

HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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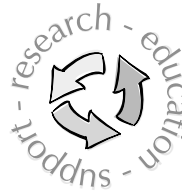
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Aims and Scope

HIV Nursing has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

HIV Nursing is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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Time to hear the patient story

Jane Bruton

HIV Nurse Manager, Chelsea and Westminster Hospital, London

December 1st 2007 marked the twentieth World AIDS Day, with global publicity and events from the Brikama Health Centre in Gambia, where over 200 Gambians and representatives of international NGOs gathered to commemorate the day [1], to Wenceslas Square in Prague, where the Czech AIDS Help Society gave out leaflets and information from decorated trams [2].

This year, with new and better epidemiological data, our understanding of the epidemic has been enhanced. The UNAIDS report shows that in 2007 the global prevalence of HIV, that is the percentage of people living with HIV, has levelled off and the number of new infections has decreased from last year [3]. With more access to treatments and a decreasing death rate the total number of people living with HIV continues to rise and now stands at an estimated 33.2 million. Every single one of these people has a patient story.

Dr Peter Piot, UNAIDS Executive Director, warned:

'Unquestionably, we are beginning to see a return on investment - new HIV infections and mortality are declining and the prevalence of HIV levelling. But with more than 6800 new infections and over 5700 deaths each day due to AIDS we must expand our efforts in order to significantly reduce the impact of AIDS worldwide.' [4]

In the UK, what more do we need to do? The Health Protection Agency report *Testing Times* [5] describes the state of sexual health in the UK; although there is some good news, overall it makes depressing reading. The estimated number of people living with HIV has increased to 73,000, with up to one-third of these HIV infections remaining undiagnosed. Of particular concern is the rate of new HIV infections among men who have sex with men (MSM). Dr Valerie Delpech, Head of HIV surveillance at the HPA said:

'We are still seeing high levels of HIV transmission in gay men in whom we anticipate that there will have been just over 2700 new diagnoses of HIV infection in 2006. In recent years we have seen steady increases in all sexually transmitted infections (STI), including HIV, in gay men and since 2003, the number of HIV diagnoses reported annually has consistently increased and exceeded the annual number of diagnoses throughout the 1980s and 1990s.' [6]

While the levels of heterosexual HIV transmission remain relatively low, there continues to be a

steady increase, especially in the black minority ethnic (BME) population. There are also worrying signs that transmission of HIV among injecting drug users (IDUs) may be increasing.

Patient involvement in prevention and testing has never been more important. Without a coherent safe-sex message from government, it is the patient voice that has to speak to those at risk.

There has been a major shift over the past decade in the geographical distribution of people living with HIV across the UK and this is posing a great challenge in the provision of services and expertise. Worryingly, there is evidence that a significant proportion of those who present for the first time sick with CD4 cell counts below 200, that is late presenters, had been in contact with healthcare professionals in the preceding year due to HIV-related symptoms.

Both the HPA and UNAIDS reports recognise that HIV-related stigma and discrimination are a major barrier to HIV testing and accessing care and a serious threat to the health and wellbeing of those living with HIV.

Stigma has a hugely negative impact on patient involvement, which is one of the foundations of patient-centred care. Stigma can make disclosure impossible. It often stifles the patient voice depriving carers of the insight into the experience of living with HIV. It can prevent people living with HIV fighting openly for their rights to treatment and access to or improvement of services.

The patient voice must be heard. That means giving time and importance to patient stories. As nurses we hear stories every day. We share them at handover or informally with our colleagues. They add to our tacit knowledge, to our experience and expertise. Sadly much of that learning is not collective because the stories are rarely written down. Gradually, many of these stories begin to fade from our memory.

In this issue we are privileged to be able to share with Fernandez the experiences of the patients he interviewed and give over our pages to the patient voice. Storytelling is powerful and yet too often the structures of consultations and episodes of care confine the patient to a set of questions and a time frame.

The second aspect to patient involvement is the partnership between clinician and patient. In a recent US study on shared decision-making on antiretroviral therapy, Kremer *et al.* concluded that most patients living with HIV perceive that the

decisional role they have is not the one they actually desire [7]. The research showed that one-third of people taking antiretroviral therapy said they were less involved in the decision than they wanted to be; and a half of those declining antiretroviral therapy perceived a lack of physician involvement. The study emphasised the importance of meeting patients' ideal decisional roles through simply asking them to specify their preferred role at the start of the partnership.

