations that support group members have of Isibani Hospice and their involvement with the group as a whole. Thus, the need to partake in group projects and events is not the first priority amongst the support group members, but this aspect is a very important priority for Isibani. Another factor is that members often lack the

resources, skills, and training to successfully implement the projects that both Isibani and the support group members discuss and aspire to. Additionally, the notion of autonomy is evident because the support group members discuss amongst themselves a plan of action (for projects), but then will request input or direction from Isibani, and not engage in the group plans until doing so. For example, the Nawe Sondela group began discussing plans for a World AIDS Day project, and one member exclaimed, *"I am not sure what we are going to do, but Isibani [team] will probably tell us"*. Although these statements are applicable to many of the support group members, it does not hold true for every member, and at times, the support groups as a whole are doing things contradictory to the statements made above. Examples of these instances are seen in descriptions of group projects and events throughout the year for both Nawe Sondela and Asibemunye (in Chapter Four and Chapter Five).

9.2 GOALS OF PROGRESS AND PLANS OF ACTION

The following ethnographic accounts provide examples of projects, goals, and ideas within each support group and highlight several key themes of expectations, inactivity/activity, autonomy, and loyalty.

9.2.1 ASIBEMUNYE

The first ethnographic account describes a discussion amongst the Asibemunye members on plans to begin a project. The account highlights the need for action, the need to be

independent and simultaneously exemplifies frustrations members have when it comes to planning and implementing group projects.

As I entered the support group meeting, Thobeka said in a loud commanding voice, *"Do you understand?"* She smiles as she repeats the phrase a second time. A member says, *"Yes sir"*. Thobeka responded, "*It's 'yes m'am'. I am serious here—Serious!"* Thobeka is advising the group to start their own business, telling the group, that she wants to raise and sell chickens. *"We have to find something to keep busy"*. Nolu said, *"I wish one day we could have our own projects, so we can make some money"*. Njabulo suggested to the group, *"I can do many things like gumboot dancing, singing, acting—so many things"*. Edward asked the group, *"What have we ever done since we started [the group] besides the garden (referring to the garden the YAA helped set up for the group), which failed?"* Thobeka said, *"We have a machine for sewing for the group, but we don't use it, and when the machine is at people's home, the whole group can't use it"*. Thobeka said, *"We must plan!"* Njabulo and Thobeka started talking about planning for a drama; the two members stand up and start dancing in the middle of the room. Later on, the members began discussing the prospects of the chicken business proposed by Thobeka. At the end of the meeting Nolu told the group, *"We should have a conclusion for what we are talking about and do something"*. Thobeka responded, *"From all that we are talking about, we should pick one [project] that we think can work"*. Bongiwe also mentioned, *"If I can add on, that no one can help those who do not anything [themselves]. People can only add on to what you are doing. So that is why I always say do something so people can recognize you by the work that you do"*.

In this example, the group members express the desire to *"keep busy",* to implement group projects, commenting that planning is essential to attaining their goals. In affirmation of the members' goals, Bongiwe confirms that what the group members are discussing is exactly what the Isibani team expects of the group. For instance, Bongiwe asserts that one cannot expect to receive when the recipient does nothing in return (i.e. the obligation to give of Isibani Hospice and the obligation to repay of the support group members). Furthermore, Bongiwe's statement that *"People can only add on to what you are doing"* exemplifies an ideal view that Isibani has of their relationship with the support group members, in other words, Isibani views their role of support as supplementary to what the support group members are in theory already doing for themselves. The disconnect between the ideal and the reality of Isibani's expectations becomes apparent. Moreover, this disconnect for both Isibani and the support groups is a primary basis for the need to negotiate terms of reciprocity.

Similarly, the following description on Asibemunye's planning for Hospice Day (refer to section on group projects and events in Chapter Five for an elaboration of the event) reveals notions of autonomy, and additionally reiterates expectations that Isibani Hospice has for the support group members.

