Life-Centred Learning in the Context of HIV and AIDS: Monitoring and Evaluation of Home-Based Caregiver Training

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Abstract

South Africa faces a serious challenge in its inability to stem the HIV tide. Recent survey results revealed 469 000 new HIV infections in 2012. This means there are 6.4 million people or 12.2% of the population living with HIV. In a context where education to prevent infections are not successful, education to manage the disease and enhance healthy living for the infected and affected becomes paramount. This article reports on an example of such education provided by a large health non-governmental organisation (NGO). It discusses the design piloting, evaluation and monitoring processes involved in creating a life-centred learning programme in response to HIV and AIDS. This work was undertaken as an action research project and produced much learning for all involved. The first part of this article deals with the learning that took place during the course by learners (caregivers) and discusses some of their future learning needs. The second part discusses the learning that took place within the partnership between Caregivers International and the Centre for Adult Education (CAE), specifically catalysed through the action-reflection process. Implications from this research include the need for post-course support of learners and for attending to the injustice of placing the burden of care on the most vulnerable sector of society.

Keywords: *home-base care, caregivers, HIV/AIDS, learning, action research*

"A long and healthy life for all South Africans" (South African Government: Priority Outcome 2, 2009-2014)393

1. Introduction

The most recent and authoritative report on HIV infections in South Africa (Human Sciences Research Council, 2014) raises several concerns, some of which have implications for education. The survey found that there were 6.4 million people living with HIV, some 12.2% of South Africa's population. This amounts to an additional 1.2 million infected persons since the last survey in 2008. Of serious concern and an indication of the inability to stem the HIV tide, the survey revealed that there were 469 000 new HIV infections in 2012, almost as many as there were in 2005. These figures must be understood in a global context where the tide against HIV has turned significantly. According to a recent report of the World Health Organisation (2014, p. 2) after "years of increasing incidence of HIV infection and related deaths, the pandemic appears to have peaked. AIDS-related deaths have fallen by 25% in the past decade, and new HIV infections by more than 20% since 2006". South Africa has bucked this trend. Its new infections indicate that large-scale educational campaigns and promotion of safe sex have not had the desired effect. Clearly, the outcome of "a long and healthy life for all South Africans" as expressed in Priority 2 of government's 12 priorities, is under threat. In a context where education to prevent infections is not successful, education to manage the disease and enhance healthy living for the infected and affected becomes paramount. This article reports on an example of such education provided by a large health non-governmental organisation (NGO).

It is now abundantly clear that HIV and AIDS are not just health problems. The pandemic intersects with most aspects of life, namely, the social, economic, political and educational. HIV/AIDS is dealing a devastating blow to social development in Sub-Saharan Africa, more devastating than previous wars in the sub-continent. The pandemic is also shifting learning needs within affected communities and homes. In the context of widespread sickness and death resulting from the pandemic, a part of lifelong learning has become literally about the need to learn how to enhance health and prolong life. The need to reassert the case for *life-centred* and *people-centred* lifelong learning grows daily. This article examines one intervention in response to the learning needs created largely by the pandemic. A substantial part of the article focusses on the systematic process of reflecting on the impact of the intervention on learners and on the training provider. The value of combining an action-reflection approach with such training interventions is discussed. The reflections in this article constitute yet another part of the action-reflection, with a view to making a contribution to the field

of education and training for social development.

2. The Context

As indicated earlier, South Africa's HIV-infected population of 6.4 million, combined with improvements with anti-retroviral medication provision means that the country has a very large number of people living with HIV/AIDS. The province of KwaZulu-Natal has the worst HIV prevalence rate (16.9%) in South Africa.

The pandemic is also affecting teaching and learning as large numbers of teachers die and the number of child-headed households increase, thereby forcing learners to shift their attention to caring for parents and siblings. While HIV/AIDS is impacting on conventional learning, it is also creating other learning needs as people grapple with caring for the sick. As alluded to in the title of this article, large numbers of the population need to learn how to prolong and enhance life.

Health-care needs in South Africa continue to exceed the capacity of the country's health care system (Shisana et al., 2002). The AIDS pandemic, together with other diseases (eg. Tuberculosis), continues to wreak havoc on a system initially fractured by decades of apartheid policy and subsequently remaining inadequate because of resource constraints and poor management. The health care system is simply unable to care for the large numbers of sick people. It is now accepted that an increasing portion of present and future health care and social welfare provision will need to be home-based or community-based, delivered by non-professionals, often on a voluntary basis. There are currently both government and civil society projects involved in training community health workers or home-based caregivers. (Department of Health, 2001; Uys, 2002).

