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## Understanding HIV/AIDS through the dark lens of poverty

### ABSTRACT

The article highlights a process followed to bridge the gap of alienation between the church and the AIDS community in a very poor urban area of Lilongwe, Malawi. The research illuminated the fact that although it can be done, in so doing, discoveries were made regarding other essential, but unanticipated factors. Disillusionment came when the pious idea of church volunteers reaching out to assist their neighbours in need, revealed the true source of their motives, compounded by the reality and impact of abject poverty.

### INTRODUCTION

This article is based on a D Th dissertation,<sup>1</sup> which aimed to ascertain, in a practical theological way, how to bridge the gulf between the congregation, and the AIDS community using home based care as the vehicle of change. The initial hypotheses of the research were based upon a model initially developed by World Vision in Nkhotakota, Malawi.

The research initially asked the following questions:

1. Can the negative attitudes, prejudices and behaviours which are held and demonstrated by many in the church towards those suffering with HIV/AIDS, be changed by using deliberate attempts to alter their perspective of this pandemic by providing accurate information, in juxtaposition with the demonstration of Christ's love and compassion to this community?
2. In conjunction to this first question comes a second: Can the compassionate outreach of the church, as it follows Christ's mandate to love, change the perspective of those in the HIV/AIDS community so that instead of viewing the church (as a whole) as cold and unloving, their perception will change with the demonstration of such love and compassion by its membership that they begin to see the church as a source of hope and love?

One of the fundamental assumptions involved in this research concerned the approach of using the church as the foundation of the work. By keeping the focus on the church and the work coming through the church, the potential for a continuing, viable programme that the people involved could take ownership of emerged. Research has shown (Dudley 1996:115) that churches who worked to develop ministries that were consistent with aspects of their own history, vision and mission, instead of seeking new programmes which were very different and foreign to their

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<sup>1</sup> Janet Brown. HIV/AIDS alienation: between prejudice and acceptance. Unpublished D Th dissertation, Stellenbosch University. 2004.

already accepted procedures tended to have less radical and more predictable and satisfying outcomes.

In this article we will outline the research process, the results of the questionnaire measuring the attitudes of the church people and the AIDS community before the Home Based Care (HBC) was introduced and the result of the questionnaire one year later indicating to what extent attitudes changed. The praxis methodology of the research also produced unanticipated findings that changed basic assumptions held by the researchers. These will also be discussed.

## THE RESEARCH PROCESS

### **Home base: African Bible College.**

The research was done with the help of students from African Bible College (ABC) in Lilongwe, Malawi, acting as field workers under the guidance of Janet Brown in conjunction with Partners in Hope, a department of the ABC Community Clinic. Partners in Hope's mission involves reaching out to those suffering with HIV/AIDS in Lilongwe.

Initially, the project used ABC students participating in the HBC (pastoral care visits) outreach as an activity designed to meet the students' scholastic practical application requirement. In these initial meetings, the vision was eventually expanded to include a medical component. With the proper funding, it was hoped that a full department of medical home care would be developed in conjunction with the ABC Community Clinic (ABCCC). This will include the use of registered nurses and other medical staff who will work to meet the physical and spiritual needs of those suffering with illnesses that confine them to their homes.

Funding for the research project was obtained from the USA. However, it became apparent that it was essential for this to be a programme designed with a commitment to *empower the local church* as opposed to one that would be a source of gifts and supplies to be given to the churches. With this as a priority, it was therefore determined that the programme must be developed in order to avoid donor dependency, enabling it to be fully "owned" by the local church, with only training and facilitation provided by an outside source.

### **Village permission**

In order for the project to proceed in a harmonious way, it was deemed necessary to obtain the permission and blessing of the Mtsiliza Village chief. It was determined that the best approach would be to avoid any obvious connection with the ABC in an attempt to minimise the concept that this programme was connected with resources which could be manipulated by the chief for his financial gain. Throughout the formation of the programme, and including these beginning meetings, it was emphasised that this was to be a "grass roots" type of programme which would empower the local church to mobilise itself in reaching out to the sick and dying in the community, as opposed to a Western backed programme from which funds and material items could be extracted.

The area where the research was done was collectively known as the Lingadzi<sup>2</sup> area. It is a densely populated community known for its poverty, with very poor infrastructure. People are mostly uneducated, Chichewa speaking and unemployed or pieceworkers. Few people have bicycles, most travel by foot. Houses are made of mud bricks with grass, or an occasional tin roof.

