

**An evaluation of a home-care  
project for people  
with HIV and AIDS**

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for a Master of Arts degree in Psychology in the Faculty of  
Social Science and Humanities at the University of Cape Town.

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by

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**Abbreviations**

AIDS: Acquired Immune Deficiency Syndrome

ASET: The AIDS Support and Education Trust

ATICC: The Aids Training Information and Counselling Centre

CHW: Community Health Worker

CPA: Cape Provincial Administration

HBC: Home Based Care

HIV: Human Immunodeficiency Virus

MRC: Medical Research Council

NACOSA: National AIDS Convention of South Africa

PHC: Primary Health Care

PWA: People with AIDS

RSC: Regional Services Council

WHO: World Health Organisation

## **Abstract**

This dissertation documents the evaluation of a community health pilot project initiated to care for people living with HIV and AIDS. The evaluation, which was conducted at the request of the project management, emphasises the importance of evaluation for project workers, participants, funders and policy makers, as well demonstrating the role that academics can play in supporting and informing the work of community projects. The evaluation was conducted in two stages. The formative evaluation was initiated in February 1994 and results presented to the project in August 1994. The second phase of the evaluation began in February 1995 and was presented to the project in October 1995.

### ***Formative evaluation:***

The objective of the formative stage was to provide the project with information that would assist in the development of an appropriate and sustainable model of care. The evaluation was based on qualitative methods and a record review of project documentation. In-depth interviews with PWA and their families and household members, observation on visits by project staff to clients' homes, interviews with project staff and committee members, and interviews with people involved HIV clinics in local hospitals, HIV/AIDS organisations and primary health care projects were conducted. The evaluation recommended:

- A reduced focus on attendant home nursing of PWA.
- A revision of the organisation of care, with professional nursing staff passing more responsibility to the community home-carers.
- The extension of services offered to include secondary prevention of AIDS-related illness and increased psychosocial services.
- The adoption of the principles of primary health care.

### ***Secondary evaluation:***

The main objective of this phase of the evaluation was to obtain a more quantitative description of clients' experiences of the project. A simple random sample (N=36) of 50% of the project's clients were interviewed to determine their demographic and health profiles; the nature of their involvement with the project; their needs and the extent to which these had been met by the project; their assessment of the services; and their HIV/AIDS knowledge. It was found that most respondents (83,4%) lived in the townships and 75% were unemployed. Most were healthy, with only 17% saying they could not perform strenuous activities; three percent could not perform moderate activities and no respondents were unable to look after their personal needs. Almost 40% reported having infrequent contact with the project - having last seen project staff more than a month ago; and

almost 20% said they had never had contact with the project. Only six percent had ever had contact with home-carers. A description of respondents' material, psychosocial and health needs showed that many of these needs had not been addressed by the project. Few respondents (less than six percent) reported needing home-help services. Six percent rated the service as 'excellent'; 28% as 'very good'; 42% as 'fairly good'; eight percent as 'poor' and 17% did not comment. However, 50% said the project had improved their quality of life. An analysis of HIV/AIDS knowledge showed that no respondents were rated as having 'excellent' knowledge; 22% were considered to have 'good' knowledge; 58% 'poor' and 19,5% 'very bad'.

It was recommended that the project re-evaluate its focus. As the pilot project was organised, it was unable to meet its stated objectives of providing material, psychosocial, health care and home nursing to clients in need. One suggestion was to focus on the needs of clients with AIDS-related illness who were no longer able to care for themselves and required services and support to allow them to die with dignity. If the project wished to maintain the broader focus, a commitment to re-organising the model of care was necessary. A crucial component of this was the transfer of responsibility for delivery of services from project's qualified nursing staff to the home-carers.

### ***Conclusion***

Despite an attempt to present the negative findings in a constructive manner to the project, the evaluation results and recommendations were not fully utilised. Nevertheless the evaluation was useful in that it provided accurate information for potential funders, contributed towards the development of another pilot project to care for children with HIV and AIDS and added to the knowledge of the issues involved in caring for people with HIV and AIDS in South Africa.

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## Chapter One: Introduction

The Western Cape region of the Red Cross Society initiated an AIDS home-based care pilot project in conjunction with other organisations working in the area of HIV/AIDS in September 1993. The aim of the pilot project was to establish a model of community-based care for people with AIDS (PWA) in an urban setting.

Home-based care has been identified by the National Aids Convention of South Africa (Nacosa) as an important element of the national AIDS strategy to reduce the personal and social impact of HIV (Nacosa, 1994). Although the Red Cross project was initiated before the adoption of the Nacosa plan by the Department of Health, many of those involved with the project were part of the conceptualisation of this plan. Although advocating home-care, the Nacosa plan did not contain specific recommendations about the model of care to be provided. The Red Cross pilot project therefore fitted directly into the government's strategy to "pilot and evaluate (home-care) projects in order to achieve sustainable programmes" (Nacosa, 1994).

### *Rationale*

The perceived need for the project was based on a recognition that the number of people with HIV in South Africa is increasing rapidly. At the time the project was initiated it was estimated that there were 19,684 HIV-positive people in the region and 309 PWA (Esterhuyze, 1994). The Cape Provincial Administration (CPA, 1994) reported that HIV-related illnesses accounted for 2,828 in-patient days in CPA hospitals in the first three months of 1994. The number of HIV-positive people in Cape Town was expected to increase to 120,840 by the year 2000 – 6,991 of these would be sick with AIDS-related illnesses and 5,392 AIDS deaths were expected (Esterhuyze, 1994). Projections showed that in 1996, 62,560 people were expected to be HIV-positive, 2,123 to have AIDS and 1,103 to die from AIDS-related illnesses (Esterhuyze, 1994). These figures were based on projections generated by the Doyle actuarial model (Doyle, 1991). Research by the MRC into the response of the health services in the Cape Peninsula to the HIV epidemic (Metrikin, 1993) suggested that alternate approaches to hospital care needed to be developed as hospitals would soon be unable to cope with the demand for care of PWA.

A further motivation for home-care related to the specific needs PWA. Hospitals provide a primarily curative service, which has been seen as inappropriate to people living with a terminal illness (Metrikin & Steinberg, 1992). PWA require a range of services, including counselling, psychosocial support, pastoral care and advice on nutrition and infection control. Families and household members of PWA similarly require support and assistance. There was an assumption that home-care services would be more appropriate to AIDS-related illnesses, which do not require intense medical intervention but rather long-term nursing care and support; that they may be preferred by clients, who may wish to die at home rather than in hospital and that home-care may facilitate the provision of more comprehensive and holistic care for PWA. Also, many people in Cape Town live extremely far from hospital facilities and it was expected that home-care services would be more convenient for clients.

Another perceived advantage of home-care was the opportunity that it provided to increase AIDS awareness in the community by the training of lay home-carers and the combination of care with prevention. Because South Africa is in the relatively early stages of the epidemic, HIV/AIDS remains a somewhat invisible disease. It was hoped that community-based services would hasten the public's response to the epidemic, thus facilitating preventative efforts (Metrikin & Steinberg, 1992). Similarly, it was hoped that home-care would promote community acceptance of, and support for, people with HIV and AIDS.

These arguments presented a strong case for community-based home-care. However, many of the assumptions remained untested. Do PWA prefer to die at home, or would home-care place additional demands on already overburdened family structures and resources? Would home-care provide second-rate services and shift the responsibility for the care of PWA from health services to under-resourced communities? Would home-care actually reduce the burden on hospital beds? Also, even if home-care was appropriate, how best should it be carried out – what is meant by 'community-based home-care'? What kind of training do home-carers need; at what stage should PWA be referred to the project; what services are required and what can feasibly be provided? The Red Cross pilot project was established in an attempt to answer these and other questions. The evaluation of the project, therefore, had two objectives. Firstly, to provide information that would assist in the design and formulation of the model of care offered by the project, and secondly to assess the progress and effectiveness of the project.

## ***Literature review: Community-based care for HIV/AIDS***

Throughout the world, the rapid increase in the number of people with HIV has demanded the development of alternatives to hospital treatment (Mor, Fleishman, Piette & Allen, 1993; Morrison, 1993). Many different approaches to community-based care programmes have been formulated, and many important lessons have been learnt. This review describes some of the community-based models of care undertaken in other countries and discuss the issues raised by these initiatives. Projects in both developed countries, mainly the United States (US) and Britain, and developing countries, particularly Africa, will be discussed. 'Community-based' is used here to include all approaches to care that are undertaken outside of a hospital setting. Rather than attempting to describe all the projects undertaken, this review will focus on a summary of the different services available.

### **Community care in developed countries**

Community-based AIDS organisations have been established in the US and Britain since the early 1980s. These services were motivated by:

- The stigma attached to HIV/AIDS and the resulting hostility and discrimination in existing facilities (Katoff, 1992).
- The lack of adequate counselling and support for people with HIV (Katoff, 1992).
- The limited capacity of hospital services (McCormick, Hopkins, Wood, Wood, Deyo & Inui, 1993).
- The perceived economic benefits of community-based care (McCann, 1991; Mello-Udine, 1992).
- The perceived improvement in quality of care, patient satisfaction, independence, and level of functioning (McCormick, Inui, Deyo & Wood, 1991; Rothkopf, 1992).
- The danger of a potentially contagious hospital environment to people with compromised immune systems (Mansell, 1988).
- An increase in the need for supportive care between times of severe illness because improvements in available medical treatment have meant that PWA are recovering from acute episodes of illness and living longer (Mor, Piette & Fleishman, 1989; Morrison, 1993).

## Services

The services provided by community-based organisations are varied and include:

- Pre- and post-HIV test counselling (Katoff, 1992).
- Support groups and counselling services for people living with HIV and their friends and family (Katoff, 1992).
- Social assistance, including help with legal issues, housing, etc. (Smits, Mansfield & Singh, 1990).
- Transportation services (Morrison, 1993).
- Volunteers providing 'buddy' services such as visits, shopping, emotional support, paying bills, etc. (Community Support Network, 1991).
- Home-aides doing housework, cooking meals and providing practical support (Trudel & Mainville, 1990).
- Qualified nurses providing basic nursing (for example pain control, bed baths, nutritional advice, symptom monitoring) in the home, on a 24-hour basis if necessary (Benedict, 1990).
- Specialised teams consisting of medical doctors, physiotherapists, dietitians, speech therapists, etc., visiting clients in their homes to provide intensive home-care (Rothkopf, 1989).
- AIDS care training for friends and families of PWA (Rose & Catanzaro, 1989).
- Case management or care co-ordination services, which include client assessment, development of a plan of care, referral to necessary services, and periodic re-assessment of needs (Bergen, 1992).
- Respite houses where PWA can spend a few weeks to relieve their families and care-givers (Ensor, 1989).
- Terminal residential care in hospices (Rhymes, 1990).
- Bereavement counselling and support (Venning, 1990).

These services are provided from different sources, including non-profit organisations, private agencies and state health services. Non-profit organisations tend to provide less intensive services – including counselling centres, support groups, and buddy programmes – and are staffed largely by volunteers. Some organisations, however, do provide more intensive care, for example the London Lighthouse which combines training and counselling with residential facilities for PWA (Ensor, 1989). Twenty-four-hour home nursing is offered by private agencies, both generic and AIDS specific. State health departments also offer visiting nursing services.

Some home-care programmes are intended to supplement hospital services, eliminating unnecessary in-patient stays, while others, such as New Jersey's Aids Community Care Alternatives Programme, are designed to replace in-patient visits (Mello-Udine, 1992; Rothkopf, 1989). These programmes provide extensive medical services at home, including intravenous infusion, artificial ventilation and dialysis, requiring specialised equipment and professional attendance. A number of issues arise in the literature from the experiences of these projects:

### **Specialised services**

Most of these services are specifically targeted at people with HIV and AIDS. Where generic services are available (e.g. home nursing agencies and hospices), separate services developed because of ignorance and prejudice in these programmes and because of the need for specialised training and facilities to care for PWA. Some writers, however, suggest that maintaining separate services can increase the marginalisation and isolation of PWA and can result in a loss of confidentiality for those using the services, as well as causing the services themselves to be stigmatised (Layzell & McCarthy, 1993). For these reasons, programmes like the AIDS Homecare and Hospice Programme in San Francisco have started to integrate care for both AIDS and non AIDS clients (Fraser & Hesse, 1988).

### **Service co-ordination**

A problem of co-ordination of services has arisen, with some clients receiving duplicate services and others falling through the cracks in the service networks (Piette, Fleishman, Mor & Dill, 1990). Also, in different areas, some services are replicated while others are not available. These problems highlight the need for planning and co-ordination of services and care. Communication between different service providers is essential to avoid clashes over conflicting approaches to client care and to ensure that the lines of responsibility remain clear (Layzell & McCarthy, 1993). Case-management agencies – both privately and publicly funded – have arisen in an attempt to improve continuity, access, co-ordination, comprehensiveness and accountability of services (Indyk, Belville, Lachapelle, Gordon & Dewart, 1993). These agencies, although reporting favourable outcomes, have documented many difficulties in implementation, particularly in the co-ordination and co-operation between hospital- and community-based services (Mor et al., 1993).

## **Staff support and training**

Another lesson that has been learnt from community-based initiatives is the strong potential for burnout in AIDS carers (Mor et al., 1989). This is true of both volunteer workers and paid staff. Many home-care projects have built staff/volunteer support structures into their programmes. Some have developed guidelines such as stipulating that volunteers do not take on a new client for six months after another has died (Community Support Network, 1991). Also, there is a need for effective screening procedures in the selection of staff and volunteers, as well as a comprehensive training programme covering practical as well as emotional components of care for PWA (Trudel & Mainville, 1990).

## **Volunteers**

Many of these projects are at least partially staffed by volunteer workers. Certain advantages to the use of volunteers have been suggested:

- cost-effectiveness;
- flexibility of volunteers who are not bound by rigid protocols established in the formal health services;
- increased possibility for quality of care and individual attention;
- the accessibility of volunteers who may not be as intimidating as health professionals;
- empowerment of community members through training as carers and the passing on of skills in the community; and
- cultural sensitivity in that volunteers are often drawn from the same sub-culture and community as clients (Katoff, 1993).

However, some problems with the use of volunteers have been raised. Firstly, there is concern that with the increasing HIV population, the supply of volunteers will not meet the demand, and volunteer-dependent programmes will not be sustainable (Morrison, 1993). Also, projects have documented a problem of volunteer accountability, where other commitments take priority over care with detrimental effects for the client and the programme (Mor et al., 1989). Another potential problem is that of confidentiality, where volunteer workers may be members of the same community as their clients, who might feel their anonymity is threatened.

## **Economic benefits**

As mentioned earlier, community-based services were motivated by an expectation of substantial savings in the costs related to caring for PWA. This expectation is justified by a recognition that by far the highest costs in health care are generated by hospital care (Mansell, 1988). A study of the New Jersey AIDS Community Care Alternative Programme showed that the average cost of treating AIDS patients in hospital was \$750 per day, compared to \$200 per day for comparable services at home (Rothkopf, 1992). An economic evaluation of a home-care programme in Italy similarly found home-care to be cost-effective (Tramarin, Milocchi, Tolley, Vaglia, Marcolini, Manfrin & De Lalla, 1992). However, this study found that resource use and costs were affected mainly by client socioeconomic characteristics, and this particular programme was restricted to clients in high socioeconomic groupings – indicating that higher costs would be experienced if this strict eligibility criterion was not adhered to. Also, there is a tendency to ignore the informal costs of home-care, for example the opportunity cost to volunteers and family members. It is therefore possible that home-care succeeds in transferring a substantial portion of care costs from the national health system onto individuals, families and communities (Tramarin et al., 1992). Some evaluations have found that community-based services increase access to care, thereby stimulating utilisation and actually increasing the total cost of care (Mor et al., 1989).

## **Reducing hospital utilisation**

The biggest risk factors for institutionalisation have been found to be:

- low socioeconomic status (Mor et al., 1993; Tramarin et al., 1993),
- living alone or lacking an available support person at home; and
- advanced stage of AIDS illness (McCormick et al., 1993; Mor et al., 1993).

Services which are intended to reduce hospital admissions need to consider these factors in the design of a model of care. Mor and his colleagues (1993) reported that the availability of a 24-hour care service was essential to avoid prolonged hospital stays. Other crucial factors are the provision of housing facilities and transportation services (Katoff, 1993; Mor et al., 1993). Many projects, particularly those incorporating intensive home-care, do report reduced admission to hospitals (Rothkopf, 1992; Tramarin et al., 1992), but in most instances no systematic attempt has been made to assess whether home-care alleviates the burden on hospitals. A study of AIDS deaths in the US reports that the percentage of PWA dying in hospital facilities decreased from



92% in 1983 to 57% in 1991 (Kelly, Chu & Buehler, 1993). The authors attribute this partially to the increased availability of community-based services.

### **Client preferences**

A survey of the long-term care preferences of PWA seems to support assumptions that PWA prefer to use community-based services and to die at home (McCormick et al., 1991). This is supported by many anecdotal reports in descriptions of projects which claim increased client satisfaction, independence and improved levels of functioning (Butters, Higginson, George, Smits & McCarthy, 1991; Carney, 1990; Ensor, 1989; Indyk et al., 1993). An evaluation of case-management services reported that clients had fewer unmet needs after entering the programme (Mor et al., 1993). However, there are warnings that community based services are not intrinsically beneficial to clients' quality of life. Inadequate resources at home, conflict or prejudice in the family, fears around issues of confidentiality, and increased isolation can all detract from the benefits of home-care (Carney et al., 1990; Indyke et al., 1993). These issues need to be considered in the planning of services.

### **Community care in Africa**

Community-based projects in developing countries can be expected to differ from the developed world because of the differences in available medical and social resources and the different nature and structure of the population. Unfortunately, many of the projects that have been initiated in developing countries have not been well documented (Schietinger, Almedal, Marianne, Jacqueline & Ravn, 1993). The World Health Organisation conducted a descriptive study of six home-care programmes for people with HIV and their families in two African countries, Uganda and Zambia. Projects in South Africa (Soldan, Q Abdool Karim & S Abdool Karim, 1993); Rwanda (Schietinger et al., 1993) and Zimbabwe (Foster, 1991) have also been documented. The discussion here is based on a review of these projects.

Community-based services in Africa have largely been initiated because of a fear that the HIV epidemic will overwhelm existing health services (WHO, 1989). In several African countries as much as 30% of the health care budget was already being spent on the care of HIV-positive and AIDS patients in the early 1990s, with no indication that the epidemic had reached a plateau

phase (Chela & Siankanga, 1991; Metrikin & Steinberg, 1992). These projects are therefore strongly directed towards reducing admissions to hospitals, with the exception of the South African project which emphasised the preventative opportunities offered by community-based care.

### Services

The projects provide some or all of the following services (Chela, Campbell & Siankanga, 1989; Chela and Siankanga, 1991; Chipipa; Sinkutu & Sichinga, undated; Foster, 1991; Schietinger et al., 1993; Soldan et al., 1993; WHO, 1989;):

- Medical care at home, including dispensing of medicines
- Nursing care at home
- Counselling to PWA and their families – including encouraging PWA to inform families of their diagnosis, and education around infection control
- Pastoral support
- Contact tracing
- Material support – including food parcels with hi-protein supplements and condoms
- Educational activities in the community
- Transportation services
- Income-generating projects
- Social contacts and support groups
- Training for family members on the care of PWA
- Training of community health workers

Many of these projects were initiated from and are based at hospitals, while others have been developed by non-governmental organisations (WHO, 1989). Most of the projects receive referrals from hospitals and clinics. Because HIV infection is often only discovered when people become symptomatic, clients are generally referred to home-care projects at a late stage in the course of infection (WHO, 1989). The emphasis on reducing hospital admissions means that home-based care is seen as an alternative to in-patient treatment, except in the case of severe illness if carers believe that hospital treatment will be effective and beneficial (Chela, Campbell & Siankanga, 1989). PWA are generally sent home or left at home in the terminal stages of

illness, both to reduce the burden on hospital beds and because it is believed that people prefer to die at home in familiar surroundings (Foster, 1991).

### **Lack of resources**

The most consistent problem facing home-care projects is the lack of available resources and the vast number of people requiring care (Schietinger et al., 1993). Evaluators have recognised the need to utilise existing structures for the care of PWA (Foster, 1991). One project in Monze, Zambia, attempts to mobilise existing primary health care workers, where available, to visit PWA (Chela & Siankanga, 1991). This has been found to be more successful in increasing coverage than projects which take on all responsibility for home visits. (Chela & Siankanga, 1991; Foster, 1991). Also, projects have recognised the importance of working together with traditional healers (WHO, 1989). The lack of rudimentary supplies, including food, in homes has meant that projects need to supply material aid to facilitate care (Schietinger et al., 1993). Inadequate transportation facilities and the lack of available housing have also hampered the operation of home-care projects (Soldan et al., 1993; WHO, 1989).

### **Urban areas**

Most of these projects provide weekly or monthly visits to PWA, with the intention of supporting families who will provide daily hands-on care (Soldan et al., 1993; WHO, 1989). However, in urban areas it has been found that there is often no-one available to care for the PWA during the day (Chipipa, undated; WHO, 1989). Some projects are therefore training community members to care for PWA where there is no extended family (Chipipa, undated).

### **Specialised services**

Although the projects were set up specifically to care for people with HIV, the same problems of stigmatisation have arisen as in developed countries (WHO, 1989). Some projects have suggested the incorporation of clients with other illnesses, particularly tuberculosis, into home-visiting programmes (Foster, 1991; Soldan et al., 1993). Home-care has been seen as a way to improve quality of care of all people suffering from chronic and/or terminal illness, particularly in countries with inadequate existing health facilities (Schietinger et al., 1993).

## **Outcomes**

The few evaluations of home-care programmes that have been conducted suggest that the programmes have been at least partially successful in meeting their objectives. A comparison of home-care and hospital care in Chikankata showed that home-care was considerably cheaper (including the cost of medication) and provided equivalent quality of care (Chela et al., 1989). The authors suggest that home-care enables symptoms to be treated at an early stage, thus reducing the cost of drugs and preventing re-admission to hospitals. A study of home-care projects in Uganda and Zambia found that home-care reduced the burden on hospitals and that, although no definite conclusions could be drawn, it appeared home-care was cheaper than hospital care (WHO, 1989). However, the KwaZulu/Natal study found that home-care increased access to the health system and thus increased hospital admissions, and that home-visits were equivalent in cost to 2,4 days in hospital. The KwaZulu/Natal service was, however, very young and not running at maximum efficiency, and the evaluators suggested that a more established service would cost less than half as much (Soldan et al., 1993)

A study at Chikankata found that 88% of PWA preferred to be cared for and die at home (Chela & Siankanga, 1991). The WHO evaluation (1989) and the KwaZulu/Natal evaluation (Soldan et al., 1993) reported that patients and their families preferred home-care when given the option; that they were generally satisfied with home-care; and that staff members felt that home-care had improved the quality of life of PWA. The largest problem experienced was that of increasing coverage, with projects recognising that only a small proportion of people in need of services were reached (Soldan et al., 1993; WHO, 1989).

## **Programme evaluation**

HIV/AIDS is a relatively new disease, without established protocols of how best to provide holistic and appropriate care to those affected by the epidemic. Community-based projects therefore need considerable support and information to assist in the development of models of care. The evaluation of programmes can provide a method of assessing the work that has been done thus far and of making recommendations for future improvements (Mathews, Yach & Buch, 1989), and has been suggested as a means to bridge the gap between researchers, policy makers and practitioners (Thompson, 1992). However, it is essential that evaluation design is

tailored to the needs of the particular programme, which will differ according to the type of programme, the stage in the programme life-cycle, and the requirements of various stakeholders (Rossi & Freeman, 1989).

Clearly it is important that programmes be evaluated to ensure accountability and an efficient allocation of limited resources, however, conflict has at times arisen between the need to provide funders and other stakeholders with proof that the project is successful, and the informational needs of those involved in the project (Hughes, 1992). Evaluation design must balance the external needs for accountability with the internal needs for programme development (Walt, 1990).

New programmes tend to require formative research to assist in planning and implementation – it is more appropriate to concentrate evaluation efforts towards descriptive information than a rigorous assessment of impact and outcome (Posavac & Carey, 1992). The information derived from a full-scale impact assessment or cost-benefit analysis conducted at an early stage of a pilot project would not be useful, since the project would not be operating at maximum efficiency (Rossi & Freeman, 1989). However, even new, developing programmes may require some assessment of outcomes so as to motivate for continued funding. When outcome evaluation is appropriate, it is essential that outcomes are contextualised:

The establishment of a successful outcome is of little practical value unless one knows what factors are necessary for it to happen (structure) and how it was achieved (process). (Clark 1983, in Barriball & Mackenzie, 1993, p403).

Broadly speaking, the literature suggests that home-care projects are intended to be beneficial in two areas, firstly, to the health care system because of reduced costs of care and a reduction in the demand for hospital beds, and secondly, to PWA and their friends and family because of improved client satisfaction and quality of life.

### **Assessing benefits to the health care system**

Some evaluations of home-care projects have attempted to demonstrate that home-care is cheaper than hospital care. This has been done by measuring (or estimating) all the costs involved in both types of care, and comparing these costs (Chela et al., 1989; Soldan et al., 1993;

Tramarin et al., 1992). Some problems with this approach, in terms of hidden costs, have been raised above. Meaningful interpretation of cost analysis is only possible if home-care and hospital care are considered equivalent, that is if they are providing the same type of care; and if projects are running efficiently. If home-care is intended to complement hospital care, a more meaningful measure of the benefits to the health care system may be to demonstrate that home-care results in a reduction of hospital utilisation.

### **Assessing benefits to clients**

Many projects have administered quality of life scales, surveys or questionnaires to clients in an attempt to assess client satisfaction with the service, reduction of unmet needs, impact on quality of life etc. (Mor et al., 1993; Tramarin et al., 1992). However, quality of life is a multifaceted concept which is difficult to measure with any certainty, particularly in relation to clients facing a terminal illness (Aaronson, 1991; Williams, 1994). Also, quantitative data generated from scales, questionnaires and surveys can only be useful if a sufficient number of clients exist to allow for meaningful analysis and interpretation. In developing projects with relatively few clients, qualitative data generated from in-depth interviews may be more useful in coming to understand the aspects of 'quality of life' and client satisfaction which are relevant. Such data will not provide rigorous proof of a successful outcome, but may assist in developing indicators of client benefits which can be used in evaluating the project at a later stage.

## **Chapter Two: Formative evaluation**

### ***Introduction***

The Red Cross home-based care management committee approached the researcher in February 1994 to assist with the evaluation of their pilot project. After initial discussions with the committee it became clear that committee members had many expectations of the evaluation. They wanted the researcher to provide information about other community projects that would aid their work; to document their own work so as to assist future projects; to make recommendations that would help in the development of an appropriate, effective and sustainable model of care; and to provide proof of a successful project that could be used for fundraising.

It was decided that the project was too new to conduct an outcome assessment at that stage. Although the Red Cross Society had been training home-carers and providing home-care to PWA on a limited scale since January 1993, the organisation of this training and care had been somewhat haphazard and there were not enough clients for the project to be operating at maximum efficiency. Therefore it was decided to divide the evaluation into two stages. The first, formative stage focused on collecting information that would be used to improve the project, rather than attempting to evaluate the success of the work undertaken thus far. An important part of this was to systematically examine and document the project's history and operation so that an understanding of the project's work was not dependent on anecdotal information (Nightingale & Rossman, 1994). This was also necessary because documentation of HIV/AIDS projects in developing countries - particularly Africa - was sorely lacking. Also, because no needs assessment had been conducted before the initiation of the project, a significant function of the formative evaluation was to examine the needs and care preferences of people with AIDS. The secondary evaluation (Chapter Three) was conceived as being more outcome oriented, and was intended to provide results that the project hoped would help motivate for continued funding.

## ***Methods***

### **Research objectives**

The overall aim of this phase of the evaluation was to make recommendations for the design of the project that would maximise its chances of meeting its goals and facilitate the development of an appropriate, effective and sustainable service.

### **Sources of information**

In order to meet this objective, the evaluator identified certain relevant sources of information. Posavac and Carey (1992) stress the importance of using a variety of sources so as to avoid consistent biases in the information gathered. The sources used in this evaluation were:

- Project records
- PWA referred to the project and their family members
- Community workers, called home-carers, involved in the project
- Project staff
- Management committee members
- People involved in HIV/AIDS work or primary health care projects
- Evaluator observations

This diversity of sources was used so as to gain different perspectives on the project's work. Clients involved in the project and their family members were in a good position to assess many aspects of the service provided and to suggest areas for improvement. Home-carers were also considered an important source of information because of their close involvement with PWA and day-to-day knowledge of the operation of the project. In a similar way the contribution of project staff and management committee members was vital. The views of others working in the field of HIV/AIDS and community health care were elicited so as to learn from the experiences of other projects and gauge acceptance of the Red Cross project. Evaluator observations were essential in learning about the project and making sense of the various forms of data collected (Posavac & Carey, 1992).



## **Research design**

Because of the exploratory nature of this stage of the evaluation it was decided to adopt a qualitative approach to the study. Qualitative studies are less bounded by the assumptions of the researcher, and are more likely to be sensitive to unexpected findings (House, 1994). A qualitative approach is also necessary to explore in-depth the experiences of a small number of clients, and it was hoped the information gained in this way would help develop indicators for use in the second phase of the evaluation. Qualitative observational methods also help the evaluator understand and gain experience of the project being studied (Posavac & Carey, 1992).