A large health NGO, referred to as Caregivers International in this article, undertook the redevelopment of its Basic Home Care Course. The redevelopment was undertaken in order to ensure that the course complied with new national accreditation requirements, met organisational objectives to address critical health needs in the country and was guided by sound educational principles. The Centre for Adult Education (CAE) at the University of Kwa-Zulu-Natal was commissioned to undertake this work. It became important to ensure that the redeveloped course was successful in meeting its objectives, was owned by geographically diverse parts of the organisation, and impacted positively on those who attended the course, those for whom they care, and the broader community within which they live and work. To meet such information needs, a thorough action-reflection process of piloting, evaluation and monitoring was undertaken over a two-year period. During this time more than 5000 learners had completed the new course. Most of the learners were women with a grade 9 (9 years of schooling) level of education.

3. Action Research Methodology

Educational action research has its origins in the work of Lawrence Stenhouse, Stephen Kemmis and John Elliot in the 1970s. More recent contributions to this literature are from Campbell and Groundwater-Smith (2010) in the form of a three volume collection on action research in education. Jack Whitehead's dialectical approach and Jean McNiff's generative transformational approach (see McNiff & Whitehead, 2002) are examples of critical action research in education. Cohen, Manion & Morrison (2001, p.227) note that "action research is designed to bridge the gap between research and practice … thereby striving to overcome the perceived persistent failure of research to impact on, or improve, practice". Action research often involves cycles of planning (designing a course), acting (implementing a course), observing and reflecting (through evaluation and monitoring), and then re-planning, and further such cycles. According to Reason & Bradbury, 2008, p. 4) action research "seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities." The action-reflection process implemented with the Caregivers International project was undertaken which such purposes in mind and provided a valuable learning opportunity for Caregivers International, the Centre for Adult Education and for the participant caregivers. This article discusses the learning within this project at two levels. Firstly, a significant part of this article deals with the learning that took place during the course by learners (caregivers) and discusses some of their future learning needs. Secondly, the article discusses the learning that took place within the partnership between Caregivers International and the CAE, specifically catalysed through the action-reflection process that was embarked upon. In a sense, this article constitutes yet another part of the reflection, by examining both levels of learning that took place in the project with a view to making a contribution to the field of education and training for social development.

4. The Basic Home Care Course

The redeveloped Basic Home Care Course was designed as an intensive four-day course. It comprised 20 units, including units such as "the caregiver and the community, the caregiver and the patient, dressing and undressing patients, feeding and nutrition, wound care, medicines, caring for people with HIV/AIDS, death and dying and support for the family". Designed to be highly participatory, the course made use of methods such as role-plays, case studies, practical demonstrations, a patient record chart and a resource directory that learners develop according to their needs. Learners received a workbook and an assessment package, both of which also served as reference material for them to use at home after the course. A facilitator's manual with detailed instructions and activities for teaching the course was developed for Caregivers International training staff.

4.1 Piloting the course

Once the Caregivers International course was redeveloped, pilot courses were offered at four Caregivers International centres in different parts of South Africa. All facilitators completed a detailed questionnaire on the course and participated in a telephone conference with CAE staff at the end of each day of the pilot course, in order to provide feedback on the new course in operation. In addition, CAE staff observed the pilot training at two centres as a means of gathering independent information on the implementation of the new course. The piloting process thus drew on the views and experiences of facilitators and yielded crucial information that helped to revise the course and learner materials. The piloting led to substantial rewriting and redevelopment of the course. The initial course development process had mainly involved the training managers within Caregivers International. This was necessary to guide the curriculum development, but also important in initiating "buy-in" from this key sector of the organisation. Most facilitators, who are employed on a part-time basis, had not been involved in the course development phase. The pilot, however, signalled to Caregivers International that their facilitators would require additional support in order to deliver the new course. In some centres, orientation sessions and peer support workshops were subsequently organised for facilitators. The evaluation phase (discussed below) which followed, showed that facilitators had become more comfortable with the new course after such interventions. This was one early example of how the action-reflection process led to positive change and built capacity within the organisation.

4.2 Evaluating the course

Four months after the pilot, the revised course entered the evaluation phase; the next phase of action-reflection. The evaluation phase was conducted in two stages with a four month interval (from July to November), in order to ascertain changes over time. The evaluation phase was designed to draw on a wider range of perspectives and therefore consulted learners, their patients, the broader community, and some client organisations of Caregivers International, in addition to the facilitators. This process was similar to that reported by Uys (2001) who conducted evaluation research of an integrated community-based home care model. The evaluation targeted six Caregivers International centres in various parts of the country. The evaluation phase was designed to assess the impact of the course on the level of care that learners were providing to their patients and the impact of the course on the broader community of learners. The evaluation also appraised the level of satisfaction with the course of both learners and those (client organisations) paying for them to attend.