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2 The villages included in the Lingadzi area include the following: Mtsiliza, Chimbaleme, Pearson and Mtandira.

### **Needs Assessment**

A randomised cross-sectional quantitative survey was developed, targeting the Lingadzi area villages adjacent to the ABC campus, to assess their perception of the attitudes of those in their community who are suffering with HIV/AIDS and their families as they view the church. The single-system design (De Vos 1998:140) was used to specify the problem as well as establish a baseline for measurement of change as the researchers worked to ascertain the prevailing attitudes of those in the village, as they perceive the attitudes of the church towards those in the community suffering with HIV/AIDS. This was done to assist in determining the needs of the community as well as for formulating the baseline information for use as a comparison for future studies and surveys. This information would also establish the baseline criteria necessary to determine the effectiveness of the programme once it has had an opportunity to impact the target population.

The pilot testing of the questionnaire was done with ABC students who were sensitive to the cultural understanding and mindset of the test population. A substantive grounded theory began to emerge as the above data was analysed and evaluated (De Vos 1998:266). From this point, information surfacing had application in the congregational, as well as the individual setting, which led to the formation of a praxis theory as well as a sustainable strategy on how to implement it.

### **Implementing Home Based Care (HBC)**

When the churches and students selected were prepared and ready to begin, the churches were asked to identify those within their midst who were sick. There was no attempt at determining if these are truly AIDS<sup>3</sup> patients. This is due to the strong denial system that is present, as with many other African cultures, in the Chewa culture. If it were to become known in the initial phases of the ministry that this was an outreach to AIDS sufferers, there would be no one who would allow a visit that would effectively identify them as an AIDS patient.

No attempt was made to limit patients to those who attend, or are members of, or are in good standing with, the churches cooperating in the programme. It was recognised that most of the patients, especially in the initial phases of the programme, would be comprised by members of those participating churches, and it was hoped that as word spread about the services offered; those outside the church's direct sphere of influence would then seek HBC assistance for themselves and their loved ones as they began to recognise this as a beneficial service that could help them.

The initial focus of this study was the goal of changing the attitudes of both the churches participating in the study and the local HIV/AIDS community. By observing the local congregation's action plan, the churches in the surrounding community will see the example of Christ's love in action, witnessing the impact it is making in their own community. If these churches follow the pattern, they will want to become participants in the programme so that they too can begin reaching out to HIV/AIDS victims and their families in a loving and compassionate way, and therefore acting out Christ's commandment to "love one another".

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3 Realistically, it is presumed that most of the homebound patients who will be involved, even in the initial steps of this program will indeed be HIV/AIDS sufferers based upon statistics given for both the general population and those who seek medical attention.m

### **Staffing and HBC volunteers**

During the initial phase of the HBC, the staffing consisted of ABC students participating in the HBC programme as part of their college outreach requirement. Amos Chigwenembe from World Relief came to ABC to help the students understand the basic components of HBC, using various teaching methods such as PowerPoint presentations, small group question and answer sessions, and informal lectures. After sharing the initial vision for HBC, the students familiar with the churches within in the targeted village area were asked to consider which churches would be most likely to want to participate in the programme. The Chimbaleme Assembly of God congregation was identified as the key congregation in the Lingadzi area. The ABC students began to immediately seek volunteers from the cooperating church to become the primary HBC visitors.

It was important from the start to delineate and establish the roles of the ABC students. They were never to be seen as the primary visiting force, but only in a supplementary role of the HBC programme from within the church. Although this aspect was recognised in the initial stages of development, its significance was not fully appreciated until the visitation actually began. Because of the ABC class and semester schedule, it was deemed essential that the students take a secondary role to the church's volunteers in order to maintain continuity of care for the patients during holidays and breaks from classes for the students.

Another significant development became apparent when the students began making visits. As the students teamed up with the volunteers, the volunteers had a natural tendency to take a secondary position, with the assumption that since the ABC students were Bible college students, they were more educated, and therefore in some ways superior to the village volunteers. Noting this tendency from the start, appropriate measures were taken to avoid this mindset in both the students and the village volunteers.

The criterion for selecting volunteers was to search for those demonstrating a "heart" for the sick and homebound from within the church membership. It was envisioned that as more churches enter the programme, each church would have their own members who would become HBC volunteers for their own respective congregations. ABC students were to be seen as resources for assisting and encouraging the churches as they develop their own programme.