## **Data collection**

The description of the project was based on record reviews of minutes of meetings and project documents, interviews with those involved in setting up the project and direct observation. The researcher also accompanied one of the community sisters on seven visits to clients. Semi-structured interviews were conducted with the target groups identified above. Key members of these groups were identified and interviewed:

- Interviews were conducted with 12 of the project's clients.
- Seven home-carers were interviewed.
- The three staff members were interviewed.
- All seven members of the Red Cross HBC committee were interviewed.
- Interviews were conducted with four health workers from AIDS clinics at Red Cross Children's Hospital, Somerset Hospital and Tygerberg Hospital; six people involved in non-governmental organisations working with HIV/AIDS and two people working for primary health care projects.

## **Interviews with clients**

### **Respondents**

PWA and their partners or family members were considered to be clients of the project. Twelve interviewees were chosen from project records to include representatives of various sub-groups, based on gender, amount of care received and residential area. They were asked by project staff

if they would mind being interviewed, and were assured of anonymity. No clients refused to be interviewed. The respondents were not considered to be a representative sample of the project's clients, but were rather chosen to represent maximum diversity so as to obtain as many views and as much information as possible from a small sample of clients. All of the people interviewed had had experience with and exposure to the needs and problems experienced by sick (often bed-ridden) PWA – in accordance with the focus of the project at that time.

The clients with whom the researcher had contact were:

- two bed-ridden men with AIDS (both of whom had died by the time of presenting the results of the formative evaluation)
- one man with symptoms of HIV-related illness
- two women with AIDS
- one healthy HIV-positive woman whose husband had recently died of AIDS
- two caregivers (one grandmother and one mother – who is ill herself) of HIV-positive babies
- the mother of a woman who had died of AIDS related illnesses
- the partner of a man who died of AIDS
- two family members of people with AIDS

Two of the respondents lived in Greenpoint, one in Rosebank, one in Walmer Estate, one in Retreat, two in Fairways, two in Guguletu and three in Khayelitsha. The socioeconomic conditions of clients ranged from middle-class home-owners to people living in shacks in squatter camps. Of the clients interviewed, five were black, four coloured and three white. Three clients were living with partners/spouses, three with partners and children, one alone with children and five with relatives and children.

### Content

The interviews were semi-structured, in that the researcher had a broad idea of the content areas to be covered, but hoped to gain rich detail by allowing for flexibility in responses (Nightingale & Rossman, 1994). Broad questions were asked (for example, “How has being HIV-positive affected your life?”) and respondents were given time to answer, then particular areas of interest were followed up by the researcher. This method also allows for an understanding of what the

respondent considered the most important aspects of the area under investigation to be (Burman, 1994). The following themes were probed by the researcher:

- Impact of diagnosis on living conditions; employment; relationships
- Problems experienced because of diagnosis
- Ways that these problems could be alleviated
- Extent of illness and care preferences
- Experiences of home-care project
- Contact with staff
- Feelings about death

The client's feelings about death were raised at the end of the interview, because of the sensitive nature of the topic.

### Nature of interviews

Once consent had been obtained, the researcher visited clients' homes to conduct the interviews. The length of interviews varied from 30 minutes to two hours. The subject matter of the interviews was often troubling for respondents, many of whom found it difficult to talk about intimate relationships, illness and death. Some were apprehensive about the interview, and one terminated prematurely as she said she could not talk anymore. However, many of the respondents welcomed the opportunity to talk about things on their minds. Some respondents were moved to tears during the interview, and reported afterwards that it had been helpful for them to discuss these matters. Often respondents had specific queries, or requests for advice, which were referred to project workers. The five Xhosa-speaking clients were interviewed with the assistance of an interpreter. The researcher had discussed the research with the interpreter beforehand, and she had a good understanding of the sort of information required, as well as the nature of open-ended, semi-structured interviewing. During interviews the researcher spoke directly to the respondent, not looking at the interpreter. This method of working had been role-played by the researcher and interpreter before the interviews. Two of the interviews were conducted in Afrikaans, a language with which the researcher is comfortable, and the remainder in English.

### Problems with interviews

It was at times difficult to speak to very ill PWA because of fatigue, weakness and breathing problems. The researcher sometimes found it difficult to probe too deeply into troubling areas, and some of the interviews terminated before certain content areas had been covered, because of respondent fatigue. Also, as is inevitable with research of this nature, there are problems with the expectations created by asking people about their needs and difficulties. This can create the expectation that the researcher will be able to meet these needs in the short-term, and thus lead to disappointment. Furthermore, in-depth interviews require the researcher to develop a rapport with the respondents and use their responses and language (terminology) to explore their world. Obviously this is made more difficult when working through an interpreter. Despite these problems, respondents were remarkably forthcoming in sharing intimate feelings around their experiences of HIV.

### **Interviews with home-carers**

#### Respondents

Seven of the eight home-carers who have been involved in caring for PWA thus far were interviewed by the researcher. The researcher had requested interviews with all the active home-carers, but one was not available as she was outside of Cape Town at the time of the evaluation. The home-carers were all women, six of them were black and lived in either Khayelitsha or Guguletu, and one was coloured and lived in Retreat. The home-carers ranged in age from being in their twenties to sixties. All of them joined the Red Cross as volunteers, working as home-carers for elderly people – one woman had been involved with the Red Cross since 1969. Three of the women had worked in an old-age home before joining the Red Cross. They had all completed the home nursing and AIDS awareness courses, and three of them attended the Red Cross first aid course.

#### Content

The following themes were probed by the researcher:

- Feelings about their work in the Red Cross project
- Activities undertaken

- Attitudes to HIV/AIDS
- Problems experienced in their jobs
- Best and worst parts of the job
- Feelings about working with 'town' and 'township' clients. (The project staff and the home-carers had developed the euphemisms of 'town' and 'township' to speak about the differences between working with white and black clients. This terminology was adopted by the researcher to facilitate understanding.)

### Nature of interviews

Each home-carer was asked (by the HBC community sister) if she would mind speaking to the researcher. They all agreed, and were assured of anonymity. Five home-carers were interviewed individually at Ulunthu Centre and two at the homes of people they were caring for (one home-carer was interviewed twice to clarify certain points raised). The interviews lasted between 30 minutes and an hour. The first five interviews were conducted in English. The researcher recognised this to be a problem and an interpreter was engaged for the interview with the remaining Xhosa-speaking home-carer.

### Problems with interviews

In addition to the language problem raised above, problems may have arisen in that the researcher was seen as a member of the project staff and some home-carers initially perceived the interview to be a form of assessment. (The women were familiar with oral assessments which were used to evaluate course participants). They were initially reluctant to raise problems with their work or to be seen to criticise the project, and were careful to mention only the positive components of their job. Also, there could be a problem with a white researcher attempting to explore black women's feelings about caring for 'town' versus 'township' clients. The researcher's 'town' status could have silenced some issues. Despite these problems, the home-carers relaxed as the interviews progressed and were able to raise issues that concerned them.

## **Interviews with staff and management committee**

### Respondents

The researcher held interviews with the three staff members and all seven committee members involved with the Red Cross project. Some respondents were interviewed on more than one occasion, and the researcher had frequent contact with project participants at meetings and in the offices.

### Content

Respondents were asked broad questions about:

- Their impressions of the Red Cross project
- Their feelings about their role in the project
- Strengths and weaknesses of the project
- Their future hopes for the project

## **Interviews with ‘outsiders’**

### Respondents

The researcher held interviews with people involved in HIV/AIDS and other aspects of health care. Four of these interviews were with hospital doctors involved with HIV clinics, two with people involved in primary health care projects and six with people involved in non-governmental organisations working in the area of HIV and AIDS. The respondents were chosen based on recommendations and referrals to ‘key’ people in particular areas.

### Content

Respondents were asked broad questions about:

- Their impressions of the Red Cross project
- Their feelings about home-care for PWA
- Perceived or potential problems with the project

### Nature of interviews

The interviews were informal and all seemed eager to comment, and pleased that their views had been sought - even those who were fairly critical of Red Cross and the project.

### **Observation on home-visits**

#### Nature of visits

As mentioned earlier, the researcher also accompanied the community sister on a typical day of home-visiting. This form of non-participant observation is a useful way to gain fresh insights into the workings of projects and problems experienced by project workers (House, 1994). In this case the researcher was able to experience the difficulties of finding clients' homes in the township, and the frustration of discovering that clients are not at home at the time of the visit. When clients were at home the community sister introduced the researcher, and asked if the client would mind answering a few questions. If relatives were unaware of the client's HIV status, the client was asked to come outside or sit in the car to talk to the researcher. The researcher took detailed notes, although the discussions were not recorded.

#### Problems with visits

None of the seven clients visited refused to speak to the researcher - possibly because the researcher had come with the community sister (and the all-important food parcels) and it was felt that such a refusal would endanger their chances of receiving future food parcels. The community sister was also able to select the clients visited by the researcher and thus perhaps influence the data received. Also, no interpreter was present during these visits and the researcher spoke to the four Xhosa-speaking clients in English. This obviously hampered the researcher's interaction with clients. The community sister could not be asked to interpret because of the influence her presence would have had on responses. For these reasons the information on clients gained in this way was limited, but the observation provided useful insights into the working of the project.

## **Data documentation**

Most of the interviews were tape-recorded and transcribed (See Appendix F for transcript conventions), although some interviews with bed-ridden PWA could not be recorded. These, and the informal conversations on home-visits with project staff, were immediately documented when the researcher left the premises. The researcher also kept an evaluation diary - a daily recording of any information relating to the project obtained during meetings, conversations with staff etc. that was considered important.

## **Data analysis**

Although the researcher had broad content areas or themes in mind when conducting the interviews, as outlined above, many unexpected issues were raised. Thus the themes considered for analysis arose largely out of the data received. Interviews with the different categories of respondents were loosely coded according to the ever-changing system of classification. Participants' responses on particular content areas or themes were then compared, using standard thematic/content analysis techniques (Burman, 1994).



## ***Results***

### **Section 1: Development and progress of the project**

#### **Brief history**

The need for a home-care project was identified in late 1991 by the regional AIDS co-ordinating forum, after an examination of the resources available for health care in the Western Cape. The Red Cross Society had also identified the need to incorporate HIV/AIDS work into their programme. Many workshops were held in 1992 between organisations and health services involved in HIV/AIDS work to identify available resources and gaps in services for people with HIV/AIDS. (See Appendix A for a complete list of organisations involved in this process.) Staff members from the Aids Training Information and Counselling Centre (ATICC) and the Red Cross were largely instrumental in developing the original proposal for the project. The Western Cape Region of the Red Cross Society agreed to take on the co-ordination of this project, although it was decided that the project would be run by an external management committee, and that funding would be raised from outside of the Red Cross.

The Red Cross AIDS home-care management committee was officially inaugurated in September 1993 and a representative of the AIDS Support and Education Trust was elected as chairperson. Representatives of the Cape Provincial Administration, Department of National Health and Population Development, the Red Cross Children's Hospital, Somerset Hospital, ATICC, and other interested individuals were invited to serve on the management committee. The management committee established four sub committees, each with a co-ordinator: Health services liaison, research/evaluation, communication/PRO, and community liaison.

The home-care project was envisaged as a pilot project that would develop and test a model of care, to run from September 1993 to October 1994. The completion date was later extended to October 1995. The Red Cross Society has continued running the project since then.

## **Funding**

Funding for the project was received in 1993 from the then mayoress; the state Health Department, the Douglas Murray Trust, Syfrets and various individuals. Clients who were financially able paid the HBC project R5 per hour for home-carers, and also covered the costs of equipment used. Some clients had left money to the HBC project in their wills. The management committee continued to raise money from the government and private organisations to fund the project. The MRC has conducted an economic costing of the project which includes a detailed list of funders and costs (Hardien, 1995).

## **Objectives of project**

The first task undertaken by the researcher was to assist the project to clarify its goals and objectives. Although there was broad agreement as to the goals, these had not been clearly stated, and this exercise was seen as important to guide both the project and the evaluation. The Red Cross AIDS pilot home-care project identified its objective as being to develop an appropriate, effective and sustainable service that would improve the quality of life of PWA and reduce the burden on hospitals. A subsidiary goal was to increase AIDS awareness in the community.

The geographical area targeted by the project stretches northwards from Cape Point, the Atlantic seaboard, the inner-city area, the southern suburbs and the townships. A similar home-care project – the Northern Areas Action group was established to service areas north of this.

The early proposal for the project covered a wide range of services, focusing on co-ordinating the care of people with HIV between hospitals, clinics and AIDS organisations. The lack of terminal care facilities was identified as a particular problem that could be met by this project. The proposed model (Appendix B) envisaged a holistic service to clients, with the project either providing the service itself, or referring clients to other agencies. The model identified the need for counselling with HIV, education and training, volunteer ('buddy') support for people with HIV, home-care, and material and legal assistance.

Despite these broad objectives, the home-care workers were (at least initially) largely involved in terminal home-care for bed-ridden PWA. The committee identified that the original model, although necessary, was unrealistic in that the project did not have the resources to provide

services to all people with HIV. They decided to target the service at symptomatic HIV-positive people, and PWAs. The researcher was present during these debates, and was asked to help the committee revise the goals and objectives of the project. After a review of project documentation and discussions with committee members, the management team agreed on the following:

The aim of the Red Cross home-care project is to test the feasibility of establishing a community home-based care programme for PWA in an urban setting which is intended to reduce the burden on hospitals and to enhance the quality of life of PWA. A subsidiary goal is to AIDS awareness in the community.

The objectives include:

- Project co-ordination: To set up a functional unit to co-ordinate home-care for people with AIDS.
- Home-Carers: To select, train, support and supervise community home-carers.
- Provision of care: To provide medical, psychosocial and nursing care, meeting certain minimum standards, to clients in their homes.
- Community Liaison: To identify community resources, structures and networks that can be enlisted by the HBC project, and to identify omissions in the services available to people with HIV.
- Project Promotion: To promote the acceptance and utilisation of the project in the community and health services.
- Evaluation: To ensure a process of ongoing evaluation of the project according to its goals and objectives.
- Future Recommendations: Based on the above, to make recommendations for the establishment of a HBC programme, whether run by the Red Cross or any other governmental or non-governmental organisation.

The committee felt that these objectives were still too broad, and many debates were held over issues such as co-ordination of services versus hands-on provision; what exactly was included in the scope of home-care; etc. The researcher was asked to help the committee draw up a list of specific objectives. The researcher drew up a rough outline of specific objectives (Appendix C) and requested input from the sub-committees involved in the different areas. The list was discussed in the management committee, and it was decided that they were not in a position to

finalise the document. It was felt that the formative evaluation would provide information necessary to complete this process.

## **Progress**

### Management structure and sub-committees

As mentioned earlier, at the time of the evaluation a management committee and sub-committees had been established. The management committee consisted largely of professionals co-opted from the participating organisations: two doctors, a health psychologist, two health administrators, a minister of religion and a businessperson. The committee was meeting monthly, and an operations meeting, attended by the chairperson, the care co-ordinator, the community sister, the administrative co-ordinator, the community liaison co-ordinator, and the researcher also met monthly to discuss more practical issues. Two editions of the newsletter *Update* had been produced and distributed.

The subcommittees (communication, research, health services liaison and community liaison) did not prove successful and failed to meet regularly. Co-ordinators of the subcommittees tended to work alone, reporting to the management committee.

### Staff

In addition to the project co-ordinator - a full-time staff member at the Red Cross, a community sister was assigned to the project. An administrative co-ordinator was employed in 1994. The project structure allowed for the employment of two additional nursing sisters, to supervise and co-ordinate home-carers, as the need arose. In May 1994 the community sister's increasing work load prompted a recognition that at least one sister should be employed on a part-time basis as soon as possible. Numerous difficulties were experienced finding a qualified Xhosa-speaking sister to fill the post, as most applicants stated a preference for full-time work. At the time of the evaluation the part-time posts were merged, and advertisements for a full-time sister placed.

### *Project co-ordinator*

The project co-ordinator's official job description covered broad areas of responsibility and has been included as Appendix D. Her activities include the following:

- Attending the HIV clinics at the participating hospitals to receive referrals for the project and discuss any medical problems with clinic staff
- Visiting and assessing new referrals in the town area
- Supervising home-carers in this area and responding to problems arising
- Counselling clients and families in this area
- Attending numerous meeting on HIV/AIDS and health care
- Assisting with the home-care and AIDS awareness courses and assessment of trainees
- Organising food parcels
- Arranging the payment of home-carers
- Collating and updating patient information
- Supervising the community sister
- Attending the HBC management committee and operational meetings
- Numerous other activities such as fetching medication for clients, speaking to potential home-carers and volunteers, supervising a social work student and speaking to external groups about the HBC project

Although the HBC project was officially separate from the rest of the Red Cross, in practice the project co-ordinator remained involved in certain non-HBC Red Cross activities. This was particularly true at the time of the evaluation, when the Red Cross was involved in intensive flood-relief efforts.

#### *Community sister*

The sister's official job description read as follows:

- Assess all people needing HBC and place home-carers
- Report on the condition of patients on a weekly basis
- Organise weekly meetings with home-carers
- Organise food relief for those awaiting disability grants
- Organise support groups for PWA, or refer to existing support groups
- Organise and run HBC courses and AIDS courses in the townships
- Identify resources available in the townships and method of referral
- Attend co-ordinating meetings

Before being transferred to the home-care project, the sister was responsible for co-ordinating the home-care of elderly people in the townships. Although she was officially transferred, no-one was appointed to take over her work with the elderly, which continued to require her attention.

#### *Administrative co-ordinator*

The administrative co-ordinator was responsible for the administration of the project, including:

- Taking minutes at all meetings
- Typing and distributing minutes, agendas and memos to committee members
- Responding to queries about the project
- Doing administration for the home-care and AIDS courses
- Arranging dates, venues, refreshments etc. for meetings
- Updating the patients' records
- Facilitating communication between committee members and staff
- Numerous other adhoc activities

#### Home-carers

In the theoretical model of the project, it was envisaged that most of the hands-on work would be done by home-carers, who were initially called volunteers. This policy of incorporating volunteer workers was in line with the approach taken by many other AIDS projects, and brought with it the strengths and weaknesses mentioned above. In recognition of the problems inherent in expecting unemployed people from low socioeconomic groupings to voluntarily provide their services to community projects, the management team began seeing the volunteers as 'home-carers', and decided to provide limited remuneration. These home-carers were members of the community who received basic training from the Red Cross. The model suggested a system whereby project staff co-ordinated and supervised the home-carers, who provided daily nursing care and support to clients.

#### *Selection*

All of the home-carers who had been active in the project at this stage were previously involved in the Red Cross's elderly care programme. These home-carers were all women and lived mostly in Guguletu and Khayelitsha. The carers were selected from those completing the basic home nursing course, and the AIDS awareness course. The courses were open to anyone, regardless of

educational qualifications. Successful completion required that trainees passed an oral evaluation at the end of the course. Trainers also observed the trainees during the course, to assess their suitability. As the community sister said:

I do some screening at the same time (as teaching the course). I know so and so is very good. I don't send them just because they are interested, but I know which ones I can send.

Thus home-carers were carefully selected, although there was no formal (or documented) criteria for this. The same procedure took place when assigning particular home-carers to particular clients: "I decide who will suit that client".

### *Training*

The Red Cross Society (not the home-care project) ran courses in basic home nursing. The project staff contributed towards the teaching and assessment of these courses. The home-care project also ran an AIDS-awareness course. Courses were advertised in community newspapers and on local radio stations. They were run at Red Cross House in Wynberg, Ulunthu Centre in Guguletu, and other Red Cross venues in the townships. Red Cross volunteers paid R30 to attend the course. At the time of the evaluation about 250 people had been trained in home nursing, and about 120 in AIDS awareness. Only about eight of these people had been used as home-carers for PWA. Some of the others had since taken other forms of employment.

The home nursing course ran for 20 hours and was the same one that was offered by the International Red Cross Society around the world. It included the following components:

- The role of the caregiver
- Practical and safe surroundings
- Comfort and mobility
- Washing and bathing
- Clothing
- Eating and drinking
- Medicines
- Elimination
- Rest and sleep
- Body temperature

- Inflammation and caring for a wound
- Communicable diseases
- Breathing difficulties
- Communication
- Recovery and rehabilitation
- Recreational activities
- The person who is dying

The AIDS awareness workshop ran over four days, covering the following areas:

- Attitudes to HIV/AIDS
- Human sexuality
- Sexually transmitted diseases
- Overview of HIV/AIDS
- Medical facts
- Stress and the immune system
- Infection control
- Living with HIV/AIDS
- Confidentiality
- Counselling (1 hour)
- Assertiveness
- Safer sex
- Resources and referrals

Some of the home-carers had completed a basic Red Cross first aid course. Most of the active home-carers had attended a four-day AIDS home-care course in Port Elizabeth. They had also attended a once-off lecture from a Red Cross Children's Hospital doctor on caring for children with HIV.

#### *Conditions of employment*

In line with the Red Cross policy, the home-carers were originally intended to receive R5 per client per day. After much debate, the management committee decided that the level of care required in this project was higher than other Red Cross projects, and the home-carers were



given R5 per hour spent at clients' homes. The project also reimbursed their travelling costs. The length of their shifts depended on the clients' needs. When 24-hour care was being provided, home-carers tended to work 12-hour shifts, with four home-carers assigned to one patient. Sometimes one home-carer would work eight hours a day during the week and be relieved by another on the weekends or at night. Thus the home-carers did not have a fixed, reliable income – they received payment only when they were nursing clients. When clients died or went to hospice/hospital, the home-carer was out of a job until another client was assigned to them. Since the project was only providing home nursing to two clients at this stage of the evaluation (as had been roughly the average for the duration of the project up till then), not all the home-carers had work. The home-carers did not attend any project meetings.

## Care

### *Referrals*

Although the project was only officially launched in 1993, the Red Cross had started nursing its first PWA in mid-1992. Most clients were referred to the project through the three participating hospitals – Somerset Hospital, Groote Schuur Hospital and Red Cross Children's Hospital. Some people have been referred through other structures such as ASET, St Luke's Hospice and the district sisters.

According to project records, 85 people had been referred to the project at this stage. Of these, four had been referred to other agencies; five were uncontactable because of incorrect addresses; one person was HIV negative; two had moved away from Cape Town; 26 had died since referral. Of those receiving care:

- the care-givers of 23 HIV-positive children were receiving support and visits from the community sister;
- two adults were being nursed by home-carers; and
- 24 adults were receiving support and visits.

Of the 26 people who had died since being referred to the project, 12 people had received care by home-carers for between two days and six months. The average length of time (32 days) is misleading, because of the vast discrepancies in time nursed:

- six patients for less than 10 days;
- three for less than 20 days;
- one for two months;
- one for three months; and
- one for six months.

The patients that died without receiving home-care were either receiving support and visits (five), had been referred elsewhere (four), or were referred to the project too late (four). Some families refused home-care as they were themselves able to cope. Two women refused because they felt it was their responsibility (for religious and cultural reasons) to look after their husbands themselves. Of the people who have died, 13 lived in white areas, six in townships areas, six in coloured areas, and two in residential shelters. Only one person from outside of traditionally white areas (of the 12 referred to the project) received home-care – and then for only a few hours a day. Obviously the numbers are too small to draw meaningful conclusions, and the changing face of the epidemic must be remembered when interpreting this information.

#### *Provision of care*

Although the model of the project suggested that home-carers would have most contact with clients and would be supervised and supported by full-time staff, because of transport problems all home-visits were carried out by the community sister. Home-carers were only involved when clients required nursing at home and had not thus far been involved in visits before clients were bed-ridden.

#### *Services*

The type of services that the project had provided included:

- Assessing patients on discharge from hospital (or on referral from clinics/other bodies)
- Visiting patients in their homes to answer queries, provide support/counselling
- Supplying and distributing food parcels to households in need
- Home-visits and support for care-givers of HIV-positive babies
- Providing baby milk where necessary
- Doing daily dressings
- Training the family to care for the patient

- Providing home nursing and household assistance for up to 24 hours a day
- Relieving family members for short periods of time
- Reminding clients of their clinic appointments and encouraging them to attend
- Providing (or organising for the provision of) equipment such as suction machines, pressure mattresses, Paul's tubing, urinary bags, blankets, etc.
- Referring patients to St Luke's hospice or other organisations where necessary
- Providing assistance with welfare such as disability grants, insurance queries
- Assessing when it was necessary for the patient to go to hospital
- Arranging ambulances to take patients to hospital
- Arranging 'mercy flights' to take terminal patients to their original homes
- Bereavement counselling for families

As mentioned earlier, at this stage of the project there was no stated agreement by the management committee on exactly what services would be offered. In practice what happened was that the project staff provided the types of services that they were familiar with from their work at the Red Cross, limited by the resources available to them. Many of the services offered by other projects in Africa (as discussed in Chapter One), for example contact tracing, income-generating activities and support groups, were not undertaken, as these were not the types of services traditionally offered by the Red Cross Society. The training and allocation of resources was geared towards home-nursing - similar to HIV/AIDS projects in developed countries.

## **Section 2: Needs of PWA and their household members**

No needs assessment was conducted before the initiation of the project, and much of the understanding informing the model of care adopted by the management committee was based on anecdotal information and assumptions about the needs of PWA. While a full-scale needs assessment was beyond the scope of the evaluation, an examination of the needs identified by respondents was essential to inform the evaluation process. Although the particular needs and problems experienced by PWA vary greatly between individuals and according to stage of illness and social circumstances, certain broad categories recurred regularly in the data collected. These have been divided into material, psychosocial, spiritual, and medical needs. These categories are presented here separately, but there is much overlap, with the different areas affecting each other.

### **Material needs**

The existing social problems experienced by disadvantaged communities have been exacerbated by the HIV epidemic. Although problems with employment, housing, food etc. are by no means limited to HIV-positive people, the problems accompanying an HIV-positive diagnosis make it even more difficult to gain access to limited resources.

### **Employment**

Some people with HIV lose their jobs when their HIV status becomes known, because of stigma in the workplace. Others are forced to stop working because of physical disabilities. As one partner of a PWA reported:

He was in hairdressing, so when he lost his co-ordination we couldn't let him loose with scissors.

(Interview C7)

Another HIV-positive mother reported the threat of being fired because of the amount of time she had to take off work to take her baby to the clinic. The Red Cross Children's Hospital requires that mothers accompany their babies while they are in the drip room – often for extended periods of time. Mothers' problems were exacerbated by the fact that children attended a clinic in one hospital, while they themselves attended a different clinic in a different hospital –

doubling the amount of time taken. Clients reported spending almost an entire day waiting at the out-patient clinic. This not only caused inconvenience and discomfort, but also severely disrupted the working day:

He was working at the time and it was extremely problematic for him to get away for virtually the whole day – you know what hospitals are like. (Int C7)

Families of PWA also found their jobs threatened, because of a need to care for PWA and accompany them to hospital. As one woman reported:

I used to work all day, but then as he got worse I had to stop working in the afternoons. And we need the money because he lost his job ages ago. (Int C3)

#### Disability grants and welfare assistance

Disability grants are only available to people classified as having stage four AIDS. One person, who was dismissed from work supposedly because he was too ill to function, was told by the clinic doctor that he was not sufficiently ill to receive a disability grant. Even when PWA do qualify for grants, there are numerous bureaucratic difficulties, and delays in receiving compensation are notorious. As the community sister said:

The doctors don't fill in the form properly, or whatever, and then they (PWA) don't get the money – it just doesn't arrive and no-one tells them why (Int S2).

Clients reported needing help obtaining disability grants, as well as assistance with practical matters such as insurance claims, preparing for funerals and planning for the future of orphaned children.

#### Accommodation and resources

Many of the project's clients, particularly young women with babies, were dependent on relatives for accommodation. These women often reported being too scared to tell their relatives of their HIV status, or to disclose what was wrong with their babies, for fear of being kicked out of the house. Even people living in rented accommodation feared for the security of their homes:

They are suspicious of us already ... they will just throw us out and we have nowhere else to go.  
(Int C3)

Also, many of the project's clients lived in shacks without adequate material resources, as one home-carer reported:

There isn't soap, there is no food, there isn't paraffin, no blankets and no stove – just cold water.  
(Int H5)

Another problem with crowded homes was privacy:

I don't want to die here, it is too busy. The people are so nosy, they always look at me. (Int C2)

Even relatively well-off people experienced financial problems because of the illness:

After three years of medical expenses and AZT and DDI etc., we were flat broke and my property was bonded as far as it could go. (Int C7)

### Food

PWA have particular nutritional needs because of extreme weight loss and a compromised immune system. Disadvantaged communities in South Africa have difficulty providing healthy families with adequate meals, and this becomes even more important for adults and babies with HIV. The wife of a PWA said:

He is so thin, he needs the Ensure, but it is so expensive. (Int C3)

A home-carer reported her experience of caring for PWA:

They don't sometimes leave anything for him to eat. There's nothing, and you are worried because she is hungry, she wants something to eat. (Int H3)

### Transport

Many people reported having problems getting to and from the hospital. The lack of an adequate public transport system, particularly in township areas, has resulted in ill people having to walk

long distances from taxi ranks or bus/train stations home. There was also a problem in taking PWA to hospital in emergencies, as ambulances have to be booked a few days in advance.

### Assistance at home

Clients reported requiring assistance at home in the later stages of illness. As the partner of one PWA said:

He developed to the stage where he could not then, he couldn't walk to the toilet unaided, even with guidance, so we had to carry him to the toilet. (Int C4)

This created problems if PWA were at home alone during the day, as one HIV-positive man said:

When you are sick and you are alone you need someone, for example when you want to go for a bath, and you can't walk properly then you need some-one to help you. (Int C11)

Even if family members were at home, many reported that they found it "difficult to cope" with the additional demands preparing meals for the ill person, washing soiled linen, nursing the ill person, as well as carrying out their usual functions. This was especially true if household members were working and/or themselves HIV-positive.