The level of involvement that the patient wants cannot be assumed and is never set in stone. There are times when patients relinquish their desire to be involved in the decision. The key point from the research was that we can never presume.

The third development explored in this issue is patient involvement through organisation. Both within voluntary and statutory organisations patients are coming together in order to gain strength and support from each other and to effect change in service provision. Nurses are increasingly involved in patient forums, either within their own service or at a Hospital Trust level. There are several models of patient involvement at this level. In this issue, Campbell *et al.* and Greenham give examples of their experience.

Individual patient stories are often seen simply as a series of anecdotes in the context of a systematic approach to care. However, their impact is transformed when they are written down and collected: they can become a powerful tool to change practice, shape service provision and take the prevention message to a new generation.

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Living with chronic HIV-hepatitis C co-infection: patients' illness narratives

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Introduction

Co-infection with HIV and hepatitis C (HCV) can prove challenging, as each disease can complicate the natural progression of the other [1]. In addition, co-infected individuals face stigma and isolation due to negative public attitudes.

An abundance of biomedical research masks a distinct lack of qualitative research in this area; therefore a small research study was undertaken to give a voice to marginalised individuals, thus widening the reader's understanding of this phenomenon.

A literature review illustrated that illness narratives have been used to research several chronic illnesses, for example multiple sclerosis [2], arthritis [3], diabetes [4], cancer [5] and even HIV/AIDS [6]. Through a process of reconstructing past events and sharing hopes for the future, the narrative proved useful for collecting important information about living with chronic illness. Narratives were consistent in illustrating how people's lives and sense of identity were disrupted, as they explored the complex relationship between their illness, their body and their self.

Research methods

The study explored the illness experiences of a small group of co-infected individuals, using illness narratives, which have emerged as an important source of data in an increasingly evidence-based world [7]. Methodological choices regarding how the research would be structured, analysed and presented were influenced by extensive work on narrative analysis [8].

Following institutional approval, recruitment was undertaken within a London hospital amongst patients diagnosed with co-infection for at least 5 years. The depth of the interview data permitted a small sample size with four individuals participating in the study. To protect their confidentiality their names have been changed; biographical details are summarised below in Table 1

Each participant was invited to tell their story of living with co-infection. It was anticipated that they would start with their lives before diagnosis and move forwards from there. However, in view of the devastating impact of their illness, the stories were often erratic and disordered. Each interview was taped, which facilitated a word-for-word transcript and allowed supplementary note-making that assisted in the analysis. Interviews lasted between 1 and 2 hours.

The data analysis extended beyond the interview content alone to include the style of the narrative. It consisted of repeatedly reading the transcripts, and listening to the interviews to form different perspectives, whilst preserving the participants' significant words. Making the research persuasive and maintaining a continuous and open communication with the participants, added to the reliability and validity of the research thus making it more rigorous and credible.

Findings

Data analysis yielded four different themes: 'a shattered life', 'a life of illness', 'a life regained' and 'a future life', which are presented with supporting data from the narratives.

Table 1: Biographical details of the study participants.

Pseudonym Gender	Age	Country of origin	Occupation	Mode of infection	Sexual orientation	No of years diagnosed with HIV	No of years diagnosed with HCV
Cassie Female	43	United Kingdom	Housing officer	IDU	Heterosexual	19	19 (approx)
Jose Male	46	Spain	Cleaner	IDU	Heterosexual	5	5
Esteban Male	43	Spain	Unemployed	IDU	Heterosexual	13	13
Monica Female	41	Italy	Unemployed	IDU	Heterosexual	14	14

IDU, injecting drug use.

1. *A Shattered Life*

Each participant's narrative started years before their diagnosis with events that led them to start injecting drugs. Whether drifting into a world of squatting and petty theft or moving in increasingly affluent circles, their initial drug-taking quickly led to addiction:

'My first boyfriend was a drug-user who was 8 years older than me. That's how I started taking drugs. I was 14 when I started smoking and by 15 I was injecting.' *Cassie*

Whilst participants expressed no blame for their injecting, it did not prevent feelings of regret about the legacy of losses that it has left them. As well as citing it as the cause of their co-infection, it accounted for feelings of low self-esteem, guilt and exclusion. Drug-use brought with it a series of losses: wasted time, money and opportunities, which in a life shortened by disease, were a source of constant regret.