### **Training HBC volunteers**

Work then commenced on the development of the proper curriculum. After much discussion and needs evaluation development, a comprehensive overview was developed of the four critical areas identified below, with full translation into Chichewa, since most of the villagers participating in the programme would not have reached an educational level that equipped them to adequately comprehend instruction in English. Home Care workers will be equipped to function as agents of the ABC Home Care Programme in the following ways:

1. Each HBC volunteer will be required to attend the HIV/AIDS awareness class giving evidence of a thorough understanding of the basic components of the HIV/AIDS virus as well as how the human body reacts and responds to it. Within the framework of this class, participants will become knowledgeable in the prevention, transmission, and various manifestations of the disease, as well as the treatment modalities, available worldwide, as well as in Malawi in particular.
2. Each HBC volunteer will be taught the basic principles of aseptic technique to assist in the reduction of transmission of germs and disease. Basic medical assistant skills will be

taught in order to fully equip the Home Care workers to give basic physical care in a safe and compassionate manner.

3. Each HBC volunteer will be instructed on basic counselling and listening skills in order to assist and equip them in dealing with patients in a caring and emotionally sensitive way.
4. Each HBC volunteer will be taught various ways of sharing their faith so that they will be fully equipped in order to, as stated in 1 Pet 3:15,

But in your hearts set apart Christ as Lord. Always be prepared to give an answer to everyone who asks you to give the reason for the hope that you have (NIV).

An unforeseen turn of events evolved as Rev David Phiri, the pastor of the church initially selected as the study church, the Chimbaleme Assembly of God, took it upon himself to solicit interest from other churches in the local village area to join with him in this project. With his encouragement, fifty-two individuals from ten churches, representing ten different denominations, from a conglomeration of several villages contained in the Lingadzi area stepped forward to have some of their members participate in the training programmes.

At the end of the four-week session, *all fifty-two* participants had met the requirements, and were therefore qualified to receive certification of completion and begin changing their community. The unexpected total commitment and enthusiasm of this group exceeded the expectations of all those participating in the facilitation of these training sessions. At least a significant amount of this commitment can be attributed to the fact that Rev. Phiri, and those interested in this programme held an all night prayer meeting the night prior to the first meeting, seeking God's will, vision and intervention in this project. In addition to their comprehensive HBC training manual, each person completing the course was given a certificate of completion, a Partners in Hope T-shirt and tote bag, a Chichewa Bible, a folder with necessary paperwork and an official picture name badge indicating they had completed the course and were recognised as an official HBC worker by their church and the ABC Partners in Hope HBC Programme.

The requirements of an article prevent the researchers from outlining all they have learned during the year between the two questionnaires. The praxis theory was continually moulded and reformatted as the events unfolded. During their initial year, from the graduation of the first class to the evaluation done at the completion of their first anniversary, many anticipated as well as many unexpected factors became apparent.

## SURVEY RESULTS

One of the unexpected findings that came to light from this survey was the fact that the initial information used in the most preliminary planning stages was in error. Instead of the community being completely replete of home care (as had been reported by the local authorities), there was indeed a HBC programme already established in the community which had on a limited basis, obviously made some inroads towards the objectives of this study within the particular scope of

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4 The 10 churches participating in this initial training class were as follows: Assembly of God (18 participants), CCAP (14), Roman Catholic (9), End Time Pentecostal (7), Anglican (2), African Chipangano (2), Zambezi Evangelical (1), Pentecostal Holiness (1), Baptist (1), Church of Christ (1)

their work. This programme was developed and run by the local Roman Catholic diocese and was primarily, although not entirely, limited in scope to the community belonging to the Roman Catholic Church. The focus of Partners in Hope was also substantially different in its scope than the Roman Catholic programme.<sup>5</sup>

The survey also revealed that 78% of the study population from the target villages claimed to be Christian and of those, almost one third (31%) were Roman Catholic. Therefore, since they were obviously aware of their own programme, a larger than anticipated number of respondents responded in a positive way when asked if they believed the church was having a positive effect on the attitudes of the people.

One year following the initial survey, and subsequent to the HBC workers continuously visiting in the villages, another single-system designed randomised cross-sectional quantitative survey was performed. In an effort to control variables, only one surveyor was used so all respondents were questioned in the same manner. The survey was identical in nature and method to the first, with the exception of only using one surveyor, and the inclusion of two additional questions, of which one read:

Question #9: Do you think the HBC has helped to change attitudes between the church and the HIV/AIDS community?