I was working and then I'm coming home and I must still look after him ... I have to get up at night ... That's why I was getting ill at that stage, 'cos my body was worn out. (Int C5)

Another man described the difficulties at home as his partner became increasingly ill:

He would call my name (at night) ... then he would stop and I would go to sleep but an hour later he would start again. You can't sleep through that because it digs too deep. (Int C7)

A woman spoke of the problems of balancing the demands of her husband and child:

She (daughter) also needs my attention and to play with her and fetch her, and then he calls me. He needs a lot of help. (Int C3)

Families also reported feeling unqualified to nurse the PWA, as they did not always know what was best, as the partner of a PWA said:

His sister tried to do it (nurse him) but it wasn't possible, she lacked the skills and we lacked the equipment. (Int C4)

Family members and home-carers mentioned the need for equipment such as commodes, special mattresses to prevent bed sores, catheters, nappies, etc. to make home-care easier.

### **Psychosocial needs**

In addition to material needs, clients reported many psychosocial problems arising from an HIV-positive diagnosis.

#### Accepting diagnosis

Many respondents identified the period of diagnosis as a particularly difficult time. Many learnt of their diagnosis only after they themselves, or their babies or partners, became symptomatic. One person interviewed said he felt:

... despondent and very lost, like an outcast. (Int C10).

The partner of a man who has since died of AIDS-related illness said:

He just fell to pieces at the knowledge. He lost a terrific amount of weight, but the real weight loss was due to his general lassitude and depressed state. (Int C7)

Some PWA denied their diagnosis, as one partner said:

He still don't accept it, he says he's not HIV-positive, he's just got TB. (Int C5)

#### Disclosure

Another PWA raised a common concern:

I thought my family and friends would discard me when they found out. (Int C2)

Such is the prevailing stigma of HIV/AIDS that many of the project's clients have not told their household members about their diagnosis. This has increased feelings of isolation and loneliness:



I feel socially isolated ... I don't tell people what is wrong, they will not accept me. (Int C8)

Many PWA were only able to tell their family of their diagnosis when they were really ill, and needed family support and care. One PWA asked his doctor to tell his family:

It was much easier to ask my doctor to tell them ... It was a relief when they knew and they supported me. (Int C10)

Family members similarly suffer from anxiety and uncertainty when the diagnosis is not known:

We phoned doctor, we were quite a nuisance, we phoned her almost every day while he was away to find out what was wrong. But of course she couldn't tell us.

(Int C12)

### Problem solving

Many clients felt they needed advice on specific problems that had arisen because of the illness. One women mentioned difficulties in knowing how best to deal with her young daughter in relation to an ill father:

I am in two minds about it, you know ... I want her to see him, but I don't know what is best. (Int C3)

Another family wanted advice on how to approach the minister to visit the PWA, and what to say when friends and relatives asked what was wrong with him.

### HIV information

Some people expressed a need to know more about HIV and AIDS, particularly in relation to infection control. The partner of a PWA reported what had happened when his partner's family first heard **that he had AIDS**:

The **brother** was full of hurt because he thought his wife might have contracted it by shaking (his) hand or by wiping his face when feeding him. (Int C4)

## Relationships

The partner of a bed-ridden PWA describes some of the problems that the disease has caused in their relationship:

He feels guilty that he infected me ... maybe there is something that is bothering him or me, but we just don't talk anymore. (Int C5)

This quote raises the issue of guilt over infecting a loved one. In this relationship, it has driven a wedge between the partners. There is also guilt over leaving a loved one to cope with the responsibilities of raising children alone, and of the burden of care that is placed on families or partners. One partner spoke about the effect of this additional burden on him:

He was irritating me ... you haven't got the energy or the patience, not that you care for the person less. (Int C3)

Another problem in relationships relates to the needs of partners at different stages of the illness, as one partner reported:

I know I will get sick but in the meantime I want to go out, enjoy my life, but he wants me here the whole time. But you can see, he is sleeping all the time, but when I go out and I come back, it's: 'Where were you'. He's trying to pull me down to his level. (Int C5)

The stigma of HIV/AIDS also raises issues of blame:

I would like to know how he actually contracted the disease, but I will never ask him. (Int C5)

The illness has also interfered with parent's relationships with their children:

She (three-year-old daughter) doesn't even want to go and say hello to him. And it upsets him. Because before he was so sick he used to rock her on his knee, you know, play horsey-horsey, and now she doesn't understand why he won't play with her. (Int C3)

The societal taboos about talking about death and illness have reduced support available to PWA. The sister of a PWA said she did not talk to her brother about his illness because it would be:

Sort of reminding him what's actually wrong. Because I don't want to hurt him. (Int C12)

An inability to share emotional distress is also evident in the following quote, by a relative of a PWA:

And the other night he was also crying and I said ... what's wrong, why are you crying (and he replied) 'No, I am just thinking'. (Int C12)

### Emotional distress

The difficulties in relationships and communicating with loved ones increase peoples' experiences of loneliness and isolation. Respondents reported feeling "depressed", "lonely", "bored" and "hopeless". Much of this distress is also related to a drop in functional status:

I am a very outgoing person, I always try to live a full life. But now you can see me, I can't live. I am merely existing. (Int C2)

The partner of a PWA described how talking about these issues helped to alleviate emotional distress:

We learnt a lot about how to handle emotions and deal with them, express them to each other, it was three months of interesting, um, whatever, but we began to talk it through and pray it through, we accepted it. (Int C7)

### Death and bereavement

The lack of communication and denial mentioned above, as well as prevailing social taboos, had resulted in many PWA and their loved ones being unable to talk about and prepare for death. Talking about death was seen to be an acceptance of it, or a kind of "giving up", which was frowned upon. The sister of one PWA said she could not talk to him about death because:

I don't think of my brother as a dying person. (Int C12).

The avoidance of the issue led to anxiety and confusion. One PWA discussed his questions about his own death:

What bothers me is that people say I have five years left ... (but) nobody tells me, I don't know where they heard this. (Int C11)

Another interview revealed the lack of acceptance that a partner was going to die:

We could still have like two or three good years together, you know. We could go out, go to the Waterfront, go to movies, stuff like that. But he is laying there all the time. (Int C5)

This man's partner died three weeks later.

Respondents also reported difficulties in dealing with the death of a loved one. One woman, whose husband died several months ago, said she was unable to talk about his death because:

I have still got a broken heart (Int C1).

### **Spiritual**

Many respondents expressed needs for spiritual support. Spiritual distress centred around anger at God for allowing their illness to happen, as well as fear of being punished. Spiritual preparation was seen by some as an important element of preparing for death. One PWA reportedly:

... has fear about whether God would punish him. (Int C4)

One bed-ridden PWA reported that his minister had been extremely helpful:

(The minister) was here the other night, ja, it helped me. (Int C11)

Whereas another PWA's brother said that he had been neglected by the church:

You know he was a big church-goer, and now, I feel today he is being neglected. The chap, he might be busy but I really think he should try and extend visitation. I was going to speak to him and (brother) said no, forget it, he don't want to bother him. (Int C12)

### **Medical**

Although a thorough discussion of the clinical and medical problems experienced by PWA is beyond the scope of this evaluation, certain common problems were reported. Home-carers and

PWA spoke of problems with fatigue, loss of weight, TB, weakness, bed sores, nausea, diarrhoea, ulcers, incontinence and susceptibility to infections. HIV-positive babies suffered mainly from chest infections, dehydration, diarrhoea, and nutritional problems. Medical care was provided at HIV-clinics at the major hospitals, with people attending out-patient clinics at three monthly intervals, and more often as the illness progressed. Although most respondents said they were satisfied with the medical care received, the problems of getting to the clinic, mentioned above, prevailed. PWA also reported difficulties in getting hold of medication, as only limited prescriptions were given, requiring frequent trips to hospital.

### **Section 3: Clients' experiences of the project**

The project's clients were uniquely placed to comment on its strengths and weaknesses since they were the ones actually receiving the service. Their feelings on which services were most useful, as well as their preferences for care, are essential for future planning.

#### **Overall response to project**

The response to the home-care project by PWA and family members was positive:

The care that (he) got from the Red Cross Home-care, you could not duplicate anywhere. (Int C7)

Home-carer) is very helpful, I trust her. She helps my wife to relax, to have a break. (Int C11)

It took a lot of weight off my shoulders ... I couldn't cope without (her) at the moment, she does a lot for us. (Int C3)

One client complained that the relief home-carer who came on Sundays was not a very good cook and he didn't like the way she made tea.

#### **Assistance at home**

Many respondents spoke about the benefits of the project in assisting at home. This relieved the burden on family members, and often allowed partners and families to continue working, where previously it would have been impossible:

Without her I wouldn't be able to work at all, and we need the money. (Int C3)

It also diffused tension in relationships, because of a reduced demands on family members and partners. Also, it was a comfort to PWA not to be at home alone:

I'm sorry I heard about it so late, I used to be here all alone ... I would have liked some-one to come earlier. (Int C11)

### **Material assistance**

Clients also reported being very thankful for the food parcels received from the home-care project. In some cases this was the only source of food for the household. One client reported that the “atmosphere in the home” had changed since receiving food parcels, as relatives were no longer resentful at providing for extra mouths who were not bringing in income. Many care-givers reported that their babies’ health had improved significantly since the distribution of food parcels.

One woman also said that Red Cross had been helpful with her husband’s insurance policy:

(Staff member) has been a big help with the insurance – I don’t care about the money for me, I just want to pay for his funeral, I don’t want him to have a pauper’s funeral. (Int C9)

The mother of a woman who died of AIDS said that project staff had arranged an ambulance to take her daughter to hospital, when no-one would respond to her call.

The equipment provided by the project also benefited clients:

Red Cross provided a special chair for him to sit up in bed so that he was able to be fed, they provided a waterproof sheet and some sort of thing to prevent bed-sores. (Int C7)

### **Counselling**

Many client’s reported that the full-time project staff had been very supportive and had provided counselling in times of emotional distress. However, many said that they felt unable to approach home-carers for support:

I don’t think the home nurses are equipped to counsel. (Int C12)

Two white clients mentioned cultural differences with home-carers in this regard:

Because there is a cultural gap which must be bridged before the home nurses can do counselling ... if indeed it can be addressed. (Int C7)

We can’t talk though, we don’t communicate well. We get on, but we have a different sense of humour. I would like to talk but we are in different worlds. (Int C5)

This communication problem seems to be limited to white clients, as one black women spoke of the “very strong relationship” that had developed between her daughter and the home-carer.

### **Spiritual**

Some clients reported receiving spiritual comfort from home-carers. The partner of a man who died of AIDS-related illness said:

She would sit and comfort him, hold his hand, pray with him and read the bible to him. He was devotedly Christian so it was really good, exactly what he needed. (Int C7)

### **Medical**

Most clients said that they had not received medical treatment from the home-care project, as all medical care was undertaken at hospitals or clinics. Many said it would have been helpful if regular clinic visits could have been avoided or reduced, because of problems with transport and the time taken by these visits.

### **Care preferences**

Some clients reported that they would prefer be ill and die at home than in hospital, as the partner of a man who did die at home said:

Oh it was much better here, there is no comparison. (Int C7)

Two other PWA said:

I prefer to be at home, because I am more able to do my own thing, friends feel more at ease here, they can come and visit me, I’m more comfortable here. (Int C5)

Here, if I want to be alone I can be alone, if I want to play my music loud then I can do it. It’s important. (Int C10)

However, one PWA said that his home was not peaceful enough:

I don’t want to die here, it is too busy, the people are nosy, they always look at me. It would be more peaceful [meer rustig] in hospital. (Int C11)



Some family members also said that they did not want their loved ones to die at home:

I preferred her to die in hospital – I cannot stand to see her suffering anymore. (Int C6)

Another man said he did not want to wake up “with a cold body next to me”, another that she “dreaded” the thought of her son dying at home. One woman said she did not want her child to see her father’s dead body.

Some clients said that they although they appreciated visits and food-parcels, they did not need hands-on assistance at home from home-carers. Some felt that this would compromise confidentiality, others said that there were household members at home who could cope. Two women reported that it was their “duty” to look after their husbands. One said that her husband’s family would criticise her if she got outsiders to help, that she would be seen as a “bad wife”. Most PWA and family members said that there was no need for a home-carer unless the sick person was bed-ridden.

## **Section 4: Home-carers' experiences**

The community workers or home-carers were a crucial component of the project, and well-placed to comment on the operation of the service. Also, it was useful to get an understanding of who the home-carers were and why they were working in the project, to aid future planning and recruitment. This section outlines the results of the interviews with home-carers.

### **Motivation for joining Red Cross**

The home-carers reported having heard about the Red Cross courses on the radio, through friends, or through talks given by Red Cross workers. Many of them said they did the courses because they wanted to help people in the community:

I want to help our people who are suffering. (Int H2)

I want to help my people, my sick people ... sometimes they haven't got anybody at home, they are just there by themselves. (Int H1)

The time when my mother was ill, I started to have that feeling then and I wanted to help sick people – I grew up helping sick people. (Int H6)

Another women said she wanted to help prevent the spread of the AIDS epidemic:

Because it would help me to help, because it (AIDS) could spread to the whole world, to everybody and also my children, so if I can help the AIDS people then I also help (everyone). (Int H5)

One woman said she had taken the course because she hoped to get a job in an old-age home in the future:

My aim is to go to the old-age home to nurse the old people. (Int H6)

### **Feelings about home-care**

All of the women were enthusiastic about their work, saying they “liked it very much”, “loved it”; “enjoy the work”:

I like it because also in my community I like to be involved in many things. (Int H2)

The women also take pride in their position as carers:

When I put on my uniform and I am going to nurse a person I feel (good). (Int H3)

### **Training**

No formal evaluation of the training conducted by the Red Cross was carried out, but the following comments on the courses were received. The home-carers all reported that they had enjoyed the courses, and said they had learnt a lot. As one carer put it:

I enjoyed it because I learnt a lot of things. I used to think I could not cope with nursing, because I had seen the hospitals, but when we were doing the course we were taught and everything was explained and we did practicals – I felt I could cope. (Int H4)

The opportunity for further training was an important motivation to remain with the Red Cross:

I prefer Red Cross because at (X) I only did the home nursing, at Red Cross there are many courses that one can learn. (Int H4)

They all expressed enthusiasm for future training. Many women said they would like more counselling training.

We were taught a little bit of counselling, (but) it isn't enough because you get different people, different questions. (Int H3)

They also said they would like to be given more medical skills to assist PWA, although they said they were learning a lot from the project staff:

I watched her and I learnt what to do, now I can do it myself (cleaning and dressing a patient's ulcer). (Int H6)

The home-carers who had completed the first-aid course reported that it had assisted them in their work, and they felt that other home-carers needed this knowledge.

## Some home-carers mentioned the need to learn what to do when people are dying:

Then it struck me, maybe this guy is going, I thought 'What must I do?'. (Int H1)

Sometimes we are not yet taught how to look after somebody – you just do it from your own general knowledge then, if somebody is dying. (Int H2)

## Activities

The work done by home-carers varied according to the needs and situation of the patients, as one carer said:

It is different, for instance here these people have no-one working for them, everything is done by me. That is cleaning the house and taking care of the patient. In other places you find that there are people who do housework, you only have to look after the patient. (Int H2)

## Duties include:

- You wash him, give tablets and medicine, and to escort him to hospital if there is no-one else. Also to put in the catheter if the patient uses one. To assist those who are asthmatic when they use the pump. (Int H3)
- I come in the morning and help with his washing – give him a bed bath. I make his breakfast and sometimes I do a little housework. I clean his ulcer and change the dressing. The other one I just go and check on him and bath him, give him something to eat. (Int H6)
- Sometimes she is incontinent and you look after that because you don't want her to get bedsores. Then you wash her and you massage with soap and spirits for the bedsores, and turn her. (Int H1)
- I used to read the Bible and console him, and do everything – change him and put him on a chair, and do his bed. And if I notice something is wrong I phone the sister and they come. (Int H5)

## Some home-carers reported doing a lot of housework:

I do cleaning, washing, ironing, the housework, everything ... its part of my job. (Int H2)

Another said:

No, its not part of the job, they told us if you do it, its not because you have to. (Int H6)

### **Problems**

A problem experienced by home-carers working in township areas relates to the lack of resources in clients' homes:

With people in our communities where they are suffering, the problem is there isn't soap, there is no food, there isn't paraffin, no blankets and no stove – just cold water ... I have to take water with me in a flask from my house. (Int H2)

Sometimes you come there and there isn't anything for him to eat ... and sometimes he hasn't got clothes or anything. (Int H3)

A further problem relates to transport, as none of the home-carers have cars:

I've got a problem when I am travelling around here ... it is a long distance and I must walk ... there is a taxi but not exactly here. (Int H6)

Two home-carers reported problems dealing with family members of PWA:

She was difficult that one who was there ... she would complain and say "I don't think he is lying right" ... and you know what is right for the patient and the families mustn't tell the nurses their work. (Int H1)

(At the one place) we were not happy (because) whatever you did, you did not feel sure if it was right. We were very uncomfortable ... She did not want anyone in the place. (Int H6)

Home-carers also reported that the job could be extremely demanding at times:

Sometimes you change him now and he messes, you change him (again) and the gloves are finished and everything is finished and you are alone. (Int H3)

Many home-carers developed close relationships with their clients, and experienced great loss when they died:

Your patient is sometimes like a friend and when he dies it is as if its one of your family members.

(Int H5)

Because (X) was such a nice guy, he loved me too, and it comes like my family or somebody, or like my husband so I did cry. (Int H4)

### **Counselling**

Many of the carers found difficulty talking to clients, particularly in their second language. Also, they have not received much counselling training, and so were often uncertain as to how to approach distressed clients:

I'm scared to ... If I talk to them about it, they might think I am laughing at them because they are going to die. (Int H5)

One home-carer said that when a client was depressed about his illness, she told him:

Everyone is sick, other people got cancer or headaches, its just the same, it is exactly like this, (at least) you are alive. (Int H3)

Another said:

Because sometimes they feel it is the end of the world that they are like that and you tell them everyone can suffer ... you had better accept it because it is in God's hands. (Int H2)

A home-carer reported stopping a client's relatives from crying after his death:

They tried to cry and I said to them: "That is not right, because he was sick and he didn't like to be like this ... so you mustn't cry". (Int H1)

Although these women undoubtedly meant well, clients could have felt that their distress was not being taken seriously. These responses contradict widely accepted counselling principles such as empathy, non-directedness and acceptance.

Also, some of the home-carers are very religious and see caring for a terminal patient as a chance to put them in touch with God. One carer said:

(X) didn't care much about Christianity, but I would attend to him and read the Bible to him. (Int H2)

While this might have suited clients with similar beliefs, it would not be appropriate for everybody.

### **“Town vs township”**

Because no home-carers had been recruited in the inner-city, black women from the townships had been caring for white clients in town. In some case home-carers reported that this was better for them, because houses were well equipped and made their jobs easier. Also, although they had further to travel, more public transport existed to and from town areas than in the townships themselves. But some home-carers reported difficulty communicating with English patients:

And sometimes you know other people ... don't accept my broken English, so I am frightened to talk because people will laugh at you. (Int H6)

We don't talk a lot, only when I come in I ask how they feel. (Int H5)

Also, a home-care supervisor said:

I know one problem they have got when they work in places like town is the cooking. They panic that ... they're not cooking in the right way, but here in the township they know how to cook for our people. (Int S2)

The issue became more complicated because, at that stage in the project, clients in the townships had tended to receive a visit for an hour or two a day, while town clients had received more full time care. As the home-care supervisor said:

They prefer working in town – especially on the financial side. In town they are not working an hour or two, they are there for the day. So one knows that if she is working in town she is going to get more money because she's working more hours. (Int S2)

Also, one home-carer reported that she had been given extra money for doing housework in town areas. It seemed that home-carers working in the townships did not do much housework, in

contrast to those working in town. Also, home-carers appeared to be more confident when working within their own community. A home-care supervisor sister said:

They are not as free with people in the town as they are with the people in the townships. (Int S2)

### **Working conditions**

Most home-carers said that they did not mind the long shifts, but one reported that:

One nurse for a week is a bit strenuous ... the whole day if you get in at seven and then leave at six, it is too much for one person ... when you are tired like this you say "Just wait man, I'm tired". (Int H3)

All home-carers said they would like a higher rate of pay – but only after being prompted by the researcher. As one home-carer put it:

You see the problem is that we are not permanently employed by the Red Cross, we are just casual, it is difficult to ask for things. For instance I would like to see that all these people who are sick could be kept in a hospice where we could look after them, because now for instance when your patient dies your job is also finished. (Int H5)

We cannot say that the money we are getting is too little ... I am scared that they could say "no we do not have that money, you can leave the job and we will go to people who accept that money". (Int H6)

Thus because of job insecurity, the carers found it difficult to request different working conditions. Most said that even though the remuneration was low it was better than nothing, given the high rate of unemployment in the townships. When asked what she would like to say about her job, one home-carer said:

I would like to ask that the person should be permanently employed, then you can know you are working right through non-stop. (Int H6)



### **Relationship to project staff**

Despite the problems mentioned above, all the carers reported positive relationships with the project staff. They said that the staff responded promptly to requests for assistance, and provided support with issues such as dealing with client's death. One home-carer said:

You know what makes you like a job is the people working with. (The staff) are very kind to us, they sisters, they don't take themselves as people who charge, everything we do it's the same, we listen other ... we work well together ... they respect us. (Int H2)

### **Knowledge/attitudes to HIV/AIDS**

The home-carers HIV/AIDS knowledge and attitudes were not formally assessed during the evaluation, so no objective measures exist, nevertheless the interviews did provide some indication of their level of awareness. Most home-carers reported not knowing much about HIV/AIDS before the course. One said:

I was frightened, I didn't want to just hold a person. I thought you couldn't use the spoon or the clothes or anything, that you must sit away from him and not come close to him. (Int H3)

One carer said that even after the course:

When (supervisor) told me I was going to look after (an AIDS patient) I was so scared. I was shy to go there. But when I went I just found he is a sick patient, just like the others ... The only thing that is different is that you must use gloves. (Int H5)

They reported that the course had changed their attitudes, and most of the home-carers were emphatic that they were not worried about HIV-infection. They were all aware of how the virus could be transmitted, and, most importantly, how it could not. They said they were careful, and used gloves when necessary, but did not go to unnecessary lengths:

I am not afraid, they told us that we can't get it if we use the gloves when there is fluid. (Int H1)

One carer was quite mocking towards the St Luke's nurses' over precaution:

They said "why aren't you wearing gloves" (when she was in the car with a PWA), ... and I said "I have got no cuts and there is no fluid", ... and they said "Ooh, ooh, you are going to get infected." (Int H6)

Some home-carers reported encouraging family members to accept the PWA, relieving their fears about infection by teaching them infection control.

One home-carer reported that she was worried about being infected:

It also dangerous, like working with those people, if you're just falling down, nobody can help you if you get that AIDS. (Int H4)

Although all home-carers were non-judgmental towards their individual clients' HIV status, certain elements of blame towards others did emerge in the interviews. One women said that the youth were "very naughty" – having sex with their boyfriends, thus exposing themselves to infection. Another spoke of a women who was infected after "going with the truck drivers" in a judgmental way.

### **Confidentiality**

All of the home-carers were aware of the need to keep their client's HIV status confidential. They said that if people asked what was wrong with the client, they would say they did not know, that "only the doctors know, we nurse all patients". Most said they would not inform family members, unless the patients agreed to this, but would encourage family members to wear gloves when nursing the patient. They also encouraged PWA to tell their families of the diagnosis. One home-carer was perhaps a bit over-enthusiastic in this encouragement, saying she would tell her patient:

"You must tell them because sometimes they will hear from the doctor and from other people and they must also know that this can happen to them ... and sometimes there is no home-care and if you hide it too much they will be careless, and they will use your things sometimes without gloves and they will be infected." (Int H4)

### **Prevention/education work**

In addition to educating families of PWA about HIV/AIDS, many of the home-carers reported talking to their own family and friends about HIV. One said her family had been reluctant for her to do this work:

My children say: "Oh Mommy, I heard on the radio that AIDS can affect you, you mustn't do that job Mommy." And I say: "No" – I try to explain it. (Int H3)

**Another said:**

We must tell them how to protect themselves. If she is at the stage of having a boyfriend she must have one partner, she must use condoms and all those things. (Int H5)

**Support meetings**

As mentioned earlier, the home-carers felt adequately supported by the project staff. However, many mentioned a desire to get together with other home-carers regularly, to talk about their experiences and to learn from others:

We must have a workshop at least one day a month for the home-carers, and if there is a new thing in the caring you know sometimes these are different people (with different problems). (Int H6)

Also, one home-carer mentioned the possibility of competition between carers, because at that stage of the project work was limited. She said that regular meetings would iron out any problems that might arise when a client had a preference for one carer over another. She had on one occasion been called on to replace another home-carer, and was concerned that there would be ill feeling towards her.

## **Section 5: Staff and committee members' experiences**

The material presented here is based on interviews and frequent informal discussions with committee members and project staff, as well as on comments made in meetings.

### **Management committee**

Most respondents felt that the performance of the committee had improved a great deal over the last year. Initially the committee was disorganised and unfocussed, but gradually a functional structure had emerged. Respondents felt that this was largely due to the business-like facilitation of the chairperson, and the orderliness provided by the administrative co-ordinator. However, a certain lack of consensus as to the direction of the project was still reported as a problem. Some felt that this was inevitable when entering "uncharted terrain" such as AIDS home-care in Cape Town. Some participants felt that the process of setting goals and laying out objectives needed to be revisited, and very concrete plans established. As one committee member said:

I would like to see a list of objectives, under each area, and then progress reports at the meeting: (so we will know) "this has been done, this is outstanding". (Int M4)

This type of approach had been successful with regards to small issues raised in meetings. An 'action list' was produced, with the name of the responsible person, and distributed with minutes. This action list was then discussed at the beginning of each meeting. This committee member felt that such an approach should be extended to incorporate the broader objectives of the programme.

Another problem raised with regards to the committee was its lack of representativeness. The committee members were all professionals (mostly white), and no HIV-positive people were represented on any project structures. Attempts have been made to incorporate the two 'out' HIV-positive people who were active in HIV/AIDS committees, but although expressing support for the project, they were both already over-stretched. The committee felt it was impossible to attempt to coerce people who are not out about their HIV status because of the prevailing stigma that awaited such public announcements. Also, the lack of community representation on the committee was identified as a problem.

Another problem raised was the division between the project management and the home-carers. Some committee members felt that they were too far removed from the actual operation of the project:

There is no sense of the project within the management team, we are too removed from the home-carers. We have never met them, don't know what they do, who they are ... (Int M3)

This member felt that a huge chasm existed between the professionals who made decisions about the project, the community home-carers who did a lot of the work, and the clients who received the service.

### **Health services**

A large problem that had confronted the project was the fragmentation in the health care services. As one staff member said:

Half the day hospitals fall under CPA and the other half under the municipality and then RSC. And there's no consistency in the services. ... So you have a problem with day hospital A, and you phone CPA, – "no, it's not my day hospital". So you phone the next one – it's frustrating. (Int S1)

The lack of communication and co-ordination between the different services was also a problem. This sometimes resulted in clients receiving duplicate services, for example food parcels, as no record was kept of who was being supplied by different organisations. This problem also arose in hospitals:

Lots of patients go to Groote Schuur, Conradie, Somerset, depends where the ambulance is going. Then you go through all the tests and that again – a waste of time and resources. (Int S1)

One committee member suggested a patient-held card, detailing where the person had been seen, in an attempt to alleviate these problems.

Another problem experienced related to the referral of PWA to the project by the hospitals. It was felt that some PWA were being referred too late to provide any meaningful service. Although the unpredictability of the course of the illness hampered effective referral, staff felt

that hospital personnel needed to be more conscientious about referring patients when the project could be of use.

Project staff identified the lack of counselling at the hospitals to be a problem, particularly for Xhosa-speaking clients. They reported encountering people who had been tested and counselled in hospital, but did not understand the nature and implications of HIV-infection. Although it was recognised that hospitals could not undertake long-term counselling of all HIV-positive patients, staff felt that certain minimum standards needed to be set.

The broader problems of inadequate health service delivery also impacted upon the project. Project staff reported that under-staffed clinics and over-stretched hospitals compromised the quality of care offered to PWA. Since the home-care project did not undertake intensive medical care at home, staff were reliant on hospitals to provide these services. It was anticipated that this problem would escalate as the HIV epidemic spread.

Staff and committee members recognised that the Red Cross project could not be expected to resolve all the problems relating to health care delivery in the Cape Town region. Although the project was initially conceptualised as a co-ordinating forum for HIV/AIDS care, there was consensus that this function was best carried out at the regional co-ordinating forum, the Care and Resources meeting, where most organisations working in this area were present. At the time of the evaluation, the Care and Resources forum was reportedly “slowly starting to iron out the communication problems”.

### **Training**

Red Cross' programme of broad-based training received mixed responses from the committee. Some people felt that offering training as broadly as possible was a way of developing community skills, providing a possibility of jobs for trainees outside of the project, empowering people to look after their own family members and increasing general AIDS awareness. Others questioned whether broad training and AIDS education was the role of the home-care project, and felt that the project should concentrate on the people who had already been trained:

If people don't use their skills they will forget them – we should focus on the ones we have already trained, build them up and train them more, rather than training new ones. (Int M5)

There was consensus that home-carers should be given more extensive psychosocial skills.

### **Stigma of AIDS**

The stigma of AIDS was identified as a large problem hampering the provision of home-care. Staff reported that many clients had not told their household members of their diagnosis, thus making counselling during visits to crowded homes extremely difficult. The HBC community sister had developed an innovative way of dealing with this problem – she asked the clients to help her get the food parcel from her car, and then talked to the client outside sitting in the car. Although this afforded some privacy, it was not an ideal setting for counselling. Also, the community sister reported that household members become suspicious if the client remained outside for too long, or if this happened too often.