The support group members were discussing celebrating Hospice Day in April 2009. Hlengiwe, an Isibani care worker tells the group, *"Make sure you do something fast because after next week it is a month away. And everything must be in order at the event in KwaMakhutha because timing will be important. Are you [the group members] still*

practicing and rehearsing?" Sbonisile and Njabulo both explain to Hlengiwe, *"We have told the others to sing and do dramas, but not one listens to us".* Hlengiwe says, *"I always thought that after we [Isibani team] brought the food, you were rehearsing. What would I tell the manager [Sister Joyce Sithole and Isibani management] if they came with us [Hlengiwe and Isibani team] to see what you are practicing now? What would you tell them if you were sitting and not doing anything for the Hospice day?"* A month later, after the Hospice Day had occurred, (the group did not perform); Noxolo asks the group, *"Are you still going to practice singing even though the hospice celebration is over?"* Nolu responds, *"We are practicing. We won't stop now".*

This ethnographic description displays the disappointment that the Isibani team (Hlengiwe, in particular) has over the fact that Asibemunye was not practicing for Hospice Day. The support group members do not express a sincere interest in planning or practicing for an event that is important to Isibani Hospice, thus indicating that the support group members are aware of Isibani's expectation for the group members to be involved with this event, but choose to do otherwise. So, 1) the support group members are aware of the expectations, 2) the expectations are directly related to the notion of support (e.g. *"I always thought that after we [Isibani team] brought the food, you were rehearsing"* and 3) the choice, the negotiation that implicitly takes place amongst the support group members in the decision to not practice for Hospice Day.
The final ethnographic example presents a dialogue between Hlengiwe and the support group members on issues of "laziness" and both the group members and Hlengiwe, a part of the Isibani team, express dissatisfaction in a lack of successful projects.

Hlengiwe told the group, *"You [group members] must learn to do things"*. Njabulo asked Hlengiwe, *"How can you [Hlengiwe/Isibani team] make us stop being lazy?"* Hlengiwe told Njabulo, *"You will stop [being lazy] when you are ready because you are not children. I won't say anything to anybody [the group members] because you do not listen. You must work as a group. Try to do better things for yourselves"*. The following week, Isibani Hospice had not arrived so Sbonisile suggested the group members start singing. After the singing session, Ayanda explained to the group, *"We must pull our socks up because what I have seen at YAA was very interesting [Ayanda and several members attended a youth day function at YAA]. The youth were doing drama and singing"*. Sbonisile responded, *"People from Asibemunye are not serious"*. Ayanda stated, *"If we can make things of our own, we can make the difference. We don't have communication with each other, so that is why it's very hard to keep on going with useful thing"*. Fanele responds, *"People are not serious. If you are serious, others [in the group] take you as a joke. The group has been wanting this [to have successful projects] for so long, we are tired now"*.

This account exemplifies the member's frustrations in that the group wishes to do something and fails to achieve their goals, and what become apparent are a lack of motivation, and more importantly, a sense of disillusionment amongst some of Asibemunye's members. This disillusionment ties in with the fact that in many cases, the group does not implement projects, thus not fulfilling the expectations that Isibani Hospice has for the group. So, in addition to the notion that support group members choose not to participate in the obligation to repay (as seen in the example of Hospice

Day); an additional aspect is the fact that there is a lack of drive, i.e. motivation to participate.

9.2.2 NAWE SONDELA

Ethnographic accounts of situations regarding projects within Nawe Sondela will be discussed. The first account relates to the ongoing gardening project in the group, and reflects frustrations of several support group members, as well as several Isibani team members in relation to the gardening. Additionally, expectations of Isibani for the support group, and the support group member's expectations of one another is a common theme throughout this description.

Slindile asked, *"Will anyone go to the garden with me tomorrow because the plants are dying. You [support group members] must tell me now if you are not coming".* Buhle told Slindile she is not coming tomorrow because it is important she go to town tomorrow. Thusile responded, *"I will go if it's not raining".* Thobeka then said, *"Sister Ngcobo told me that next week we [the group] will meet at the garden, so those who come will receive a food parcel".* Lee then whispered to Noxolo, *"Everyone will go [to the gardens] on Tuesday, even those who don't usually come [to do the gardening]".* Slindile, at a later stage, told Noxolo and me that members do not come to the garden because *"They don't want to work. They are very lazy because they only come to the garden when the Isibani sisters promise them food parcels. That is the only time they come to the garden".* Slindile wants to make an attendance register for the garden

sessions, for example keep a record of what time members arrive and leave, and then, Slindile wants to show the register to the Isibani team. Bongiwe or Sister Ngcobo, depending on who was at the meeting on a particular day, often enquire about how the gardening sessions are going. On one occasion, Mbali responded, *"I tried yesterday [to garden], but no one was interested in going to the garden"*. Therefore, Bongiwe asked the group, *"If you as a group are lazy in the gardening, what else do you want to do?"* On another occasion, I enquired what time the group would be going to the gardening this week because I would like to attend. Lee explained, *"We should go on Monday and Tuesday, but maybe Sister Ngcobo will tell us when we should go"*. Sister Ngcobo explained to the group, *"People don't want to go there [to the garden], and I know that people hate me for that. But the truth is those who are going to the garden are not wasting their time because the food they plant is for them [not necessarily to eat, but to sell for profit]. End of story—for those who do not want to go to the garden, you must forget about getting any of the food that they [those attending the gardening sessions] plant"*.

