

# Kaleidoscope: a 5-year action research project to develop nursing confidence in caring for patients with human immunodeficiency virus in west India

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## Keywords

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## Abstract

As the human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) epidemic rapidly unfolds in India, nurses have to acquire new competencies in order to provide appropriate care to an increasing number of affected persons. In response, an Indo–British action research collaboration was initiated to build clinical confidence and facilitate relevant changes in nursing practice. During a 10-day educational programme, a change intervention was applied, culminating in the development of individual and partnership action plans focused on bringing about changes in nursing practice within well-defined fields of action. Following implementation of their action plans, participants were reassembled 12 months later for a follow-up workshop to discuss their progress and describe those factors that either helped or hindered them in achieving their objectives. They then developed new action plans for the next 12-month period. This article reports on the results from six cohorts ( $n = 160$ ) in India who participated in this project between 1995 and 1999. Action plans were frequently focused on infection control, primary prevention, curriculum development in preregistration nursing programmes and in-service nursing education. The majority of participants reported significant achievements in realizing their action-plan objectives. Data analysis revealed that the change intervention itself,

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together with multidisciplinary support from colleagues, the senior status of the participant, and anticipating and attending the follow-up workshop, were all positively correlated with achievement. The lack of personal authority and resistance from managers were the two major factors negatively correlated with achievement. This method for facilitating changes in nursing practice has been successfully adapted and replicated by our group in other countries.

## Introduction

The global pandemic of human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS) was late arriving in India, the first person with AIDS not being identified until 1986. However, the Indian epidemic quickly escalated and, at the beginning of the new millennium, 3.7 million people in this country were living with HIV/AIDS. India had now positioned herself to become the new global epicentre of the HIV/AIDS pandemic, already home to a greater number of HIV-infected persons than any other country in the world, except South Africa (UNAIDS/WHO 2000). In this nation of over one billion persons, HIV infection spread rapidly out of high-risk groups, such as commercial sex workers and their clients, and, as a result, became firmly embedded in the general population of young adults (UNAIDS/WHO 1998).

As rapidly increasing numbers of persons developed serious HIV-related illnesses, it became clear that facilities and resources for treatment and care were practically non-existent. An over-burdened, impoverished and rigidly bureaucratic health care system in west India was already at the point of collapse before the advent of AIDS. It then only took the arrival of just the first few thousand patients with AIDS to open the door to a frightening spectre of ignorance, stigma, neglect and the ill treatment of HIV-infected patients in private and public hospitals throughout India (UNAIDS/WHO 1999).

Effective, long-term antiretroviral treatment will never be available to the vast majority of the increasing millions of HIV-infected people in this country. However, India does have a large and relatively sophisticated nursing force, theoretically able to offer competent and compassionate care to persons

with HIV-related illnesses. Most would agree that this is the least that citizens have a right to expect when they become ill as a result of HIV infection. Yet, this too is being denied to them because nurses, doctors and other health care workers are seemingly overwhelmed by a collective fear of contagion.

To offer help and support to Indian nurses faced with the need to quickly acquire professional and clinical confidence within the arena of AIDS patient care, a tripartite action research collaboration was initiated by the British Council in Mumbai (formerly known as Bombay), the Leelabai Thackersey College of Nursing at Shreemati Nathibai Damodar Thackersey (SNDT) Women's University in Mumbai and the Richard Wells Research Centre, Wolfson Institute of Health Sciences at Thames Valley University, London, UK. This project, consisting of a succession of shifting phases, was known as 'Kaleidoscope', and took place in west India (and Bahrain) during a 5-year period between 1995 and 1999 and has now been extended into west Africa (Nigeria).

This article presents a description of the action research process and evaluative survey data that identified significant factors affecting the success of participants in implementing their action plans.