Project workers reported that mothers often left their HIV-positive children with care-givers who are not aware of their illness. In an attempt to prevent infection, project staff encouraged care-givers to use gloves when dealing with any body fluids, saying that it was more hygienic and protected the child.

Some clients reportedly refused home-care because they feared that their confidentiality will be compromised:

One patient in the townships said they didn't want a home-carer because they said the neighbours are going to know. (Int S2)

### **Home-visits**

The HBC community sister reported a difficulty in carrying out home-visits and delivering food parcels to all the clients in the townships. Much of her time was spent travelling around the vast township areas. Clients were often not at home, even when the visit had been arranged in advance – many clients did not have telephones to confirm appointments. Also, hospitals sometimes supplied the incorrect addresses and time was wasted searching for clients. Although she said it would be preferable if home-carers could conduct home-visits, she envisaged problems because the home-carers did not have transport to fetch food parcels and take them to clients. Even if this transport was available (or home-carers lived sufficiently close to clients) problems arise because:

Home-visits are not only for delivering food, but also to check on client's health and to provide counselling. (Int S2)

Home-carers were not trained to do this. As things stood, the community sister reported that she did not always have time to provide quality care on visits, as she had too many to get through in her busy schedule.

She also reported being met by numerous other requests for assistance while working in the community:

People who have never worked in the community will never understand it. But now if you ever work in the community you are a social worker. (Int S2)

The community sister spent some of her time based at an office in Guguletu, and was often inundated by queries (from non-clients) about grants, pensions, maintenance, relatives in prison and so forth. She often found people queuing outside her office when she arrived at work in the morning.

### **“Town vs townships”**

Project staff identified a difference in the level of care requested by clients of different races and socioeconomic circumstances:

The cases in the townships ... there are relatives who look after them. Then the home-carer just goes in for a few hours at the end ... Not like the cases in town one goes there for about 12 hours, the whole day, the whole night ... sometimes there are also relatives there. (Int S2)

She felt that this may be due to differing expectations and experiences:

I think (in the townships) we have got people who are used to doing things for themselves. They don't say so easily they can't cope, you know, because they are not used to getting outside help. Now the people in Green Point and Sea Point are used to getting outside help and then they can take advantage of that. (Int S2)



### **Empowering health workers**

Some committee members expressed concern about the type of tasks undertaken by home-carers in clients' homes. As one said:

If they are seen as home-aides or domestic workers, this is not recognisable as a health service, it's charity or welfare. We need to empower them as health workers. (Int M8)

Committee members felt that a position as a "home-aide or domestic worker" was not consistent with the role of counsellor or respected health worker.

### **Staff**

Many of the staff's concerns were mentioned above. In addition to these, both full-time care-staff reported feeling overworked and over-extended in their duties. They worked long hours and often had meetings at night. They were both concerned about the organisation of care in the project and the increased pressures when more people were referred to the project.

## **Section 6: Outsiders' views**

As discussed earlier, the views of people involved in HIV/AIDS and other aspects of health care were elicited so as to gain a different perspective on the project's work, and to learn from the experiences of other projects.

### **General views**

Most of the respondents had had some form of contact with the Red Cross project. Although critical comments were raised, most people expressed support for the work done by the project and the principle of home-care. One member of another AIDS-care organisation said that the co-operation between his organisation and the project over patients' care was working "wonderfully well" (Int O2), despite initial communication problems. Another said that the Red Cross was doing "sterling work" and deserved to be congratulated (Int O4). Some less complementary points are raised below.

### **Hospitals**

All the hospital doctors interviewed expressed support for the project, and felt that the aim of reducing hospital admissions and length of stay in hospitals was feasible:

Secondary prevention through early diagnosis can avert the crisis, then they will spend less time in hospital, and have less severe illness. Also it could reduce unnecessary clinic visits. Providing support and nutrition will also reduce infections. (Int O3)

One doctor explained why he sometimes referred patients "too late":

AIDS illness is not a gradual decline, rather there are acute periods of illness which require intense medical intervention – when this is stabilised, the patient is fine and doesn't need home-care. Home-care is only feasible when the patient is terminal and there is nothing more that can be done in hospital. The timing of referral is difficult, as we don't know which will be the last acute illness. (Int O1)

Another doctor suggested that the project should take on more secondary-preventative care of patients, including assessment, oral rehydration, pain control and certain medical interventions. He felt that if the project took on this role, patients could be referred at an earlier stage:

We don't often see fancy exotic diseases here, it is the common medical problems – chest infections, gastro, nutritional problems. (Int O9)

He felt that home-carers could be trained to recognise danger signs and to act appropriately:

They can learn simple algorithms to follow: If fever, check this. If vomiting, drowsy, irritable, more than ten stools a day – refer to hospital. That kind of thing. (Int O9)

A doctor at the children's HIV clinic said that mothers could not be taught these things in hospitals, as they were often too distracted by concerns for their child's health and did not remember what they were told. Home-carers could therefore educate care-givers.

Another said that hospitals were often not the best place to assess patients:

Some patients don't cope very well in hospital. Particularly AIDS dementia, like (X), we can't assess him properly because by the time I see him he is tired, cold and annoyed at having waited so long. If he could be assessed at home it would be much better. (Int O1)

One clinic doctor felt that the project could play a particularly helpful role in combating the spread of tuberculosis:

It's been recommended that every HIV-positive person be given a three-month course of TB drugs, but the problem is compliance. If these people don't finish the course we will see an epidemic of drug-resistant TB. Maybe home-carers could supervise the treatment. (Int O7)

He went on to say that if the intersection between AIDS and TB in the Western Cape was not tackled it would "finish" the health care system.

Another doctor who has been involved in counselling people with HIV in clinics felt that the HBC project was ideally placed to look for opportunities for disclosure. He felt that home-carers could be trained to facilitate this.

### **Association to Red Cross**

Some people interviewed felt that the association of the project to the Red Cross Society was positive, as the Red Cross has a reputation internationally for assisting disadvantaged

communities. However, others said that the Red Cross did not have credibility with political and community structures in South Africa:

Red Cross has a bad reputation in the community for just going ahead and doing their own thing – even recently, in the flood relief. Other NGO's are very angry about what happened. (Int O11)

Another person said that community structures (many of which are highly politicised) had reservations about the apolitical and “charitable” nature of the Red Cross. Respondents explained that in the past a “non-political” stance tended to mean a failure to challenge the previous inequitable system of government. Many respondents felt that the Red Cross in South Africa needed to take a firmer stance with regards to advocating for the rights of the disadvantaged. Respondents were also concerned that the Red Cross might be exploiting community volunteers in a way that was not consistent with community empowerment.

One interviewee took issue with Red Cross' policy of “random” training:

There is no clear vision of what they want from this. I don't think you can just throw training out – you must train for a specific purpose. (Int O11)

### **“Dumping”**

Some of those interviewed were concerned that the project could be used as a “dumping ground” to justify inadequate care by formal health services:

Hospitals could use this to avoid their responsibility and send people home to die without caring for them. (Int O12)

The government may then justify not doing more for PWA, and the community will bear the brunt of it, its like brushing the problem under the carpet. (Int O2)

I fear that patients may be dumped on the Red Cross by hospitals. They claim the patient is untreatable, when that might not be true. (Int O10)

Although these people said they were not opposed to the principle of home-care, they felt that the project should not be “cheap option” that could result in inadequate care.

### **Feasibility of home-care**

Some respondents expressed reservations about the feasibility of quality home-care in disadvantaged communities:

Home-care is OK for the middle-classes with resources (but) the infrastructure in the community is not geared for home-care. There is no transport, no beds, no water. (Int O6)

There was also concern over whether home-care was sustainable, given the large expected numbers of people HIV:

Maybe it should be about mobilising family and friends and neighbours, because there just won't be enough money. (Int 05)

Others wondered whether 24-hour nursing was necessary:

They sleep most of the time you know. Maybe they need help once a day with bathing and that, but its a waste of manpower you know (to have home-carer there all the time). (Int O8)

### **Primary health care**

Some respondents felt that the project needed to incorporate the principles of primary health care if it was to gain credibility in the community and provide a meaningful service. An important aspect of this was said to be community consultation and participation. Participants warned that incorporating these principles would not be easy and would require much time and commitment:

Some people only hear from the community what they want to hear. ... Communities are also immersed in particular ways of seeing things, you need to listen carefully and not take the first response, but explore this with the community. (Int O11)

They stressed that community consultation did not merely consist of talking to the leaders of organisations, but also involving the targeted population.

Some respondents said that the adoption of a community health worker programme was a "huge task", taking many years to fully operationalise. They questioned whether the Red Cross was in a

good position to co-ordinate such a service. They suggested that the home-care project develop close links with other community health worker projects in target areas.

### **Prevention work**

Many people stressed the potential for home-care to facilitate preventative efforts. By caring for PWA in the community, it was hoped that more people would become aware of the seriousness of the epidemic and would be motivated towards behaviour change. Respondents felt that home-carers could provide “pockets of enlightenment” to assist in countering the spread of HIV.

## ***Discussion and recommendations***

The researcher joined the project in February 1994 and was present at almost every project meeting since then. At times this close association with the project may have been problematic, as the distinction between participant and observer could have been lost. However, this experience gave the researcher valuable insights into the workings of the project that an external observer would not have gained (Nightingale & Rossman, 1994).

The preceding sections raised many of the strengths and weaknesses of the project, as perceived by respondents, and introduced important areas for debate. Clearly 'home-care' did not mean the same thing to all people. Differing visions of home-care were evident not only in outsiders' responses but also amongst project participants. The following discussion raises some of the issues highlighted in the findings and considers broad questions facing the project at the time.

### **Section 1: Summary and discussion of clients' needs**

The project needed to establish which of the needs identified by PWA and their associates could realistically be addressed by home-care and which should be referred to other service organisations.

At the time of the evaluation the home-care project helped clients with disability grants and welfare queries, referral to terminal accommodation, home nursing equipment, food-parcels and emergency transport to hospitals and provided assistance in the home, allowing family members to continue working. Other needs such as employment, long-term accommodation and the placement of orphans had been identified as being beyond the scope of the project and clients were referred to organisations such as Wola Nani in this regard. Gaps in services available needed to be placed on the agenda of HIV/AIDS co-ordinating structures in the region (such as the Care and Resources meeting). The project staff were well positioned to notice such omissions and had played an instrumental role in bringing these issues to the attention of the relevant organisations. However, the boundaries of the project needed to be remembered to ensure that the quality and coverage of care was not compromised.

**Food parcels**

The sustainability of the provision of food parcels needed to be assessed in relation to the anticipated future demand. Although it had been claimed that food parcels constituted a charity or “Band-Aid” type service which failed to address the root causes of problems, the particular difficulties and needs of people with HIV needed to be borne in mind. Clients (and doctors) had identified this as a beneficial and essential service. By incorporating the distribution of food parcels into a more comprehensive service including counselling and secondary prevention this criticism could be avoided. Thus it was recommended that every effort be made to maintain the service and ensure that it was not abused. Additional fund-raising was recommended if necessary.

**Psychosocial needs**

In the face of overwhelming material needs, it was at times difficult to focus on the more subtle but nevertheless crucial emotional distress and psychosocial problems evoked by HIV. The need for psychosocial interventions was all the more critical because of the identified problems with counselling in hospital settings. Home-care has been seen as presenting an ideal opportunity to help clients come to terms with diagnosis, facilitate disclosure to family members, pass on HIV-related information, address problems in relationships and emotional distress, and help clients prepare for death and dying. Although the full-time project workers had assisted clients in these areas, it was impossible for these workers to adequately counsel all of the project’s clients. Experiences in other projects have demonstrated the effectiveness of non-professional counsellors, however the training provided to home-carers left them largely unqualified to deal with psychosocial problems. Also, the language and cultural gaps between black home-carers and white clients did not allow for effective communication and counselling. The status of the home-carer as either a respected health worker or a domestic assistant was also relevant in this regard.

The project had recognised the need to include a counselling component to training programmes and at the time of this evaluation arrangements were underway for the core group of carers to receive intensive counselling training from ATICC. It was recommended that the content of this training be carefully examined in relation to the needs of clients and the anticipated function of home-carers. Also, training courses needed to be evaluated to assess whether or not participants had benefited. This issue will be discussed in more depth below.



**Spiritual needs**

Spiritual support had been identified as a very important component of home-care. Home-carers had already been helpful in providing spiritual comfort to clients, but differing religious beliefs had to be respected and upheld. The training of home-carers should stress the importance of tolerance towards beliefs which might contradict their own.

**Medical needs**

The home-care project did not undertake to provide medical treatment to PWA. However, as the number of people with AIDS-related illnesses escalated, HIV-clinics in hospitals would find it increasingly difficult to provide quality care to all of those in need. The practice of symptomatic HIV-positive people regularly attending out-patient clinics for monitoring and assessment would prove impossible to sustain (Metrikin, 1993). These regular check-ups were essential so as to catch infections at an early stage and minimise the extent of the illness and cost of the treatment. In many models of home-care in other African countries, home-carers functioned as primary health workers. They were trained to recognise and respond to danger signs of HIV-related illness. Also, by visiting clients in their homes the problems relating to attending clinics were avoided. This proved to be a feasible and effective means of providing basic medical attention to PWA (WHO, 1989). The feasibility of incorporating such secondary-preventative work into the Red Cross project is discussed below.

**Section 2: Discussion of project's progress**

The project had made significant progress during the period of evaluation. A management team had been established, comprehensive budgeting and fund raising undertaken, and a newsletter produced and distributed. Committee members had liaised with other service providers and were able to resolve many of the early communication problems with health services. Health services had given their support for the project at the highest level. Broad-based training in home nursing and AIDS-awareness had been conducted and a core group of eight home-carers were active in the project. The project had provided home nursing to 14 PWA and regular home-visits and support to a further 52. Much positive feedback on the project's activities had been received and the care provided by the project had received a favourable response from clients.

### **Management structure**

The management committee had identified a problem with the representativeness of project structures. Also the subcommittees were not meeting regularly. This suggested a need to re-examine the current structure of sub-committees and re-assess their necessity. If these committees were identified as being important, efforts needed to be made to set objectives, allocate tasks and organise regular meetings.

### **Staff**

Staff members were enthusiastic about and committed towards their work. Their compassion and dedication had brought glowing reports from clients and co-workers alike. They had established good relationships with home-carers.

### Project co-ordinator

The co-ordinator's job description covered broad areas of work such as financial planning, fund raising and project promotion. Many of these functions were (and should have been) carried out by the management team. Her job description also included the area of devising and implementing prevention programmes, which might have been seen as outside of the scope of a home-based care programme. The project co-ordinator's direct responsibilities needed to be clarified. She worked long hours and spent many evenings in meetings. An analysis of a two-week period showed that the largest portion of her time (19%) was spent in various meetings – both external and internal to the project structures. These meetings needed to be rationalised to allow her to concentrate on the co-ordination of care within the project. In the time-period monitored she spent more time in direct contact with clients than she did supervising the care provided by home-carers. A re-allocation of responsibility for care would have relieved some of the pressure on the co-ordinator.

### Community sister

The community sister's job description presented her with an impossible work load. It described her as responsible for all assessments, weekly reports on patient's conditions, weekly meetings with home-carers, support groups for PWA, running all home nursing and AIDS courses, as well as identifying township resources and attending project meetings. This allocation of responsibility needed to be rationalised. The sister was also responsible for all home-visits in the

townships, which took up most (almost 40%) of her time. She reported that the time available for visits was too limited to adequately assess clients or provide extensive counselling. She also spent considerable time (nine percent) on non-HIV related queries. Again, a revised model of care would have enabled her to concentrate on more appropriate areas of work.

### **Broad-based training**

Although the Red Cross home nursing course did not strictly fall under the auspices of the home-care project, it continued to consume project resources. Similarly the AIDS awareness course took up a lot of the community sister's time. Although these courses provided a valuable service to the community, their function in a home-care project needed to be questioned. It was recommended that the home-care team concentrate resources on more extensive training of limited numbers of home-carers and left broad-based courses to Red Cross staff outside of the project and organisations with a specific education and training focus.

## **Section 3: Introducing recommendations**

### **Projections of future numbers of clients**

The Doyle model, when applied to the Cape Peninsula, estimated that there were 309 people who were AIDS sick in the year of evaluation – 1994. Based on clinic attendance at that time – and recognising that many PWA did not attend HIV clinics – this figure was thought to under-represent the number of PWA in the project's target area. Also, once clinic doctors and PWA became more aware of the services offered by the project, the number of clients (relative to the number of PWA) was expected to increase dramatically. Based on these considerations an approximate projection of clients reaching the home-care project would be in the region of 50% of the number of sick PWA estimated by the Doyle model in any given year. Thus, the following figures provide approximations of projected clients:

1995 – 324

1996 – 615

1998 – 1,688

2000 – 3,496

These estimations included only people with stage four AIDS, not HIV-positive symptomatic people. The figures show a doubling-time of slightly more than a year.

### **Three general recommendations**

#### **Reduced focus on home nursing**

A strong initial focus of the project lay in the provision of home nursing to bed-ridden clients. While those clients who had received home nursing reported it to be a much needed and beneficial service, the overall experience of the project suggested that the prioritisation of this service should be revised. Only a portion of the project's clients (14 out of 76) had received intensive home nursing. Many families of bed-ridden patients (particularly in township areas) refused home nursing as they felt that family members could cope. In most instances where home nursing had been provided, relatives and other household members were present in the home during the day. Also, home nursing had usually been required for very short periods of time. Thus, although home nursing was necessary in certain instances to allow family members to work or to provide temporary relief from the burden of care, this constituted a small proportion of the overall needs of clients. A staff member reported that one of her biggest problems was "too few clients". Of course, as the number of bed-ridden PWA escalates there will be an increase in the demand for home nursing, but this will be accompanied by a proportionate increase in the need for all the other services – visits, support, counselling, assessment and so forth.

#### **Revision of organisation of care**

Given the greater need for services other than attendant home nursing, it was recommended that the allocation of responsibility within the project needed to be revised. The project's full-time nursing staff were taking responsibility for all home visits, including the distribution of food parcels, on-going assessments of clients' health, assistance in practical queries, and counselling clients and family members. Home-carers were only called upon (and only trained) to provide attendant home nursing and general assistance in the home. This division of responsibility resulted in an under-utilisation of home-carers and the over burdening of qualified nursing staff. To sustain such a model in the face of growing numbers of clients, significant numbers of professional nurses would need to be employed.

#### **Extension of services**

In the light of the above comments it may have seemed strange to suggest an extension of services offered by the project. However, after considering the role of home-care in other

African countries, it was felt that this project could feasibly make a considerable contribution to relieving the burden on the health care system by incorporating secondary-preventative work as discussed above (under medical needs). Also, the extensive psychosocial problems impacting on the quality of life of PWA and their families required more intensive interventions than the project had been able to provide. A more extensive training programme for home-carers and a revision of the organisation of care, moving responsibilities from staff to home-carers, was recommended to allow the project to incorporate these aspects into its function.

The above discussion has introduced some of the recommendations suggested by the evaluation. In addition to these, but also fundamentally interlinked, were considerations of broader questions surrounding the philosophy and focus of the project. These related to issues such as the structure of the management committee, the staffing of the project, the adoption of secondary prevention and the credibility of the project in the community. The following discussion attempts to address these and other issues.

#### **Section 4: Primary health care**

There had been much discussion within the project's structures about the concept of Primary Health Care (PHC), which was seen as a model to inform the project's work. However, there was some confusion as to what this entailed. PHC has been defined by the World Health Organisation as:

Essential care based on practical, scientifically sound and socially acceptable methods and technology, made universally available to individuals and families in the community through their full participation and at a cost they can afford. (Alma Ata, 1978: Article V).

The principles of PHC include:

- Equitable access to services and a concentration of services in areas where there is the most need
- Active community participation in planning, organising, managing and evaluating services
- The provision of appropriate, affordable and holistic services
- A focus on prevention and promotion work
- An inter-sectoral and collaborative approach to health care.

Thus rather than supplying rigid protocols or models of care, a PHC approach provides an underlying philosophy to guide health care delivery systems (Rex, 1991). PHC projects attempt to decentralise health care so that it is closer to the places where people live and work. Community health workers have often been seen as the cornerstone of a PHC approach (Berman, Gwatkin & Burger, 1987). CHW are typically elected by community members and live in the areas that they serve. They are lay people trained to provide basic health services to members of the community. An essential function of a CHW is health promotion through the education of community members. PHC is also informed by a recognition that health cannot be separated from social and economic conditions and that health services must challenge discriminatory practices in our society. PHC projects strive to contribute to the empowerment of disadvantaged communities (Mathews, Hewitson & Van Der Walt, 1992).

### **Assessing the project's PHC potential**

In many ways the Red Cross project was ideally suited as a PHC project. The basic intention – to provide support and care to PWA and their household members in their homes – was directly in line with the principle of decentralising health services and making care accessible. Also, the HBC project was affordable to clients who were never refused care for financial reasons.

It has been suggested that specialised AIDS services are contrary to the PHC principle of integrated services meeting all health care needs. However, in the absence of a comprehensive, functioning PHC structure in South Africa, small specialised services have been developed. Co-ordination and co-operation between PHC projects can prevent the fragmentation and inefficiency that vertical services are thought to create. Also, a functional model of primary home-care for PWA can be extended to include other chronic illnesses such as TB and cancer in the longer term. A small-scale focus may be initially preferable to facilitate the development of such a model, but should not be seen as an end point in service development. The most important principle here lies in co-ordinating services with other health projects.

A related issue concerns the PHC focus on prevention and health promotion. The principles of PHC stress that preventative efforts should be prioritised, but do not distract from the importance of caring for sick members of the community and minimising the impact of disease. An approach towards care which includes a focus on secondary prevention and which works closely

with related prevention and promotion programmes should not be seen as contrary to this PHC principle.

However, there were certain areas of the project's approach that did not conform to PHC principles. The most notable was the role of the home-carers, which was not consistent with that of community health workers. Home-carers were not elected by the community, they did not (often) live in the areas that they worked, they were not active participants in the running of the project and they were not trained in health promotion and PHC skills. Rather they were seen as home-aides or nursing assistants. The practice of sending a black woman into a white man's home to carry out domestic duties can be seen to reinforce existing inequalities based on race, class, geographical location and gender. Also, the lack of job security within the project and the token salaries provided to extremely hard-working and committed home-carers raised the question of (unintended) exploitation. This discussion was a difficult one to raise with the project, and was not meant to detract from the benefits of the project or to criticise those involved, but rather to introduce a recognition that many accepted ways of working needed to be carefully (and painstakingly) re-examined should the project decide to adopt a PHC approach.

The provision of care also missed out on important opportunities to empower families, friends and community members to gain confidence in their own ability to provide care to PWA in their homes. Primary health care focuses on educating community members and transferring skills in the interaction between the community health worker and client.

Another important aspect of PHC is community participation. The project had recognised this to be a problem within its structures – as well as in many HIV/AIDS organisations in this area. HIV and AIDS initially affected mainly white homosexual men, who became active in organising around the issue. Many of the people (not all of them white homosexual males) who were involved in early HIV/AIDS organisations remain active at the time of the evaluation and the same people tended to sit on various committees. This had led to a somewhat closed circle dealing with HIV/AIDS in the Cape Town region. An acknowledgement of the spread of the disease to the heterosexual population and the increased prevalence amongst black township residents needed to be accompanied by an intense effort to incorporate these groups into all spheres of HIV/AIDS work. Again, community participation is not a simple process and many existing and comfortable ways of working needed to be changed to facilitate this process. For

example, lengthy meetings – at night, in town, in English – were unsuitable to Xhosa-speaking township dwellers, especially those already struggling with the double shift of child-care and day-time jobs. Also, many community members have been disempowered by exploitative practices and community work thus requires a non-threatening style of operation, with emphasis on participation, building confidence and skills, and democratic procedures. Community consultation can be a time-consuming and at times frustrating process, requiring a sensitive and skillful approach.

Another area of concern lay in the equity of service provision. Although no intended discrimination existed, the experience of the project had been that white clients from advantaged backgrounds requested more extensive home-care services. Disadvantaged clients often reported that they did not need attendant home-carers. Disadvantaged clients certainly benefited from the service, largely in the form of food-parcels, material assistance and family support. It could be, as a project worker suggested, that white clients were more used to receiving outside help and also that middle-class homes were more conducive to the provision of home nursing. Therefore a focus on the provision of attendant home nursing may be inconsistent with the PHC principle of providing services where there is the greatest need.

### **Section 5: A model of primary home-care**

After a consideration of the principles of primary health care, bearing in mind the particular focus and strengths of this project, the following recommendations for a ‘primary home-care’ project were offered:

#### **Clients**

It was recommended that the project maintain its selected focus on symptomatic people with HIV, people with AIDS, care givers of babies with HIV, and their families, household members and partners. Once the model of care was fully functional, the service could be directed towards elderly people and people suffering from chronic diseases, as well as healthy people with HIV.



## **Home-carers**

### Selection

Although PHC principles suggest that CHW are elected by the community which they are to serve, this objective is difficult to achieve in a specialised AIDS service. Clients' confidentiality would be compromised if home-carers identified with the AIDS project were seen entering clients' homes. Also, it would not be very 'empowering' for the project to dismiss the active home-carers and engage new, elected ones. The principle of community accountability of home-carers could be slowly integrated in consultation with other PHC groups and as the service took on responsibility for non-AIDS illnesses.

### Training

The home nursing course syllabus tended to cater for home-aides in Western homes and required extensive revision. Home-carers needed to be educated in basic medical skills, such as nutrition, the recognition of dangers signs of AIDS-related illnesses and the appropriate action to be taken – including when a referral to a more qualified health worker is required. In addition to medical skills, home-carers needed to be equipped with extensive psychosocial skills including assertiveness training, mobilising and training community members, talking about human sexuality, counselling, welfare assistance and helping community members confront death and dying. The WHO has produced an AIDS home-care handbook which has been successfully utilised to train health workers to carry out these tasks (WHO, 1993). The handbook educates health workers as to how best to train family members, provides basic HIV/AIDS information, discusses living positively with AIDS, care of the dying and the management of common symptoms of AIDS in the home. The handbook is geared towards use in poorly-resourced communities and no expensive equipment or medicines are suggested. The handbook could be adapted, in consultation with organisations such as ATICC and the Progressive Primary Health Care (PPHC) network, for use in local conditions.

### Conditions of employment

Such training would require considerable investment by the project in home-carers, as well as by the home-carers themselves. To prevent dissatisfaction and rapid turn-over of qualified home-carers, and according to the principles of community and staff empowerment, it was recommended that a group of home-carers be employed on a full-time basis by the project.

Employing home-carers would prove more cost-effective than employing additional qualified nursing staff and was seen as a necessary financial outlay if a commitment to this model of comprehensive care was to be undertaken.

### Location

Although community health workers typically reside in the areas in which they work, this principle may need to be slightly compromised because home-carers have already been selected, and because of the problem of maintaining confidentiality in close knit communities. Despite this compromise, it was recommended that home-carers be made responsible for all clients in a particular geographical area. This would reduce transport problems and facilitate convenient home-visiting. It was seen as crucial that home-carers were not expected to counsel clients in a language unfamiliar to them or placed in positions where existing status differentials might undermine their positions as health workers. This raised the question of who would provide services to the project's "town" clients, which needed to be further explored by the project.

### Activities

Within this model, the primary focus of home-carers would be to educate and support household members to care for PWA. Regular home visits would be undertaken to assess clients' health and make referrals where necessary. Also, extensive psychosocial support and counselling would be provided to clients. Food parcels and material assistance would be provided where necessary. Home-carers would at times be required to provide attendant home nursing, but this would not be the primary focus of their work. The feasibility of home-carers supervising client's TB medication could also be explored.

### Participation

The model required the participation of home-carers in the management of the project. As mentioned above, this would require adaptation of existing management structures. It was recommended that home-carers meet regularly amongst themselves to discuss problems experienced and plans for the future, and that a home-care representative sit on the management committee. Home-carers would need to be given the authority to implement decisions. An ultimate goal may be for the home-carers and project staff to take over the running of the project with representation from clients and other community structures.

**Staff**

The adoption of this model would reduce the burden on existing staff members and convert their function from hands-on provision to supervision. For example, instead of staff members visiting each client to provide food parcels, these food parcels could be dropped off with the home-carers responsible for each client. Home-carers would then distribute the parcels on their regular visits. It was felt that a decision to employ home-carers on a full-time basis may have removed the need for an additional qualified sister.

**Management structure**

As mentioned above, it was recommended that the lack of community representation on the management team be addressed as a matter of urgency. A first step towards this would be the incorporation of home-care representative(s). The committee was advised to critically analyse its style of operation so as to provide an accessible and non-threatening environment to newcomers. The project needed to workshop strategies for increasing community participation.

**Collaboration with other PHC projects**

Many community health worker projects had been established in the areas targeted by the service. It was recommended that a priority of the 'new style' of operation be to organise meetings with representatives of these projects to discuss collaboration in health service provision. In an attempt to increase coverage of services, areas in which CHW projects were active could be omitted from areas assigned to HBC home-carers, and potential clients in these areas referred directly to other CHW projects. This could resolve the problems in white areas, where many home-care services existed and were increasingly being established (although most of these were not PHC projects). Regular meetings needed to be arranged between home-carers working in particular areas and other health services such as day hospitals and community clinics operating in those areas. There had been a tendency for the care co-ordinator and community sister to attend all external project meetings. Passing some of the responsibility for this onto home-carers would lessen their workloads and develop the skills and confidence of home-carers.