Similar to the examples of Asibemunye, this description reveals that a handful of Nawe Sondela members are motivated and committed to making the garden project work, but do not receive support or participation from the majority of Nawe Sondela members. The members who do not participate in the gardens are aware that they will still receive donations from Isibani Hospice even if they fail to garden. Moreover, these members will attend the gardening sessions on Tuesday because Isibani brings donations. This act exemplifies the notion of negotiated reciprocity. Sister Ngcobo acknowledges that many of the members do not want to garden, but notes that these members will not benefit from

the garden, e.g. receive money from selling vegetables, or receive vegetables to consume. Yet the Isibani team wants the group to do something in order to carry out the members' obligation to repay—*"If you as a group are lazy in the gardening, what else do you want to do?"*

The following description elaborates on several group members' aspirations to take part in a project, as well as Bongiwe expressing her wish that the group finds something they would like to do.

Bongiwe asked the group, *"How many of you want to learn sewing? If you are interested in sewing, we [Isibani] have lots of machines [sewing]. But if you don't use the sewing machines, Isibani Hospice will take them [sewing machines] away from the group because no one can come and give us money [referring to support group members, but includes herself], but we have to try to make money for ourselves".*

At another meeting, Thobeka told the group, *"Let's do something for ourselves. Sitting like this isn't going to help us".* Nomula responded, "*I've been here since 12 o' clock and I do not hear anything. I've got stress. I'm hungry. We [she and other members] don't have uniforms [for their children] or money to pay school fees. Let's talk about something that is going forward [with regards to resolving problems within statement]".* Phiwe told Nomula, she is not listening because she has explained everything, *"Everything has a plan, so we [the support group] have to plan for everything we want to do. Vision is important. If we don't have vision, we won't go anywhere".*

Similar to the previous example, the Isibani team is encouraging the members to become involved/active in a project, such as sewing. Some members express motivation and "vision", whereas other members express disillusionment and dissatisfaction with the support group. The dissatisfaction expressed by Nomula also indicates that she believes Isibani is not fulfilling her expectations, i.e. she is in the same situation now as she was before she came to the meeting that day.

Section 9.3 also provides an example of this "dissatisfaction" of support group members' view of Isibani Hospice and their role within the support group.

9.3 SUPPORT GROUP MEMBERS VIEWS OF ISIBANI

This brief description provides insight into the variety of instances in which Nawe Sondela support group members were unhappy with the services Isibani Hospice was providing. Additionally, the dissatisfaction reveals several expectations that the members believe Isibani should fulfill. In addition to these descriptions, the events within Section 9 in Chapter Six also reveal issues members have with the Isibani team (refer to Andiswa's complaints about Sister Ngcobo).

At the beginning of a meeting in January 2009, Nomula told the group, *"We [support group members] should have lots of changes this year for the group. We don't have school uniforms for our children. Today, we expected the letter for Isibani to bring the letter] to take to our children's schools because we don't have enough money to pay*

school fees. And as we are all here now, we don't have the letters because sometimes Isibani Hospice doesn't think about us". The previous year (2008), Isibani Hospice had provided support group members with letters to give to their children's schools. These letters explained the financial situation of the support group members, and their inability to pay school fees for their children. Mbali said, *"We [support group members] need to talk with them [Isibani team] about our problems".* Nomula responded, *"We don't even have a house to meet in. They [Isibani] promise to help us all the way but they are not coming [to that meeting] and school is opening next week".* The following week, Bongiwe explained to the group that Isibani Hospice would not be bringing letters for the members. One member asked, *"How am I going to pay my child's school fees?"* Bongiwe suggested that the members speak with the people in charge at their children's schools and *"work something out"*, such as paying R 5 per month. Bongiwe said that if this does not work, then Isibani will provide the member with a letter. To date, the issue has not been resolved.

