THE PREPARATION OF RELATIVES OF AIDS PATIENTS FOR HOME-BASED CARE IN THE BETHESDA SUB-DISTRICT: A NURSING PERSPECTIVE

by

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DECLARATION

I declare that **"The preparation of relatives of AIDS patients for home-based care in the Bethesda sub-district: A nursing perspective"** is my own work and that all the sources that I have used or quoted have been identified and acknowledged by means of complete reference.

Signed: P.B. Harrison

P.B. HARRISON

DATE: 20.04.01

DEDICATION

This study is dedicated to:

1. My husband, James Harrison, for his inspiration, understanding, encouragement and co-operation.

2. My children Thomas, Peter and Elaine for their love and understanding.

3. My mother Phumaphi Daisy Myeni who was the source of inspiration, love and encouragement.

4. My sisters Gladys, Beauty and Princess.

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ABSTRACT

The purpose of this study was to investigate the preparation of relatives of AIDS patients for home-based care in the Bethesda sub-district. The researcher's objectives were to:

- Establish the nature and extent of preparation of AIDS patients relatives by nurses for looking after the patients at home.
- Determine the reason for relatives apparent inability to care for a relative with AIDS, in a home-based environment.
- Identify the nature and variety of problems that AIDS patients have in getting the needed support and acceptance from relatives.

Nursing literature revealed that the preparation of relatives of AIDS patients by nurses is hardly mentioned. Most of the literature only revealed the reactions by caregivers, attitudes etc. but nothing specific to preparation of relatives of AIDS patients by nurses.

Such a study is of significance in that it is concerned with enhancing of HBC skills which in turn could result in the:

- Reduction of hospital workload of HIV/AIDS patients
- Increase of knowledge base and skills for improvement of home-based care
- Prevention cross-infection whilst caring for the HIV/AIDS patient
- Removal of myths and biases that exist around HIV/AIDS and HBC.
- Assist in planning for and evaluating of the HBC programmes.

The researcher used a descriptive design for this study to solicit the information needed on home-based care. As the study was descriptive in nature, it proceeded with the question as "*To what extent are relatives of aids patients prepared by nurses to provide the home-based care?*"

As the study was confined to the professional nurses, stratified random sampling was used. Questionnaires were used to obtain information. Questions formulated were partly open-ended and partly close ended. With the information obtained from the respondents, one can deduce that all the objects of the study were met.

- The findings of this study cannot be generalised because the study was conducted in only one District. The sample used for the study was small. The study was also limited by financial constraints, as travelling to other health care district would be costly since this study was not funded.

It was discovered that:

- establish the nature and extent of preparation of AIDS patients relatives by nurses for looking after the patients at home.
- Determine the reason for relatives' apparent inability to care for a relative with AIDS, in a home-based environment.
- Identify the nature and variety of problems that AIDS patients have in getting the needed support and acceptance from relatives.

The researcher recommends that:

- Modules on HBC should be developed. These HBC modules should be developed for all health workers and various professionals. AIDS is a major problem that affects everyone. Therefore, everyone should be trained as to how to handle HIV/AIDS patients or their relatives.

- The HBC modules should encapsulate the following:

- Basic information on HIV/AIDS
- counselling skills on HIV/AIDS
- Home-based care skills and Home visits for AIDS patients
- Involvement in self-help projects of communities e.g. Gardens etc
- Life skills and coping skills

It is the thinking of the researcher that if the above issues can be added, the HBC program can be most effectively implemented.

- PHC trainers should be trained as AIDS PHC Specialists. They should be able to train others on HBC and evaluate HBC programmes from time to time, etc.
- Research should be conducted on the Involvement and preparation of community health workers (CHW) on home-based care. The community health workers are the closest people next to the communities. They are trusted by them since they are chosen by the communities. CHW do visits to homesteads, therefore their input can be great if utilised effectively so far as preparing the relatives of AIDS patients for home-based care.

- Similar study be undertaken at a larger scale to include other districts in the region to identify if this is a general problem or not.
- The study on the preparation for HBC be undertaken as a comparative study to urban areas.

ABBREVIATIONS

1. ACW	-	Aids Care Workers
2. AD	-	Assistant Director
3. AZT	-	Zinovudine
4. AIDS	-	Acquired Immune Deficiency Syndrome
5. DD1	-	Didanosine
6. DOH	-	Department of Health
7. DNHPD	-	Department of National Health and Population Development
8. HBC	-	Home-Based Care
9. HCW	-	Health Care Workers
10. HIV	-	Human Immune Virus
11. KZN	-	KwaZulu Natal
12. MCH	-	Maternal Child Health
13. PHC	-	Primary Health Care
14. PN	-	Professional Nurse
15. PWA	-	People with Aids
16. SAHWCO	-	South African Health Workers Congress
17. SA	-	South Africa
18. SANA	-	South African Nursing Association
19. SEN	-	Senior Enrolled Nurse

20.SPN	-	Senior Professional Nurse
21. STD	-	Sexually Transmitted Disease
22. WHO	-	World Health Organisation

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CHAPTER 1

OUTLINE OF THE STUDY

INTRODUCTION

The first and the last persons to care for HIV victims are their relatives. They (the relatives) are the people who should be armed with basic caring skills (of home-based care). Such skills can help them to cope with the ordeal of HIV infections. There is therefore, a great need to prepare the relatives for the home-based care. However, any teaching and learning situation requires that an investigatory (pre-knowledge) exercise be undertaken. With this study, the researcher aims at following this didactic principle. The importance of HBC is confirmed by Zarit and Pearlin (1993:304) as they note that: "*At the heart of the question of interface are issues of what the responsibilities of family and government ought to be and how formal services can best be integrated with informal or family caregiving.*"

This descriptive study, therefore, is an exploration on the preparation of relatives of HIV/AIDS patients for home-based care in the Bethesda sub-district. Because of its focus on the concept of "preparation," this study addresses questions such as "how, when, and "under what" circumstances formal HIV/AIDS care could be integrated with the informal

(home-based) care giving.

Over the course of the last decade, there has been a rapid shift from hospital-based to community- or home-based HIV/AIDS care (Crystal & Jackson, 1989; Kelly, JJ., CHU, BUEHLER, J.W & the AIDS Mortality Project Group (1993). Bethesda Hospital is now beginning to explore the issue of home-based care. As Assistant Director - in charge of the Nursing Services for Bethesda subdistrict - the researcher decided to embark on this research. The specific motivating factors are explained below.

MOTIVATION FOR THE STUDY

The researcher was motivated by the escalating cases of HIV / AIDS in South Africa. More specifically, the increase incidence in KZN and at Bethesda Sub-district. The figures are reported as follows:

HIV incidence in KwaZulu-Natal (KZN)

According to Irlan and Mthembu (1996:1), it is estimated that 52, 500 people in the province of KwaZulu-Natal have developed AIDS. The Department of Health HIV antenatal clinic survey – of pregnant women - results in KZN were as follows: -

In 1996 - 19.9% were HIV positive

In 1997 - 26.9% were HIV positive

In 1998 - 32.5% were HIV positive

Whiteside (1999:11) states that there are already between 78, 470 - 100830 AIDS orphans in KZN.

HIV incident at Bethesda sub-district

The antenatal HIV survey done at Bethesda Hospital reflected the highest increased HIV incidence. The results of the survey were as follows:

In 1997 - 21 % were HIV positive

In 1998 - 26.7% were HIV positive

With the statistics reflected above indicating alarming figures for AIDS cases in the Bethesda sub-district, the researcher has been motivated to embark on this study.

NB: It should, however, be noted that the actual numbers of AIDS cases is unknown because of underdiagnosing, incomplete reporting and reporting delays (Esterhuyse & Doyle, 1993:14).

The demand by patients' relatives

The researcher is an Assistant Director for nursing service at Bethesda Hospital and its clinics. She is directing and controlling the nursing service. She is also responsible for human resource development within the sub-district. As an AIDS counsellor at Bethesda Hospital, she sees many AIDS admissions. In most cases, the relatives demand that their HIV infected next of kin remain in hospital indefinitely.

Repeated admissions for HIV/ AIDS cases have caused a great concern. Therefore, the preparation of the relatives of AIDS patients for home-based care is of great necessity. This will not only help to release the hospital beds but also ensure that HIV/ AIDS are properly cared for at home.

PROBLEM BACKGROUND

Despite the HIV awareness campaigns, people still get sick and die of AIDS; many are cared for at home. Many AIDS cases are sent home to be cared for by relatives who cannot afford to pay for the intravenous therapy, nutrition, and pain medications (Drysdale, 1999:1). The medical aids have not been paying for home-nursing care but due to an increase in AIDS cases and negotiations of late there has been a great improvement for almost all medical aid schemes are paying even though the benefits are limited.

Contracting HIV is associated with immoral behaviour because of its mode of spread - which is mainly through sexual intercourse. Therefore, HIV carries a social stigma. All HIV patients/ clients tend to be fearful of isolation and rejection by relatives (Christie and Hickson, 1990:26). The abovenamed authors further state that all HIV patients experience loss of control of autonomy, self-blame, feelings of guilt, anxiety and depression. There are also some fundamental aspects of HIV/ AIDS health care such as fear of the disease, the care for the sores/ wounds, nutrition, mental support, etc. The abovementioned health care aspects require basic caring skills which demand special training for people who are charged with caring for HIV affected people.