## **Section 6: Challenges facing the implementation of the model**

Many of these recommendations required a radical revision of the operation of the project. The model presented above did not provide concrete or detailed plans for implementation, but rather offered general guidelines for consideration by the project. The researcher stressed that the process of planning the implementation of the recommendations needed to be carried out in consultation with community structures and primary health care projects, if the recommendations were accepted. The researcher realised that this process would not be a simple one for the project, and attempted to pre-empt this by offering the following suggestions:

### **Financial**

The most immediate practical constraint related to the financial planning and fund-raising of the project. The budget at the time of the evaluation did not accommodate the salaries of full-time home-carers. Although at first glance the revised model may have appeared more expensive, a more thorough (and realistic) examination of the structure suggested that it was not. If one home-carer provided home-nursing to one client for 10 hours a day, five days a week, for a month, the salary paid to the home-carer (excluding transport) was R1,000. Under the new structure, the same home-carer could provide care of different intensity to numerous clients. S/he may visit an average of five clients in one day. Some clients may need to be visited daily; s/he may need to spend an afternoon with another client to relieve family members; other clients could be visited weekly or even monthly. In the same month the project could provide more holistic care to 20 households affected by HIV. This was provided as an example, not a concrete plan of operation. The salaries offered to home-carers needed to be decided in consultation with other community health worker projects.

### **Practical issues**

Various practical issues such as the number of home-carers to be employed, the number of clients that home-carers could feasibly be assigned, transport for home-carers, communication between home-carers and health services, where home-carers should be based and so forth, had to be considered when planning the implementation of this model. The experience of other primary health care and community health worker projects was expected to provide invaluable assistance

and information in this regard. This was also seen as an ideal opportunity to build contacts and co-operation with these projects.

### **Credibility of the Red Cross**

As mentioned in earlier sections of this report, the Red Cross Society was not seen as a credible structure by some community organisations because of its lack of accountability and history of poor community consultation. Although this credibility problem did not extend to all members of the community – as evidenced by the popularity of Red Cross courses and the demand for Red Cross services in the townships – the problem needed to be resolved to ensure widespread community acceptance of and participation in the project. Poor credibility can also hamper fundraising efforts. The lack of acceptance of the Red Cross by political organisations was also a result of the previous politically divided structure of our society. However, at the time of the evaluation political conditions were changing and many new collaborations were forming. The researcher felt that if the Red Cross showed a commitment to the principles of a primary health care approach, most notably consultation, equity and empowerment, in the implementation of this project, the problem of acceptance by community structures could be overcome. This was seen to provide an opportunity for both the Red Cross and other organisations to form new alliances that would be ultimately beneficial to recipients of health care services.

### **Style of operation**

As previously mentioned, the style of operation of both the Red Cross Society and the HBC management team would need to shift to accommodate the demands of meaningful consultation and participation. The researcher warned that this could mean taking a step back from work in progress, placing decisions and commitments around budgets, training schedules, funders reports etc. on hold, and entering another phase of community-based operation, and recognised that this may prove frustrating for project participants. It was recommended that the management committee consider engaging the services of an external consultant, specialising in organisational development, to assist in this process.

Although the above discussion may seem critical of the project, it was based on a recognition that the model of care in the way it practised was not sustainable. This was not meant to detract from the very important work that had been done. Valuable lessons had been learnt from this

work and essential skills developed. The challenge now lay in developing and targeting these skills into a sustainable model of AIDS home-based care.

## ***Conclusion: Response of the project to formative evaluation***

The findings and recommendations described above were documented in a report that was distributed to committee members and staff, as well as some health workers involved with the project and the Western Cape Red Cross Society management. A week after the report was distributed an evaluation workshop was held where the above stakeholders were invited to discuss the recommendations of the formative evaluation. There was some resistance to the report, with staff members in particular feeling that it was overly critical of the project. This was discussed and the evaluator attempted to stress the positive components of the evaluation. Despite this resistance there was overall agreement on the need to change the operational style of the project. The concept of primary health care was accepted in principle by the participants, but certain aspects of the evaluation - most notably the full-time employment of home-carers - did not receive their support.

## **Progress**

### **New structure**

The chairperson of the management team, after being mandated by the evaluation workshop, met the researcher to discuss a new project structure incorporating the recommendations of the evaluation. According to the structure that was agreed upon, the home-care staff were divided into geographical areas, with a full-time staff member supervising a group of home-carers who would provide hands-on care to clients. Because most of the project's clients lived in either Guguletu or Khayelitsha, it was decided that a community sister would be responsible for each of these areas. The project co-ordinator would be responsible for clients living in and around the town area. This revised model was accepted by the management committee, and another community sister was employed to be responsible for Khayelitsha. Despite this agreement in principle, there were problems implementing the revised operational style (outlined below), and at the end of the secondary evaluation the nursing staff continued to be responsible for most of the home visits and delivery of food parcels.

### **Counselling course**

In response to the finding in the formative evaluation that more counselling training was needed for home-carers, and in accordance with the recommendation that training should be targeted at a smaller group of active home-carers, a six-week once-weekly counselling course was run for the home-carers. The course was facilitated by experienced HIV/AIDS counsellors from ATICC, and incorporated participatory learning methods, role-playing and practical experience. The course was attended by about 20 home-carers, and included topics such as HIV/AIDS knowledge, talking about sex and sexually transmitted diseases, and dealing with death and dying (Soal, Van de Velde & Isaacs, 1995).

### **Support group for staff**

The formative evaluation noted that the project staff were over-extended and that HIV/AIDS home-care could be extremely demanding and stressful. Because of this a support group for project staff was formed. Full-time staff members met monthly with a clinical psychologist and reported that the support group had been beneficial, both professionally and personally.

### **Support group for clients**

One of the major problems identified in the formative evaluation was that full-time staff - qualified nursing sisters - spent more time delivering food parcels than delivering nursing care. One suggested way of alleviating this was to ask healthy clients to visit the project offices to collect their food parcels. Another benefit to this approach is that clients are able to meet with other people in similar positions to discuss common problems. This approach was successfully implemented in Guguletu, although at the time of the secondary evaluation it was still operating on a small scale.

### **Paediatric project**

A new project, aimed at children with HIV/AIDS, was developed by the UCT Child Health Unit in conjunction with some of the participants of the Red Cross home-care project. This project encompassed many of the suggestions of the formative evaluation, and was seen as a secondary-prevention service, incorporating the principles of primary health care. At the time of the secondary evaluation the project was still in the process of being implemented, and had trained



community health workers in the recognition and management of common symptoms of paediatric AIDS. A core group of community health workers had been selected, and were to be employed on a permanent basis to visit clients in their homes, training caregivers to look after children with AIDS. A nursing sister had been employed to supervise the community health workers.

### **Barriers to implementing the new model**

Unfortunately, although there was agreement in principle to the recommended new model of care, the project was unable to put this into practice. The following factors were seen to contribute towards this:

#### **Uncertainty in the Red Cross Society**

The Red Cross Society had been through a difficult transition period, resulting in a lot of uncertainty for the project staff. The Western Cape region of the society had had three managing directors during the time of the pilot project, and there had been budget cuts and retrenchments, with the accompanying effects on staff morale. These changes had meant that promised items, for example a staff car for the new community sister, were no longer available.

#### **Staffing difficulties**

Largely in response to the above problems, the community sister employed for Khayelitsha resigned her position in January 1995, and the post was frozen until August 1995, when a new sister was employed. This made it impossible to implement the new, geographically-based model, and placed extra demands on remaining staff. Also, staff had been involved in a number of activities not directly related to the home-care project, resulting in competing responsibilities.

#### **Funding**

Although the state Health Department had promised to fund the home-care project at the end of the pilot phase, the changes in the Health Department at the time meant that the allocation of all new funds was put on hold while new funding criteria and priorities were developed. This

contributed to uncertainty in the project and fear for the future of staff jobs. The lack of funding also motivated the project's decision not to employ home-carers on a permanent basis - a crucial component of the recommendations.

### **Conflicting management**

Although the home-care pilot project was managed by a separate management committee made up of volunteers, conflict sometimes arose because the staff of the project were still accountable to the Red Cross Society. Decisions made at project management meetings, for example to restrict staff members' responsibilities to project-related activities, were not always implemented.

### **Operational style**

The Red Cross Society had traditionally operated in a different way to the primary health care approach advocated by the formative evaluation. The project staff members had worked for the Red Cross Society for a number of years and were well-accustomed to a particular way of working. The difficulties in adjusting to a new style of working, together with the obstacles outlined above, contributed to the problems with the implementation of the formative evaluation recommendations.

## **Chapter three: Secondary evaluation:**

### ***Introduction***

At the beginning of the evaluation it was envisaged that the second phase would constitute a more outcome-oriented study that would assess the project's success in meeting its stated objective of developing an appropriate, effective and sustainable service that would improve the quality of life of clients and alleviate the burden on formal health services. The recommendations of the formative evaluation were made with these objectives in mind. The formative evaluation suggested that the service was not appropriate because the activities of the project were geared towards home-nursing for bed-ridden PWA, when this constituted a small portion of the needs of the target clients. The project was also seen to be unsustainable in the face of increasing referrals, because the primary responsibility for care was placed on the staff members and not the home-carers. Also, in order to alleviate the burden on the formal health system the project would need to undertake secondary prevention work, as discussed above, which it was not doing. Since the project had been unable to utilise the recommendations of the formative evaluation, the necessary components for the project to achieve its goals were not in place. Following Posavac and Carey (1992) it was felt that an assessment of outcomes at this stage would be premature.

The one area that did lend itself to more rigorous scrutiny was clients' experiences of the project. There had been an increase in referrals since the completion of the formative evaluation, and staff had reported that the nature of the client population was changing, given the changing face of the HIV epidemic. It was therefore felt that it would be useful for the second phase of the evaluation to describe the demographic and health profiles of clients being referred to the project, as well as examining the needs of these clients, based on categories established during qualitative interviews in the formative evaluation. It was furthermore hoped that a description of the coverage and accessibility of the project, as well as an assessment of the success of the project in meeting clients' needs, would support the findings of the formative evaluation and help motivate the project to change its style of operation.

Since the project had a stated aim of improving the clients' quality of life, it was decided to include this component in the secondary evaluation. Of course there are well-documented problems with assessing quality of life, particularly in relation to clients facing a life-threatening disease (Williamson, 1994; Aaronson, 1991). This is especially true in South Africa, where no widely-accepted Quality of Life scale has been standardised across diverse cultural groups. It was therefore decided to rely on self-assessment, which has been found to be at least as accurate as other approaches (Posavac & Carey, 1992). As described in the formative evaluation, the project considered teaching people about HIV/AIDS to be an important part of their work. This variable lends itself more easily to assessment than others, and the researcher decided to include an examination of clients' HIV/AIDS knowledge as a way of assessing the project's effectiveness.

An evaluation of the economic costs of the project was conducted by MRC researchers during the secondary evaluation, and is described in *Economic Costing of the Western Cape AIDS Home-Based Care Pilot Project* (Hardien, 1995).

## **Goal**

The main goal of the second phase of the evaluation was to describe client's experiences of the project.

## **Objectives**

- To provide a demographic and health profile of clients referred to the project.
- To describe the interaction between the project and clients.
- To examine the material, psychosocial and medical needs experienced by clients.
- To describe the extent to which these needs had been met by the project.
- To establish the clients' opinions of the quality of the services received and the impact on their quality of life.
- To assess the clients' HIV/AIDS knowledge as a measure of the effectiveness of the project.

## ***Methods***

### **Population**

The study population was all clients referred to the project who were actively in the care of the project. At the time of sampling (six months after the presentation of the results of the formative evaluation, February 1995), 145 people had been referred to the project. Of these, an analysis of project records showed:

- 38 clients had died
- 13 had been referred to other organisations
- seven had moved away
- 15 were uncontactable because of incorrect addresses

This left 72 active clients. The active status of each one of these clients was verified with the project staff.

The researcher had originally hoped to interview a sample of relatives of the 38 PWA who had died since being referred to the project. A questionnaire for relatives was drawn up, and a simple random sample selected. However, not one of the selected sample in the township areas could be interviewed, either because the family had moved away, all adult members of the family had died or the relatives did not know that their loved one had died of AIDS-related illness. This meant that no true quantitative representation of relatives' experiences could be obtained, and since qualitative interviews with selected relatives had already been conducted in the first phase of the evaluation, this aspect of the study was abandoned.

### **Sample**

A simple random sample of 50% of the study population was selected by choosing each alternate client referred to the project. Although certain variables, namely geographical area and gender, were thought to be relevant to clients' experiences, the sample size of 50% (36 clients) of the population was sufficient for these to be proportionately represented. However, many replacements were necessary. Three of the selected sample died before they could be

interviewed, interviewers were unable to locate seven people because of incorrect addresses, and one person had been sent to prison. Missing respondents were replaced with the next unsampled person on the list of active referrals.

### **Questionnaire**

The questionnaire (see Appendix E) was intended as a structured interview schedule to guide field workers. The questions were mostly open-ended, and field workers were encouraged to explore clients' answers. It contained questions about respondents, their interaction with the project, their experiences of the project, and their knowledge of HIV/AIDS. The questions on clients' needs and experiences of the project were designed from information obtained in the qualitative phase of the evaluation. In an attempt to counter the subjective nature of the data, if clients said the project had helped them in a particular area, they were asked to give an example of how they had been helped. For example, if clients said the project had helped to resolve conflict in the family, they were asked how this had been achieved. This also added depth to the data received. Because many of the interviews were to be conducted in Xhosa, the questionnaire was translated into Xhosa, and then back-translated by a different field worker. The two English versions were compared, and a few minor adjustments made.

Ten interviews were carried out to pre-test the questionnaire, and some of the questions were adjusted so as to obtain the desired information. This also served as a useful training exercise for field workers. These interviews were not included in the results.

### **Interviews**

Two Xhosa-speaking field workers were engaged to interview Xhosa-speaking clients. Both the field workers were trained nurses who had worked with the MRC AIDS programme as research assistants in the past. The researcher felt it was important to have field workers who were familiar with HIV/AIDS issues, and would be sensitive to the experiences of PWA. As preparation for the interviews the field workers read copies of the formative evaluation report and the researcher held two workshops with them to discuss the study and role-play interviews. During these workshops the field workers and researcher took turns to interview each other,

while the third person observed and made comments on the interview process. Each participant had a chance to conduct three interviews this way. The researcher also accompanied the field workers on their first few interviews. The interviewers translated comments made during the Xhosa interviews into English, so that they could be understood by the researcher. The researcher conducted the interviews with English and Afrikaans-speaking clients.

Interviewers visited the clients at their homes and asked if they would mind participating in the study. Interviews lasted between 40 minutes and two hours. In some cases, family members were not aware that the client was HIV-positive, and interviews had to be conducted in the car or outside. If family members were in earshot, one interviewer would tell the clients, by writing on a piece of paper, that she would refer to AIDS as TB, so as to maintain confidentiality. Despite these precautions, confidentiality was broken during one interview, when a field worker inadvertently informed a relative that her daughter and grand-daughter were HIV-positive. This generated tension in the family, who were referred to the project for counselling. Fortunately the conflict in the family was resolved.

### **Analysis**

The researcher read through the completed questionnaires and set up a system of codes for the open-ended questions, based on the responses received (Appendix F). These data were then captured and analysed using EpiInfo. No sophisticated data analysis was required as the study relied on descriptive statistics.

## Results

### Demographic profile

#### Age

Respondents' ages ranged from 20 to 45, with most (54,7%) in the 25-35 age-group.

#### Residential area:

The majority of respondents (83,4%) lived in the townships, with most living in either Guguletu (36,1%) or Khayelitsha (27,8%).

### Place of residence

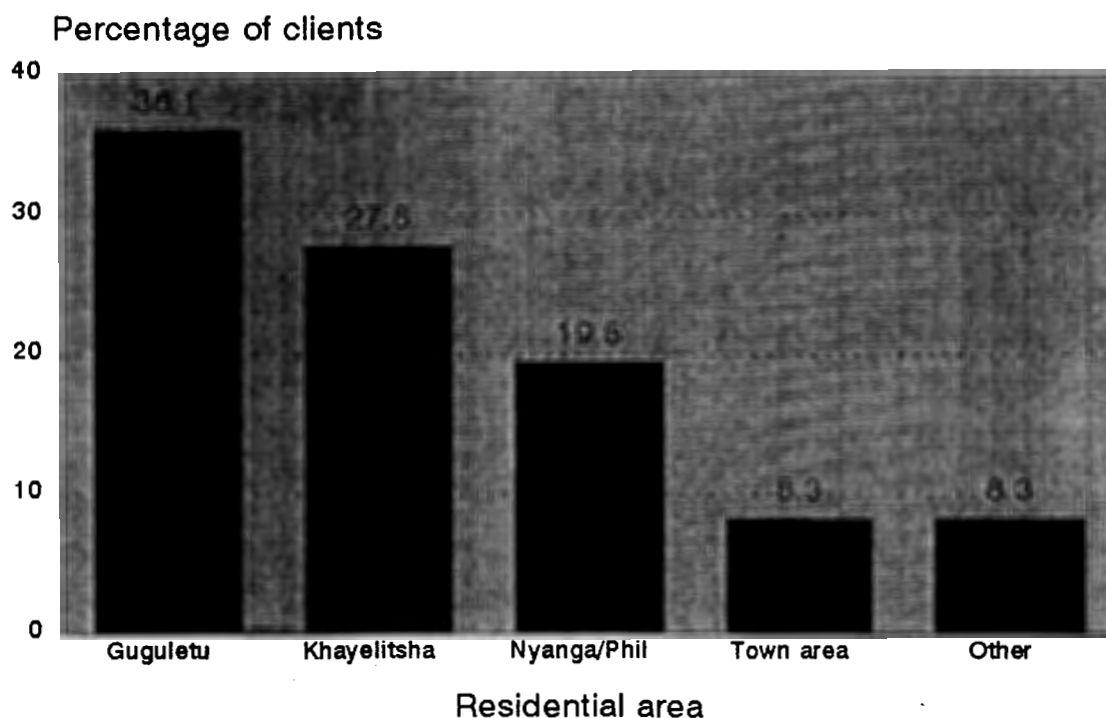


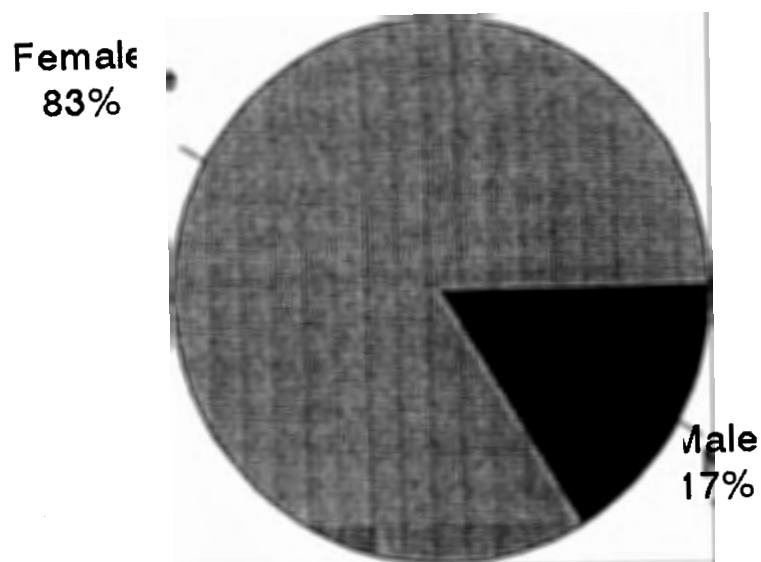
Figure 1: Place of residence



## Gender

By far the majority of respondents (83%) were women.

## Gender

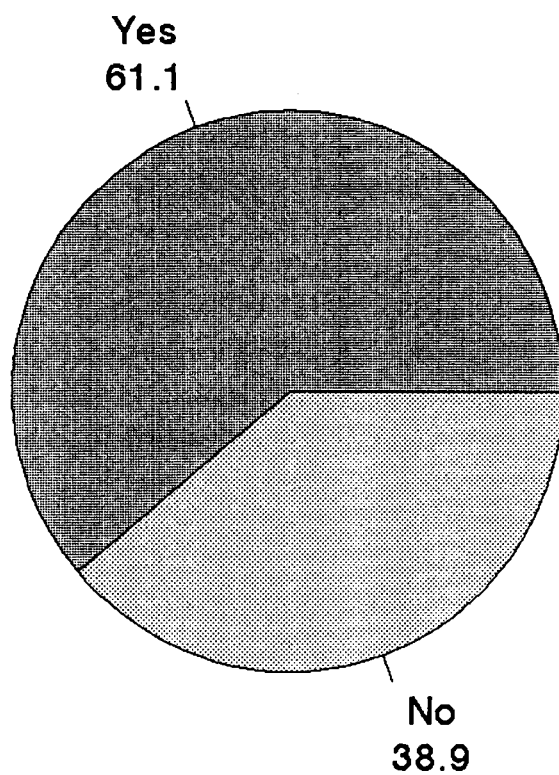


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**Figure 2: Gender**

**Parental status**

Sixty-one percent of respondents were women with young HIV-positive children.

Do you have a child who is HIV-positive?

---

**Figure 3: Parental status**

## Employment status

Most of the respondents (75%) were unemployed, with 14% having casual jobs. Forty-seven percent of those without jobs said they weren't working because no jobs were available, 33% because of HIV-related illness, and 13,3% because of child illness.

## Employment

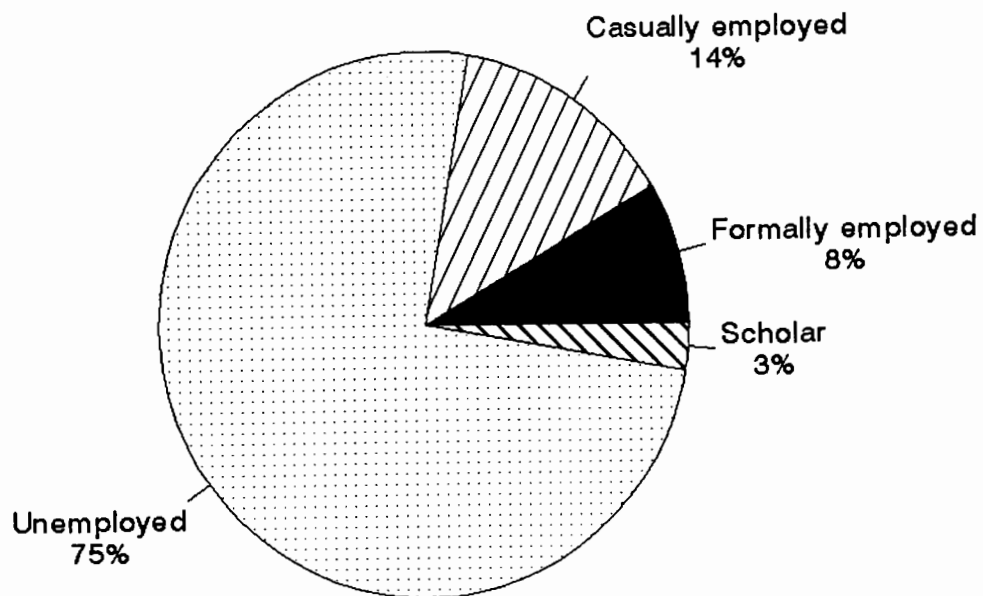


Figure 4: Employment Status

## Socioeconomic status

The low socioeconomic status of respondents can be seen in the bar graph showing client and household income below. However, it can be expected that some respondents under-stated their income, in the hope of receiving more services from the project, despite an extra appeal for honesty on these questions. Respondents reported that between one and 11 people were dependent on the household income, with mean of five dependents. Some respondents (29,4%) receive disability grants of R290 per month, and 11,8% said they were waiting for their grants to be processed.

### Monthly income

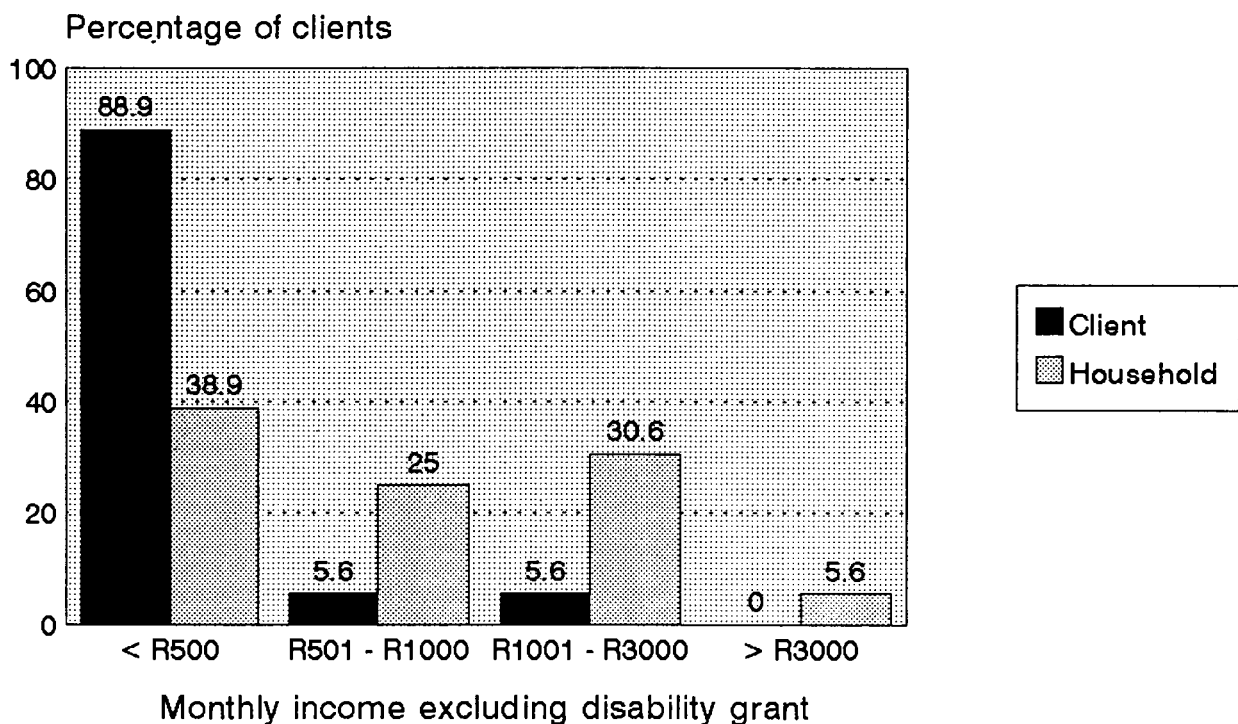
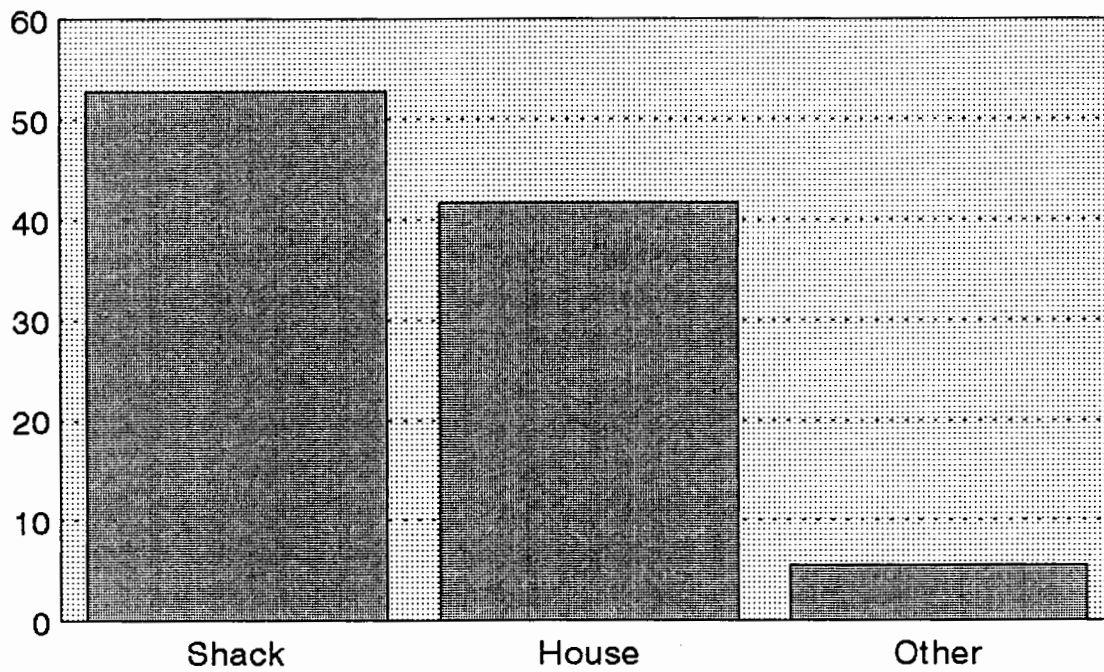


Figure 5: Monthly income

## Type of abode

Respondents' living conditions impacted on the project's ability to provide quality home-care. As seen below, most respondents (52,8%) lived in shacks, and 41,7% lived in houses.