These questions were added in an effort to ascertain whether or not the community as a whole was becoming more aware of the HBC programme and if they had any perception of its impact among the people of the community. The same guiding principles used in the first survey were utilised for the methodology of this follow-up survey. From the results of the first study, a comparison was then made between the results of this second survey one year later. These results and the comparison study from this survey are as follows:

#### **The clergy were wrong**

The results from this initial survey question significantly contradicted the beliefs held by the clergy in the community. Clergy from at least four different denominations were interviewed extensively and each one confirmed the facts as they saw them. From their perspective, the congregations held primarily negative views towards those suffering from HIV/AIDS up until the recent past. At the beginning of the test period, the pastors were estimating that between 60-75% (average figure of 68%) of those within their own congregations continued to have negative attitudes but did feel optimistic that they were becoming more open to change. However, only 38% of the general population of the area responded that the community had a negative view, indicating a full 62% positive response! It is an interesting phenomenon to note that there is almost an exact inverse relationship between the perceived views of the clergy toward the church, and those of the surrounding community toward the church.

As a precaution against the tendency for those being interviewed to respond in a manner reflecting their perception of the "desired" response, the questions were deliberately worded so that the individual responding would not feel "on the spot" by being asked to give *their own*

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5 The Roman Catholic work had been established years ago and was primarily focused on meeting some of the physical needs of the community in a multi-faceted approach. Although they were making an impact, it was seen as spread too thin to be effective. Partners in Hope's focus was inverted from the Catholic work in that it was spiritually based as its primary task, with the meeting of physical needs as secondary.

*personal* opinion. In Malawian culture, a person will try to give the answer they believe the questioner would be most pleased with, even if it means they are not telling the truth by doing so. Therefore, the questions were worded so that the responder would be giving his or her opinion of what *other* people in the community think about the issues at hand. It is hoped that by doing this, a more honest result would be obtained about the actual views of the community.

### **Significant changes in attitudes**

The follow-up survey one year later revealed a significant decrease in negative attitudes, dropping from 38% to only 4%. (*Question #1: How do you think people in the church feel about those suffering from HIV/AIDS?*) 96% indicated in the follow-up a year later that people in the church want to reach out to them with the love of Christ and do all they can to relieve their suffering. .

On the second question: *How do you think people in the AIDS community feel about the Church?* The positive answer moved from 64% to 85% that “People with HIV/AIDS feel love and acceptance when they are in the church or around Christian people.” Question 3 confirmed that the people in Lingadzi area thought that attitudes changed between the church and the HIV/AIDS community. More people were willing to admit that they have family members suffering with AIDS (42% to 56%).

*Question #9: Do you think the HBC has helped to change attitudes between the church and the HIV/AIDS community?* This question was not designed to require interpretation on the part of the respondent, only a general indication of his or her perception about the changing of attitudes, and whether or not the HBC programme has had any impact in this area. Again, it must be noted that although measures were taken to avoid answers given with the intention of attempting to please the interviewer, it must be realized that with a question like this one, there is a significant possibility of this type of risk as the participant is fully aware that this survey is being performed by Partners in Hope HBC. The respondent may therefore, because of his or her cultural background be tempted to provide at least a neutral, if not a positive response. Even with this consideration the findings are optimistic as everyone reported a positive change with the larger majority (58%) affirming a more significant change, and the remaining 42% feeling that at least some change for the positive has taken place.

### **Hypotheses proven**

By comparing the results of the two questionnaires one can deduct that the two hypotheses set for the research has proven that HBC can indeed change attitudes and bridge the alienation gap between the church and the faith community. However, with the implementation of a praxis research methodology a substantive grounded theory began to emerge as the above data was analysed and evaluated (De Vos 1998:266).