In this account, the fact that members are upset with Isibani's unwillingness to provide the letters indicates that their expectation for Isibani to provide this service is unfulfilled. The expectation exemplifies the notion that members expect assistance from Isibani, because as perceived by the support group members, the donor/recipient is a main aspect of the relationships and interactions between the support group and Isibani Hospice. The dissatisfaction of the members lays a foundation for future attempts by the support group members to negotiate the terms of reciprocity. For if Isibani does not fulfill their obligations, why must the support group members and vice versa. Hence the need and

existence of negotiated reciprocity, which allows for the support groups to continue to function.

The purpose of this chapter has been to elaborate on the system of reciprocity existent between Isibani Hospice and each support group, particularly a system of negotiated reciprocity. In the analysis of the three obligations (to give, receive, to repay), it becomes apparent that the system of negotiated reciprocity within these support groups has manifested as a means to fill the gap between the ideal and actual perceptions that Isibani Hospice and the support group members have of their roles and participation within both Nawe Sondela and Asibemunye.

The following chapter provides a summary of the ideas and concepts discussed within this study.

CHAPTER EIGHT-CONCLUSION

This study began with unraveling the concepts of care and support that are inherent within the formation of HIV/AIDS support groups throughout the world. Subsequently, a description of hospice and palliative care describe a process in which to provide care and support to people living with HIV/AIDS, particularly, the way in which Isibani Hospice provides services to individuals attending the two HIV/AIDS support groups, Nawe Sondela and Asibemunye. The elaboration on the various facets of these two support groups, introduce the main actors and settings, and provide a backdrop for the comprehension of themes discovered within the operation of the support groups under study.

The themes, which emerge from the study of these two HIV/AIDS support groups, are conflict and negotiated reciprocity. The analysis of conflict and negotiated reciprocity, reveal the varying perspectives and relationships/interactions of members within each support group, Nawe Sondela and Asibemunye, and with Isibani Hospice and the support groups. These themes also illustrate the fact that instances of conflict and negotiated reciprocity play a substantial role in the way that Isibani Hospice and the support group members view the goals and purpose of the group, and additionally, affects the structural components of the support groups.

A brief summation of the theoretical frameworks used throughout this study in the analysis of conflict and negotiated reciprocity illuminate the connections between these

two concepts. In the analysis of conflict within each support group and Isibani Hospice, Victor Turner's social dramas proved useful in analyzing instances of conflict and reciprocity, as well as providing a method to portray these conflicts within the ethnography. Through the analysis of conflict via social dramas, several key themes arise from the instances of conflict within each support group—autonomy, stability, and loyalty.

These three concepts are illustrated throughout Chapter Six and Chapter Seven, as the concepts are also integrally linked to the system of negotiated reciprocity within the support groups. The notion of autonomy relates to the idea that support group members attempt to create a space of their own, i.e. the support group, in which the members have symbolic control over decisions that affect their lives, particularly in relation to living with HIV/AIDS. At times, this 'sense of autonomy' amongst the support group members leads to conflict, and additionally, contributes to the way in which members negotiate the terms of reciprocity between each group and Isibani Hospice. The concept of stability becomes evident through the discourse amongst the support group members and Isibani Hospice on meeting venues, and income-generating projects. The idea is if the support group members had the opportunity to be stable, i.e. a permanent meeting venue, then the members would be able to partake in income-generating projects, and the group would be, as expressed by many members, a means for each support group to be successful. The attainment of 'stability' would then, in theory, also provide members with independence within the context of the support groups, and additionally, the ability to make money from income-generating projects could contribute to a sense of

independence in the members' personal lives. Finally, the importance of loyalty amongst the group members relates to the sensitive nature of the support groups (all members are living with HIV/AIDS), and the fear of stigma and discrimination from the community intensifies this need/want for loyalty amongst the support group members. In addition to members expecting loyalty from other members within the group, Isibani also expects loyalty from the support group members, and when this loyalty is breached, by either party, conflict often ensues. The notion of loyalty also contributes to the ideas of negotiated reciprocity, mainly the obligation to give, receive, and repay.