'That year was one of the darkest of my life. Everything was negative. I just destroyed my life. It's like I dug my own grave.' *Esteban*

Giving drugs up was a significant achievement but was frequently followed by the negative impact of a diagnosis of co-infection that elicited feelings of inadequacy and shame. Furthermore, this threatened their sense of identity, leaving them feeling incomplete and unable to function normally in society. Participants described unsatisfying relationships and the absence of sexual intimacy. It is significant that none of this particular group had children. They also described stigmatisation from their illness's association with drug-use, made worse by the seclusion of cutting all drug-using ties when they stopped injecting:

'I have two problems: sickness and solitude. Loneliness is my biggest problem.' *Esteban*

Guilty feelings from being infected and from the harmful media portrayal of drug-users, made them wary of disclosing their status, so they frequently kept it secret.

'People are so narrow-minded. You hear things like: "Once a junkie, always a junkie". Every time you hear those comments it's painful' *Esteban*

Participants referred to putting up defences, such as 'holding a shield' to their chest or 'wearing a mask' to avoid being judged, which in narrative terms serve as metaphors for protecting their vulnerability from an outwardly hostile world.

2. *A Life of Illness*

The narratives illustrated the complexity of living with not just one, but two life-threatening infections; its effect on their health and fears of becoming sick.

It was like being diagnosed with HIV all over again and I thought if I'm not going to die from one I'm going to die from the other.' *Cassie*

Morbid feelings were prevalent when illness was at the forefront of their thoughts, such as around diagnosis and starting treatment.

'I didn't have nightmares before but now I have lots, relating to death and hospitals. My life has changed a lot.' *Jose*

'When the hospital suggested treatment for my hep C, I thought "Well, I must be dying" because they've offered me the treatment.' *Cassie*

These constant ups and downs reflect the unpredictability of living in a world where medicine is advancing but uncertainty and the fear of death remain a concern. The dual perspective of treatment being both a means of survival as well as a source of side-effects and dependence is complex. Participants depicted HCV treatment as inflicting the most debilitating side-effects. Depression, desperation and feeling out of control when coupled with weight-loss, rashes and alopecia, led to further withdrawal from society.

'After the interferon injections I'd get fever for three days and just lie in bed. Then I got anaemia and felt so weak. But it just went on and on and I thought there must be something else going on. And sure enough they discovered my thyroid gland had gone because of the treatment.' *Monica*

Participants expressed feelings ranging from elation and relief when they responded to their treatment to a guarded optimism, but always tinged with regrets.

'Twenty years down the line I tell myself: "God I'm lucky". I'm so fortunate in the treatment I've had. But throwing pills down your neck and taking injections? You do want to just sometimes magic it all away - the HIV and the hep C.' *Cassie*

3. *A Life Regained*

In time, participants took measures to regain control of their lives, from fighting the disease itself to altering their perspective on life in the light of ongoing problems.

'There was a peer-group around that time. There was "Mr 1985" (diagnosed in 1985) who was one of my beacons. He was doing alright until suddenly he died. In this group of 11 people, five had died and I was "1986". I wanted to live forever not die in a couple of years so I started looking for a better hospital.' *Cassie*

Here 'beacons' serve as a metaphor for the race against time, and whilst participants faced a hard, slow struggle, none appeared to give up. Instead

participants hoped that things would improve or they simply changed their perspective to appreciate the smaller goals achieved.

'It is painful to talk about this stuff. But in a way it helps. If I don't talk about it for a year or so, when I do talk I realise that things have moved on and I've gained a little bit more strength.'

Monica

Fighting back consisted of taking controlled and measured action, to actively organise their health, disclose their status and seek support, which could be painfully slow.

'Sooner or later I'm going to get out of this circle of loneliness. If I start with just one friend behind that friend comes their friend. Then I will have two friends. And so on ...'

Jose

The difficulties and hostility they have experienced appear to have heightened their sense of humanity, in terms of what qualities they would look for in others, as well as what they aim to improve within themselves. Their narratives valued acceptance, tolerance and actions towards others that really made a difference.