## Background to the project

In 1995, the British Council in Mumbai contracted the Richard Wells Research Centre to develop and implement a series of HIV/AIDS-related training courses for nurses, based in the College of Nursing at SNDT Women's University in Mumbai. An initial training needs analysis was conducted, incorporating direct observation of nursing practice and selected interviews of nurses and other key stakeholders (e.g. managers, doctors) who were

employed in a representation of municipal and private hospitals in Mumbai, and an examination of typical nursing curricula and other documentary evidence. This analysis revealed profound deficits in the specific knowledge pertaining to HIV/AIDS, negative professional attitudes and poor-quality nursing interventions. Paramount was the fear of contagion. Lacking a basic understanding of HIV biology, viral transmission and the pathophysiology of HIV disease, nurses and doctors were frightened of becoming occupationally exposed and infected. Consequently, infection-control measures were inappropriate and ineffectual, and basic nursing care was impoverished, in some instances to the point of gross neglect and abandonment. The environment into which patients were admitted was invariably one of inadequate resources for the safe delivery of care. A frequent lack of soap and running water, sterile injection equipment, clean bed linen and disposable gloves in hospital wards, all nurtured a paralysing climate of fear amongst nurses and other health care workers. Outside the major centres of medical excellence (of which there were few), doctors were equally frightened and unprepared for the medical management of patients with HIV. In private practice, medical quackery was commonplace and, almost without exception, private hospitals commonly tested and then refused to care for any person found to be infected with HIV.

### Methodology – an action research approach

As the above needs analysis clearly demonstrated a professional imperative for both individual and organizational change, an action research approach was used to develop a long-term educational strategy designed to facilitate the changes in practice needed to effectively care for patients with HIV. Action research has been defined as ‘the study of a social situation with a view to improving the quality of action within it’ (Elliott 1991). This research method was first described more than 50 years ago where early models focused on organizational problem-solving, overcoming resistance to change, creating more productive working relationships, and discovering and using general laws of social life

to inform policy-making (Lewin 1946; 1952). This methodology consists of a series of commitments to observe and identify problems in practice, and proceeds in a spiral of cycles, each composed of planning, action, observation and the evaluation of the result of the action, i.e. reflection (Carr & Kemmis 1986). The cyclic and dynamic nature of this approach is flexible and responsive. The methodology is grounded in practice, appropriately focused on real-life situations, is action-orientated, collaborative and aimed at initiating and managing change in clinical practice (Hart & Bond 1995). Because action research is context specific and always about taking action and evaluating the impact of that action on practice, a change intervention is central to the model (Lathlean 1994).

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### The Kaleidoscope model

The initial cycle of activity within our model began with a change intervention followed by five cascading and interlinking processes, or phases (Fig. 1). The change intervention (Table 1) was incorporated into a 2-week, highly interactive educational programme based on needs previously identified and structured around discrete themes (Table 2). This intervention occurred during the second week of the programme and consisted of three sets of activities. Participants were first facilitated to use a

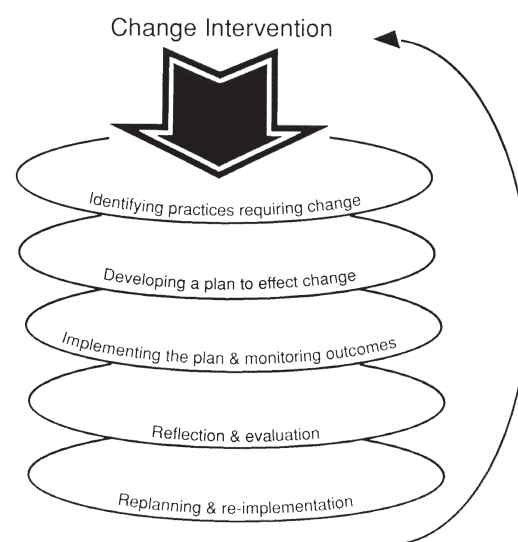


Fig. 1 Action cycle.