STATEMENT OF THE PROBLEM

According to Peter (1992:15), it is predicted that hospitals will progressively be unable to admit all cases of HIV/ AIDS. Peter further warns that lengthy stays in hospital are causing the shortage of beds. He reports that the length of stay for AIDS patients in hospital was (8) eight days compared to (5) days for general/medical patients. It should be mentioned that Bethesda - the current study's setting - is not exempted from this predicament.

However, Peter (1992) has the answer. He suggests that the length of stay of AIDS patients should be reduced and an increased emphasis should be on out patient's (home-

based) care. However, there is no sufficient on the cost and quality of service provision in home-based care in South Africa, nor has the cost to the family in economic, social, psychological and practical ways been assessed.

Christie and Hickson (1990:26-28) state that the problem of lengthy stay may result in poor personal touch for AIDS patients. They also state that hospitalisation add more problems to an AIDS patient who has already gone through a profound emotional disturbance before admission. They further point out that the hospital is a cold, sterile authoritarian environment. Therefore, unnecessary long hospitalisation should - because of its ill effects on patients - be avoided at all costs.

Most researchers (Christie and Hickson, 1990; van Dyk, 1995; Taylor et al, 1997) place emphasis on hospital care by the nurses. The care of HIV patients by relatives is briefly mentioned by some researchers such as Soal (1997), Brown and Powell-Cope (1991).

When the AIDS patients fall sick the trend is to send him or her to hospital even for minor health problems - which relatives could have coped with at home. This trend seems to suggest the lack of adequate knowledge and skills on the part of relatives. No study has been done at Bethesda sub-district on home-based care preparation of relatives of AIDS patients.

Insufficient data exist on the quality of service provision in home-based care. The quality of patient care is also unknown. The fact that the training or preparation of people for

home-based care has not been investigated poses a problem.

SIGNIFICANCE OF THE STUDY

It is hoped that the present study could emerge with a descriptive overview of the extent to which the relatives of AIDS patients are prepared by nurses and other health professionals to provide home-based care. Investigating this problem - and establishing the knowledge level - could have an important contribution in encouraging, equipping, influencing and supporting the relatives of HIV/ AIDS patients.

Through its recommendations - which is aimed at improving basic caring skills - it is hoped that this study would equip relatives with coping mechanisms in caring for AIDS patients in their familiar environment surrounded by their loved ones. Enhancing the skills for home-based care - which is the major emphasis of this study - could have the following benefits:

- The HIV admissions (and thus workload) in hospitals could be reduced.

- Through appropriate education, the relatives would be prevented from contracting the disease whilst taking care of AIDS patients.

- The skills and practical knowledge of nurses in the preparation of relatives of AIDS patients for home-based care could be improved.

- This study might render a better understanding and removal of *myths and biases* that, according to Christie and Hickson (1990:26), exist which prevent relatives from rendering the needed support to AIDS patients.

- The information on the quality of service provision is necessary for planning and evaluating the home-based care programme.

RESEARCH QUESTION

The question being addressed in this study is:

- TO WHAT EXTENT ARE RELATIVES OF AIDS PATIENTS PREPARED BY NURSES TO PROVIDE THE HOME-BASED CARE?

OBJECTIVES OF THE STUDY

The objectives of the study are to: -

- establish the nature and extent of preparation of HIV/AIDS patients' relatives by nurses for looking after the patients at home.

- determine the reason for relatives' apparent inability to care for their relatives in a home environment.

- identify the nature and variety of problems that patients have in getting the needed support and acceptance by relatives.

DEFINITION OF CONCEPTS

The concepts used for this study are defined as follows:

HIV/AIDS Patient

HIV patient refers to a person who has a virus in his blood having contracted it from

another person, destroying the immune system and leaving the body unprotected against diseases (Evian, 1993:6-7). The symptoms of HIV disease may appear 3-7 years after the first infection. It may even take up to 10 years (Miller, 1988)

In this study AIDS patient refers to somebody who has contracted the HIV but may look healthy. According to Evian (1993:6), this refers to a person who has contracted the virus causing the destruction of the immune system - leaving the body unprotected against diseases. Evian (1993) also notes that the diseases that attack this unprotected (HIV-infected) person are referred to as "opportunistic infections." In this study HIV/AIDS combination is used because HIV can only or always advances to AIDS status.

Relative of Aids Patients

According to the Universal Dictionary (1991), it means one related by kinship. In this study, it refers to the next of kin of an AIDS patient.

Home-based Care

The Oxford Dictionary defines care as a serious attention given to someone. In this study, it refers to a sympathetic, humanistic loving manner of looking after the AIDS patient by relatives at home. According to the Universal Dictionary (1991), a home means a place where one lives. In its January 1999 Newsletter - the MCHN - the UNICEF states that the

home-based care should:

- Protect the rights of clients/ patients
- Provide continuity of care
- Encourage broad participation
- Be culturally appropriate
- Develop community capacity
- Be sustainable
- Be evaluated

The UNICEF also state that the objectives of good home-based care strategy are to:

- Ensure accessibility and follow-up through a functional referral system
- Integrate a comprehensive care plan into the - formal, non-formal and informal health systems

- Empower the family/community to take care of their own health

- Minimise visits to hospital and admissions to health centres.

- Ensure an appropriate targeted education and training for the patient, the carer(s) and the community at large.

- Ensure cost effectiveness.

Preparation of relatives

The Universal Dictionary (1991) defines preparation as the state of being made ready beforehand. In this study, it refers to knowledge and skills given or demonstrated to relatives of AIDS patients by nurses.

Health workers have an important role to play in the educational process. Information and education about AIDS is a major health care priority and must form an important part of the primary care (Evian, 1993:233). According to Evian, relatives should be equipped with the following aspects of information:

- **Physical** information should include topics such as: General information about AIDS and how it is spread; reasons why the HIV virus is spreading so

rapidly and the biological determinants factors of the epidemic; how to prevent HIV infection or spreading the virus to others.

- **Social** information should include questions of safer sexual practices; examining and exploring the relationships between people and how these affect their sexual life.

- **Psychological** aspects are: acceptance and support of people with HIV/ AIDS; helping people to cope with living with HIV/ AIDS.

- **Economically** relatives should be advised on financial and self-help issues.

- **Spiritual** issues relate to peoples' belief systems.

ORGANISATION OF THE STUDY

This study comprises of (5) five chapters

- **Chapter 1: Outline of the study**: This chapter introduces the research topic. In this chapter a broad outline of this study is given. It includes topics such as the introduction to the study, motivation, problem

background, and statement of the problems, significance of the study, research question, study objectives and the definition of the concepts.

- **Chapter 2: Literature Review**: This is the review of the related literature. Conceptual framework is also formulated.

- **Chapter 3: Research Methodology**: The researcher explains the following: the chosen design, where and how the data was collected and how it was used.

- **Chapter 4: Data Analysis and Interpretation**: The analysis of the information is presented in tables, diagrams and graphs. The interpretation is also done.

- **Chapter 5: Conclusion, Limitations and Recommendations**: In this chapter the researcher discusses the conclusion, limitations and recommendations for the study.

CHAPTER 2

LITERATURE REVIEW

INTRODUCTION

The emerging literature on informal (home-based) caregiving to persons with HIV/AIDS draws many of its research questions, constructs, models and measures from the literatures on caregiving to other chronically ill and disabled persons, such as persons with Alzheimer's disease, the frail elderly and the seriously mentally ill. The following literature – addressing questions such how, when, under what circumstances and with what consequences formal support services are integrated with informal care – can be cited (Bass & Noelker, 1987; Diwan & Coulton, 1994; George, 1987; Greene, 1983; Horowitz, 1985; Lawton et al., 1989; Litwack, 1985; MaloneBeach et al., 1992; Montgomery & Borgatta, 1989; Morris et al., 1996; Noelker & Bass, 1989).

In this chapter, the literature on HIV/ AIDS and Home-based care is reviewed. In the same chapter, the researcher explains the theoretical framework on which she based this study.

HIV/AIDS: AN HISTORICAL BACKGROUND

The Acquired Immune Deficiency Syndrome (AIDS) is a new and unique disease. It was first discovered in America in 1981, after a number of men who had developed a rare pneumonia caused by a parasite called pneumocystis carinii (Evian, 1993:3). These men were all previously healthy between 20 and 45 years of age and homosexually orientated (Fleming, 1993:18). They had developed severe immune deficiency which led to the development of this rare pneumonia.

Soon afterwards, in Central Africa, health care workers were discovering a new disease causing severe weight loss and diarrhoea which they called "slim disease" (Broder & Marigan, 1994:156). This was also due to the immune deficiency. This time around it was also present in hererosexually-orientated people in 1985 (Fleming, 1993:13). In September 1983 scientists discovered the Human Immune Virus (HIV) to be caused of this new disease called AIDS.

IMPORTANCE OF HOME-BASED CARE: AN OVERVIEW

The 3rd International Conference on Home and Community Care for Persons living with HIV/AIDS, held in May 1997 in Amsterdam, focused on out-of-hospital HIV/AIDS care in both developing and industrialised countries, and in particular on the availability and accessibility of care in relation to the dimension of the epidemic and the need for care in the community (Wigersma, L.; Singh, S.; et al, 1998:4). Three central issues from the conference were highlighted concerning the AIDS Care:

- Firstly, a critical message was that issues related to women and children infected or affected by HIV/AIDS are now rightfully at the forefront of the global AIDS debate.

- Secondly, high standard qualitative research increasingly unveils the circumstances and needs of care of people affected by HIV/AIDS in all areas of the world.