In addition to the ideas surrounding autonomy, stability, and loyalty, the following comments by Victor Turner on an aspect of the "star group[31]" reveals another important and interrelated theme in the analysis of conflict and negotiated reciprocity—the perception of expectations. The ethnographic descriptions in this study reveal a "disconnect" between the ideal and actual expectations that 1) Isibani Hospice has for each support group, and 2) Each support group has for Isibani Hospice. The following comment by Turner illuminates aspects of this ideal versus actual dichotomy within each group.

"Only those who feel strongly about their membership in such a group [star group] are impelled to enter into relationships with others which become fully "meaningful", in the sense that the beliefs, values, norms, and symbols "carried" in the group's culture become so internalized in a member that they constitute a major part of what s/he might regard as

[31] Refer to Chapter Six, Section 3.1, which describes the idea of a star group. In essence, a star group relates to the group that an individual relates to the best in comparison to all other group affiliations in his/her life. For many members, the support group is the individual's "star group".

his/her identity, what makes that member a specific person. … The first is the ideal model or paradigm, the pure and perfect image of its [the group] harmonious operation. The second is the concrete manifestation of that ideal in the experience of the member. Social dramas almost always contain episodes which manifest discrepancies between components of the actual and ideal group models" (Turner, 1988: 46).

Additionally, Max Gluckman's concept of equilibrium-disequilibrium-equilibrium allows for an overall contextualization of the way in which the support groups oscillate between stability and conflict. Although the following comment by Gluckman refers to the process of ritual, and "acting out" conflict within a group, the concepts are relevant to the discussion of conflict and negotiated reciprocity within each support group. Gluckman states, "Every social system is a field of tension, full of ambivalence, of co-operation, and contrasting struggle", yet "unity despite the conflicts" may exist; in that, "equilibrium is neither static nor stable, but grows out of a dialectical process in which conflicts within one set of relations are absorbed and integrated within another set of relations" (Gluckman, 1963: 127; Lewellen, 2003: 9; Morris, 1987:248).

Similarly, what becomes evident within the preceding ethnographic chapters is the notion that for the support groups under study, these themes, conflict and negotiated reciprocity, are not only a constant, but in a way, have become the norm from which the support groups view their participation within the groups. Thus, additionally, these views affect the way in which Isibani, Nawe Sondela, and Asibemunye operate, i.e. the functioning of the support groups. Furthermore, a cyclical process becomes apparent because conflict

and negotiated reciprocity inform many of the norms within each support group, and simultaneously, the breach of these norms, may result in additional conflict amongst the support group members and/or with Isibani Hospice, or may be the basis for renegotiation of expectations amongst the support group members and Isibani Hospice.

The divergence in goals, expectations, and obligations, the ideal versus actual dichotomy, the system of negotiated reciprocity and the propensity for conflict are common themes throughout the ethnographic narratives of Nawe Sondela and Asibemunye. Despite these more agonistic concepts, Nawe Sondela and Asibemunye continue to operate—continue to exist.

A predominant concept discussed throughout this thesis is on the functioning and/or operation of HIV/AIDS support groups, and through observation of Nawe Sondela and Asibemunye, I will now provide several recommendation I believe pertinent to the understanding of HIV/AIDS support groups.

RECOMMENDATIONS

First, I recommend that similar to statements expressed by Schopler & Galinsky (1993) and Spirig (1998), there is a need for HIV/AIDS support group studies to focus on the role of the sponsoring organization, the support group leaders, and support group facilitators. For instance, an ethnographic study specifically focusing on Isibani Hospice

would prove useful, as this organization profoundly affects the functioning of Nawe Sondela and Asibemunye.

Additionally, I believe that efforts should be put in place that allow the support group members and the Isibani team to evaluate one another, whether via a questionnaire, discussion, or mediator. The "disconnect" that exists between these the support groups and the sponsoring organization also has its foundations in a lack of communication.

South Africa has over 5.7 million people living with HIV/AIDS—the largest population of people living with HIV/AIDS in the world (UNAIDS, 2009). With the advent of anti-retroviral treatment and an importance placed on access to healthcare for people living with HIV/AIDS throughout the world, a focus on HIV/AIDS and the way in which people are coping with the disease becomes paramount. Thus, an understanding of South African HIV/AIDS programs dealing with the care and support of people living with HIV/AIDS is crucial. A need exists to explore the various community initiatives that have developed, specifically, community organizations, e.g. non-governmental organizations, faith-based organizations and local and provincial clinics/hospitals, which implement and advocate the formation of HIV/AIDS support groups. As stated previously, the emergence of HIV/AIDS support groups throughout the world evolved as a means to address the challenges associated with living as an HIV positive person (Visser & Mundell, 2008).