**Table 1 Change intervention****15**

Participants were introduced to the following concepts:

- Use of a structured needs analysis to identify areas in clinical practice where change was needed
- Concept of action research and how it could be used at a local level to improve practice
- Techniques and strategies used to effectively initiate and manage sustainable change in practice
- Development of short-term individual or partnership action plans to bring about relevant and appropriate changes in clinical practice

**Table 2 Course themes**

The course was developed around the following themes:

- Understanding the basic sciences driving the pandemic and patient outcomes
- Developing effective communication skills in order to provide counselling and psychological support to clients and their families
- Exploring nursing practice and infection control issues associated with the care of patients with HIV
- Participating in primary, secondary and tertiary prevention initiatives
- Identifying and examining the professional nursing issues associated with developing local and regional strategies to care for patients affected by HIV
- Taking action to bring about sustainable changes in clinical practice

HIV, human immunodeficiency virus.

structured needs analysis to identify what changes were needed in their own clinical practice environment in order for them to be able to safely and effectively care for patients with HIV. During workshops, they next explored the use of action research and change theory to help them bring about those changes that they had identified. In group work, they were then supported in developing individual or partnership action plans to initiate and manage sustainable changes within specified action fields in their own professional practice. Nine action fields evolved through a process of categorizing activities described in those action plans developed by participants in early cohorts. These were: infection control; health education; mutual support; com-

munity action; prequalifying nursing education; postqualifying in-service nursing education; nursing practice and research; policy development; and counselling support.

Objectives within action plans were 'criteria referenced', i.e. they had to be: based on an identified need; significant; achievable; resource-appropriate; and culture-sensitive. In their action plans, participants needed to describe the proposed change, i.e. the objective, and identify how they were going to use relevant aspects of change theory to effect this change. During subsequent phases, participants then had up to 3 months to finalize their plans and 9 months to implement them. They were asked to keep a detailed record of their progress in planning and implementing their action plans, and to document the factors that had either helped or impeded their achievement.

The final phases of the cycle occurred 12 months following completion of the course. Each cohort was reassembled in a follow-up workshop to evaluate the impact of the initial course on their personal and professional lives and to share experiences of identifying and dealing with HIV-related issues in their practice environments. The principal aim of the Workshop was to afford participants an opportunity to report back to their group on:

- 1 their intended action objectives,
- 2 their achievements,
- 3 the factors facilitating achievement, and
- 4 the factors inhibiting achievements.

After reflecting on their individual and collective experience in initiating change, they reviewed change management theory and then modified or redeveloped action plans for the following 12-month period. Additionally, they identified any support and resources that they would need to achieve their intended actions and explored various change-management approaches relevant to their individual circumstances and action plan objectives. This second cycle would be complete in 12 months time and participants were encouraged to continue this process as an integral component of their continuing reflective practice development, and to share their experiences with colleagues at local workshops, conferences and through publication.

In our model, individual and partnership initiatives producing local changes in practice could provide a catalyst for more profound organizational change. The nature of the collaboration between project leaders (teachers) and participants was defined by resources and distance. Project staff were based in Mumbai or London and participants came to the project from three different States in west India. However, an ongoing collaboration was fostered by project staff who supported individual participants in developing their initial action plans, keeping in contact with them by post during the implementation period, and reviewing with them at the follow-up workshop the factors that impacted on their achievement and working with them to develop new action plans.

### Data collection

Data was collected from six cohorts ( $n=160$ ) who participated in this experience between February 1995 and December 1997. A questionnaire was devised to collect and analyse demographic and outcome data in relation to the content of action plans and the factors that promoted or inhibited success. Course participants completed the questionnaire just prior to or at the follow-up workshop. In this questionnaire, respondents were asked to identify up to five objectives (goals, actions) that they had chosen as part of their action plan and to rate their success on a four-point scale: completely achieved; partly achieved; very little achieved; no achievement. From a list of potential factors derived from discussions in previous follow-up workshops, respondents were also asked to rate all those factors that had influenced their success, identifying the three most important helping or hindering factors. To enrich and personalize the data, the questionnaire also asked a number of open questions in relation to achievement or non-achievement, which provided an opportunity for free text responses. Questionnaires were coded and data entered into a statistical software programme (SPSS® [Statistical Package for Social Scientists for Microsoft Windows®]). Analysis was undertaken using univariate and multivariate analysis and Pearson's correlation coefficient.

## Results

Of the 160 questionnaires distributed, 125 responses were received, giving a response rate of 78%.