- Thirdly, evidence is accumulating that comprehensive HIV/AIDS care, including preventive and home-based care, can only be organised close to or within the various communities.

NURSES FEELINGS TOWARDS HIV AND AIDS PATIENTS

According to Lopez (1998:129), the intensity of HIV/AIDS in Africa is difficult to asses most cases go undiagnosed and unreported (Esterhuyse and Doyle, 1993:14). This is likely to expose nurses to the risk of contracting HIV.

The above situation has far-reaching consequences on nurses' attitudes towards HIV patients. Nurses' attitudes may be manifested as follows:

- According to Kempainien, Patricia and Dubbert (1996:397), attitudes of nurses and other health care workers are often negative and characterised by the reluctance to provide care to these patients.

- Berry-Koziel (1987) as quoted by Docones (1991:333) says that some nurse are asking "If it worth nursing" these patients.

ISSUES RELATED TO WOMEN AND CHILDREN INFECTED OR AFFECTED BY HIV/AIDS

Countries in sub-Saharan Africa - of which South Africa is one - have high levels of AIDS-related mortality among adults and children. Hitherto, much attention (relatively) was paid to the fact that HIV/AIDS primarily affects the economically productive in developing countries, which, amongst other forces, negatively impacts on the gross national product of these countries.

Drew and Foster (1994:1) discuss the emergence of orphan-headed households, and present an example of a community-based orphan support programme. In Zimbabwe, volunteers, mostly widowed women, are trained to identify, visit and support orphans (Drew & Foster, 1994: 1). These programmes are relatively cheap, but have not been widely adopted because of a multiplicity of factors including:

- Lack of recognition of the scope of this problem,
- The stigma of AIDS
- The tendency to focus attention to adults, and
- The lack of resources.

The situation illustrated above reflects some basic similarities to the South African situation (Naidoo, 1999: 1). AIDS is having an increasing impact on lives of women compared to men. According to Herbst (1999:19), African women and children have been particularly hard hit by HIV/ AIDS. In South Africa HIV infections were 3,2 times more common in women than in men (Herbst, 1999:11; Coovadia, 2000:13).

The first national survey of women attending antenatal clinics, October/ November 1990 showed overall seroprevalence of 0, 76%. The figure doubled after twelve months to 1.49% and over 200 000 adults were infected in 1991. Regionally, Natal had the highest seroprevalence of 2.87%, followed by other provinces. Blacks were the worst affected at 1.84%. Other racial groups had lower percentage (Fleming, 1993:18). Women are more disadvantaged in many ways i.e. socially, economically, culturally, and educationally.

Cultural Aspect

Women rarely share authorities in matters of reproductive and sexual behaviour (Win, 1993: 19). In addition, women are mostly uneducated, illiterate and unemployed thus become dependent on their husband who has to make decisions (William and Shreedhar, 1996: 18). This is the reason why women cannot take a stand even if the spouse is unfaithful; they cannot exercise their rights for fear of loosing the financial support (William and Shreedhar, 1996: 36). As part of home based care, it is important that women are informed of their rights so that they can prevent transmission of this disease.

Economic Aspect

Unemployment rate amongst the women is high. Some women tend to work as sex workers placing themselves at risk or vulnerable (William and Shreedhar, 1996: 15). One only needs to listen to or watch the national daily news bulletin to learn that women – mostly in rural areas – work for very low income and some are sexually molested by employers.

Educational Aspect

Knowledge, according to Anderson (993), needs to be imparted to the community in order that a behaviour change takes place through peer group influence. Home-based care can only be effected if the basic information on HIV/ AIDS is known. Paying special attention to younger women and girls who are mostly vulnerable is important (van Niftrik, 1994).

Social Aspect

It is women who nurse the chronically ill and the dying (Naidoo, 1999:1). Invariably, the women are left with children of the deceased. Women in many developing countries are especially vulnerable to the combined effects of subordination, stigmatisation and isolation. When they become ill, they worry about being unable to raise their children and getting the blame for it (Wigersma & Singh et al., 1998: 4). Because of the role the women play as caregivers, Ulin (1993:19) emphasises that women must also be active participants

in the development strategies at the community level. This level is important to ensure that relatives of AIDS patients are prepared for home-based care.

THE CIRCUMSTANCES AND NEEDS OF CARE OF PEOPLE AFFECTED BY HIV/AIDS

According to Brown and Powell-Cope (1991:1), the physical and emotional devastation of HIV infections - and consequently AIDS - produces extraordinary challenges to both patients and caregivers (relatives).

Barriers to Care among Persons Living with HIV/AIDS in Rural Areas

Studies of rural persons living with HIV paint a disheartening picture of their life quality. The problems confronting HIV-affected men and women in rural areas are numerous and complex. Several studies indicate that, because of population size and the history of the AIDS epidemic, rural communities lack a sufficient number of health care professionals who can provide competent medical, dental and psychological care (Berry, Mekinneu and Mc clain, 1996; Helms, 1993; Mainous, Neil and Matheny, 1995; The Urban Institute, 1990). Furthermore, even if health care professionals are geographically accessible, there is no assurance that care will be provided (Kelly, Chu and Buehler, 1987). Clearly, accessing competent and compassionate health care is difficult for many rural people living with HIV.

Problems of AIDS affecting home-based care

A variety of problems exist which affect home-based care such as poor infrastructure in the rural area, lack of information for home-based care, fear by nurses etc (Drysdale, 1999:1). According to Mthembu (1998), the co-ordinator for KZN HIV/ AIDS, circular no. 2/35 was sent to all regions, health districts and medical superintendents of hospitals. According to the aforementioned circular, the communities and families were to be mobilised and encouraged to participate in home-based care. The preparation of the family caregivers for all HIV/ AIDS patients by nurses was not clearly spelled out in the above document.

The researcher views the effective preparation – of the relatives – as an important role of nurses in the care of HIV/ AIDS client. In addition to the above, emphasis should be placed on health education. In order to give a holistic HBC, nurses need to be aware of the following facts on both HIV/AIDS care receivers and caregivers. These factors can affect the exercise of HBC:

The experiences of an HIV/AIDS sufferer. Much of the care required by persons with HIV/AIDS is provided informally by friends and relatives (Crystal & Jackson, 1989; McCann & Wadsworth, 1992; Pearlin et al., 1994). Wardlaw (1994) states that most persons with HIV/AIDS-related disabilities rely exclusively on self-care and informal services to meet their needs.

The experiences of caregivers. Families and significant others assume heavy

responsibilities for care of HIV infected individuals. Serving as support structures, the abovementioned structures provide the cornerstone of society's response to the AIDS epidemic. Informal caregiving to persons with HIV/AIDS occurs in a dynamic context, is highly stressful and requires the development of strategies to sustain role occupancy (Folkman et al., 1994a; Pearlin et al., 1988). Informal caregivers encounter demands that exceed their normal adaptive capacities thereby placing them in a situation characterised by chronic social stress (Aneshensel, 1992; Aneshensel et al., 1995; Pearlin, 1989; Pearlin et al., 1990).

The stigma of HIV/AIDS may exacerbate caregiver stress by complicating help-seeking and increasing social isolation (Powell-Cope & Brown, 1992). Caregiving-related stress has consistently been shown to impact negatively on emotional wellbeing (Folkman et al., 1994a; 1994b; LeBlanc et al., 1995; Raveis & Siegel, 1991) and physical health (Baumgarten, 1989; LeBlanc et al., 1997; Schulz et al., 1990; Wright et al., 1993). In order for caregivers to sustain role occupancy, they must develop strategies to contain role-related stress proliferation (Aneshensel et al., 1995; Pearlin, 1989; Pearlin et al., 1990) and its negative consequences. One strategy available to caregivers is to reduce the demands of caregiving through the integration of formal services obtained from home care agencies and community-based health and social service providers (Mullan, 1993). However, the aforementioned agencies need data as to the extent to which caregivers are prepared - hence this study is conducted.

Nurses' feelings towards HIV and AIDS patients. According to Lopez (1998:129), the intensity of HIV and AIDS in Africa are difficult to assess precisely. Most cases go undiagnosed and unreported (Esterhuyse and Doyle, 1993:14). Because of its potential of exposing nurses to the risk of contracting HIV, the above situation has far reaching consequences on nurses' attitudes towards HIV patients (Downes, 1991:333). Nurses' attitudes may be manifested as follows:

- As health care workers, nurses may be negative and reluctant to provide care to AIDS patients (Kempanien, Patricia & Dubbert, 1996:397; Downes, 1991:333).

- They may portray both anger and denial (van Dyk, 1990).

- They may pass unfair judgement about AIDS patients or avoid to care. Nurses may also develop stress and burnout syndrome (Wissen & Woodman, 1994:1141).

Knowledge and understanding of HIV/AIDS. Knowledge and understanding refer to familiarity gained by experience and perception of the meaning of HIV/AIDS (Balliers Nurses Dictionary). Chamane and Kortenhout (1997:43) highlighted that fear would be worsened by lack of knowledge. Eysenick's 1988-1990 study revealed that nurses – with limited knowledge base – had judgmental and negative attitudes towards AIDS/HIV infected patients.

Another study done by Ratsaka and Hirschowitz (1995:41) explored the knowledge, attitudes and beliefs amongst the inhabitants of a highly populated settlement. The aforementioned researchers discovered that factors such as family influence, peer groups, cultural norms, the media etc. determine behaviours. These researchers also pointed out that their respondents had patchy knowledge on HIV; for example, most respondents thought that they were not at risk of HIV infection.