Thus, I advocate the need for ethnographic studies on HIV/AIDS support groups to be done, particularly studies on 1) HIV/AIDS support groups throughout the Ethekwini Municipality, and 2) throughout the province of KwaZulu-Natal. These ethnographic studies should focus on the participants, i.e. members of support groups, support group leaders/facilitators, and sponsoring organizations, the structural components of the support groups, topics of discussion within the support group meetings, and an analysis of the 'experience' of the support group members including goals and expectations of members' involvement with a HIV/AIDS support group. Additionally, there is a need to examine the role HIV/AIDS support groups plays within the wider discourse of care and support for people living with HIV/AIDS throughout the world, and in particular, South Africa.

As Parker (2001) stated, "The kind of response that anthropology continues to make in relation to the epidemic will be an important indicator to the relevance of the discipline as we enter the new millennium".

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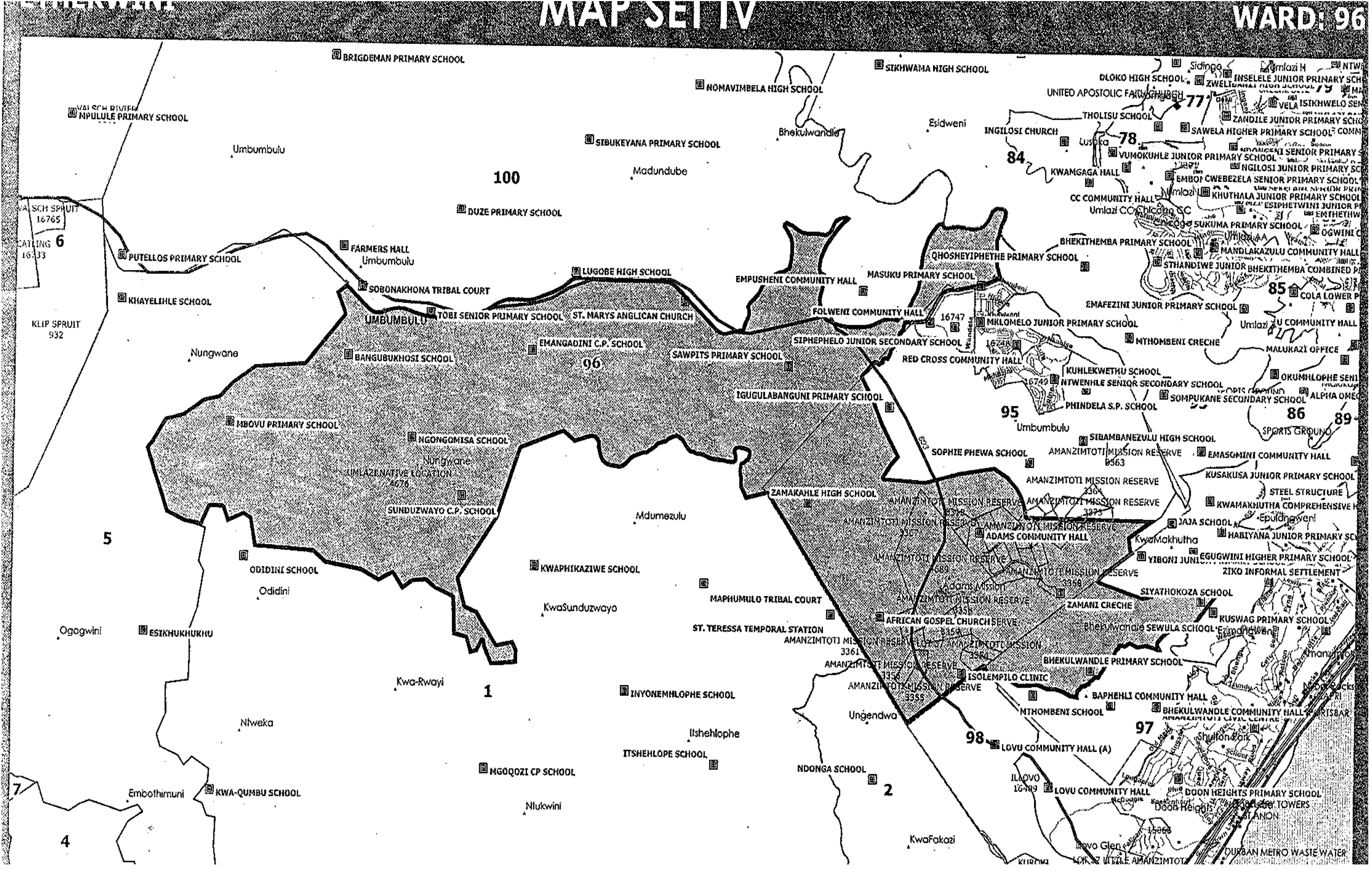
Map 1 and Map 2 (Statistics South Africa, 2003).