### Respondents' homes

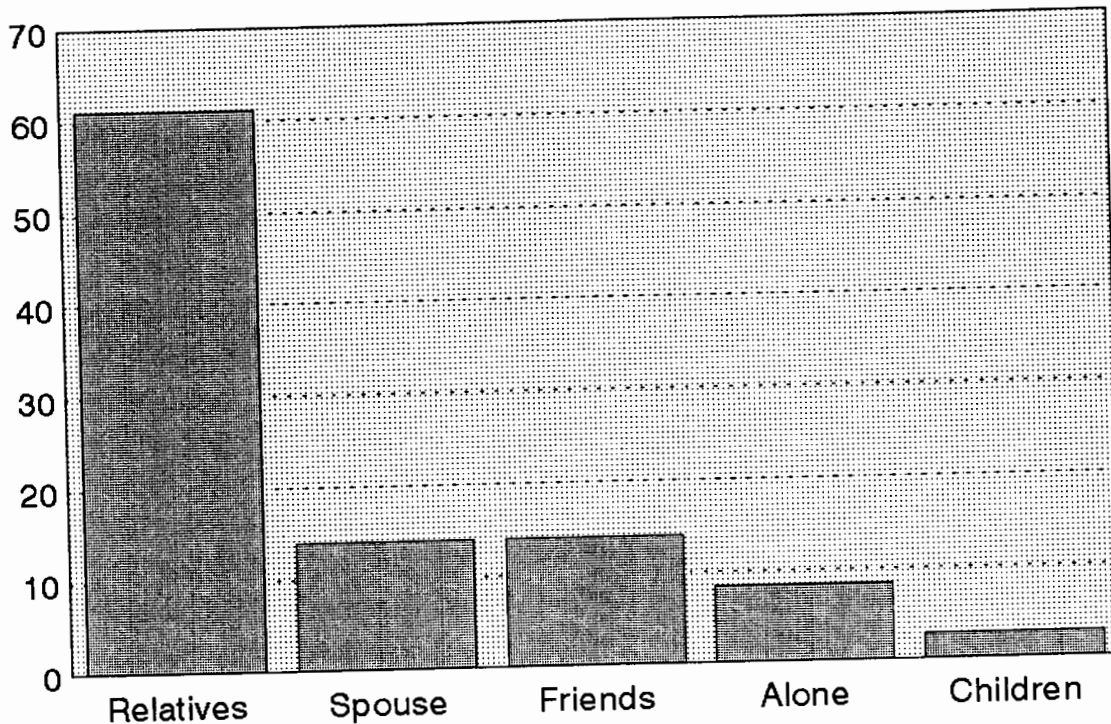


**Figure 6: Type of home**

## Living status

The bar graph below shows that most respondents (61,1%) lived with relatives, and very few (8,3%) lived alone, or without other adults (2,8%). Over 36% of respondents reported sharing their bedrooms with children, and 50% said they shared their bedrooms with more than one other adult. Fifty-eight percent of respondents reported that there was at least one other adult at home during the day, with 48% (of all clients) saying that this adult was able to look after them when they were sick.

### Who live with



**Figure 7: Living status**

## Health profile

### Health status

Respondents were asked whether, during the last four weeks, ill health had hampered them from carrying out:

- Strenuous activities such as moving furniture or playing sport;
- Moderate activities such as carrying groceries or climbing stairs; or
- Personal activities such as bathing, dressing or getting out of bed.

Their responses were coded as either:

- Can do the activity
- Can do, but more difficult than usual
- Need a little help
- Need a lot of help
- Can not do at all

The graph below shows that most respondents were able to carry out all functions without any difficulty.

### Functional performance

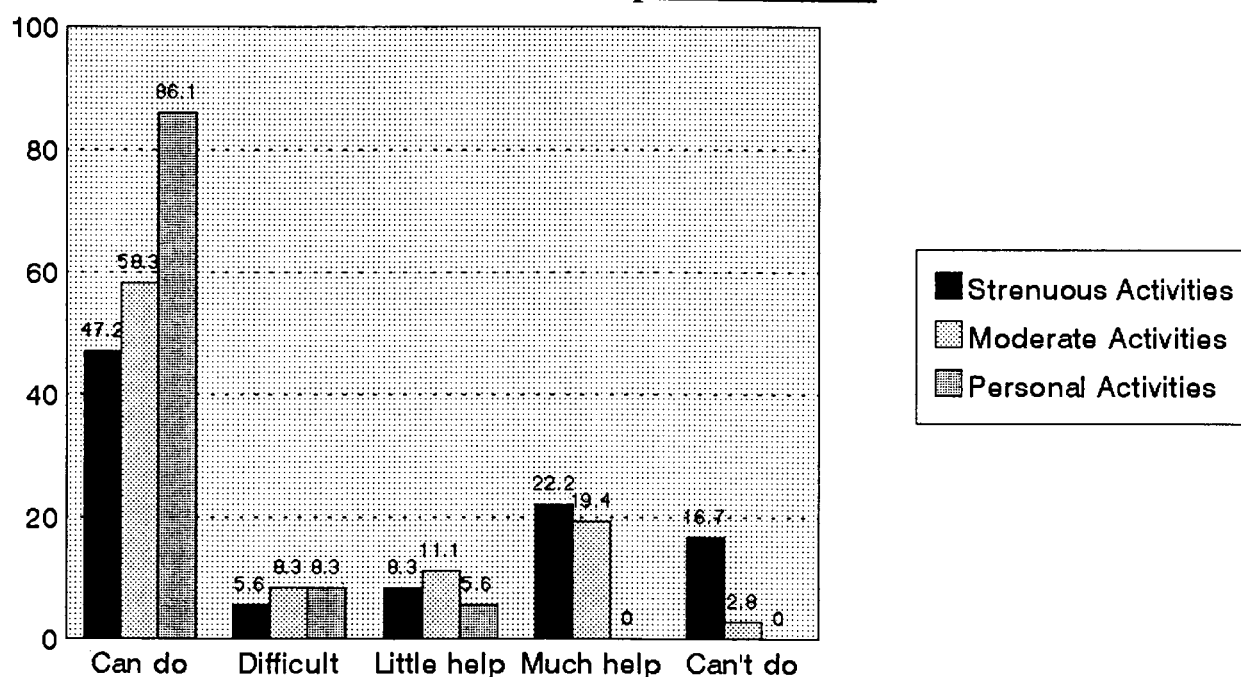


Figure 8: Functional performance

### Babies' health

Mothers of HIV-positive children were also asked to describe their babies' health. Over half of the mothers reported that their babies were healthy, and 17,4% said their babies had died.

### Child's health

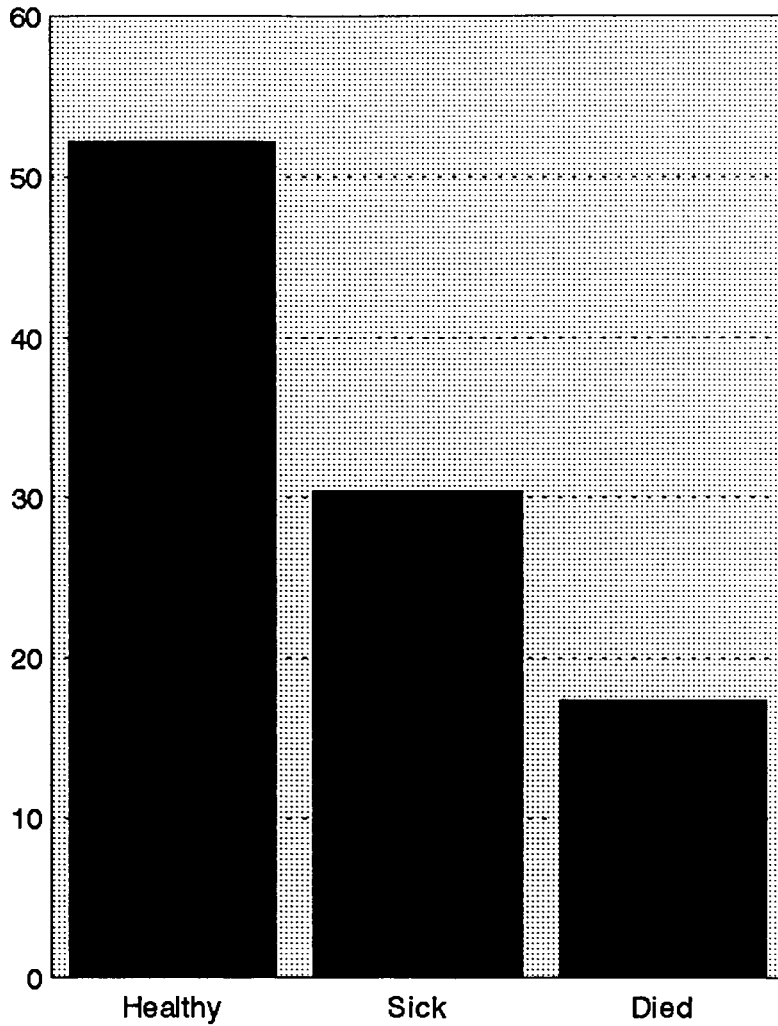


Figure 9: Child's health



### Clinic attendance

An analysis of clinic attendance showed that 61,3% of respondents attended HIV/AIDS clinics monthly, 12,3% more frequently and 22,7% less often than every month.

### Care preferences

When asked whether they preferred to be looked after at home or in hospital when sick, 69,4% of respondents said they preferred to be in hospital, citing reasons such as:

- Wanting the best possible care (22,2%)
- Their families did not know what was wrong with them (11,1%)
- No-one to look after them at home (22,2%)
- Home was overcrowded (5,6%).

Those who preferred to be looked after at home gave reasons such as:

- Being well treated at home (13,9%)
- Wanting to be with their families (5,6%).

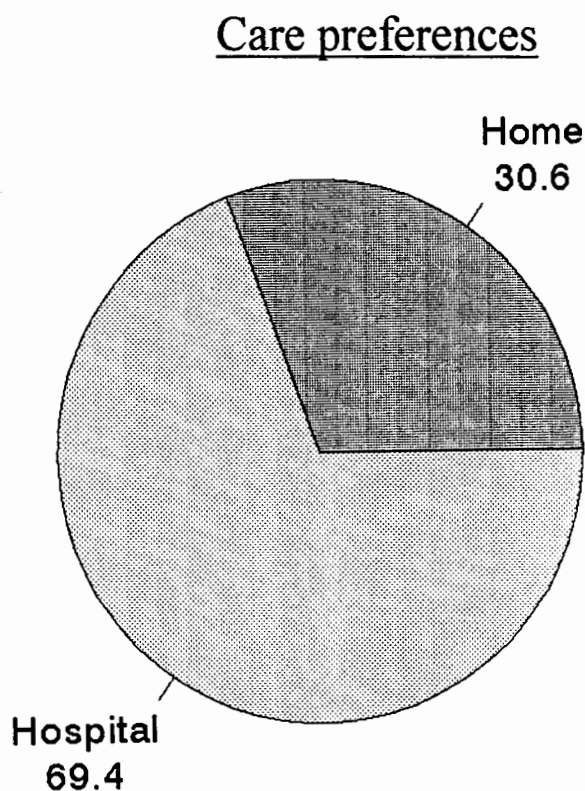


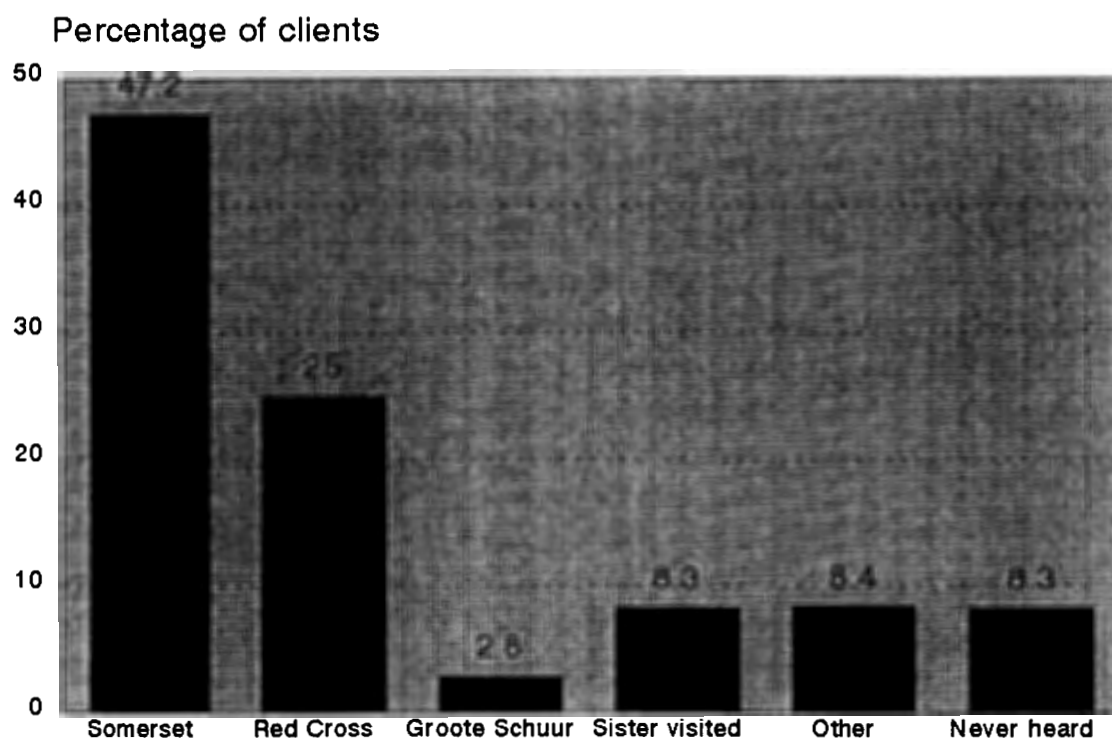
Figure 10: Care preferences

## Involvement with project

### **Referral to project**

Most respondents first heard about the Red Cross project while attending HIV/AIDS clinics. Almost half were told of the project at Somerset Hospital, and 25% at the Red Cross Children's Hospital. About eight percent said they first heard of the project when visited by the community sister, and 8,3% said they had never heard of the project.

### Where heard about the project



**Figure 11: Referral to project**

## Contact with project

This graph shows when respondents last had contact with the project, whether through a home visit, or at the Red Cross offices or hospital clinics. Nearly 40% of respondents said the last contact was over a month ago, and 19,4% said they had never had contact with the project. Some respondents did not want regular contact with the project: One saying:

I don't want her to come too much, people will start wondering why she is always coming.  
(Interview No. 10)

Others didn't want any contact at all:

They must go to the father of the child, not me. (Int 14)

### Last contact with project

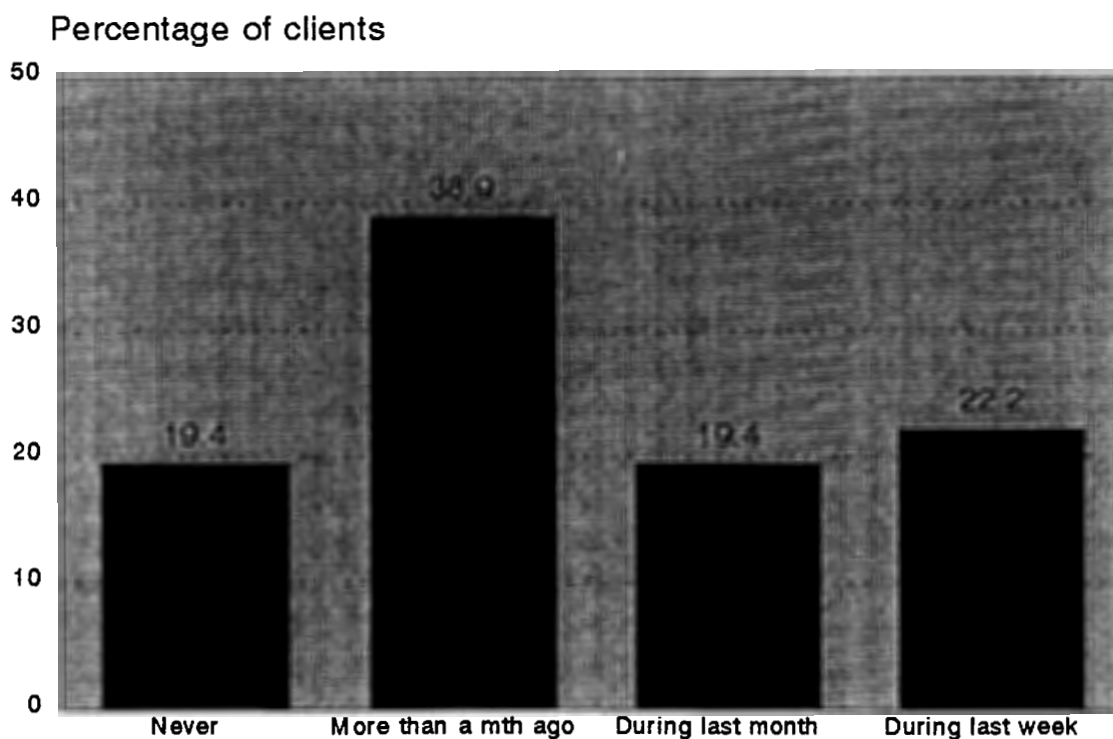


Figure 12: Contact with project

### Place of contact

Most of the respondents (63,9%) had had contact with the project staff through home visits. Again, 19,4% said they had never had any contact with the project.

### Place of contact

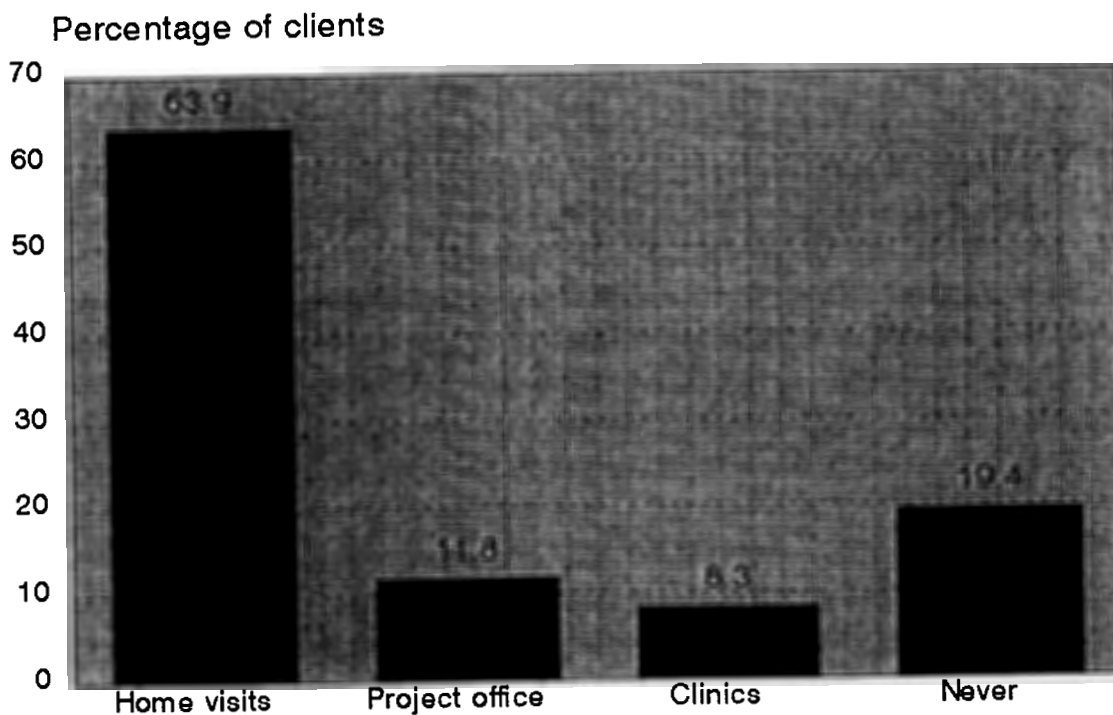


Figure 13: Place of contact

## Access to project

When asked if they were able to get hold of project staff when they needed them, 50% of the respondents said no, 11,7% said yes, they could phone the project; 28,7% said they could go to the offices; and 5,9% said they could see staff members at the clinic.

### How contact project

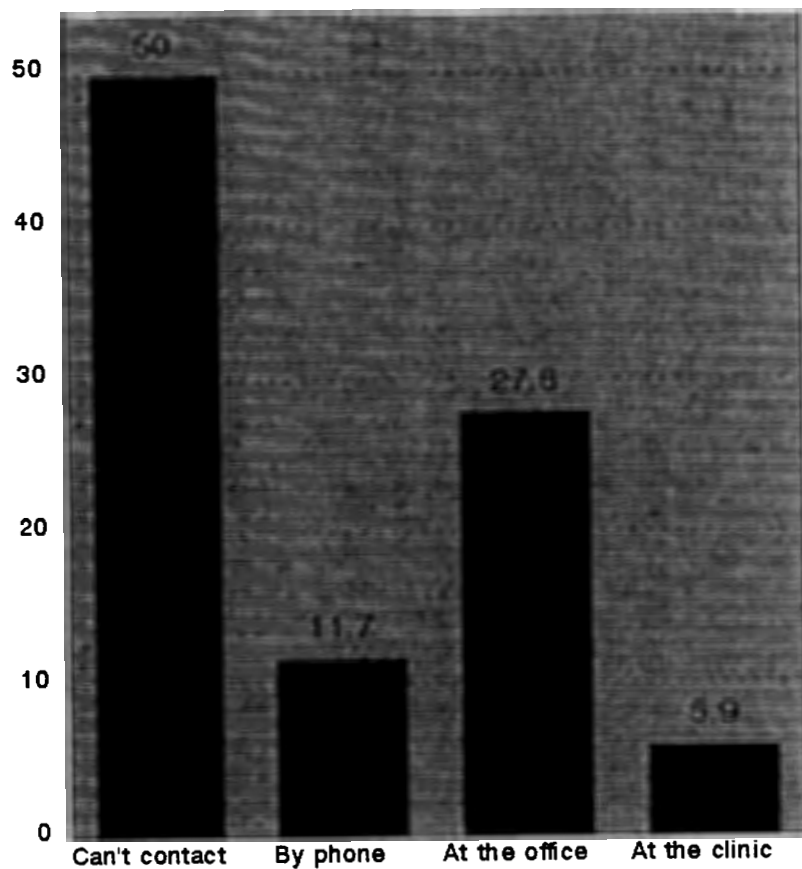
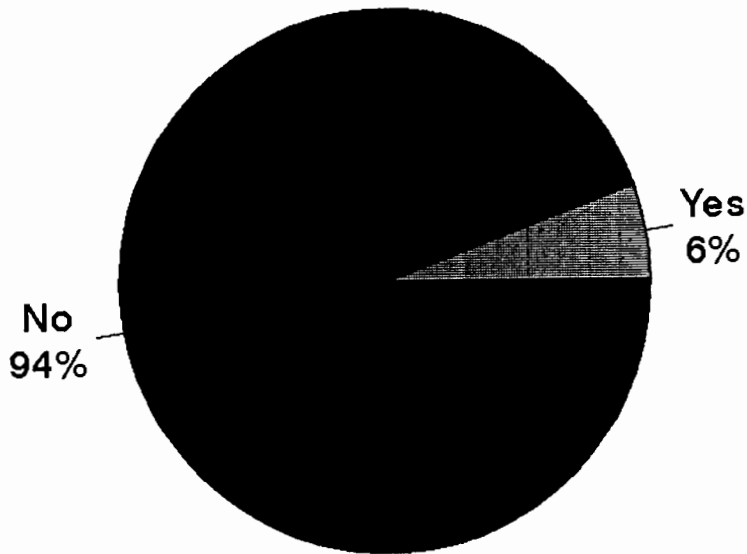


Figure 14: How contact project

**Contact with home-carers**

Only six percent of respondents reported having had any contact with home-carers.

Contact with home-carers



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**Figure 15: Contact with home-carers**

**Services received:**

Respondents who had had contact with the project (80,6%) were asked to describe what services they had received from the project during the last contact. The most frequently received services were checking on health, delivering food parcels, and checking babies.

### Services received during last visit

Service	Percentage of clients
health check	19.4%
food parcel	19.4%
check baby	19.4%
AIDS education	13.8%
disability grant	8.3%
counselling	5.5%
provided transport	5.5%
told about research	2.7%
I wasn't home	5.5%
I told her not to come again	2.7%

**Figure 16: Services received**

## Extent to which needs were met

The following tables were generated from questions designed to find out what needs respondents had and how far the project had gone towards meeting those needs. The middle column - "I needed help but did not receive it" - indicates unmet needs. The results are grouped according to material, home help, medical needs and psychosocial needs.

### **Material needs**

Although many respondents indicated having receiving material help (column 1), the second column shows that many needs had not been met.

## Material services received

Has the project helped you with any of these:	Yes, they helped me	I needed help but did not receive it	No, I did not need help
employment	6%	36%	58%
food parcels	56%	28%	16%
baby milk	30%	17%	53%
disability grant	17%	61%	22%
accommodation	0%	58%	42%
equipment at home	0%	47%	53%
financial	11%	69%	20%
transport to hospital	11%	53%	36%
drawing up a will	0%	67%	33%
making plans for your children	6%	75%	19%

**Figure 17: Material services**



## Home-help needs

Most respondents reported having little need for assistance such as receiving bed baths in the home.

## Home-help services received

Has the project helped you with any of these:	Yes, they helped me	I needed help but did not receive it	No, I did not need help
making meals or tea	6%	6%	88%
making meals for family	0%	3%	97%
bed baths	3%	0%	97%
tidying room	3%	3%	94%
tidying house	3%	0%	97%
washing or ironing	3%	3%	94%
shopping for you	0%	3%	97%
helping go to toilet	3%	0%	97%
washing soiled bed linen	3%	3%	94%

**Figure 18: Home-help services**

## Medical needs

Many medical needs, particularly relating to control of HIV-related symptoms, had not been met by the project.

### Medical services received

Has the project helped you with any of these:	Yes, they helped me	I needed help but did not receive it	No, I did not need help
relief from pain	6%	47%	47%
change dressings	0%	8%	92%
massage to prevent bed sores	0%	6%	94%
deciding when to go to hospital	14%	17%	69%
copng with symptoms	25%	39%	36%
advice about medicines	11%	50%	39%

N=36

---

**Figure 19: Medical services**

## Satisfaction with quality of service

The graph below indicates respondents' level of satisfaction with the quality of material, home help and medical services provided. Some comments received were:

I'm not satisfied, they give me a food parcel, but there is no paraffin to cook the food. (Int 1)

Nothing she promised ever materialised. (Int 9)

I do not get enough food. (Int 27)

The food parcels help because I can contribute to the household, it makes me feel more comfortable. (Int 20)

They have given me hope and help with food. (Int 13)

## Satisfaction with services

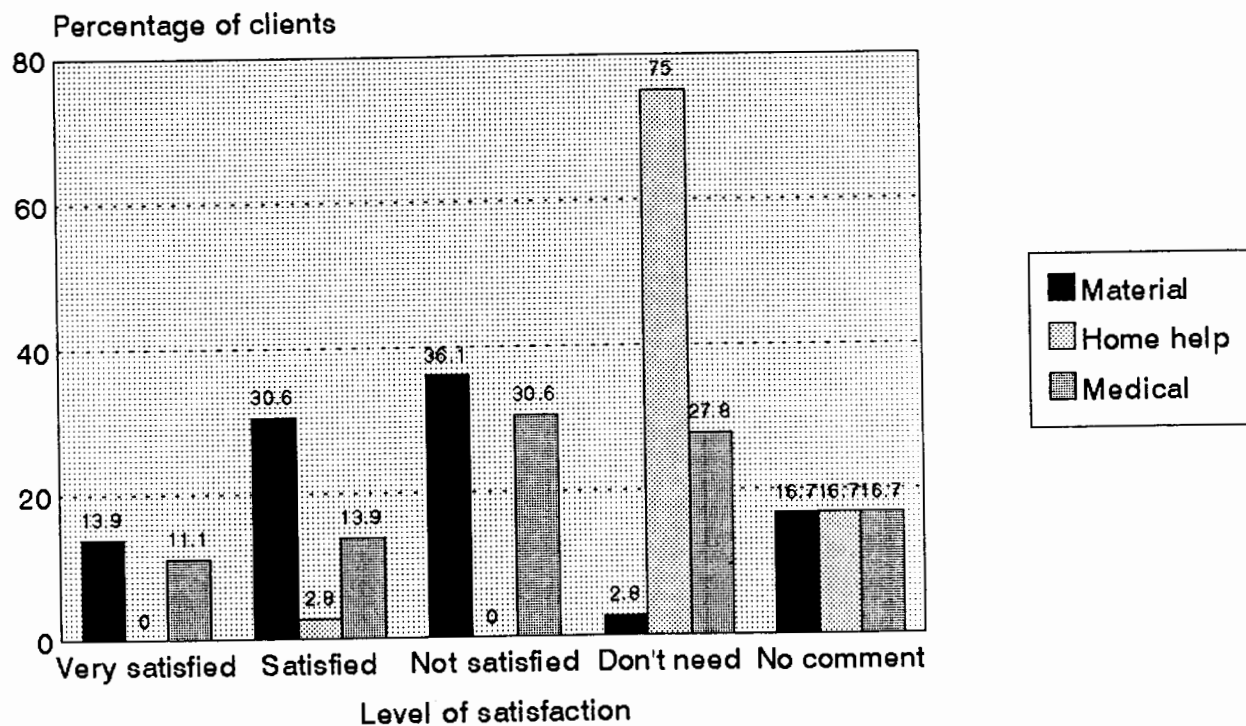


Figure 20: Satisfaction with services

## **Psychosocial needs**

Although many respondents did receive psychosocial help and counselling from the project staff, again, many unmet needs were reported. Respondents reported needing help preparing for possible death (66,7%); spiritual comfort (66,7%); wanting to talk about their problems (61,1%); having unanswered questions about HIV/AIDS (56%); and needing help accepting the diagnosis. One client said:

I don't think I am really HIV-positive. (Int 5)

The support group in Guguletu was singled out as being particularly important:

(Support group) lessens my worries because there are others in the same predicament. (Int 12)

(Support group) is very good, I get to meet with other people sharing the same problem ... it has made me feel less lonely, the advice and discussions with other HIV-positive people makes me feel happy to know that I am not alone. (Int 19)

Positive comments on psychosocial services included:

It has made me have hope, even in my darkest hour and helped me to live. (Int 12)

(Sister) made me feel strong about my whole situation by giving me emotional support, now my spirit is boosted, I have got less worries now. (Int 25)

However, many respondents said that there was no time to discuss their problems with the staff:

They have not spoken to me, they just give food parcels and go. (Int 4)

They examined the baby but we never talked about anything in particular. (Int 11)

I didn't know I could talk to them, I thought it was only a place I can come and get food. (Int 34)

## Psychosocial services received

Has the project helped you:	Yes, they helped me	I needed help but did not receive it	No, I did not need or want help
By answering questions about HIV/AIDS	19%	56%	25%
Tell family you are HIV positive	22%	17%	61%
Talk about problems/worries	11%	61.1%	27.7%
Resolve conflicts with friends/family	5.6%	27.8%	66.7%
Feel less lonely or isolated	38.9%	33.3%	27.8%
By introducing you to people with HIV	22.2%	30.6%	47.2%
Accept being HIV positive	38.9%	52.9%	8.3%
To prepare for death	22.2%	66.7%	11.1%
Get spiritual comfort	13.9%	66.7%	19.4%

N=36

---

**Figure 21: Psychosocial services**

### Most important services

Respondents were asked what services they appreciated most. Food parcels were by far the most appreciated service (69,4%), followed by counselling (13,8%) and baby care (11,1%). (Respondents were able to give more than one answer to this question.)