The evaluation revealed that learners had acquired high levels of knowledge and skill about basic health care and that those who were in positions that allowed them to apply such knowledge and skills were doing so remarkably effectively. In addition, marked shifts in learners' confidence levels and their attitudes were recorded. Learners reported significant shifts with regard to their attitudes to the elderly, to people who are HIV positive and to people living with AIDS. The shifts which were noted in the first stage of the evaluation had become more marked in the second stage. Nearly every focus group in the second stage raised HIV/AIDS as a key learning area and shifts in attitudes to people with HIV/AIDS were highlighted by learners as the most fundamental change in their own views. Comments such as the following from a learner from Nyanga, a township in Cape Town, were common, *"I was scared of HIV people. Now I'm not scared. We can eat together, but be careful of wounds."*

The views expressed from a variety of sources indicated that the level of care that learners were providing was highly regarded, respected and appreciated. Learners were also gaining new status in their communities and being seen as a community resource to draw on for care, advice and education. The benefits of drawing on multiple perspectives in the evaluation meant that these significant findings could be triangulated, as learners, facilitators, patients, professional

health workers and client organisations all concurred with these findings. Obtaining such findings and feeling secure about their validity was important to Caregivers International and the CAE. The two-stage evaluation phase also allowed one to check whether such knowledge and skill acquisition were being retained. Learners who were re-interviewed several months later demonstrated high recall of what they had learnt and remained confident about their abilities.

4.3 Monitoring learners

The monitoring phase was designed to primarily track the involvement of learners in home care, community health, and their participation in home care and other related networks and structures. The second stage of the evaluation was used to collect baseline information for the monitoring phase. A final stage of monitoring was conducted in the following year, just over six months after the second stage of evaluation. This opportunity to interact with one cohort of learners on a repeated basis was also used to gather further information on retention of key areas of knowledge and skills, some 18 months after completing the course.

In the first stage of the monitoring learners had reported that the course had impacted on their lives in a number of ways. At a personal level, learners reported greater confidence, improved status and a new sense of purpose and hope about life. Significantly, learners also revealed that the course had led to a number of behavioural and attitudinal changes regarding their own lives, for example, better nutrition and hygiene. The reported changes with regard to awareness about HIV/AIDS and attitudes towards those infected by HIV/AIDS were particularly encouraging. In addition, the course appeared to have facilitated supportive relationships and networks for learners. Such was the climate in the training environment, that some learners had disclosed their HIV+ status during the course. For a number of learners, the course was seen as a step towards fulfilling lifelong learning goals. Many learners had aspirations of entering the nursing profession and had hoped that the course would serve as a step in this direction. They did, however, mention that in some instances they are seen as a threat to nurses. Uys (2002) also reported that caregivers felt that their role and status were not respected by the formal health services.

The second stage of monitoring revealed significant shifts in the morale and involvement amongst learners. In some centres, the number of learners who were still actively involved in caring for someone had dropped. Although the retention of course content was still high 18 months after the course, there were also indications that those learners who were not practicing as caregivers could lose their newly acquired knowledge and skills. Two focus group discussions did not take place, one because the learners opted at short notice to take up short-term seasonal employment as workers on a tomato farm, and the other, because learners refused to participate as a form of protest arising from disillusionment with their positions as volunteers. Both of these failed focus groups and numerous other data emerging through the monitoring, reflect just how fragile the volunteer-model of care is and how high expectations of employment following the training were. Learners report severe difficulties in their role as volunteer health workers. Most are unemployed and work in extremely impoverished contexts. The clinics at which some learners volunteer are under-resourced and claimed that they were “unable to even offer a cup of tea to volunteers”. Some learners reported increasing dissatisfaction in their homes about their volunteer work and consequent neglect of domestic responsibilities. One learner reported that her husband had warned her that she cannot be “Mother Theresa” for the rest of her life. The majority of caregivers are women with multiple responsibilities in their own families. Akintola (2006, p. 237) makes the important observation that home-based care, “by creating a disproportionate burden on women, is exacerbating existing gender inequities”. This is an important issue requiring attention from both government and NGOs. It is an injustice to pass such a huge burden of care onto the poorest and most vulnerable sector of society. Home-based care planning and policy needs to address this injustice.