MAP SET IV
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BRIGDEMAN PRIMARY SCHOOL
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Umbumbulu
SIBUKEYANA PRIMARY SCHOOL
Madundube
DUZE PRIMARY SCHOOL
PUTELLOS PRIMARY SCHOOL
FARMERS HALL
SOBONAKHONA TRIBAL COURT
KHAYELIHLE SCHOOL
KLIP SPRUIT
932
LUGOBE HIGH SCHOOL
UMBUMBULU
TOBI SENIOR PRIMARY SCHOOL
ST. MARYS ANGLICAN CHURCH
EMPUSHENI COMMUNITY HALL
MASUKU PRIMARY SCHOOL
QHOSHEYIPHETHE PRIMARY SCHOOL
FOLWENI COMMUNITY HALL
MKLOMELO JUNIOR PRIMARY SCHOOL
SIPHEPHELO JUNIOR SECONDARY SCHOOL
RED CROSS COMMUNITY HALL
Nungwane
BANGUBUKHOSI SCHOOL
EMANGADINI C.P. SCHOOL
SAWPITS PRIMARY SCHOOL
IGUGULABANGUNI PRIMARY SCHOOL
MBOVU PRIMARY SCHOOL
NGONGOMISA SCHOOL
UMLAZI NATIVE LOCATION
SUNDUZWAYO C.P. SCHOOL
ZAMAKAHLE HIGH SCHOOL
Mdumezulu
SOPHIE PHEWA SCHOOL
AMANZIMTOTI MISSION RESERVE
ADAMS COMMUNITY HALL
ODIDINI SCHOOL
Odidini
KWAPHIKAZIWE SCHOOL
KwaSunduzwayo
MAPHUMULO TRIBAL COURT
ST. TERESSA TEMPORAL STATION
AFRICAN GOSPEL CHURCH
ZAMANI CRECHE
SIYATHOKOZA SCHOOL
KUSWAG PRIMARY SCHOOL
BHEKULWANDLE PRIMARY SCHOOL
ISOLEMPILO CLINIC
BAPHEHLI COMMUNITY HALL
MTHOMBENI SCHOOL
BHEKULWANDLE COMMUNITY HALL
Ogogwini
ESIKHUKHUKHU
Kwa-Rwayi
INYONEMHLOPHE SCHOOL
Nlweka
Itshehlophe
ITSHEHLOPE SCHOOL
Ungendwa
NDONGA SCHOOL
LOVU COMMUNITY HALL (A)
LOVU COMMUNITY HALL
MGOQOZI CP SCHOOL
Embothimuni
KWA-QUMBU SCHOOL
Nlukwini
KwaFokazi
DOON HEIGHTS PRIMARY SCHOOL
DURBAN METRO WASTE WATER
Bhekulwandle
Esidweni
INGILOSI CHURCH
KWAMGAGA HALL
CC COMMUNITY HALL
DLOKO HIGH SCHOOL
THOLISU SCHOOL
SAWELA HIGHER PRIMARY SCHOOL
BHEKITHEMBA PRIMARY SCHOOL
EMAFEZINI JUNIOR PRIMARY SCHOOL
MTHOMBENI CRECHE
KUHLEKWETHU SCHOOL
NTWENHLE SENIOR SECONDARY SCHOOL
SOMPUKANE SECONDARY SCHOOL
PHINDELA S.P. SCHOOL
SIBAMBANEZULU HIGH SCHOOL
EMASOMINI COMMUNITY HALL
KUSAKUSA JUNIOR PRIMARY SCHOOL
STEEL STRUCTURE
JAJA SCHOOL
ZIKO INFORMAL SETTLEMENT
MALUKAZI OFFICE
SPORTS GROUND