### **VOLUNTEER ATTITUDE CHANGE**

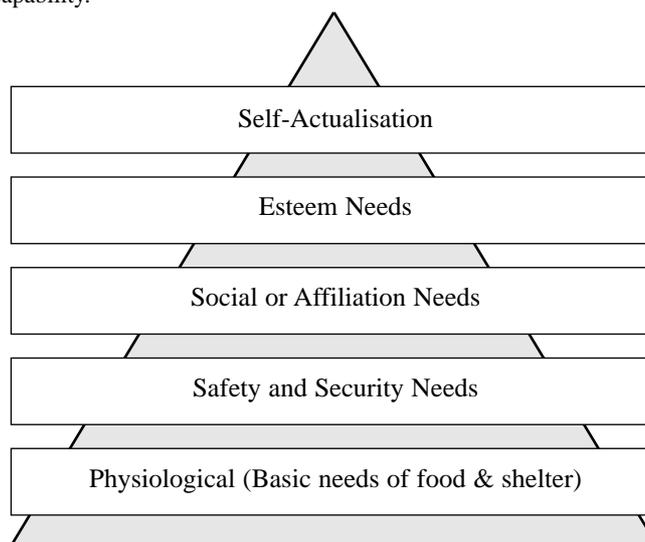
The initial plan of the HBC was to develop a functional augmentation of the visitation programme already existing in the church. This goal was modified however, in order to comply with the overriding need of allowing the group to control their own development based upon their perceived needs and vision. The initial goals and plans of this research were intentionally allowed to fade from the focus in a deliberate attempt to allow the Chimbalame group to take “ownership” of

the project. Seeing group ownership as an essential function, which would serve as a foundation of the entire programme justified the change of goals at this point in the evolution of the programme.

### **Poverty – a major impediment**

As the Chimbalame group began to identify their organisational structure, a strong central committee developed which later developed into an entity of its own (see below for further explanation of this feature). Several factors must be considered as to why this phenomenon took place. One of the most significant features that must be considered is the abject poverty that is prevalent in the Chimbalame group and the Lingadzi area.

Through the development of this study, we become acutely aware of the devastating effects of poverty. Outside of the manifestation of an overflowing divine love, coming from within and exhibiting itself in such munificent action, is simply impossible for those at the lowest levels of Maslow's hierarchy of needs (Barlow 1992:355) to give of themselves in what might normally be thought of in the idea of volunteerism (as perceived by those on the higher levels of Maslow's hierarchy). Their basic physical needs were simply too great to be able to look beyond their own seemingly hopeless situation to care for the needs of others. To ask someone to give benevolently of their own time and resources, when they themselves have not eaten was found to be simply beyond their capability.



Bate identifies this phenomenon of acknowledging poverty as a problem but then attempts to minister without ever fully addressing it. In his research, he points out that although poverty was identified in the initial planning stages, it was overlooked as an actual component of the ministry until circumstances demanded a change (Bate 2003:201),

A few projects initially envisaged a poverty relief component as an essential aspect of their work, but the majority preferred to focus their efforts on providing care which directly responded to the HIV/AIDS crisis. But most, especially those working in rural areas, eventually found that their work was impossible without a poverty relief component.

One of the effects of this phenomenon of poverty was how the Chimalame group began to intensify their identity of themselves as a group. Since most were either unemployed or if employed, they were working in temporary unstable job situations, they did not derive their sense of identity from their work situation. Another significant factor, which is akin to the poverty challenge, has to do with the fact that due to the urban nature of the Lingadzi area, they did not have the normal village community support systems in place that most Malawians have come to see as their source of identity. Because of these two reasons, the Chimalame group began to perceive its identity *from the group itself*. The committee took on a significant role in their lives and the hierarchy of the committee and the power of the ruling positions became of paramount importance. Professing to have the interests of the patients as their priority, they continued seeing the patients or often merely claiming to see the patients; with the ulterior motivation underlying of an eventual reward for their efforts, either financial or materially. Since for many, if not most of the volunteers, this was their primary motivation for service; their frustration at what they perceived a lack of items due to them becomes more understandable. Many of the Chimalame group also saw the training they received as a possible entry into employment by ABC and therefore wanted to maintain, if not intensify their relationship with the clinic and the HBC department.

This phenomenon of internal intensification at the expense of external outreach of the Chimalame group bears some resemblance to the phenomenon described by Newbigin as he discusses McGavran's concept regarding his "mission station" theory. McGavran studied the reasons why some mission churches multiplied rapidly while others in similar situations stagnated. What he found was:

As converts were detached from their natural communities to which they belonged, and attached themselves to the foreign mission and its institutions, which required them to conform to ethical and cultural standards that belonged to the Christianity of the foreign missionaries a two-fold outcome was observed. As they were removed from their own environments [cultural surroundings], they were no longer in a position to influence non-Christian relatives and neighbours; and secondly, the mission station churches soon became exhausted in their efforts to bring the converts, or more often their children, into conformity with the standards supposed by the missionaries to be required by the gospel. Both factors have the effect of stopping the growth of the church (Newbigin 1995:122).