From the aforementioned studies, it can be concluded that people need to be informed about HIV/AIDS. It can also be concluded that people with poor knowledge and understanding of AIDS will find it difficult to provide a relevant and comprehensive home-based care. The question that now becomes apparent is *what is comprehensive home-based HIV/AIDS care*?

COMPREHENSIVE HIV/AIDS CARE

Having defined the concept of Home-based care (HBC), in Chapter 1, this section seeks to explain the nature and aspects that should be looked at as far as HBC is concerned.

The complex nature of HIV/AIDS

HIV/AIDS – because of its complex socio-economic nature – presents many challenges to

health education, health services and policies, particularly for family and community members who are responsible for the care of people with AIDS. Attempts to promote behavioural changes need to acknowledge the abovementioned fact. Therefore the nature and extent of HBC programme need to be clearly defined.

The Nature and Extent of Preparation of Relatives for Home-based Care

Varieties of ways and means need to be used to make the community and individuals aware of AIDS. The nature and extent of preparation is explains below.

The areas/settings that need to be covered. According to Evian (1993:235), AIDS education and information need to be included in many different areas, such as; Health services, Schools, Workplace, Religious organisation, Community organisation, Political organisations, and Mass media.

Education programmes need to be innovative and sustained. Education campaigns need to be sustained and ongoing. "Once off" or only occasional efforts will not influence people to make the difficult change. Messages and educational programmes need to be ongoing and repetitive. According to Evian (1993), different methods should be used to communicate about AIDS e.g. talks, seminars, workshops, educational drama, role plays, puppets, colourful posters brochures, and comic books. Some of the best educators of the public are people with HIV infection/ AIDS. Health care workers can get involved in these different ways and

methods. There are other books and manuals on education, especially adult education, communication and AIDS prevention.

Preparation for Life-style changes. The number of people infected with AIDS, its mode of transmission and its impact on the whole society, have led to the conception that AIDS is not only an infectious disease, but also a social one (Ankrah, 1991). Primary emphasis continues to be placed on prevention, however, and less attention has been directed to care of people with AIDS in the community (Bennett, 1987). The HIV positive person may have to make some very important decisions and changes to his/ her life, such as:

- changing sexual habits so as to avoid passing the virus to his/ her sexual partner (Allan, 1992:46).

- adjusting to the idea that his/her life may be significantly shortened (MacGregor, 1997:26), and

- having a fear of developing serious disease (Christie and Hickson, 1990:26).

Counselling. There may be many reasons that require counselling. These may include the following:

- Many relationships may be broken up due to one partner being HIV

positive.

- People can lose their jobs. They can be rejected by their friends and family (SAHWCO, 1990:1).

- Feelings of depression, anger and guilt may result. Some people have even committed suicide after receiving their HIV test results (Wright, 1997:24). This means that everyone who has a HIV test must be properly counselled about the test before the test is done (Allan, 1992: 46). It is equally important to carefully counsel a person after the test ie a post-test counselling or interview (Piot et al, 1992:98). It is important to make a follow-up plan for the ongoing care of the person if she/ he is HIV positive (Evian, 1993;41).

Health Education on Home-based Care

Health education refers to empowering people to make their decisions (Mackenzie et al, 1992: 26-27). Home-based care refers to the empowering of relatives to participate in manner to be able to offer care in their familiar environment at home (Stanhope 1988:200). The aspect of preparation of relatives of AIDS patients has, however, never been distinctly discussed or researched at Bethesda sub-district. Brown and Powell-Cope (1991) highlight the AIDS family care giving and its outcome but not much emphasis is placed on

preparation of relatives of HIV patients by nurses.

Sapepa's article (1997) cites the assessment and planning of home-based care for PWA. She investigates how effective the project in Region "E" in the Eastern Cape was. Soal (1997) evaluates a home-based care project for PWA. An evaluation on the effectiveness of the project is highlighted. Wright (1997) stresses the importance of nurses' involvement in assisting PWA to meet their psychological, physical and spiritual needs. He also discusses death and meaning of life for both the patient and caregivers. He further emphasises the empowerment of caregivers in order to cope with the care at home.

THEORETICAL FRAMEWORK

This study is based on Dorothy Orem's self-care theory. Orem (1991) emphasises that an individual has to care for himself or herself. Orem sees "self care" as activities that individuals are able to initiate, practice and perform on their own in maintaining life, health and well being.

Orem's theory comprises of six components that are self-care, self-care agency, therapeutic self-care demand, self-care deficit, nursing agency, and nursing systems. The first four concepts relate to the patient who is in need of nursing care. Self care relates to those activities initiated, performed and practised by an individual on his own. During the early stage of the disease, the AIDS patient is able to carry out his activities without help.

During the late stage of the disease, however, the AIDS patient cannot be able to carry out his activities without help. Self-care deficit occurs when an individual cannot meet the therapeutic self care demands. Therapeutic actions will eventually need to be taken in order to meet the patient's self-care requisites. Known as nursing agency, this stage involves the implementation of actions, which compensate for and possibly overcome the patient's self-care limitations. According to the chosen theory, relatives of an AIDS patient should be able to determine and implement home-based care activities.

The researcher has chosen Orem's theoretical framework because this model deals with the nursing agency. This theory highlights the technical, psychological, spiritual, and social health care which are basic requirements for the preparation of relatives of AIDS patient for home-based care.

Entitled "Research Methodology," the next chapter explains – among other things – the research design, where and how the data was collected.

CHAPTER 3

RESEARCH METHODOLOGY

INTRODUCTION

This chapter outlines the method that was used in conducting this research. The researcher discusses the research design, sample and sampling, data collection, ethical consideration.

. RESEARCH DESIGN

The research design in this study, is the descriptive type. According to Nieswiadomy (1998:31), the descriptive design defines what the problem is, what is being investigated and what has happened. Therefore, this study described the preparation of relatives of AIDS patients for home-based care by nursing professionals.

STUDY SETTING

The study was conducted at Bethesda sub-district. Bethesda sub-district is situated on top of the Lebombo mountains as well as in the Makhathini flats. It consists of Bethesda hospital, its six residential clinics and two (2) day clinics. Bethesda sub-district is one of the four sub-districts, which form Jozini district near Mozambique in the North and Swaziland in the NorthWest. Bethesda Hospital is a 230 bedded institution. The researcher is an Assistant Director for nursing in this sub-district. Bethesda staff establishment is as follows:

STAFF ESTABLISHMENT

	APPROVED	RELEASED	FILLED	FROZEN
AD	1	14	1	-
SPN	14	14	14	-
PN	80	80	60	20
SEN	13	13	13	-
EN	82	82	62	20
NA	40	40	40	-
Pupil nurses	30	30	30	-

PILOT STUDY

The pilot study was done on (5) five Professional Nurses (CPN) who did not form the part of the main study. It was done as a trial version of the planned study - to determine the feasibility of the study by testing the instrument that was used. The researcher identified and corrected some problems in her data collection tool.

SAMPLE AND SAMPLING

To select a sample that was representative of the population and to enable generalisation to the total population, a stratified random sampling technique was used. This technique was chosen by the researcher because it ensured that every member of the population had an equal chance of being chosen. The subjects were selected by firstly having categories forming the strata i.e. senior professional nurses, senior enrolled nurses. For random sampling then every third number on the duty list was chosen. The residential , mobile clinics and night nurses were included.

The population of professional nurses and Enrolled Nurses was 195 of which the sample of 50 was selected as a target group – these included Senior Professional Nurses, Professional Nurses, Senior Enrolled Nurses, Enrolled Nurses, Non-professionals. The above were chosen because they:

- Have a wide experience in nursing administration

- Conduct and supervise the inservice and health education on HIV according to their scope of practice.

- Have a wide experience in patient care.

- The non-professionals (which included patient relatives) - are the recipients of professional health care.

DATA COLLECTION

Data collection instrument

The researcher designed the interview questionnaire as an instrument for data collection. The questionnaire contained open-ended and closed-ended questions (See appendix). Participants were asked – among others – whether:

- Their present duties included HIV/AIDS-related responsibilities.

- They had organised or participated in training courses organised by others on HIV/AIDS.

- They had provided HIV/AIDS care.

The respondents – since they were nurses – did not need an interpreter. However, interpretation was needed to the non-nursing respondents who were not AIDS counsellors.

Validity of the questionnaire

The expert validity was ensured by using – with minor alterations – previously used data collection questions. The following are related HIV studies – from which questions were taken:

- Ratsaka and Hirschowitz 1995 study entitled "*Knowledge, attitudes and beliefs, amongst inhabitants of high density informal settlements with regard to sexuality and AIDS in Alexandra Township*".

- Chamane and Kortenbout 1997 study entitled "*Professional nurses' knowledge and understanding on HIV/ AIDS infection.*"

Distribution of questionnaire

Questionnaires were handed to all respondents after explaining the purpose of the study. The researcher handed the questionnaires personally to all subjects after obtaining permission from them. The questions relating to the study were answered faithfully

although some questions were answered without giving a serious thought. There were delays with returns of questionnaires. Some respondents were reminded several times before forms were returned.

Concerning the non-nursing respondents, the researcher had to interpret questions for the two relatives of AIDS patients. Fortunately, the two relatives of AIDS patients were very open about the disease but careful not to release the name of their relatives with AIDS. The study was made easy with these positive attitudes on the part of the respondents.