'If I can help someone I will do it. I don't consider myself a good person but I am not a bad person.'

Jose

The participants' experiences led them to view society's attitudes as being symbolic of moral repression, which led them to ask for greater compassion and understanding for marginalised and morally judged individuals. However, the participants' limited progress against social injustice did not diminish their hope and determination to strive onwards and their narratives demonstrated that struggle and hardship could be a catalyst for personal and positive transformation.

'If I could go back and change anything, I wouldn't take drugs. But I wouldn't change who I am. Before my diagnosis I had all the time in the world, now I realise there's much more I want to do and so much more to life.'

Cassie

4. A Future Life?

This final theme came from participants' thoughts about the future, which was invariably approached with hesitation. They looked ahead small distances only and experienced long periods of limbo where time moved forwards but their lives seemed stagnant. This stemmed from uncertainty about their health, a sense of marginalisation, feeling ill-prepared to realise any future plans they might have and constant setbacks.

'I can only think of the future in the very short term. Psychologically it's a big problem as I am a bit confused what to do with my life.'

Jose

In biomedical terms a treatment response is a cure and end-point, however, positive responses to HCV

therapy were treated with caution and taken in isolation did not necessarily signal the end of hardship and distress.

'Eventually the hepatitis treatment was finished and my family said to me: "That's good news you can go back to normal". Normal? What's normal about my life? I've had everything stolen from me. I can't have children ... I cannot be a mother. My life is just black and grey. Being on the treatment was something I could do but now it's finished there's just nothing. Nothing.'

Monica

It is evident that participants who perceived their quality of life as bleak continued to have to deal with the legacy of their illness' effect on other domains of their life. This included unfulfilled relationships, inadequate employment and lack of social roles.

Discussion

The theme of a 'shattered life' compares strongly with the concept of 'disrupted identity', recurring within the literature reviewed whereby feelings of lack of 'fit' and dignity impinged on personal relationships. However, in this study the severity and permanency of the illness multiplied this disruption, shattering their sense of identity and threatening their existence. The stigma attached to both HIV and HCV led to low self-esteem when compared to other chronic illnesses such as diabetes [4] and cancer [5]. Further negative labelling was associated with becoming infected through injecting drug-use, which is portrayed as tragic and evil within popular culture [9]. This contributed to individuals hiding their illness, feeling guilty and not receiving the emotional support that people with other chronic illnesses would normally receive [3]. Stigma was made worse by worries about onward transmission; personal identities were concealed for fear of negative stereotyping within social encounters [10]. However, these co-infection narratives also served another purpose as they created positive moral identities for their narrators. Through their stories of addiction and recovery they elevated their status in society from 'junkie' to that of reformed addict and moreover an expert patient with a valued opinion [11].

The second theme, a 'life of illness' draws parallels with the concept in the literature of 'disrupted biography', whereby individuals' usual assumptions of good health, independence and a future life were threatened. In this study a preoccupation with morbidity, uncertainty and mortality presented as concerns about relapse, relapse into drug-use, developing resistance to HIV and concerns about recurrence of HCV after completing therapy [12]. Despite monumental treatment advances, new uncertainties have arisen, intensified by having two unpredictable illnesses. However, telling their stories

allowed participants to make sense of their health-events and data suggest that whilst treatment is arduous and somewhat overwhelming, the right care can enable individuals to reach a stage where disease is in remission. Such achievements for those who have experienced so many obstacles is only enhanced by sharing these stories, via the internet or HIV press, with others facing similar problems [13].

In the third theme, 'a life regained', participants began to fight back, taking steps towards managing their co-infection and fostering positive attitudes towards treatment. In addition, they began to rebuild lives previously ravaged by drugs and social injustice, which suggests that adversity can act as a catalyst for personal reconstruction [14]. People strive to re-establish positive identities after years of chronic illness and with normal avenues to success often closed to them, they may pursue this through alternative paths such as personal development [11]. In this study participants highly valued tolerance, humanity and compassion, qualities that really had an impact on other people's lives. Whilst disclosure of status could have sanctioned their ill health and facilitated support, it remained sensitive and carried the risk of further marginalisation. Despite continual setbacks, these narratives contained a constant thread of hope and search for personal transformation. In line with the literature reviewed, hope was portrayed as a means of coping and enduring but tended to fluctuate with the course of the illness [15].