### Characteristics of respondents

The majority of respondents were female (90%) and 79% were married. In addition to English language (a prerequisite of the course), all participants spoke some native languages, principally Hindi (82%) and Marathi (56%). Respondents had qualified as nurses by completing a hospital-based diploma programme (57%), a university diploma (10%) or a university degree (33%).

A number of respondents (63%) had been in professional nursing practice for 16 years or longer. More than half (62%) of all respondents were involved in teaching and 8% were currently working in management or administration, some as hospital matrons. The majority of respondents had some experience in caring for patients with HIV, including 26% who rated themselves as highly experienced. Only 22% of respondents declared having no experience of caring for patients with HIV.

### Impact of the initial course on respondents

Nearly all (99%) of the respondents reported that the course had altered their perceptions of caring for individuals with HIV, i.e. reducing their level of fear of contagion and increasing their self-confidence in this area. Additionally, almost all (98%) felt that it had increased their knowledge of HIV infection and the associated role of nursing in caring for affected persons.

### Achieving objectives

Respondents were asked to describe up to five intended actions. Most (83%) had completely or partially achieved their objectives for their first described action. The level of achievement success decreased with each subsequent action, with less than half (42%) of the respondents achieving any success for the fourth listed action. As over half of all respondents (59%) did not describe more than

three actions, analysis of the helping and hindering factors was limited to the first three actions described by all respondents.

The majority of action plans focused on initiating change through a number of activities within the arena of pre- and/or postqualifying nursing education (65%). Other respondents developed activities within most of the other fields of action, including infection control (18%). A description of a range of the action plans are discussed below.

### Action plans

#### *Infection control*

Typically, plans in this field involved in-service education or increasing supplies. In-service education programmes were aimed at all staff, from senior grades to the Class IV workers, and focused on the need to implement universal infection-control precautions. One nurse in Gujarat had responsibility for the delivery suite in the obstetrics department. Her plan was to undertake an audit of handwashing. Her first audit revealed inadequate handwashing owing to an insufficient supply of soap. She negotiated with her manager to increase the supply of soap and embarked upon an intensive in-service education programme. Her subsequent audit, 6 months later, showed a marked improvement in handwashing activity.

#### *Health education*

Several participants left the course with broad statement plans, e.g. 'include HIV/AIDS awareness in my health education work', and a variety of activities occurred. Industrial nurses employed at the naval shipyards in Vasco de Gama, Goa, developed and implemented a rolling programme of health education and primary prevention for harbour employees. One community nurse organized exhibitions in the villages just before and after World AIDS day, and a teacher wrote a play which her students performed on their community placements. Another group of participants developed and implemented primary prevention street theatre in their local commercial sex district.

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#### *Mutual support*

Within this field of action, efforts were made to develop a network for those involved in this area of work. In Mumbai, a group from cohort 1 established a monthly support group, to which subsequent course participants were invited. The purpose of the group was to share ideas about fulfilling action plans and lend support to each other's activities. In Gujarat, a similar group was used to continue their own education on the subject by inviting outside speakers. One group collaborated with the Trained Nurses' Association state branch to establish a specialist forum, which meant that, in the future, a national conference could be organized.

#### *Community action*

Action plans within this field focused on, 'developing HIV awareness with friends, family and community'. As in the health education field, an interesting variety of reports were received. In Goa, participants negotiated access to prisoners in Sada Sub-Jail, and developed and implemented focused health education sessions, the first time that this had ever been done. A series of talks were delivered to schools, church groups and, in Pune, one participant wrote songs incorporating safer sex messages that she sang on local radio broadcasts.

#### *Prequalifying nursing education*

Several course participants were teachers who had been sent to the course with the specific remit of incorporating HIV into the curriculum. These were often group action plans and covered nursing, midwifery and auxiliary nurse programmes. Not only did they achieve this but, in addition, many produced comprehensive teaching and resource packs. In one instance this even included a set of slides and a video – precious commodities in Indian schools of nursing.