ETHICAL CONSIDERATION

Permission to conduct research

Each respondent's permission was verbally obtained in hospital and clinics. The permission to conduct the study was obtained from the Department of Health Regional Director for Jozini District and the Deputy Medical Superintendent of Bethesda Hospital (See appendix). The research proposal and samples of questionnaire were enclosed with all letters of request.

Anonymity and Confidentiality

No names and signatures were required from the research subjects. All information was

kept strictly confidential throughout the research study. Data had code numbers only for the researcher who had a separate sheet with names.

In the next chapter, the researcher reports how the collected data was analysed. The interpretation is also done.

CHAPTER 4

DATA ANALYSIS AND INTERPRETATION

INTRODUCTION

In this chapter, the researcher reports how the collected data was analysed and interpreted. The analysis of the information is presented in tables, diagrams and graphs. The study objectives were used as basis for data analysis. It should be remembered that there were three objectives of the study – which were:

- To establish the nature and the extent at preparation of relatives of AIDS patients by nurses for home-based care.
- To determine the reason for the inability to care for the reason for them in a home environment.
- To identify the nature and variety of problems that AIDS patients experience in getting the needed support and acceptance by relatives.

The chapter's sections – apart from Section A, the Biographical Information – were divided according to the existing objectives of the study. Therefore, analysis was done under four

sections/units. The sections are now discussed.

SECTION A: BIOGRAPHIC INFORMATION

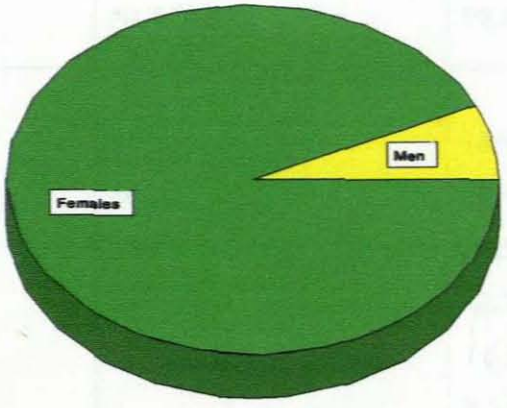
The aim of this section was to obtain biographical information of the respondents.

Figure 1: Age distribution

YEARS	NUMBER	PERCENTAGE
20 – 29	9	18.3%
30 – 39	24	48.9%
40 – 49	11	22.3%
50 – 59	5	10.5%
60 onwards	0	0%
TOTAL	**49**	100%

This distribution indicates that the majority (48%) of respondents were young – with the age range of 30 - 39 years. Brown and Powell-Cope (1986: 339) highlights that young caregivers – particularly those who are still sexually active – have an additional strain. These young people have to deal with the effect of the (sexuality-linked) life-threatening illnesses. It is safe to regard the aforementioned population as the "At a risk group." It is, therefore, of utmost importance that during these sexually active and childbearing years they familiarise themselves with home-based care.

Fig 2: Gender Distribution



This distribution indicates that the majority (93%) of respondents were females. This distribution also confirms the fact that nursing profession in South Africa - if not in the world - is female-dominated. This is a good and promising prospect for HBC. Firstly, it is a general belief that women tend to be more nurturing than men. Secondly, the majority of respondents are young and thus physically active and would find it easy to move around doing home-based care.

Figure 3: Years of experience of nurses

YEARS	NUMBER	PERCENTAGE
2 – 3	9	18.4%
4 – 5	10	20.4%
6 – 10	13	26.5%
11 – 15	6	12.2%
16 – 20	7	14.3%
21 onwards	4	8.2 %
TOTAL	**49**	100%

From this table, the majority (26.5%) of respondents had 6 - 10 years of experience. This wide experience in nursing could have a positive effect in HBC. According to Mbowane (1994:37), nurses with less experience could have negative perceptions of caring - which could hinder the preparation of relatives of AIDS patients.

SECTION B:THE NATURE AND VARIETY OF PROBLEMS AND ATTITUDES

The aim of this section was to identify the nature and variety of problems that aids patients have in getting the needed support and acceptance by relatives. It was also to elicit the attitudes of nurses or people living with AIDS.

Figure 4: Nurses' feelings when nursing a patient with HIV/AIDS

	SAD	HAPPY	AFRAID	CONFUSED	INDIFFERENT	TOTAL	%
SPN	5	1	3	0	1	10	20.4
PN	9	2	2	0	1	14	28.5
SEN	3	2	3	0	2	10	20.4
EN	4	5	4	O	2	15	30.6
	21	10	12	0	6	49	100%
TOTAL	42.8%	20.4%	24.6%	0%	12.2%	100%	

This distribution indicated that the majority (42.8%) of respondents had a negative feeling – of being sad. 24.6% of respondents said they were afraid to nurse an AIDS patient – this is also a negative attitudes. This has an implication on nurses attitude – barring them from being positive towards the preparation of relatives for HBC.

Figure 5: Nurses' fear of HIV/AIDS

CATEGORIES	SCARED	NOT SCARED	TOTAL	%
SPN	10	-	10	20.41
PRN	12	2	14	28.57
SEN	8	2	10	20.41
EN	10	5	15	30.61
TOTAL	**40 (82%)**	**9(18 %)**	49	100%

The majority (82%) of respondents expressed the fear of HIV/AIDS. It is presumed/believed that the fear was due to great risk of contracting the HI Virus. Chamane and Kortenhout (1997:44) express a similar view "*The lack of knowledge and fear of HIV infection could be the cause of fear of HIV/AIDS.*" Mbowane (1994: 39) also concurs "*Most of the nurses might fear to nurse AIDS patient because they are at risk of*

contracting AIDS."

Some of these nurses are Aids Counsellors but still fear HIV/ AIDS. Some nurses gave reasons that they may be having AIDS themselves hence they fear it. Surely, fear can be regarded as a problem, which delay the preparation of relatives of AIDS patients for HBC.

Figure 6: Non-Professionals' fear of HIV/AIDS

CATEGORIES	SCARED		NOT SCARED		TOTAL	%
PWA	2		-		2	50
AIDS COUNSELLORS	-		2		2	50
TOTAL	2	(50%)	2	(50%)	4	100%

The half (50%) of respondents admitted that they fear AIDS because they were having the disease (PWA). This was an indication that they have not accepted the disease. The other half 50% was positive about AIDS - they did not fear AIDS.

Figure 7: Nurses talking about HIV/AIDS

CATEGORIES	TALK ABOUT HIV	DO NOT TALK ABOUT HIV	TOTAL	%
SPN	7	3	10	20.41
PRN	11	3	14	28.57
SEN	5	5	10	20.41
EN	12	3	15	30.61
TOTAL	35 (71.43%)	14 (28.57%)	49	100%

The distribution indicated that the majority (71.43%) of respondents said that they found it easy to talk about AIDS. Many of these were AIDS counsellors in their wards and clinics. One wonders how truthful was this response because 82% of the nurses had said that they feared AIDS. It could thus be doubted under these circumstances whether HBC can be implemented effectively.

Figure 8: Non-Professionals talking about HIV/AIDS

CATEGORIES	TALK ABOUT HIV	DO NOT TALK ABOUT HIV	TOTAL
PWA	1	1	2
AIDS COUNSELLORS	2	-	2
TOTAL	3 (75%)	1 (25%)	4

Most (75%) of the respondents found it easy to talk about AIDS. However, these respondents were happy to talk as long as people do not know their HIV status. This may not be useful if the client does not disclose his/her HIV status. From these responses, it can be deduced that there is a need for AIDS counsellors – who should communicate and share information with AIDS patients. There was no response from the relatives of AIDS patients.

Figure 9: Availability of HBC information to nurses

CATEGORIES	Availability of HBC information	Unavailability of HBC information	TOTAL
SPN	8	2	10
PRN	7	7	14
SEN	5	5	10
EN	10	5	15
TOTAL	30 (61%)	19 (39%)	49 (100%)

The majority (61%) of respondents did know where to obtain the information on HBC. It was quite shocking to see such a large number of professional nurses (39%) who did not know where to get information on HBC. The same applied to enrolled nurses who also did not know where to get information. This lack of knowledge has a negative implications on the preparation of relatives for HBC.

SECTION C : THE NATURE OF PREPARATION AND THE REASON FOR THE INABILITY TO CARE

The aim of this section was to establish the nature and the extent of preparation of relatives of aids patients by nurses for home based care. It also seeks to determine the reason for the inability to care for them in a home environment. In order to elicit the aforementioned, the researcher had to concentrate on the all aspects of preparation, that is technological, psychological, social, and spiritual preparation.

Figure 10: Technological preparation

CATEGORIES	TECHNOLOGICALLY PREPARED	TECHNOLOGICALLY UNPREPARED	TOTAL
SPN	8	2	10
PRN	6	8	14
SEN	3	7	10
EN	6	9	15
TOTAL	23 (47%)	26 (53%)	49 (100%)

The majority (53%) of the respondents had no information on HBC technological

preparation. These responses show that the majority of nursing professionals at Bethesda sub-district have no background information on home-based care. Nurses, therefore, would be unable to prepare relatives for HBC.

At the writing of this study, only a few of the nursing professionals have gone through the HBC programme. Some nurses are showing interest. However, the staff shortages are a hindrance. Nurses need to initiate the programme on home-based care. This lack of information on HBC indicates that there is a lack of technological preparation for HBC.