Similarities to the findings in this HBC study begin to surface when one examines the eventual outcomes. *Chimalame, which maintained a strong identity with the ABC, severed their identity with their individual churches, and lost all interest in looking outward, thus losing their focus and vision of serving the Kingdom.* This led to their ultimate demise as they became so self-serving (as did McGavran's stagnating church) that they could no longer function.

#### **One year evaluation Chimalame HBC:**

The first trainees began their initial classes in early February 2002. Although they began with one heart and one focus, once the HBC project had been in place and actively working with patients in the local area several degenerative changes became increasingly apparent. Although the volunteers continued to claim commitment to the programme, a number of disruptive undercurrents began to surface based upon the rational described above.

After investigating the situation more thoroughly, several areas of discontent became apparent from amongst the volunteers. Up until this point, these areas were not brought to the attention of those overseeing the programme. The main catalyst for the discovery of the problems was the hiring of a full-time, experienced home based care nurse to assist the volunteers with the medical components relating to their patients care. During this initial year of practice and development, the HBC volunteers were functioning primarily in the role of chaplains, giving spiritual support and comfort to those they were seeking to help. In accordance with the initial goals of the project, the medical training received by the volunteers was intentionally very rudimentary. They were therefore not equipped with the necessary skills needed in order to allow them to actually assist with any medical decisions for the patients in any real way.

As the one year anniversary of the HBC programme approached, evaluations were done concerning the viability of the programme. From this data, it seemed feasible to seriously consider the option of outside funding to enable the hiring of a registered home care nurse to aid in the development of the medical component of the programme. Because of the nature of the HBC patients, who were primarily suffering from AIDS or other disease processes causing them to be confined to their homes; many of the volunteers expressed feelings of frustration with a sense of helplessness when visiting patients having such obvious physical needs.

By the end of the first year, funds became available through Partners in Hope to hire a full time nurse, who would act in the role of medical liaison. An experienced Malawian HBC nurse was hired to work primarily in the village areas, supervising the home care volunteers, and overseeing the medical needs of the patients involved in the programme.

The volunteers continued to meet regularly for feedback and follow-up. The HBC Planning Committee took deliberate pains to work within the guidelines established, with the goal of keeping the ownership of the programme within the hands of the volunteers themselves. Therefore, other than monthly updates, and encouragement of the volunteers, additional obvious oversight was kept to a bare minimum. Time was given for the volunteers to assess their own needs and then bring these needs to the attention of the HBC Planning Committee instead of direct intervention begun when a need began to surface and reach the attention of the trainers.

The programme trainers made regular visits to the field, but kept these visits limited in scope due to the disrupting effect these visits had. It became quite apparent when Janet Brown made visits with the volunteers, that the patients, although quite gracious and most likely genuinely pleased by the visit, felt quite unnerved by the fact that there was an *azungu* (white woman) in their house. What inevitably happened would be a degeneration of the actual purpose of the visit to provide loving concern and comfort to the patient; and instead the visit turned into a time when the patient would feel compelled to express continued gratitude. Because of this tendency noted in the patients most contact and evaluation of patient status was done through the opinions and judgment of the volunteers.

These factors caused a considerable amount of difficulty in getting an accurate picture of the actual home and patient situation due to the cultural tendencies of Malawians to please along with their willingness to offset the actual truth with what they perceive would be the information desired by the researcher. It was not until the Chichewa speaking, Malawian-born, full-time HBC nurse was hired and actually began making visits to the patients that some disturbing underlying problems were discovered in the HBC programme.