#### *Postqualifying nursing education*

Similarly to those involved in prequalifying programmes, teachers in this field of action developed a

range of educational initiatives. In Ahmedabad, nurse teachers cascaded training (which was based on the knowledge that they had acquired during the course) throughout the entire State of Gujarat, eventually reaching the majority of nurses practising in that State. In Mumbai, 3-day multidisciplinary workshops were offered to all those closely involved in HIV care.

#### *Nursing practice and research*

Participants involved in nursing education often combined their programmes with small-scale studies of attitudes and knowledge. One nurse in Gujarat undertook an audit of handwashing and, in Goa, a group wrote three standards for caring for people with HIV.

#### *Policy development*

Although few elected to work in the action field of policy development, those who did achieved significant success. One of the first course participants worked in the state health department and influenced the state's policy on HIV/AIDS, particularly the need for nurses to receive training. One nurse in Gujarat was elected to the state's AIDS cell (the Government's co-ordinating forum) and given responsibility for organizing all in-service education. Participants from the Armed Forces, stationed in various bases throughout India, negotiated and agreed local policies for the appropriate care of HIV-infected soldiers and sailors.

#### *Counselling support*

Although counselling support was not initially their chosen field of action, several reported that counselling became an important aspect of their work, particularly for those in the community. Within this action field, one nurse in Mumbai persuaded her hospital to fund her to undertake a counselling course, following which she ran a support group for HIV-positive patients and their families. In Goa, supportive communication skills were incorporated into the curriculum. As a result of their community actions, three nurses reported that they

**Table 3 Factors positively correlated with achievement success**

<i>Factor</i>	<i>Correlation coefficient (r)</i>	<i>P-value</i>
Support from doctors	0.191	0.047
Support from other nurses	0.273	0.004
Support from other health care workers	0.231	0.015
Senior status of respondent	0.225	0.016
Increased confidence as a result of attending the initial course	0.187	0.042
Anticipating and being able to attend the follow-up workshop	0.225	0.001
Learning about change theory and action planning	0.227	0.023

intended to make this the focus of their next action plan.

#### **Factors associated with successful or unsuccessful achievement outcomes**

A number of factors were positively correlated with the achievement of successful outcomes (Table 3). Their increased confidence as a result of attending the course, and their initial introduction to change theory, were important factors identified by some for successful achievement. Additionally, the more senior the status of the participant, the greater the chance of their success. For many, the anticipation of reporting back on their progress to colleagues at a follow-up workshop, and their ability to attend this workshop, was linked to achievement. Finally, and perhaps most importantly, the ability of participants to garner support from their colleagues in the practice arena was crucial to achieving positive outcomes.

The nurse's own personal commitment, the type of action plan they chose, their increased knowledge or reduced fear, their nursing qualification, or their previous experience of nursing patients with HIV, were not significantly associated with successful (or unsuccessful) achievement outcomes.

Respondents identified two factors that were important in constraining or hindering achievement success: lack of personal authority ( $r=0.237$ ,  $P=0.029$ ); and resistance from managers ( $r=0.224$ ,  $P=0.048$ ). These were particularly common in projects aimed at primary prevention or areas of the hospital beyond their control. In one example, efforts to reach secondary school children were thwarted when the teachers refused to co-operate. One nurse wanted to put up a display in the outpatient department but she met resistance as her responsibility was in-patients and the manager for out-patients did not share her interest. The success of educational programmes involving medical staff or Class IV workers was reported to depend on the willingness of their managers for them to become involved. Additionally, in many areas Class IV workers are not normally involved in in-service education programmes and their union representatives required to be persuaded of the need to include them.

Other factors tested that did not reach significance were: lack of knowledge; resources; experience in implementing change; and resistance from colleagues.

## Discussion

Almost all participants in this programme were women, who in India, as elsewhere in many parts of the world, have a lower socio-economic status than men. Furthermore, nursing is not a highly ranked profession in this country, where doctors (mainly men) control the management and administration of health care institutions. Combined with the powerful cultural barriers in India, which prevent the participation of women in many HIV-specific primary prevention activities, e.g. discussing explicit sexual behaviour with male patients, it is encouraging that so many reported successful action plans.