### Most appreciated services

Service	Percentage of clients
food parcels	69.4%
counselling	13.8%
baby care	11.1%
money for transport to hospital	8.3%
support group	8.3%
medical	8.3%
disability grant	8.3%
health education	8.3%

**Figure 22: Most appreciated services**

## Clients' assessment of services

When asked how they rated the project, the largest number of respondents (42%) said it was 'fairly good'. Comments included:

Project was very good, it helped to make peace in my home. (Int 3)

Project seems good, but I would like to know more about it. (Int 7)

I was not aware what the project was about, now I will ask for more. (Int 1)

Why do I never see them? (Int 35)

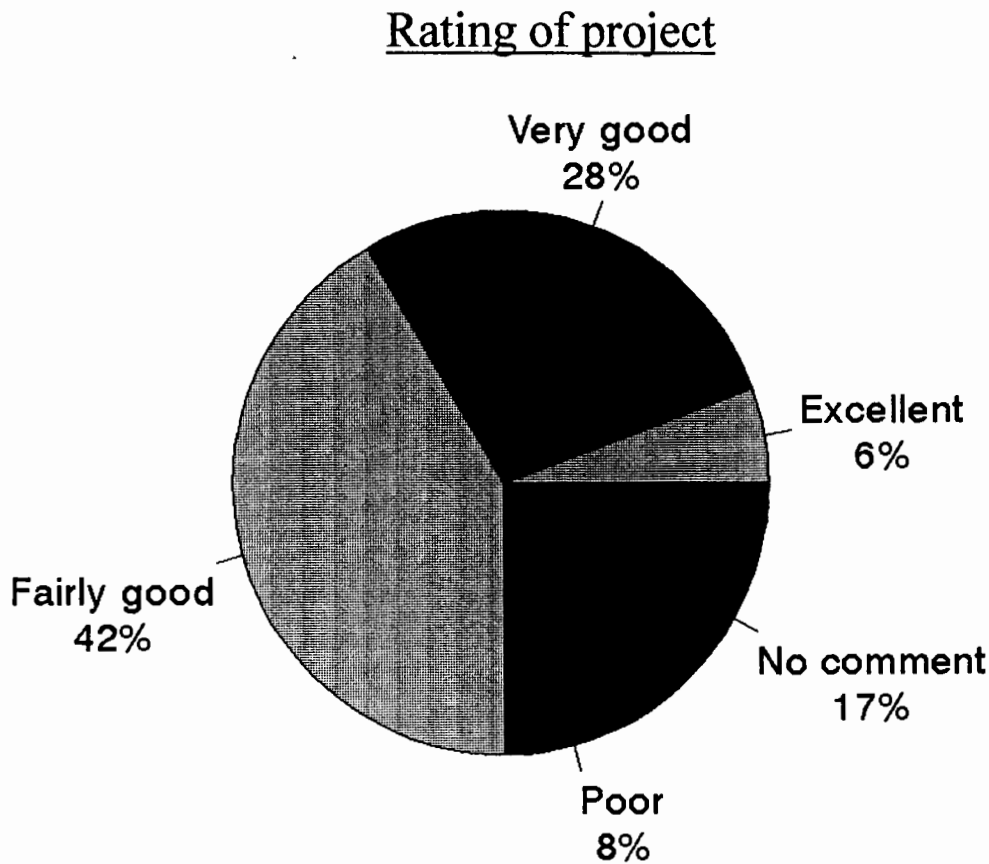
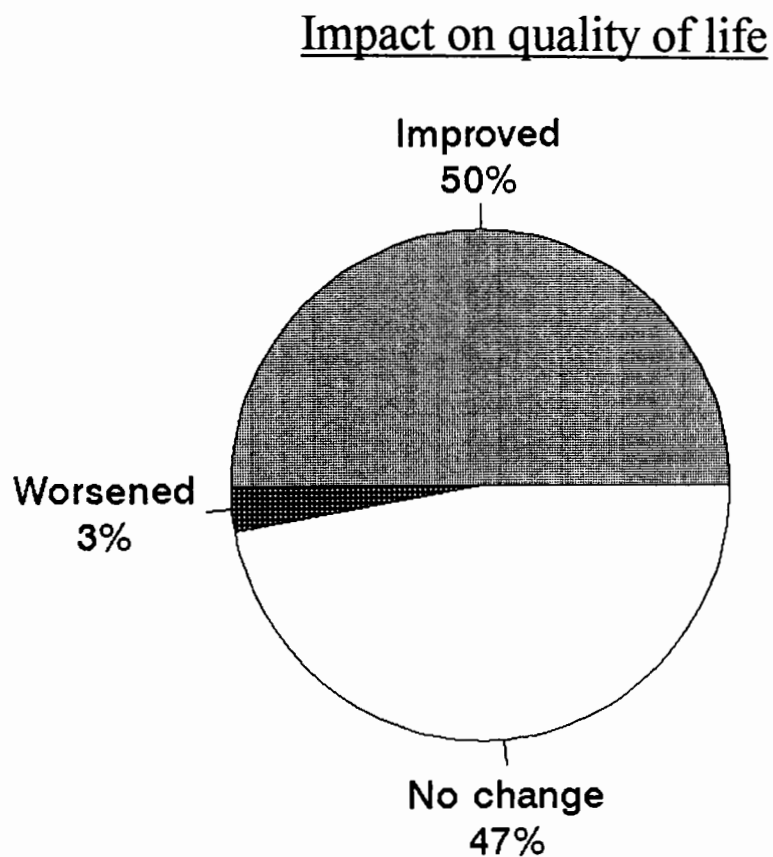


Figure 23: Rating of project

## Quality of life

Half the respondents said the project had improved their quality of life, and 47% reported no change.



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**Figure 24: Impact on quality of life**



## HIV/AIDS knowledge

### **Transmission of virus**

Most respondents knew how HIV could be transmitted, but many misconceptions around transmission remained. Over 25% thought HIV could be spread by hugging some one and 15,6% by sharing cutlery. Also, 30% were unaware that condoms could protect partners against the virus.

### Can the AIDS virus be transmitted:

QUESTION	YES	UNCERTAIN
By sharing cutlery with an HIV-positive person	17.6%	0%
From a mother to her unborn child	94.1%	0%
From a mosquito bite	29.4%	11.8%
By hugging an HIV-positive person	26.5%	2.9%
Through sexual intercourse	100%	0%
Blood entering through body cuts or sores	94.1%	2.9%
Sexual intercourse with a condom	38.2%	0%

**Figure 25: Transmission of virus**

## Household precautions

Only 11,8% of respondents said that bleach should be used to clean up body fluids from people with HIV. Some respondents (17,6%) said no special precautions should be taken, and 35,3% did not know what to do if body fluids were spilled in the home. One client said:

I must burn the cloth I use to clean it, so that no one gets infected. (Int 12)

### What can you do with split blood or body fluids?

ANSWER	PERCENTAGE
Use bleach to clean it up	11.8%
Use gloves	14.7%
HIV+ person must clean	11.8%
No special precautions	17.6%
Don't know	35.3%
Other	8.6%

**Figure 26: Household precautions**

## Safer sex

Despite most HIV/AIDS experts stressing that people with HIV should use condoms even when having sexual intercourse with other people with HIV to prevent the possibility of re-infection, with its devastating consequences for health, respondents seem to be unaware of this precaution. In reply to the question: "If both partners are HIV-positive, should they use a condom?", 41,7% of respondents said no. One client asked:

Why, if we are already infected, there is no need for us to use condoms? (Int 26)

Some respondents were unsure (16,7%), and 13,9% said a condom should be used to avoid pregnancy.

### Should you use condoms?

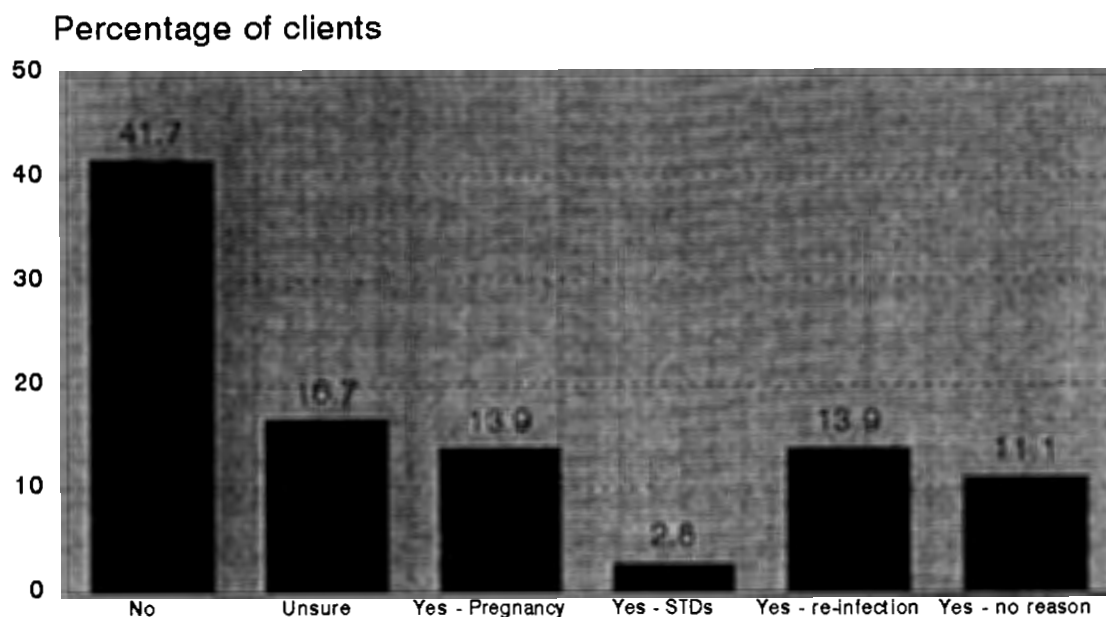


Figure 27: Safer sex

### HIV/AIDS knowledge index

The number of correct answers to the questions on HIV/AIDS knowledge were tallied. Very strict criteria were applied to the answers: A client was not noted to have answered correctly if s/he did not mention bleach or disinfectant for cleaning infected body fluids, or re-infection as a reason for using condoms when having sexual intercourse with a HIV-positive partner. The graph below shows the results. Again strict criteria for levels of knowledge were used. AIDS knowledge was considered excellent if all nine questions (two questions were excluded because of inconsistency between interviewers) were correctly answered (none), good if two incorrect answers were given (22,2%); poor if four incorrect answers were given (58,3) and very bad if less more than four answers were correct (19,5%).

Some comments indicated the lack of knowledge about HIV/AIDS:

I don't know enough about AIDS to ask questions, I need more education. (Int 10)

Can (HIV/AIDS) be cured? What happens if I go out of Cape Town? (Int 12)

### HIV/AIDS knowledge index

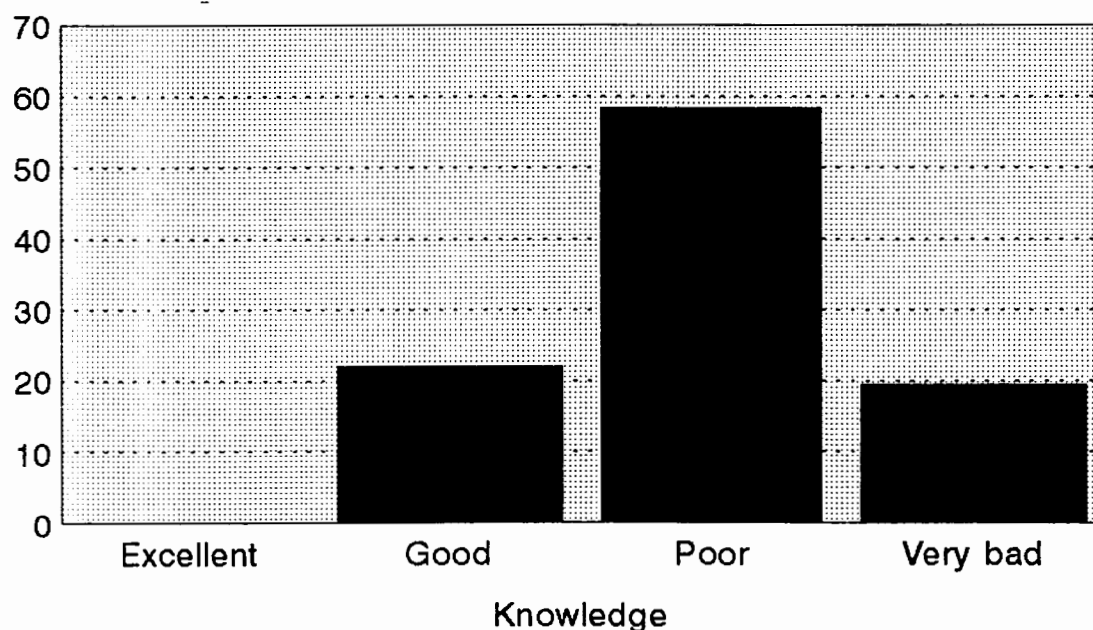


Figure 28: HIV/AIDS knowledge index

## ***Discussion***

### **Limitations of data**

There are three main limitations to the results presented above: The number of replacements necessary because field workers were unable to locate sampled clients; the exclusion of clients who died before being interviewed; and the subjective nature of some of the data received.

### **Uncontactable clients**

Attempts to trace sampled clients generated much sympathy for the task of the community sisters trying to visit clients. Field workers experienced enormous problems locating respondents, and seven replacements were necessary because clients were uncontactable at the given addresses, or the address could not be found. Also, many clients did not have stable homes and tended to move frequently, often not leaving a forwarding address. Some clients moved between urban and rural homes without notifying the project. The exclusion of the most difficult to contact clients in the sample is expected to over-represent the amount of contact with the project and the services received, because these were the clients that the community sisters were also unable to contact.

### **Ill clients**

The exclusion of three clients who died before being interviewed is expected to under-represent contact with home-carers and the needs of terminally ill clients, although discussions with project staff revealed that an average of two or three clients were receiving terminal home-care at any point in time, therefore not having a significant impact on results.

### **Nature of data**

The questions relating to satisfaction with services provided, rating of the project and impact on quality of life elicited subjective responses from clients. It can be expected that clients experiencing extremely difficult living conditions and facing a life-threatening illness may be

overly critical of all services provided. Also, as mentioned above, clients may under-represent their resources in the hope of receiving material help from the project. Other variables, most notable clients' HIV/AIDS knowledge, were able to provide a more objective assessment of the project's effectiveness.

## **Discussion of results**

### **Demographic profile: Who are the clients?**

At the initiation of the pilot project, it was agreed that it would be impossible to provide services to all people living with HIV/AIDS in the Cape Town region. The management committee decided to accept referrals based on two criteria:

- Healthy HIV-positive people who were in need of material or psychosocial services; and
- People with AIDS-related illness who required nursing at home.

The demographic profile of clients suggested that most clients met the first criterion. The project's clients were largely healthy people living with HIV from historically disadvantaged communities, which is in line with the primary health care principle of providing services where there is the greatest need. This also reflected the status of the epidemic in the Western Cape, where the number of people with AIDS-related illness is relatively low, indicating that material and psychosocial needs outweigh those for home-nursing.

### **Referral to project**

Most clients were referred to the project through HIV/AIDS clinics in state hospitals. However, the numerous comments expressing a desire for more information about the nature of the project suggested that the initial contracting process needed to be improved. Prospective clients should have been informed of what services were available and been able to discuss their own particular needs and preferences with project staff. This would also have avoided project staff wasting time on reluctant referrals, and would cut down on the number of incorrect and inadequate addresses supplied.

## **Provision of services**

### Contact with project

The results show that the project was not able to reach all clients, with nearly 40% of respondents not seeing project staff regularly, and nearly 20% saying they had not been involved with the project at all, despite being considered active by the staff. Some of the reasons for this have been touched on above - including the inaccessibility of many clients and the over-burdening of qualified nursing staff. It must also be recognised that not all clients wanted regular contact, some preferring to contact the project themselves when they needed something. This should be established when the clients is referred to the project, as discussed above.

### Unmet needs

The high percentages of unmet material, medical and psychosocial needs indicated that the project needed to improve the quantity and quality of services supplied to clients. Although food parcels were rated as the most important service and were supplied to over half the respondents, 36% reported needing food parcels and not receiving them. The researcher recognised that the project could not be expected to provide employment, accommodation and financial support to all clients, but felt that the type of support available needed to be clarified and supplied consistently to those in need. The description of medical needs indicated that more attention needed to be paid to health care, including helping clients cope with symptoms of HIV-related illness. Psychosocial needs had been identified by the project management committee as an area where people living with HIV/AIDS were particularly needy, and where the project could make a substantial contribution. Although the results indicated that many clients were helped, many psychosocial needs remained unmet.

### Home nursing

That so few respondents reported needing help at home suggested that this should not be a strong focus of the project's training and activities, although the need for these services was expected to increase in the future. But the feasibility of nursing bed-ridden clients at home had to be examined, since most clients lived in shacks which were often over-crowded. This was seen to have contradictory implications for home-nursing. The presence of other relatives at home meant that these relatives could be trained to look after the client when sick, but a lack of privacy in

shared bedrooms, together with few amenities at home, resulted in a preference for hospital care when very ill (almost 70%). These findings combined to suggest that many alternative services were needed, including:

- Training and support for family members
- Attendant home-nurses where family members were absent or could not cope
- Alternate housing such as hospices for those whose homes did not provide a comfortable environment
- Hospital services when intensive medical treatment was needed.

### **HIV/AIDS knowledge**

The assessment of respondents' HIV/AIDS knowledge countered some of the subjective criteria used to evaluate the services provided. The strict criteria applied to determine levels of knowledge were used because the questions tested a relatively low-level of AIDS knowledge in a group of people for whom this knowledge was crucial - those living with HIV and AIDS. The poor results can be seen as a measure of inadequate counselling at hospitals, as well as an indication that the project was not fulfilling its obligations to all clients. However, the project staff commented that many clients, despite having been educated about HIV/AIDS, either denied that they knew anything or failed to internalise this knowledge, because of the stigma of HIV/AIDS. Nevertheless, the results demonstrated that alternative counselling techniques needed to be developed to overcome these problems.

### **Quality of life**

Despite the problems mentioned above, half the respondents said the project had improved their quality of life. Because most respondents were from low socioeconomic groups, the provision of regular food parcels alone could significantly improve their well being. This demonstrated the potential for a substantial impact on quality of life, should the coverage of services provided be increased.



## ***Recommendations***

The results of the evaluation were disappointing for those involved with the project, since many clients reporting limited contact and dissatisfaction with services, coupled with the large number of unmet needs and poor AIDS knowledge. However, these results need to be seen in the context, not only of the difficulties that faced the project mentioned above, but also of a continuing tension within the project between trying to meet the needs of healthy clients and the demands of those dying of AIDS-related illness. The formative evaluation, as well as researcher observation during the second phase, suggested that the project had been effective in meeting the needs of terminally ill clients. Discussions with project staff indicated that caring for clients in their last few weeks of life had taken up considerable time: The project had organised clients' access to hospices, provided home-carers to nurse clients at home, responded to health crises and helped families during this difficult time - suggesting that caring for the minority of ill clients (an average of two or three) had consumed many of the project's resources.

The results suggest that, as the project was organised, it was unable to adequately attend to the needs of the growing number of healthy HIV-positive clients requiring a range of material, psychosocial and preventative health services, as well as care for those who were no longer able to look after themselves. Attempting to maintain the focus on both healthy and ill clients would require a substantial commitment from all those involved in the project to workshop, structure, implement and maintain the alternate ways of working suggested in the formative evaluation.

### **Reducing the focus**

One option available to the project was to limit referrals to people with AIDS-related illness who required services and support to allow them to die with dignity and in comfort. This was seen as an extremely important service which the project was well positioned to provide. Home-carers had been trained and were experienced in home nursing, project staff had good contacts with terminal care facilities and hospital clinics, and were themselves qualified nursing sisters geared towards providing this type of service. Although the number of clients requiring home nursing was limited at the time of the evaluation, this number was expected to increase substantially.

A decision to limit the focus to home nursing may have affected the project's fund-raising ability, since the priority of most funders lay in the provision of preventative or primary health care services. Nevertheless, this could be overcome by well-targeted funding proposals, given the National AIDS Convention of South Africa's recognition of the need for services to allow people to die in dignity. Also, limiting the focus would greatly reduce the costs of the project.

It was recognised that if the focus of the project was reduced, an alternate service to meet the material, psychosocial and preventative health needs of people living with HIV would be required in the region. This service could draw on the experiences of the Red Cross pilot project. Since most of the project's clients (61%) were mothers with HIV-positive babies, it was envisaged that the paediatric project described above would address many overlapping needs.

### **Maintaining a broad focus**

The researcher recommended that should the project reject this option and decide to maintain its broader focus on supplying a range of services to both healthy and symptomatic clients, it was crucial that the model of care be revised. The economic evaluation of the home-care project found that it cost the project R713 to care for one client for one month (Hardien, 1995). (This amount includes all clients considered active by the project staff, even though the evaluation showed that many of these were not receiving care). Given the health care crisis in the country and the limitations on donor and state funds, these costs were not justifiable in the light of the findings of the evaluation. The model suggested in the first phase of the evaluation, which should prove to be a more cost-effective and sustainable option, had not been fully implemented. The following steps were considered necessary to initiate that implementation:

### **Management**

Conflicting approaches by the project management committee, the regional Red Cross Society and decisions taken at a national level prevented the successful implementation of any chosen model. The project management committee had been given the responsibility for managing the project, without always having sufficient authority to implement decisions. The researcher recommended that lines of accountability be determined and a common model agreed upon after consultation with all involved. Once this had been done, the model required a commitment from

all levels of authority. Staff also needed to be given the resources and authority to implement decisions, and be released from other responsibilities.

### **Involving the home-carers**

The most crucial factor in improving the project's ability to extend the service and reduce costs was seen to be the passing of responsibility from community sisters to home-carers. The barriers preventing this needed to be explored and resolved. The experiences and approaches of the paediatric project, which was using home-carers to provide care under the supervision of the community sister, could be drawn upon to assist with this.

### **Referral to project**

The initial contact with clients was seen to be extremely important and it was suggested that a minimum requirement of this contact should be that clients came away knowing the name of the project and being aware of what the project could and could not offer. The project had produced a pamphlet explaining the nature of the service which was hoped to assist with this. It was recommended that the pamphlet be translated into Xhosa and Afrikaans and made available to prospective clients. It was also recommended that project staff obtain informed consent from clients as to their willingness to participate in the project and discussed their needs and preferences. If clients wanted to be visited at home, instructions as to how to get to their homes should be documented. Clients also needed to be told how to contact the project when necessary.

### ***Conclusion***

The Red Cross Home-care project had reached the end of its pilot phase and needed to make decisions about its future direction. This evaluation recommended that those involved in the project seriously consider the two suggested options:

1. To limit the aims of the project to providing services and support needed by people with AIDS who are unable to look after themselves. The particular services required - training the family to care for the client, providing home nursing, or helping clients gain access to other health services - were seen to depend on the particular needs of each client.

2. To maintain the broader focus of providing a range of services to both healthy and ill clients. Given the inability of the project to adequately play this role in the pilot phase, the researcher felt that a decision to maintain these objectives should be accompanied by a commitment to reorganise the model of care. The pivotal component of this reorganisation was passing the responsibility for the hands-on provision of services to home-carers. The recommended model suggested that the community sister in charge of each area organise and supervise home-carers' activities. This would allow the project to increase both the quantity and quality of services provided, as well as reducing the cost of caring for each client.

Despite the disappointing findings of the evaluation, the Red Cross home-care project deserved recognition for initiating and supporting this study - in sharp contrast to many projects that continued to use donor and state funding without exposing their work to external scrutiny. The project's willingness to undertake this exercise demonstrated their commitment to providing the best possible service to people living with HIV/AIDS.

## Chapter four: Conclusion

### *Understanding the project's response*

If the aims of this evaluation are seen only in terms of the Red Cross Home-care pilot project, then this work could be seen as a failure as the recommendations were not immediately incorporated by the project. Perhaps this can be understood by noting that one of the most conspicuous features of the evaluation was that it exposed the differences between project staff and management. The primary health care approach had the support of most members of the management committee, but was substantially different to the way the staff were used to working. The evaluation made it clear that the project's resources were being unfairly distributed between clients, with few clients receiving a high level of care and many clients receiving almost no care at all. The management committee were unaware of this before the evaluation, and the findings caused some friction within the project. The researcher tried to anticipate this, firstly by the recommendations of the formative evaluation and secondly by feeding some of the preliminary results of the secondary evaluation back to the management committee before the final report was presented. The management committee decided in principle that the model of care should be reorganised, but that reorganisation did not take place in practice.

In addition to the factors hampering the reorganisation of the project mentioned in the preceding chapters, this failure to change can be seen as partly due to resistance from project staff, who, despite sincere attempts to present the negative findings in a constructive manner, felt that their efforts were being undermined and that their way of working was under threat. This discussion is not meant to scapegoat the project staff, as throughout the evaluation it was clear that their commitment to their patients could not be questioned. They worked long hours and were prepared to go to extraordinary lengths to help patients in need. As mentioned earlier, the staff had been in the employ of the Red Cross Society, with its more charity-oriented style, for many years, and had been trained in the hierarchical environment of the formal health sector. They found it difficult to adapt to the challenge of primary health care and to hand responsibility over to home-care workers. They were also more comfortable working with ill patients in need of nursing care than healthy clients with overwhelming material needs. Thus they differed from the

management team with respect to their vision for the project, not their dedication to caring for PWA. The problems experienced by this project are therefore not inherent to the concept of home-care, but rather suggest that more careful consideration should be taken when initiating and staffing projects and deciding on their management structure.

### ***Benefits of research***

One obvious use of this research is its role in alerting potential funders to the problems experienced by the project so as to ensure that limited resources for the care of PWA can be directed to projects more able to provide appropriate and equitable care.

The research was also initiated in an attempt to answer some of the questions raised in the first chapter. Many of these questions remain unanswered, such as whether home-care will reduce the burden on the hospital services – although it has been suggested that this is feasible, if home-care projects undertake secondary prevention work, including the early detection of HIV-related illness during regular home visits. This type of work would reduce the need for costly drugs and intensive inpatient care. Also it was found that some questions – including whether PWA prefer to die at home or in hospital – did not have a simple answer. Yet the research has added to an understanding of the variables that need to be considered when planning services for terminal patients. Other information that should prove useful relates to the training of home-carers and the importance of counselling skills; the crucial role of the initial contracting process and the benefits of working with other community projects. These are only a few of the recommendations made in the preceding chapters, the rest of which will not be repeated here, that can be of use to future projects.

These recommendations have already been utilised by the pilot project for children with AIDS initiated by the UCT Child Health Unit. Some of the members of the Red Cross home-care project management committee are involved in the paediatric project, which has drawn on the experiences of the Red Cross project and largely followed the model suggested by this evaluation. The results of the evaluation were also presented at the *Second International Conference on Home and Community Care for persons living with HIV/AIDS* in Montreal in 1995, and have been distributed and discussed among HIV/AIDS workers in South Africa. The

evaluation has therefore assisted policy makers and community workers by adding to the knowledge and understanding of issues surrounding home-care for people with AIDS in South Africa. The research also provides an example of the role that professionals, including psychologists, can play in supporting and informing the work of community projects.

### *Difficulties for researcher*

On a more personal level, this study proved far more difficult than anticipated. Nothing brings the seriousness of the HIV epidemic home more clearly than meeting people whose lives have been devastated by AIDS. The memory of one particular client interviewed from his bed, struggling to breathe, wide-eyed with uncertainty as he spoke about death, will remain clear forever. At one stage the researcher dreaded speaking to the care co-ordinator, as she seemed to introduce all conversations with “(client) died yesterday”. Almost all of the clients interviewed in the formative evaluation are now dead. It was also distressing to speak to healthy HIV-positive men and women, knowing that they faced a similar fate. Interacting with HIV-positive children, some of whom seemed so invincibly healthy, others trembling with fever and pain, was the most difficult of all. It is also impossible to rely on the hope of a medical cure for AIDS for comfort, because it is clear to the researcher that such a cure will never reach many of the people interviewed for this study.