Psychological Preparation

The psychological preparation refers to the acceptance and support by relatives of a HIV/AIDS patients.

Figure 11: Acceptance and support

CATEGORIES	Willing to accept and support	Not willing to accept and support	TOTAL
SPN	2	8	10
PRN	8	6	14
SEN	4	6	10
EN	5	10	15
TOTAL	19 **(39%)**	30 **(61%)**	49 (100%)

The majority (61%) of respondents have never given any psychological care to relatives. This confirms the findings that the majority of nurses were not well informed about HBC, therefore have never prepared relatives of AIDS psychologically.

Figure 12: Attitudes

CATEGORIES	DENIAL	FEAR/ BLAME	CONFUSION/ NEGLECT	DEPRESSED	NON ACCEPTANCE BY RELATIVES	DO NOT KNOW
SPN	2	3	2	1	2	-
PRN	2	3	3	1	4	1
SEN	1	3	3	-	3	-
EN	2	4	4	1	4	-
TOTAL	7(14.2%)	13(26%)	12 (24.4%)	3 (6.1%)	13 (26%)	1 (2%)

This distribution indicates that the majority (26%) of respondents reported that they were afraid. The other attitude expressed by the other major group (26%) was non-acceptance.

Figure 14: Social Preparation

CATEGORIES	SOCIAL STIGMA	FINANCIAL PROBLEM	UNACCEPTANCE BY RELATIVES	ISOLATION	LACK OF SUPPORT BY RELATIVES	NO RESPONSES
SPN	2	1	3	2	2	-
PRN	2	3	2	4	3	-
SEN	2	2	1	3	2	-
E/N	3	1	3	5	2	1
TOTAL	9(18.3%)	7(14.2%)	9(18.3%)	14 (26%)	9 (18.3%)	1 (2%)

The majority (26%) of respondents reported that isolation was the main reason for their inability to care for themselves at home. If the relatives are prepared for HBC isolation could be prevented or at least reduced.

Figure 14: Spiritual Preparation

CATEGORIES	ABSENCE OF A PRIEST	FEELING OF BEING PUNISHED BY GOD	CONDEMNATION	LACK OF INFLUENCE BY OTHER PWA	NO A CHURCH GOER	NO RESPONSES
SPN	2	1	3	2	1	1
PRN	4	4	3	2	2	-
SEN	2	3	2	2	1	-
E/N	5	4	3	1	2	-
TOTAL	13 (26%)	12(24%)	11(22.4%)	7(14.2%)	6(12.2%)	1(2%)

This distribution indicates that the majority (26%) of respondents reported that the absence of a priest was a major issue where most support could be obtained.

In the next chapter, the researcher discusses the conclusion, limitations and recommendations of the study.

CHAPTER 5

CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

In this chapter, the researcher discusses the conclusions and recommendations of the study. Limitations of the study are also highlighted.

CONCLUSION

With the information obtained from the respondents, one can conclude that all the objectives of the study were met. It has been established that there exists some information gaps amongst the nursing profession on HBC. According to the findings of this study, there is an absence of a well-established HBC programme. This has an adverse effect on the preparation of the relatives for the HBC. The following were notable examples of these effects:

- The nursing neophytes are not properly prepared for the home-based care in their training.
- On the level of professional nurses – the much needed in service education on HBC was not done.

LIMITATIONS

The present study has several limitations worthy of comment. All research participants lived in a single Bethesda District, thus the extent to which this study's findings can be generalised to other geographic regions is unknown. Also, the operational definitions of rural and urban may influence the generalisability of study findings; different definitions of what constitutes rural and urban could yield different results. In spite of these limitations, the researcher believes that the current study sheds light on the preparation for HBC and problems confronted daily by nurses and people living with HIV.

RECOMMENDATIONS

The researcher recommends that:

- Modules on HBC should be developed. These HBC modules should be developed for all health workers and various professionals. AIDS is a major problem that affects everyone. Therefore, everyone should be trained as to how to handle HIV/AIDS patients or their relatives.

- The HBC modules should encapsulated the following:
  - basic information on HIV/AIDS
  - counselling skills on HIV/AIDS
  - home-based care skills and Home visits for AIDS patients

- involvement in self-help projects of communities e.g. Gardens etc
- life skills and coping skills

If these issues can be added, the HBC program can be implemented more effectively.

- PHC trainers should be trained as AIDS PHC Specialists. They should be able to train others on HBC and evaluate HBC programmes from time to time.

- Research should be conducted on the involvement and preparation of community health workers (CHW) on home-based care. The community health workers are the closest people next to the communities. They are trusted by them since they are chosen by the communities. CHW do visits to homesteads, therefore their input can be great if utilised effectively so far as preparing the relatives of AIDS patients for home-based care is concerned.

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Appendix A

Application for Permission to do Research

15.11.98

The Medical Superintendent
Bethesda Hospital
Private Bag X602
UBOMBO
3970

Dear Sir

Re REQUEST TO CONDUCT RESEARCH

I kindly request for the permission to conduct research from December 1998 and August 1999.

May I request the AIDS Team to interview their clients to get a feel of their views with regard to the preparation for home based care for AIDS patients and relatives. I am pursuing the Masters of Arts Cur Degree with the University of Zululand at the Main Campus KwaDlangezwa.

The title of my research is:-
An investigation into preparation of relatives of AIDS patients for home based care in the Bethesda Sub District: Nursing Perspective.

Yours faithfully

Mrs P.B. Harrison

Appendix B

Permission from the Medical Superintendent (Bethesda Hospital)

Friday, 11 December 1998

The Matron
Bethesda Hospital
Private Bag x 602
UBOMBO
3970

Dear Matron

I am happy to give you permission to do research about the preparation for home based care of AIDS patients in Bethesda subdistrict between December 1998 and January 1999.

Yours faithfully

Dr.A.J.Grant
Acting Superintendent

Appendix C

Permission from Human Resources Manager (KwaZulu-Natal Province)

PROVINCE OF KWAZULU-NATAL

DEPARTMENT OF HEALTH

ISIFUNDAZWE SAKWAZULU-NATALI

UMNYANGO WEZEMPILO

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Reference: HRD Research
Enquiries: Dr L.L. Nkonzo-Mtembu
Extension: 2275

Date: 17 April 2000

The Regional Director
Jozini Region
Private Bag X002
JOZINI
3969

APPLICATION TO CONDUCT RESEARCH : MRS P.B. HARRISON

The request to conduct research on "The Investigation into the Preparation of the Relatives of AIDS patients for the support of Home-Based Care" is approved.

The Regional Office is requested to ensure that the researcher submits the following:-

- the research proposal
- scope of research
  - institutions that will access
  - sample size
- ethical consideration
  - confidentiality
- undertaking to share the research results.

DIRECTOR : HRD
Mkhize_application (2)

Appendix D

Permission from the Regional Director (Jozini Region)

DEPARTMENT OF HEALTH

PROVINCE OF KWAZULU-NATAL
JOZINI REGION: HEALTH CARE DIRECTORATE

THE OFFICE OF THE REGIONAL DIRECTOR

Postal Address : Private Bag X002 Jozini 3969	Telephone: (035) 5721021 Fax : (035) 5721251
Date : 25 September 1997	Email : sipho@dhrde.db.healthlink.org.za
Reference : S2	ENQUIRIES: S.M. NGXONGO

The Secretary
Department of Health
Private Bag X9051
PIETERMARITZBURG
3200

APPLICATION TO CARRY OUT RESEARCH: MRS P B HARRISON

This office has received the enclosed application from the above officer. The increasing incidence of HIV/AIDS is causing concern as it reflects the inability of the interventions to stop the transmission. Any efforts or research to find a solution or to build a partnership between the health service and the community in the fight against HIV/AIDS should be supported.

Mrs. Harrison intends conducting an investigation into preparation of relatives of AIDS patients for home-based care. This study is relevant as the AIDS crises is reaching to a points where the majority of the patients can no longer be admitted, as hospitals are already full of AIDS patients. It is obvious that in this situation the home-based care will play a critical role.

The above application has the support of this office. It will be appreciated if it is given the approval by the department.

S M Ngxongo
REGIONAL DIRECTOR: JOZINI REGION

Appendix E

Questionnaire

QUESTIONNAIRE

AN INVESTIGATION INTO PREPARATION OF RELATIVES OF AIDS PATIENTS FOR HOME-BASED CARE IN THE BETHESDA HEALTH WARD: NURSING PERSPECTIVE.

SECTION A

AIM

To gather the biographic data of the respondents.

1. BIOGRAPHICAL DATA

1.1 Number of respondent ☐

Directions to respondents
NB: TICK THE APPROPRIATE

1.2 **Age** 20-29 ☐

30-39 ☐

40-49 ☐

50-59 ☐

60-69 ☐

70 – onwards ☐

1.3 Sex

Female ☐

Male ☐

1.4 Marital Status

Married ☐

Single ☐

Divorced ☐

1.5 Subgroups

1.5.1 Professionals

Senior Professional Nurses ☐

Professional Nurses ☐

Senior Enrolled Nurses ☐

Enrolled Nurses ☐

1.5.2 Non-professionals

People living with AIDS patients ☐

AIDS counselor ☐

1.6 Years of experience in nursing

2 – 3 ☐

4 – 5 years ☐

6 – 10 years ☐

11 – 15 years ☐

16 – 20 years ☐

21 – onwards ☐

SECTION B

AIM

To elicite the attitudes of nurses or people living with AIDS patients:

2. ATTITUDE

2.1 How would you feel when nursing a person with HIV/AIDS?

Sad ☐

Happy ☐

Afraid ☐

Confused ☐

Indifferent ☐

2.2 Do you have fears about AIDS?

Yes ☐

No ☐

2.3 Do you find it easy to talk about the AIDS disease?

Yes ☐

No ☐

2.3.1 If yes, why?

.....
.....
.....