Within action-research the trend is usually from small change to larger change. Caregivers International was able to respond to the research data during the process and implement some change. An area of need that had become abundantly clear was the need for post-course support for learners. Support and supervision of caregivers was also found to be of cardinal importance in the study by Uys (2002). This has signalled a serious problem for training providers like Caregivers International. The organisation had focussed on its core function as a training provider and had been successful at this. However, if learners lose interest in the work that they were trained for, or are not given opportunities to practice their skills, the value of the training is undermined or lost. Training providers can choose not to be involved in the post-training context that their learners find themselves in. Caregivers International however, began a debate about possible roles that the organisation could play beyond the training offered. What was noteworthy about this is that in responding to the information that emerged in the research process, Caregivers International was considering important operational shifts within the organisation. This is a feature of a learning organisation and action-research serves such processes.

With indications that the AIDS pandemic has not been arrested (HRSC, 2014), the role that health care volunteers are playing becomes more urgent and important. Systems of support and further training will need to be put in place. Clearly, government cannot shun its responsibility in this area and should not be allowed to. Volunteers feel that government should at least be paying for their transport and food costs. A nurse at a clinic summed up the plight of the volunteers most aptly by saying, *"They cannot continue to be dedicated on a hungry stomach. They have to teach others about nutrition but they themselves do not eat healthy"*. The monitoring research has shown that 83% of learners were not being paid for the care that they provided. The communities in which the care is provided are simply too poor to pay for such a service. This is a serious challenge for such a vital service and appears to be a common one internationally. Chevalier et al., (1993) identified inadequate or irregular pay as the main reason for caregivers to discontinue their work in the Solomon Islands.

Partnerships between government, the business sector, donor agencies and civil society are needed to rapidly secure and sustain the fledgling home-based care operations through programmes of support and further training. Caregivers International, with a well-established national structure and a good reputation, could be an important partner in such programmes, possibly through piloting creative support mechanisms and developing models of such systems. The creation of "learning communities", that is, "organised human community which builds and becomes engaged in its own educational and cultural project to educate itself, its children, young people and adults, within the framework of endogenous, cooperative effort and solidarity, based on an analysis not only of its deficits but, above all, of its strengths" (Torres, 2001, p. 29) could serve as a useful model in this regard. At many of the Caregivers International sites, groups of learners have initiated the beginnings of such learning communities. The monitoring showed that learners had actively attempted to increase their knowledge of health issues and had sought, and in many cases secured, additional training in order to increase their health-related skills. Furthermore, learners continued to be involved in community health networks and structures. These efforts can be important starts of lifelong learning and life-centred learning.

5. Reflecting on the Process

The piloting, evaluation and monitoring phases collectively constitute a comprehensive longitudinal action-reflection process that involved 46 interviews and 56 focus group discussions with all role-players. What is the value of such an extensive process? For a large national health NGO, such as Caregivers International, which was delivering training on a mass scale and needing to raise substantial funding, there was clearly a need for reliable and authentic feedback. In this regard, the evaluation and monitoring provided ample evidence that the course was having an extremely positive impact in respect of the knowledge, skills and attitudes gained by learners, and in terms of the care that learners were providing to their patients and the role that they were playing in their communities. Such positive roles of community caregivers have also been reported by Uys (2002). For a new training intervention that intended to impact on a critical area of need in the country, understanding the level of impact was both necessary and responsible. For a university adult education department committed to social development and quality curriculum and materials development, such an action-reflection process was a valuable, and somewhat rare, educational experience. The process enhanced the quality of the work of CAE and informed other similar projects. We too benefited as a learning organisation.

One further positive spinoff of the action-reflection process was the interest that it created within Caregivers International for institutionalising and making evaluation and monitoring a regular part of their work. The CAE was subsequently approached to help Caregivers International to develop systems and tools that would allow for evaluation and monitoring to become an ongoing, routine internal process. Such a system would serve the organisation well as it strove to generate information that helped it to improve quality, initiate change and to grow, in other words, to become a true learning organisation.

6. Conclusion

Uys (2002, p.108) reminds us that "AIDs is not a disease that makes for easy nursing or for a good death." This statement underscores the importance of home-based caregivers in the South African context of the high levels of disease and poverty.

The piloting, evaluation and monitoring of the Caregivers International Basic Home Care Course constituted as an action-research project which fostered much learning for all those involved. It also generated some important policy implications regarding post-training support of caregivers, the need for partnerships between government and NGOs, and the need to understand the gendered nature and injustice of caregiving. A critical understanding of how home-based and community-based models of care exacerbate the already vulnerable position of women is vital to sustain this important

service to society.

The Caregivers International course, together with the enhancements derived through piloting, evaluation and monitoring is an important response to one set of critical learning needs in South Africa. Moreover, it is an example of life-centred learning in the context of a deadly disease that we are yet to curb.

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