The reasons for prying into their personal lives were altruistic – the researcher hoped to be able to improve the type of care they (and others like them) received so as to make the rest of their lives as rewarding and comfortable as possible. Yet attempts to influence the project also seemed fruitless at times. Despite efforts to present the case for what the researcher had no doubt was a more effective model of care, many factors were operating beyond her control that prevented the utilisation of the recommendations. In frustration the researcher spoke to experienced evaluators, asking what could have been done differently, and was repeatedly told that it took time for the recommendations of evaluations to be accepted and incorporated by projects, but that inevitably the work would have an impact. The researcher took comfort from one particular story by a senior researcher at the Medical Research Council. He said that five years previously he had done an evaluation of one service offered by Groote Schuur Hospital and had recommended a somewhat radical change in the way it was organised. He was told that such a change was impossible. Then, a few days before the researcher spoke to him, he had heard a

Groote Schuur spokesperson on the radio talking about the changes in that service – in line with recommendations he had made five years previously. The researcher was reminded of this story when recently, almost 18 months after the evaluation was completed, she heard that the Red Cross project had decided to employ home-carers on a permanent basis.



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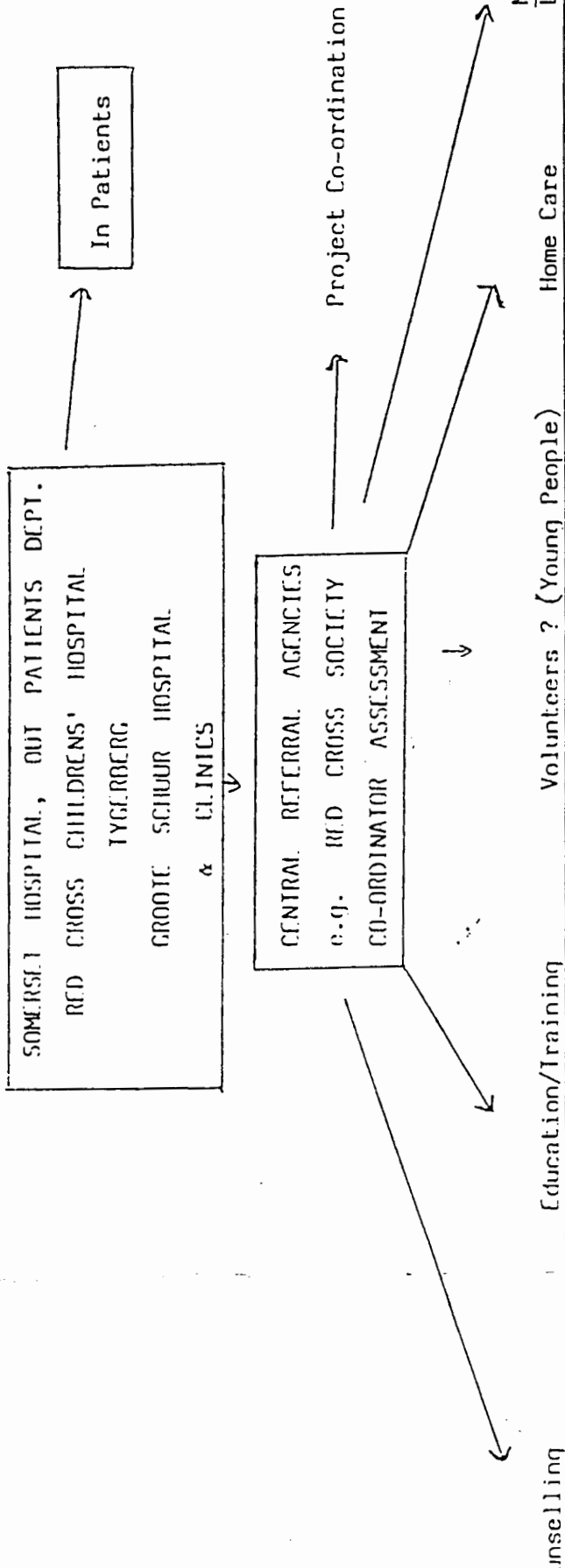
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## **Appendix A: List of Organisations**

AIDS CARE ASSOCIATION OF SOUTH AFRICA (ACASA);  
AIDS SUPPORT AND EDUCATION TRUST (ASET) HOME-CARE;  
ANC HEALTH DEPARTMENT;  
ANGLICAN CHURCH;  
AIDS TRAINING INFORMATION AND COUNSELLING CENTRE (ATICC);  
BODY POSITIVE;  
CATHOLIC WELFARE & DEVELOPMENT;  
CATHOLIC CHURCH;  
CHURCHES DEVELOPMENT INSTITUTE;  
CITY OF CAPE TOWN HEALTH DEPARTMENT;  
CONRADIE HOSPITAL;  
CPA HOSPITAL SERVICES;  
DAY HOSPITALS ORGANISATION – HOA and HOR;  
DEPARTMENT OF HEALTH AND WELFARE;  
GROOTE SCHUUR HOSPITAL;  
HOSPICE ASSOCIATION OF SOUTH AFRICA (HASA);  
HOTTENTOTS HOLLAND HIV SUPPORT CENTRE;  
IDASA;  
MEDICAL RESEARCH COUNCIL (MRC);  
PROGRESSIVE PRIMARY HEALTH CARE ORGANISATION (PPHC) AIDS  
PROGRAMME;  
RED CROSS CHILDRENS HOSPITAL;  
RED CROSS SOCIETY;  
REGIONAL SERVICES COUNCIL;  
SANTA;  
SCHOOL HEALTH SERVICES;  
SOMERSET HOSPITAL;  
ST.JOHNS AMBULANCE SERVICES;  
TB CARE COMMITTEE;  
VALKENBURG HOSPITAL;

Appendix B: Proposed model

RED CROSS SOCIETY (CAPE REGION) PROPOSED MODEL FOR HOME CARE USING AVAILABLE RESOURCES



- |                                            | Education/Training      | Volunteers ? (Young People)                              | Home Care                                   | Medical and Legal Work |
|--------------------------------------------|-------------------------|----------------------------------------------------------|---------------------------------------------|------------------------|
| Support Groups for Patients                | 1. Schools              | 1. Transport to Dr. etc.                                 | 1. Trained Home Visitors (First names only) | 1. Doctors             |
| Individual Counsel                         | 2. Clinic/Organisations | 2. Cook Meals                                            | 2. Basic Nursing                            | 2. Lawyers             |
| Monthly Social Groups                      | 3. Church Groups        | 3. Shopping for Patient                                  | 3. Buddy Support                            | 3. Dentists            |
| Family Support                             | 4. Volunteers           | 4. Food Parcels                                          | 4. Support to Family                        | 4. Social Workers      |
| Buddy Support                              | 5. Public               | 5. Collecting Food Donations and Distributing to Clients | 5. Safe Houses (Respite)                    | 5. Psychologists       |
| Volunteer & Staff Support Group            | 6. Training Home Carers |                                                          | 6. Hospices                                 |                        |
| Supervision of Home Care Counsellors       | 7. Patients & Families  |                                                          | 7. Fostering Care to Children               |                        |
| H.I.V. a symptomatic (Social Groups, etc.) |                         |                                                          | 8. Personal Care to Clients                 |                        |
|                                            |                         |                                                          | 9. Ethnic Counselling                       |                        |
|                                            |                         |                                                          | 10. Diet supervision                        |                        |
|                                            |                         |                                                          | 11. Case Management                         |                        |

## **Appendix C: Specific Objectives**

### **Project co-ordination**

- to establish and staff a unit to facilitate the provision of HBC
- to inform hospitals and medical practitioners about the programme
- to provide information on the project to people with AIDS
- to refer people where necessary to other service organisations
- to assign a patient-manager to each person referred to the HBC project
- to provide the resources (home-carers, medical equipment etc.) to make home-care possible
- to prevent any conflict arising between HBC and the health services in the management of a patient's care

### **Home-care**

- to assess the needs of patients entering the project
- to provide care meeting certain minimum requirements to each patient
- to visit HIV positive symptomatic clients
  - encourage them to apply for ID documents
  - build up relationships with the household
  - counselling to client and family
  - safe-sex info, infection control
  - pass on basic caring skills to family
  - 'quality of life' advice e.g. nutritional advice
  - refer the client to other resources when necessary
- to provide home-care to sick patients
  - nursing
  - basic counselling
  - domestic duties e.g. preparing meals
  - food parcels
  - disability grants
  - organising prescriptions for medication
  - pain relief (minimum requirement?)
  - response in crisis (minimum requirement?)
  - assessment as to when hospitalisation is required
  - referral when needs are beyond parameters of project e.g. legal
- to respect the confidentiality of the person
- bereavement counselling to family

### **Home-Carers**

- to assess the skills needed to be a home-carer
- to run workshops with the HCs trained in home nursing
- to recruit interested and competent HCs
- to provide appropriate training for HCs specific to the needs of AIDS patients, or to co-ordinate this training run by other organisations
- to alleviate home-carers' anxiety about HIV infection
- to provide support for HCs and refer them to other support structures
- to assess the relevance of the training programme and to provide for additional and ongoing training if necessary
- \* payment of HCs?

### **Community Liaison**

- to produce an extensive list of existing community resources, structures and networks that can be utilised by the HBC programme
- this should include the name, address and nature of service provided, as well as the name of a contact person.
- relevant organisations are: support groups for AIDS patients, counselling services, family support, buddy/befriender services, well HIV+ services, other home-care providers, volunteer and staff support groups, AIDS educators, etc.
- other resources required include available lawyers, doctors, social workers, dentists, psychologists, minister of religion, dietitians
- to inform other organisations of the HBC project
- referrals for orphans to develop and incorporate the Red Cross youth volunteer group, who will hopefully become self-coordinating
- to be on the look out for gaps in services available to those infected and affected by the HIV epidemic.

### **Promotion**

- to produce appropriate media so as to promote the project to potential clients funders and other stakeholders
- to make this media accessible to target constituencies
- to provide ongoing feedback on the progress and evaluation of the project



## **Appendix D: Job description**

### **FIELD OF WORK OF PROJECT CO-ORDINATOR**

**POST : HIV/AIDS REGIONAL CO-ORDINATOR**

#### **REPORTING RELATIONSHIPS:**

1. Regional co-ordinator reports to Regional Director and Red Cross Regional Council.
2. Two hospital based co-ordinators report to Regional Co-ordinator.
3. One community based networker links with 1 and 2 and ATICC.

**WORKING BASE; Red Cross Society (Cape) Regional Office.**

#### **SHORT SUMMARY OF THE JOB:**

1. Finance. Plan and manage finance. Investigate sources of financial assistance.
2. Design, implement and review the HIV/AIDS home-care project by means of a planned system of monitoring and evaluation.
3. Consult on N.A.P. policy in R.S.A. with both AIDS Unit and ANC .
4. Organise home-care and support for individuals, families and communities.
5. Promote Communication, collaboration and liaison with other NGO's and NAP's and WHO and other institutions dealing with HIV/AIDS .
6. Planning: Undertake short, medium and long term strategic planning in the multidisciplinary context for prevention and control of HIV/AIDS.
7. Plan and institute an information system for the project, with computerisation.
8. Devise and introduce preventive programmes in conjunction with other agencies e.g. counselling, health education, sex education, encouraging behavioural change.
9. Innovate with approaches and plans for implementation of the Project in diverse communities at individual and community level .
10. Practice advocacy, especially in respect of HIV/AIDS related discrimination.

Appendix E: Client questionnaire

h:hbc.doc

INTERVIEW SCHEDULE (for PWA)

Interview ID

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PLEASE ENTER THESE BEFORE INTERVIEW BEGINS

Respondent ID: PWA\_\_\_\_ Relative\_\_\_\_ Caregiver\_\_\_\_  
PWA & child\_\_\_\_

--

Interviewer: \_\_\_\_\_

--

Number: \_\_\_\_\_

--	--	--

Residential suburb: \_\_\_\_\_


Sex: Male\_\_\_\_ Female\_\_\_\_

--

Race: W\_\_\_\_ C\_\_\_\_ A\_\_\_\_ B\_\_\_\_

--

Stage of illness: \_\_\_\_\_

--

Date of referral: \_\_\_\_\_

d	d	m
m	y	y

Receiving home-care: Y\_\_\_\_ N\_\_\_\_

--

Support group: Y\_\_\_\_ N\_\_\_\_

--

Comments: \_\_\_\_\_

--	--

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I am going to ask you a few questions about yourself and about the Red Cross Home Care Project. Your answers are important because they will help us improve the service. Your answers are confidential and only the researchers will see them. (You may need to explain what the Red Cross Project is.)

1. How old are you?

\_\_\_\_\_ 

25	

2. What kind of work do you do?

\_\_\_\_\_  
\_\_\_\_\_

- formally employed
- casually employed
- self employed
- pensioner
- unemployed

v) Other (specify) \_\_\_\_\_

**ILLNESS DETAILS**

3. When did you find out you were HIV+?

Date (approx month and year) \_\_\_\_\_

d	d	m
m	y	y

4. In the last four weeks, has ill health hampered you from working or carrying out strenuous activities such as moving furniture or playing sport?

- Yes
- No

If yes, how much has your health interfered?

- i) You could not do it at all
- ii) You could do it, but you needed a lot of help
- iii) You could do it, but you needed a little help
- iv) You could do it on your own, but it was more difficult than usual

35

v) Other (specify) \_\_\_\_\_

5. In the last four weeks, has ill health hampered you from doing moderate activities such as lifting groceries, climbing stairs, or getting around (walking, catching public transport, driving)?

Yes   
No

36

If yes, how much has your health interfered?

- i) You could not do it at all
- ii) You could do it, but you needed a lot of help
- iii) You could do it, but you needed a little help
- iv) You could do it on your own, but it was more difficult than usual
- v) Other (specify) \_\_\_\_\_

6. In the last four weeks, has ill health hampered you from bathing or dressing yourself, or getting out of bed?

Yes   
No

If yes, how much has your health interfered?

- i) You could not do it at all
- ii) You could do it, but you needed a lot of help
- iii) You could do it, but you needed a little help
- iv) You could do it on your own, but it was more difficult than usual
- v) Other (specify) \_\_\_\_\_

7. When you are sick, where do you prefer to be cared for?

40

8. Why? \_\_\_\_\_

9. Under what circumstances (at what times in your illness) would you prefer to be cared for in hospital?

44

10. Under what circumstances would you prefer to be cared for at home?

\_\_\_\_\_

\_\_\_\_\_

45

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11. Do you have a baby who is HIV+?

Yes

No

--

12. If yes, how old is the baby?

m	m
---	---

 49

13. When did you find out the baby was HIV+? (approximate month and year)

--	--	--	--

d	d	m
m	y	y

 50

14. How would you describe your child's health?

\_\_\_\_\_

\_\_\_\_\_

--

**INVOLVEMENT WITH PROJECT**

15. When did you hear about RX project? (approximate month, year)

--	--	--	--

m	m
y	y

 60

16. Where were you told:

- i) Somerset Hospital
- ii) Red Cross children's hospital
- iii) Groote Schuur
- iv) Private GP
- v) Clinic (specify which)

--

 61

vi) AIDS service organisation (eg Gasa) (please specify)

vii) Other (please specify)

\_\_\_\_\_

\_\_\_\_\_

17. How did you get in touch with the project?

5

18. When was this (approx date)

--	--	--	--

m	m
y	y

19. Do the RX nurses (Sister Colleen Jacobs, Sister Harriet Mayaba, Sister Boniswa Mogale) (names for information only - do not need to specify) visit you in your home?

Yes

No

20. If yes, how often?

21. If no, where do you see them?

How often?

22. When was the last time you saw her?

23. What did you talk about/what did she do for you that time?

--	--	--

24. Do you/would you prefer to see her in your home?

Yes

No

Why/Why not?

--	--

Card Number:

	1	2	6

25. Are you able to get hold of the nurse when you need her?

Yes   
No

How do you contact the nurse?

---

26. Have you had contact with any of the RX home-carers (eg Lumke, Signoria, Murial, Dorothy (names for information only - do not need to specify)?

Yes   
No

If yes, how often do you see her?

---

When was the last time you saw her?

---

What did you talk about/what did she do for you that time?

---

---

---

	8		10

27. What are the most important things that the Red Cross project does for you?

---

---

---

			13

28. Was the RX helped you with any of these things:  
(Y=1 N=2 Not needed=3)

Material:

- employment
- food
- baby milk/formula
- disability grants
- accommodation
- equipment at home (eg mattress, catheter)
- financial
- transport to the hospital
- drawing up a will
- making plans for your children

14

17

20

23

How satisfied are with what the nurse/carer did for you in this regard?

Home help:

(Y=1 N=2 Not needed=3)

- making you meals/tea
- making meals for other people in the home
- giving you a bed bath
- tidying your room
- tidying the rest of the house
- Doing the washing or ironing
- shopping for you
- helping you go to the toilet
- washing soiled bed linen

25

28

31

34

How satisfied are with what the nurse/carer did for you in this regard?

---



---



---



Medical:

(Y=1      N=2      Not needed=3)

- Relief from pain
- changing dressings on wounds
- massage you to prevent bed sores
- deciding when to go to hospital
- help you cope with symptoms
- advice about medicines
- other (specify)

	35
	38
	41

How satisfied are with what the nurse/carer did for you in this regard?

29. Has the RX project helped with answering your questions about HIV and AIDS?

Yes

No

If yes, give an example

 44

Are you happy with the way they answered it?

Yes

No

If no, do you have any questions you need answering?

 46

30. Has the RX project helped you to tell your family/friends about your HIV-infection?

Yes

47

No

If yes, who were you able to tell?

How did the RX help you with this?

Are you happy with the help they gave you?

Yes

50

No

If no, have you told your close family/friends about your HIV-infection?

Yes

No

31. Have you been able to talk to the project staff about your problems - the things that are worrying you?

Yes

No

If yes, give an example

53

Were they able to help you resolve this?

Yes

No

If no, do you have any problems you would like to talk to someone about?

Yes

55

No

32. Has the RX project helped with resolving (conflict) problems with your friends and family?

Yes

No

56

If yes, give an example

---

---

---

If no, is there any conflict with your family/friends?

Yes

No

33. Have the project staff helped you to feel less lonely or isolated?

Yes

No

59

If yes, in what way did they help?

---

---

If no, do you feel lonely or isolated?

Yes

No

34. Has the project ever put you in contact with other people living with HIV or AIDS?

Yes

No

62

If yes, do you meet these people regularly?

Yes

No

Do you find this helpful, why/not?

---

---

---

If no, would you like to meet other people living with HIV or AIDS?

Yes

No

65

35. Have the project staff helped you to accept (come to terms with) your HIV-status?

Yes

66

No

If yes, in what way did they help?

---

---

If no, how do you think they could help?

---

---

36. Have they helped you to prepare for the possibility that you may die?

Yes

69

No

If yes, in what way did they help?

---

---

---

If no, how do you think they could help?

---

---

37. Have the project staff helped you get spiritual (religious) comfort?

Yes

72

No

If yes, in what way did they help?

---

---

---

If no, how do you think they could help?

---

---

---

74

Interview ID

1	2	12

38. If you have a child who is HIV+, has the Red Cross project helped you care for your child in any way?

Yes

No

3		

If yes, how?

---



---

		6

39. Has the project helped you in any other way? Please tell me about it.

---



---



---

		C

40. Have you ever asked the project staff for something they could not help you with?

Yes

No


If yes, what?

---


41. Have you had any bad experiences with the project?

Yes

No

	12

If yes, what?

---

	13

42. How do you rate the service:

Excellent

Very good

Fairly good

Poor

14

43. What parts of the service have been the most useful for you?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

15

44. How do you think the project has affected your life?

\_\_\_\_\_

45. Would you recommend the service to other people with HIV/AIDS

Yes

No

20

46. Do you have any other comments about the project?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

21

The next few questions are about HIV and AIDS:

47. Do you think people can contract the virus that causes AIDS in the following ways: (answer each one)

a) By sharing knives, forks and plates with some one who has the AIDS virus? Yes \_\_\_ No \_\_\_ Unsure \_\_\_

22

b) From a mother who has the virus to her unborn baby? Yes \_\_\_ No \_\_\_ Unsure \_\_\_

c) From a mosquito bite when the mosquito has bitten some one who has the virus? Yes \_\_\_ No \_\_\_ Unsure \_\_\_

d) By hugging some one who has the virus? Yes \_\_\_ No \_\_\_ Unsure \_\_\_

48. What can you do if blood or other body fluids spill in your home?

27

49. Can the HIV-virus be transmitted in the following ways? (answer each one)

a) Through donating blood? Yes \_\_\_ No \_\_\_ Unsure \_\_\_

b) Through sexual intercourse? Yes \_\_\_ No \_\_\_ Unsure \_\_\_

29

c) Through an injection from the doctor? Yes \_\_\_ No \_\_\_ Unsure \_\_\_

d) If blood enters your body through cuts or sores? Yes \_\_\_ No \_\_\_ Unsure \_\_\_

e) Through sexual intercourse using a condom? Yes \_\_\_ No \_\_\_ Unsure \_\_\_

50. If both partners are HIV+, do you think they should still use a condom with each other?

Yes \_\_\_ No \_\_\_ Unsure \_\_\_

33

52. How many children do you have

34

--	--

53. What kind of home do you live in?

- House
- Flat
- Shack
- Hostel
- Shelter
- Hospice
- Other (specify)

36

--

54. Who do you live with?

---



---

- Alone
- Your partner/spouse
- Your partner/spouse and children
- Other relatives
- Friends
- Strangers
- Other

--

55. How many people (other than you) share your bedroom?

Adults \_\_\_\_\_ (number)

Children \_\_\_\_\_ (number)

38


56. Are there any adults (other than you) at home during the day?

- Yes
- No

42

--





64. Do you receive a disability grant because of HIV/AIDS?

Yes

No

62

17

65. Do you attend an HIV/AIDS clinic?

Yes

No

66. How often do you go?

---

67. How long do spend there per visit (in hours)?

---

66

## **Appendix F: Transcription conventions**

Quotes used in the results sections of the formative evaluation are identified as coming from interviews with clients (C1-12); home-carers (H1-7); staff members (S1-3); committee members (M1-7) or 'outsiders' (O1-12)

- ... material omitted
- () words inserted
- [] original Afrikaans

## Appendix G: Codes for interview schedule

### PWA interview schedule: codes

#### Descriptive info:

Respondent ID: 1 = FWA. 2 = FWA & Child 3 = Relative

Interviewer: 1 = Mabusela; 2 = Makuala; 3 = Soal

#### Suburb:

1 = Guguletu  
2 = Khayelitsha  
3 = phillipi  
4 = nyanga  
5 = new crossroads

#### Comments:

A = looks ill  
B = looks well  
C = confused  
D = inadequate housing  
E = reluctant to talk  
F = emotionally upset during interview

#### Questions:

2. 1 = Formally employed:  
2 = Casually employed  
3 = Self employed  
4 = Pensioner  
5 = unemployed

4. 1 = can do  
2 = cant't do at all  
3 = need lot help  
4 = need little help  
5 = more difficult

5. 1 = can do  
2 = cant't do at all  
3 = need lot help  
4 = need little help  
5 = more difficult

6. 1 = can do  
2 = cant't do at all  
3 = need lot help  
4 = need little help  
5 = more difficult

7. 1 = Home  
2 = Hospital

8. A = family don't know  
B = want best care - looked after by professionals

C = problems with family  
D = no-one to look after me at home  
E = get good treatment at home  
F = home is overcrowded  
G = want to be with family  
H = need to look after children  
I = don't like hospital  
J = no where to stay  
K = for privacy  
L = stigma, people will know if nurse visits me  
M = nurses (in hospital) not provide good care

9. A = very ill  
B = can't look after self  
C = when family can't cope  
D = none
10. A = never  
B = while can look after self  
C = while not very ill  
D = always  
E = while family can manage
14. 1 = well  
2 = sick  
3 = better  
4 = dead
15. x = never
16. 1 = Somerset  
2 = REd Cross  
3 = Groote schuur  
4 = GP  
5 = clinic  
6 = Gasa  
7 = visited by sister  
8 = never told  
9 = Conradie hospital  
A = Victoria hospital  
X = no where
17. 1 = visited  
2 = never seen  
3 = introduced at clinic  
4 = referral letter to uluntu/sister
20. 1 = weekly  
2 = fortnightly  
3 = never  
4 = new referral, come once  
5 = monthly  
6 = less than monthly  
7 = more than weekly

- 21 1 = at clinic  
2 = in office  
3 = haven't seen them
- 1 = weekly  
2 = fortnightly  
3 = never  
4 = every second month
- 22 1 = during last week  
2 = during last month  
3 = more than a month ago  
4 = never
- 23 A = check on health  
B = food parcel  
C = check baby  
D = disability grant  
E = counselling  
F = safe sex info  
G = Aids info  
H = I wasn't home  
I = made me tea  
J = told about research  
K = i asked her not to come again  
L = told to come to uluntu
- 24 Y = Yes  
N = No  
W = Yes. but not too often
- 1 = family don't know  
2 = convenience  
3 = no reason given  
4 = not provide what promise  
5 = not want to be bothered  
6 = no transport cost  
7 = people would get suspicious  
8 = need help  
9 = too ill to go out  
A = more confidential  
B = I don't want contact with the project
25. 1 = phone  
2 = go to office  
3 = at clinic
26. 1 = weekly  
2 = fortnightly  
3 = daily  
4 = randomly
- 1 = during last week

2 = during last month  
3 = more than a month ago  
4 = never

1 = check on health  
2 = food parcel  
3 = check baby  
4 = talk about HIV/Aids

27. A = foodparcels/ baby milk  
B = support group  
C = medical  
D = baby care  
E = counselling  
F = health education  
G = money for transport to hospital  
H = Aids info  
I = disability grant

28. (for all)  
1 = yes  
2 = no, but would like  
3 = don't need

1 = very satisfied  
2 = satisfied  
3 = not satisfied  
4 = didn't know could get  
5 = don't need  
6 = glad to be left alone  
7 = no comment, not been helped  
8 = was satisfied, but she has stopped coming

29. 1 = did help, satisfied, appropriate example given  
2 = did help, satisfied, can't think of example  
3 = don't have questions  
4 = have questions, didn't help  
5 = don't want to talk about disease

30. 1 = did help, am satisfied  
2 = did help, not satisfied  
3 = didn't help, don't want people to know  
4 = didn't help, people know  
5 = didn't help, people don't know

31. 1 = talked, help resolve, appropriate example given  
2 = talked, help resolve, can't think of example  
3 = talked, but haven't been able to help  
4 = haven't talked, got problems  
5 = haven't talked, no problems  
6 = don't want to talk about problems

32. 1 = helped, example given

- 2 = helped, no example
  - 3 = not helped, no conflict
  - 4 = not helped, conflict
33. 1 = helped, by visiting  
2 = helped, no example  
3 = not helped, not lonely  
4 = not helped, lonely  
5 = helped, support group
34. 1 = helped, meet regularly  
2 = helped, not meet regularly  
3 = not helped, not want to meet  
4 = not helped, want to meet  
5 = meet but not really help  
6 = offered it but never happened
35. 1 = helped, by talking  
2 = not helped, not need  
3 = not helped, would like counselling  
4 = not helped, would like to meet other PWAs  
5 = not helped, need medical confirmation  
6 = not helped, don't want to talk about HIV
36. 1 = helped, by counselling  
2 = helped, by practical arrangements  
3 = not helped, not need  
4 = not helped, would like counselling  
5 = not helped, would like practical assistance  
6 = helped, by explaining course of disease
37. 1 = helped, by counselling  
2 = helped, by practical arrangements  
3 = not helped, not need  
4 = not helped, would like spiritual support  
5 = not helped, would like practical assistance  
6 = helped by encouraging me to go to church
38. 1 = no baby  
2 = have baby, helped materially  
3 = have baby, helped medically  
4 = have baby, helped counselling/spiritual  
5 = have baby, not helped
39. 0 = No  
1 = given bed clothes
40. 1 = yes. Assistance with welfare benefits
41. 1 = Not providing what promised  
2 = milk supply not consistent
42. 1 = Excellent  
2 = Very good



3 = fairly good  
4 = poor  
5 = no comment, never seen

43. A = food parcels  
B = disability grants  
C = counselling  
D = medical  
E = support groups  
F = other material help  
G = home nursing  
H = none  
I = transport  
J = employment  
H = baby care  
i = not sure  
J = visits

44. A = made life easier materially  
B = made life easier emotionally  
C = a nuisance  
D = made life worse  
E = no change

45. Y = yes  
N = no  
U = unsure

46. 0 = no comment  
1 = positive comment  
2 = nurse not approachable  
3 = would like to know more about project  
4 = food parcels very small, need more

47. 1 = right  
2 = wrong  
3 = don't know

48. 1 = clean-up  
2 = use disinfectant  
3 = don't know  
4 = use gloves  
5 = HIV+ person to clean  
6 = musn't touch them  
7 = burn the cloth you use to clean it

49. 1 = right  
2 = wrong

50. 1 = right, pregnancy  
2 = right, infection  
3 = right, no reason  
4 = wrong  
5 = don't know  
6 = right, to avoid other STDs

53. 1 = house  
2 = flat  
3 = shack  
4 = hostel  
5 = shelter  
6 = hospice
54. 1 = alone  
2 = partner  
3 = partner & children  
4 = relatives  
5 = friends  
6 = strangers  
7 = alone with children
60. A = 0  
B = R1 - R500  
C = R501 - R1000  
D = R1001 - R3000  
E = over R3000  
F = don't know
61. A = 0  
B = R1 - R500  
C = R501 - R1000  
D = R1001 - R3000  
E = over R3000
63. 1 = no jobs  
2 = illness  
3 = childrearing/housework  
4 = child illness  
5 = student  
6 = retired
64. Y = Yes  
N = No  
W = waiting
66. 1 = one a week  
2 = one a fortnight  
3 = once a month  
4 = once every 3 months  
5 = less often than above  
6 = when sick  
7 = once every 2 months