### Discussion of difficulties encountered

1. As the volunteers were becoming increasingly dissatisfied with the lack of “incentives” being received, they lost their altruistic heart. This caused their focus to change from their original goal of visiting patients for the purpose representing their church by demonstrating the love of Christ as they lovingly cared for the sick and suffering in His Name. Instead, their focus had degenerated into an opportunistic consideration of what advantages they could obtain by participating in the “programme”.
2. As the homecare nurse made visits to the patients, she became aware of discrepancies between the number of visits made by the volunteers and the number of visits reported and confirmed by the patients. Although the volunteers continued to express great satisfaction to the HBC Planning Committee, and continued to attend meetings, and training seminars, the actual number of visits being made to patients had diminished significantly. In addition to the discrepancies noted in visiting schedules, when patients were asked about items that were given to the volunteers for the patients, patients reported that they did not receive any such items. Measures were then put in place to call for more careful accountability on the behalf of the volunteers, which were met with increased suspicion and resentment.
3. *The individual churches represented by the volunteers participating were no longer the sending agency for the volunteers. Instead, the “committee” had taken on a larger role, usurping the churches role of ministering to the sick and suffering in the name of Christ. The committee had developed into an entity in itself. Members of the committee were often not making visits at all or only occasionally. The growing strength and importance of the committee had shifted to be perceived as their worthwhile cause.*
4. The expectation of the volunteers was that they should be receiving some type of reparation for their services. The practice of providing some sort of compensation, can be observed in the documentation of a “volunteer” programme describing “volunteers who work for little or no recompense” (Bate 2003:2001), which demonstrates the underlying perception that “volunteers” should be compensated in some way for their services, and that *working with little or no recompense*, was working above what could be expected. This difficulty is compounded by the fact that some governments (as Bate cites South Africa in his article) actually *provide cash incentives* for registered volunteers (emphasis ours). This increasing problem began to undermine the entire programme. The following example is offered as an illustration of the significance of the suspicion and discontent exhibited by this group: The volunteers had developed a repertoire of songs, poems and dramatic presentations that they have used for their own benefit, as well as for communicating to others about HIV/AIDS. When a visiting group from the USA expressed an interest in seeing some of these demonstrations, the HBC volunteers were asked to come together and share some of their songs, poetry and dramatic presentations with these guests. Several of the volunteers came and following the time of sharing with the guests, after the farewells were made, the home care nurse spoke to them. She expressed disappointment that more of them were not present and they told her of their disillusionment with the HBC programme. They were upset because they were not getting the ‘incentives’ they believed they deserved. They said that the Partners in Hope training team were “all getting fat, while we are getting thinner”, or in other words, revenues were surely coming in for them that were being

siphoned off by the researchers and the others in the Partners in Hope office so that the volunteers were not getting the food and money they felt they had coming to them. They were unwilling to believe the claim that no wealthy funding agency was supporting this research.

5. Another problem surfaced during the first year, of which we were already aware. A shift in enthusiasm from within the volunteer force took place after it had been active for approximately 6-8 months. The chairman of the committee, Rev. David Phiri, who had initially worked so hard to mobilise the effort of the HBC concept, was conspicuously absent from many of the activities. It was feared from the beginning that this man, who was already over-taxed with his obligations might not be able to keep up with the demands required of the committee chairman; but upon further investigation it was discovered that this pastor was purposely stepping back with the intention of allowing the progress of the HBC to diminish until it faded from existence. Apparently this pastor, who had joined so vigorously in the initial efforts, had done so with the presupposition that there would be either financial or material dividends forthcoming that would be a benefit to him personally, or for his church. When the truth of what was promised (no financial or material incentives) materialised, he dropped out of the programme. Although many of the volunteers from his church continued visiting patients, it none the less had a demoralising effect on the entire programme.

The research project progressed after this point in time. The guidelines of programme evaluation and intervention research were followed (De Vos 1998:365). The article will not, however, pursue the process further.

## CONCLUSION

Home based care can change the perceptions of alienation between the church and people suffering with AIDS. The research proved adequately how this took place in an extremely poor area in Lilongwe, Malawi. However, the research revealed something of the dynamics that play a role in the type of context where the research was done.

During the research process the researchers became acutely aware of the devastating effects of poverty. It is simply impossible for those at the lowest levels of Maslow's hierarchy of needs to give of themselves in what might normally be thought of as the idea of volunteerism. The basic physical needs of those church "volunteers" doing the work were simply too great to be able to look beyond their own seemingly hopeless situation to really care for the needs of others. To ask someone to give benevolently of their own time and resources, when they themselves have not eaten or are without job security, was found to be simply beyond their capability.

The discoveries made from this research have worked to illuminate the critical importance of understanding difficulties, initially considered secondary to the main thrust of this research, such as abject poverty. Stark issues such as poverty have often been given a token acknowledgement before going to work on to the "real" issues. This research has demonstrated that for those struggling to survive at the lowest levels of Maslow's hierarchy, there is no other issue but survival.

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