2.3.2 If no, why?

.....
.....
.....

2.4 Do you think you can get enough information when in doubt about HIV?

Yes ☐

No ☐

SECTION C

AIM:

To elicite as to how much preparation for home based care is done by professionals as well as no-professionals.

3. PREPARATION FOR A HOME BASED CARE

3.1 Technological preparation

3.1.1 Do you have information of preparation of relatives for home based care?

Yes ☐

No ☐

If "no", is it because:

(i) You have received no inservice education on the subject?

Yes ☐

No ☐

(ii) You fear talking bout it

Yes ☐

No ☐

(iii) There is no time to talk about it.

Yes ☐

No ☐

(iv) You have no interest in the topic

Yes ☐

No ☐

3.1.2 If "yes", is it because:
This person gave you the information on home-based care.
Tick the appropriate:

Nurse ☐

Doctor ☐

Pharmacist ☐

Tutor ☐

AIDS Action Team ☐

Other ☐

3.1.3 Do you think the information you have on home based care is on the following:

Causative organism ☐

Signs and symptoms ☐

Methods of contracting the disease ☐

Spread of HIV ☐

Prevention of infection ☐

Do you think the knowledge you have is adequate to be able to freely give the information on home based care to others?

Yes ☐

No ☐

3.2 Psychological preparation

3.2.1 What have you done to ensure the acceptance of your HIV patient to the relatives.

.....
.....
.....

3.2.2 Do you think the patients/clients illness must be kept confidential.

Yes ☐

No ☐

3.2.3 Have you encouraged the client/patients to be incontact with a relative or friend to discuss his/her illness/problem?

Yes ☐

No ☐

3.3 Physical Preparation

List how you prepare the relatives/AIDS patients under the following headings:

3.3.1 What information can you give to the patient/client regarding the bedding/linen?

.....
.....
.....

3.3.2 Can the use of utensils spread the HIV/AIDS?

Yes ☐

No ☐

3.3.3 Do you think HIV/AIDS could be spread by sharing of clothes?

Yes ☐

No ☐

3.3.4 How do you think the skin, open wounds, discharges, rashes can spread HIV infection?

.....
.....
.....

3.3.5 Can colds and flue spread the HIV/AIDS?

Yes ☐

No ☐

3.3.6 What importance does the diet play when a client/patient has HIV/AIDS?

.....
.....
.....

3.3.7 How can exercise assist the HIV/AIDS?

.....
.....
.....

3.3.8 Can HIV be spread by the use of the toilet/bath.

Yes ☐

No ☐

3.3.9 Do you think holding hands can spread the HIV?

Yes ☐

No ☐

3.3.10 It is possible to contract the HIV through kissing?

Yes ☐

No ☐

3.3.11 What advice can you give to patients/clients with regard to the further prevention of infection sexually?

.....
.....
.....
.....
.....

3.4 <u>Social preparation</u>

List points under which you will prepare relatives/AIDS patients socially.

.....
.....
.....
.....

3.4.1 Can the relatives/family be of an assistance to HIV/AIDS patients?

Yes ☐

No ☐

3.4.2 In what way can friends be of an assistance to an AIDS/HIV patient?

.....
.....
.....
.....

3.4.3 In what way can the support group be of help?

.....
.....
.....
.....

3.4.4 What way can the community be assisted in accepting the HIV/AIDS patients?

.....
.....
.....
.....

3.5 Financial preparation

List how you would advise the client who is still active but being HIV positive?

.....
.....
.....
.....

3.5.1 Have you ever advise a client who is HIV positive about returning to work.

Yes ☐

No ☐

3.5.2 If unemployed, have you ever advised the client about money generating projects?

Yes ☐

No ☐

3.6 Spiritual preparation

Do you advice HIV/AIDS patients to go to a priest for some advices?

Yes ☐

No ☐

3.7 Other preparations

List other points not mentioned above.

3.7.1 .....

3.7.2 .....

3.7.3 .....

3.7.4 .....

3.8 General

In your opinion, list the reasons why the AIDS patients are failing to offer the home-based care under the following headings:-

PHYSICALLY

.....
.....
.....

PSYCHOLOGICALLY

.....
.....
.....

SOCIALLY

.....
.....
.....

SPIRITUALLY

.....
.....
.....

Appendix F

Research Proposal

PROPOSED FOR MASTERSDEGREE
IN NURSING EDUCATION

NAME OF CANDIDATE:	**P.B. HARRISON**
DEPARTMENT:	**NURSING SCIENCE**
PROPOSED DEGREE:	**M.A. CUR**
FACULTY:	**ARTS**
PROMOTER:	**PROF. T.G. MASHABA**
ACADEMIC YEAR:	**1996**

TITLE

AN INVESTIGATION INTO PREPARATION OF RELATIVES OF AIDS PATIENTS FOR HOME-BASED CARE IN THE BETHESDA HEALTH WARD: NURSING PERSPECTIVE

TABLE OF CONTENTS

1. INTRODUCTION

Human Immuno Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) is a disease which is rapidly spreading in South Africa. According to the World Health Organisation (W.H.O.), it was estimated that by the end of the year 1989, the black South Africans infected with HIV aged between 15-49 years would be between 45 000-63 000, and that by year 1990 this number would be between 119 000 and 168 000 and by year 1991 it would be 317, 000 and 446, 000.

The health education given to relatives of AIDS patients by nurses appears to be either lacking or ineffective. Health Services do not seem to adequately contain or cater for the victims of this disease. Health care personnel are also apparently not enough. This study investigates the issue of empowering relatives of aids patients to effectively provide care to their next of kin at home.

2. BACKGROUND OF THE PROBLEM

One person out of every 100 persons amongst black South Africans is reported to be carrying the Human Immuno Virus (HIV). In 1994, at Bethesda Hospital there were 442 cases tested and 198 cases had a positive HIV test. In 1995 there were 692 tested and 301 cases were HIV positive thus an increase in number of cases is noted.

Contracting HIV is associated with immoral behaviour because of its mode of spread mainly through sexual transmission. HIV/AIDS carry a social stigma thus all HIV patients tend to be fearful of isolation and rejection by relatives. The patients experience loss of control, loss of autonomy, self blame, feelings of guilt resulting in anxiety and depression (Christie and Hickson, 1990:26). In rural areas it takes long for HIV test to be done thus diagnosis delays because of the counselling procedure, carrying out of HIV test, awaiting and reporting of results. Specimen are sent to urban hospitals which are about $\pm$ 400 km away and delays occur. At present, there is a great need for increased health education on the manifestations of HIV, spread and prevention of the disease. There are weaknesses on care

by the next of kin of HIV/AIDS patients. There is a great need to prepare the relatives of HIV/AIDS to cope with the disease at home.

3. STATEMENT OF THE PROBLEM

It is predicted that hospitals will progressively become unable to admit al cases of HIV/AIDS because of the influx of such cases. According to the investigation by Peer (1992) the length of stay of AIDS patients in the hospital was eight (8) days compared to five (5) days for medical patients. He suggests that the length of stay of AIDS patients should be reduced and increased emphasis should be on out-patient and home based care. Length stay in hospital will cause shortage of beds.

AIDS patients are mostly semi-chronic and victims are very ill for several months taking beds for acute general cases. The problem of lengthy stay may result in poor personal touch with AIDS patients. Christie and Hickson (1990:26) state that hospitalization add more problems to an AIDS patient who has already gone through a profound emotional disturbance before admission. They also pointed out that the hospital is a cold, sterile and authoritarian environment.

Christie and Hickson (1990:26) place emphasis on care by the nurses. Care of patients by relatives is hardly mentioned. Relatives of the AIDS patient seem to lack the skills to provide care. Health education given by nurses appear not to cover the caring component sufficiently but the cure for symptoms seem to receive priority. Hubley (1986) states that failure to health education is in the planning and communication. When an AIDS patient falls sick, the trend is to send him/her to hospital even for minor health problems which relatives could have coped at home hence one detects lack of adequate knowledge and skills on the part of relatives.

Therefore, the question being addressed in this study is to what extent are relatives of AIDS patients prepared by nurses and other health professionals to provide home care?

4. MOTIVATION FOR THE STUDY

The researcher has been motivated by the escalating incidence of cases HIV/AIDS which is reflected in the increase in statistics resulting in large numbers of hospitalized AIDS patients.

Some patients are hospitalized for minor ailments which relatives could have managed at home. As a Nursing Service Manager the researcher has been involved in the activities of Bethesda AIDS Action Team who are presently preparing for intensive health education of the community in order to get close to the relatives of AIDS patients.

5. SIGNIFICANCE OF THE STUDY

Investigating the problem will have an important contribution in encouraging, equipping, influencing and supporting the relatives of HIV/AIDS patients. Relatives will be able to cope with care for such patients in their familiar environment surrounded by their loved ones. This promotes home based care of AIDS patients. Brown and Powell-Cope (1991) advocate and emphasize family care-giving but the caregivers seem uncertain about what is expected from them. This study should highlight the importance of improving and promoting home-based care, educate relatives so as to reduce work load in hospitals and prevent relatives from contracting the disease whilst taking care of AIDS patients. The related studies on caring have been carried out by the following: Christie and Hickson (1990); van Dyk (1995); Browne and Powel-Cope (1991); Gilks and Frerichs (1994); Campbell and Williams (1990); Lachman (1991).