The interactive and participative style of the course was a new experience for almost all, yet it engaged their attention and helped them to focus on relevant nursing practice issues within the arena of AIDS patient care. The results of data analysis suggest that, for nearly all participants, completion

of the course increased their confidence and knowledge and decreased their fear of contagion. This, together with exposure to basic change theory and action research methods, was important in ensuring the achievement of their action plan objectives. Follow-up data further showed that their involvement in this course had a profound effect on many participants, frequently inspiring them to greater personal and professional commitments. These phenomena are difficult to overstate and there were many examples in each cohort of nurses changing their professional (and often personal) lives as a result of this course in order to more completely engage the issues of the care of patients with AIDS. Examples included one nurse taking a demotion in order to transfer to a more progressive hospital where she could gain better quality experience of caring for patients with AIDS. Others became role models, refocusing their entire careers to the care of patients with AIDS. Consequently, future courses should continue to incorporate this highly interactive style of facilitating learning experiences, rather than a didactic approach that is more customary in India.

The action research model was attractive to the participants and appeared to empower and encourage them. The follow-up workshop, although a novel experience for participants, focused them from the beginning on a future scheduled event where they would report their achievements. Data analysis showed that this feature was an important element in the Kaleidoscope programme, reported as significant by many in facilitating achievement success. Our experience convincingly suggests that courses based on an action research model benefit from a formal follow-up. Additionally, collaborative contact between the course teachers and participants during the implementation period is supportive and motivating. Where operational distance exists between teachers and participants, and there are limited resources, collaboration can be maintained by post, facsimile and E-mail.

To support their action plan reports, participants provided a range of material, including: curriculum and policy documents; press cuttings; photographs; evaluation forms; letters from managers; and teaching programmes and materials. These were readily

shared with the rest of the group for their future use. In Goa and Gujarat, managers were invited to the feedback sessions and this provided the participants with significant encouragement to continue their plans. Thus, by providing the participants with local supporters and stakeholders, it ameliorated, to some extent, the support that we could offer from a distance.

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The majority of participants reported significant success in achieving their highest prioritized objective. Data analysis demonstrated that when participants were able to either work together or attract multidisciplinary support for their proposed action plan, or concentrate on one wholly in their domain, they had a greater probability of achieving their objectives. This was particularly noticeable in Gujarat State where a group of 10 senior nurses were based on the same hospital site. Together they organized their activities with the permission of the matron, whose support was reported as having the greatest influence on other staff. Overall, what emerges from the reports is that where plans were very specific in terms of outcome and concerned only nurses, they were more likely to be successful. Conversely, resistance from managers was an obvious inhibitory element for some. Future modifications of the course may include more in-depth training on negotiation skills and team building.

Many participants undertaking these courses were working in nursing education or administration and were highly experienced and well educated. Data analysis convincingly showed that those participants who had the most authority and the greatest status were amongst the highest achievers, while a lack of authority was reported by some as a constraining factor. This suggests that exclusively recruiting nursing leaders to future courses may result in greater positive changes in nursing practice.

## Conclusion

Action research involves several cycles of activity and this project can only report on the first. Nevertheless, it shows that significant progress can be made. The costs of operating such a project are high as it requires two course facilitators and therefore

sustainability must be a consideration from the start. A local teacher was involved in the development and delivery of the course, so activity was not solely reliant on visits from the UK facilitators. By developing a local infrastructure and informing each group of previous course participants, it is hoped that the work will continue.

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This project demonstrates that an action research model can be used to good effect where resources are severely limited. Empowering women to be change agents may seem to have serious limitations. However, India has a female-dominated qualified nursing force numbering over 1 million, and their collective potential to bring about meaningful changes in patient care is great. To us, they represent India's best chance of developing compassionate and appropriate models of care for the rapidly increasing numbers of their fellow citizens destined to be affected, one way or another, by the scourge of HIV infection and AIDS. Developing their competency to do this through an action research process, such as the Kaleidoscope model, could be an important component of an overall national strategy designed to ensure the provision of competent and confident care for all patients, including those with HIV.

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