The studies that have been carried out mainly place the emphasis on care by nurses. The few studies carried out, did not clearly spell out the care by relatives. One study pointed out the uncertainty which existed amongst the caregivers i.e. friends, spouses, parents, children and acquaintances.

The present study is aiming to investigate the extent to which relatives of AIDS patients are prepared by nurses to provide the home-bases care in the Bethesda Health Ward.

6. OBJECTIVES OF THE STUDY

The objectives of the study are to:

6.1 Establish the nature and extent of preparation of relatives of AIDS patients by nurses for looking after the patient at home.

6.2 Determine the reason for relatives apparent inability to care for a relative with AIDS in a home environment.

6.3 Identify the nature and variety of problems that AIDS patients have in getting the needed support and acceptance from the relatives.

7. DEFINITION OF CONCEPTS

The terms used for this study are defined as follows:

HIV

H – Human - only found in human beings

I – Immuno-deficiency – breaking down of defence system leaving body unprotected against diseases.

V – Virus - is a tiny germ causing AIDS

AIDS

A – Acquired - It is passed from person to person and is not inherited.

I – Immune - This means the body's defence against disease

D – Deficiency - Not working properly - a breakdown.

S – Syndrome - It is a collection of different diseases.

(Lachman, 1991:97-124; Macklin, 1989:29-33 and notes from Attic, Empangeni, 1996)

OPERATIONAL DEFINITION

Therefore in this study the term HIV/AIDS must be understood to refer to all people showing signs and symptoms of this condition.

8. PRELIMINARY LITERATURE REVIEW

INTRODUCTION

This section presents literature on HIV/AIDS and problems that relatives of AIDS patients experience when caring for them at home.

Brown and Powel-Cope (1991) have conducted a study which describes the experience by AIDS family caregivers which in most cases cause an uncertainty in their caring due to many factors.

Steyn (1990) states that death occurs at an early age which raises a challenge for nurses to effectively prepare relatives.

8.2 AIDS INCIDENCE

AIDS is an epidemic disease which seem to affect the black population more than the other population groups. Health education seems to be ineffective. This is compounded by the nutritional state amongst the black population group whose socio-economic status is very low, (Summerbell, 1994: 7; Seeley 1994:11, Macklin 1989:93-95). According to author on Aids Scan (1990:30) one in every 100 black South African is reported to the carrying the Human Immuno Virus leading to AIDS. Most patients present as Tuberculosis yet AIDS is the underlying cause which is usually detected when the client is seriously ill.

8.3 PROBLEMS OF AIDS PATIENTS AND OF THEIR RELATIVES

There are increased numbers of AIDS cases admitted in hospital. At Bethesda Hospital during the month of January 1996 there were 32 cases of in-patient as compared to February 1996 where there were 38 known in-patients with HIV/AIDS (Bethesda Hospital Records, 1996).

AIDS patients experience personal problems as soon as they begin to have suspicion about their health status and when they are tested and diagnosed. Patients come to hospital loaded with profound emotional disturbance pertaining to financial difficulties, lifestyle restrictions and reduced social and sexual outlets and worse, to a disease with no cure (Chriestie and Hickson, 1990:26). The patients experience isolation and rejection by relatives. The relatives of AIDS patient suffer shock, disbelief and disappointment. The stigma that the disease carries usually lead to rejection and isolation of a family member with AIDS. There is also fear of the neighbours knowing about a family member with a disease.
Christie and Hickson (1990:26) state that the counseling is an important aspect of nursing care in current AIDS crisis with the dual function of providing education as well as support.

8.4 PHYSICAL, PSYCHOLOGICAL, SOCIAL AND FINANCIAL PROBLEMS

The AIDS patient experiences physical, psychological, social, financial and spiritual problems once they are diagnosed as having HIV/AIDS. Apart from his/her body being affected, the mental strain takes most of the AIDS patient strength. The relatives of the AIDS patients usually become affected by the disclosure of the disease. Relatives may not accept their AIDS patient because of the social stigma (van Dyk, 1995:52-53).

AIDS patients usually suffer the loss of Medical Aids Scheme, loss of jobs and loss of insurance covers thus the patient's financial situation is usually affected seriously. Usually these AIDS patients suffer premature death therefore the spiritual care becomes necessary when giving home based care (Campbell and Williams, 1990:23).

8.5 RELATIVES PROBLEMS

FEAR

The shock of learning about their relative who has received news that he has a positive HIV test may result in fear of the possibility that they can contract the disease themselves.

Fear can lead to neglect of an AIDS patient by relatives if health education is not done effectively (Christie and Hickson, 1990:26).

IGNORANCE

It is assumed that most people now are aware of the disease but the HIV/AIDS may not be understood clearly. Attitudes may not be easy to change and can be mistaken as ignorance. It can also lead to failure to accept the AIDS patients. Through home visits the care givers should aim at reinforcing appropriate behaviour and stress the importance of positive attitudes (Campbell and Williams, 1990:20).

INABILITY TO CARE FOR AN AIDS PATIENT

The relatives who are unable to take care for their relatives with AIDS can result in neglect or prefer to send their AIDS patients to hospital to lessen the burden for themselves. Fear is usually the cause of neglect (van Dyk, 1995:52).

8.6 EFFORTS TO INVOLVE RELATIVES

It is a practice that when a relative has AIDS, he/she is sent to hospital instead of being given home-based care because of the lack of orientation in such. Where efforts are made to involve the relatives, sometimes problems are experienced because of lack of skills to care. Some parents tend to live with a child with AIDS even is they have no skills (Siegl and Morse, 1994:11).

Home-based care is the best means of involving the relatives in their familiar environment. Confidentiality may hamper the emotional support which could have been provided by the relatives. The patient's rights must be respected. Health education can play a major role in involving a relative in the caring for an AIDS patient. (Campbell and Williams, 1990:17).

9. RESEARCH METHOLODOGY

In this section the research methods and techniques to be used in the case study will be discussed.

9.1 RESEARCH DESIGN

Case study research design will be used to describe the situation of the care by relatives to AIDS patients. Polit and Hungler (1987:168) state that the case study is the commonly used type of research. It is an in-depth investigation of a group and an attempt to analyse and understand the variables that are important to the care of the subjects.

9.2 DELIMITATION OF THE SCOPE OF STUDY

The study will be restricted to Bethesda Hospital, it seven (7) residential clinics and areas falling under the five Amakkhosi under the following tribal authorities: KwaNsinde, KwaSiqakathi, KwaJobe, Mashabane and Ezimbidleni.

9.3 TARGET POPULATION

The target population will be:-

10 Senior Professional nurses
15 Professional nurses
10 Senior Enrolled nurses
15 Enrolled nurses
Relatives of Aids patients whose exact number is not known.

These will form the entire population as described by Polit and Hungler (1987). The tentative total of respondents wil be fifty (50).

9.4 THE SAMPLE AND SAMPLING

The sample will be selected from nursing personnel and relatives of AIDS patients. Every second person will be randomly chosen from a population of Senior Professional nurses, Professional Nurses, Senior Enrolled Nurses, Enrolled Nurses and relatives of AIDS patients. Nursing staff will be chosen from the ward off duty list.

Representation of different strata will be ensured. Stratified random sampling will be used because of subgroups.

9.5 RESEARCH INSTRUMENT

The questionnaire will be used with closed-ended and open-ended questions. Questionnaires will be delivered by hand. The relatives of AIDS patients will need an assistance for completing the questionnaire.

9.6 TESTING OF THE INSTRUMENT

Questionnaires will be distributed amongst ten Primary Health Care students by hand. Thereafter errors, corrections and revision of the instrument will be done. Retesting may be necessary if the first pilot study had too many problems.

9.7 ETHICAL CONSIDERATION

As human beings will be used as subjects care will be taken to ensure that their rights are not infringed. Firstly permission will be obtained from the employing body. The subjects approval will be to be sought and also to ensure that they feel free to give information without intimidation. Confidential and anonymity will be maintained. The subjects will be assured that their privacy will not be infringed.

10. OUTLINE OF THE STUDY

CHAPTER 1 : ORIENTATION OF THE STUDY

1. Background of the study
2. Statement of the problem
3. Significance of the study
4. Motivation of the study
5. Objectives of the study
6. Definition of terms

CHAPTER 2 : LITERATURE REVIEW

Theoretical Framework

CHAPTER 3 : RESEARCH METHODOLOGY

1. Delimitation
2. Target population
3. Sample and sampling
4. Research design
5. Instrument for data collection – Questionnaire
6. Pilot Study
7. Ethical consideration

CHAPTER 4 : ANALYSIS AND INTERPRETATION OF DATA

CHAPTER 5 :

Summary

Conclusion

Limitation

Recommendations

Implications

11. WORK PLAN

ACTIVTY	TIME
1. Writing of the proposal	February – March 1996
2. Obtaining of permission	April – May 1996
3. Developing a research tool	June – August 1996
4. Collection of data	September 1996 – February 1997
5. Categorising and analysis of data	March 1997 – April 1997
6. Writing of initial report	May 1997 – July 1997
7. Awaiting remarking	August 1997 – September 1997
8. Writing of final report	October 1997 – January 1998
9. Submission of report	February 1998

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