The final theme, 'a future life', focused primarily on thoughts and concerns about their future, which like other chronic illnesses was sometimes difficult to visualise. Complex health, unpredictable outcomes and continual setbacks even in the presence of 'stable' disease, led to a cautious approach. This is consistent with Paterson's [16] Shifting Perspectives Model of chronic illness, where illness and wellness were alternately at the forefront of people's minds. It supports the concept that co-infected individuals may fluctuate between, or even simultaneously experience, very different perspectives. On the one hand feeling lucky to be alive having responded to treatment, on the other hand regretting becoming infected and being treatment-dependent. From the biomedical perspective, it is assumed that eradication of disease is an unquestionably positive experience and clinical end-point [17]. These narratives questioned that assumption. When treatment succeeded but quality of life did not improve due to underlying social issues, this was perceived as simply prolonging individual anguish and loss.

Limitations and recommendations for practice

Whilst the small sample size could be levied as a limitation of this study, the depth and quality of the data was overwhelming. In addition, in view of the

sample consisting of ex-drug-users, the findings may not be wholly transferable to other co-infected groups.

However, the research illustrates the importance of moving beyond managing the technical aspects of treatment towards being willing to work with personal issues associated with illness [18]. This requires adopting a reflexive approach that recognises our own fears and prejudices about engaging with patients as equal agents, regardless of lifestyle issues [19].

Some nurses may feel competent to engage in 'identity work' by helping individuals find meaning in their lives [20]. However, it is equally important to facilitate the use of psychology services, particularly when health assessments identify low self-esteem, relationship problems and morbid fears. Stigma can be reduced through the involvement of appropriate agencies that can ease isolation and foster stronger peer-support networks [21]. A knowledge of the complex issues surrounding prejudice is also beneficial for practitioners [22].

There is an argument for specialist services in view of the complexity of treatment, one model of which involves integrating co-infection into HIV services [23]. However, such services should have in place easy referral pathways to both psychology and drugs and alcohol services [24].

Finally, the benefit of formulating illness narratives within suitably validated forums appears under-utilised within the sphere of co-infection [25]. This process of sharing experiences can foster more positive identities for the narrator, whilst serving to educate others [26].

Conclusion

It is evident from this study that individuals living with co-infection most likely face multiple challenges that threaten their lives and sense of identity. The unique attributes of co-infection, when compared to other chronic illnesses, highlighted a complex picture, where stigma, prejudice and low self-esteem led to isolation and marginalisation. However, the illness narrative appears to be a powerful tool for reconstructing more positive identities and appreciating steady but slow progress. Sharing these narratives gave voice to individuals marginalised by their illness, whilst helping to inform others. These narratives, that needed to be heard as well as told, provided personal accounts of lives disrupted, transformed and forever altered by co-infection. Furthermore, being embedded in people's real lives they have provided an alternative to the biomedical perspective. It is hoped that bringing these narratives to the fore, will influence readers to provide the therapeutic and empathetic care that co-infected individuals require. Practitioners who can encourage patients to share their illness stories with them stand to benefit from a greater understanding

of the wider impact of illness on identity, quality of life and patients' attitudes towards treatment.

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Successful participation

Phil Greenham

Chief Executive Officer, Body Positive North West

Introduction

Once identified as a 'patient', a person is immediately assigned a role, independent of whether the condition is acute or chronic, that details how the person should behave and how others should behave towards the 'patient'. This article discusses how the participatory model offered by peer-led collectives, such as Body Positive groups, can break down the constraints imposed by a medical model of care. By sharing experiences, people within these groups offer each other very powerful peer support that enables each individual to participate in managing their own health.

History of peer-led Body Positive groups and participation

During the 1980s, Body Positive groups came into being around the UK as a response to the rapid emergence of the new and, at that time,

untreatable virus, HIV. By the mid-1980s there were 30 groups nationwide and they were among the first to use a model that highlighted the voice of the patient. Body Positive groups used a social care model that delivered direct, peer-led care services such as therapy and buddying to a predominantly young, articulate group of men who had little chance of survival. Until this time, patient participation was almost unheard of: people revered the doctor and the doctor's word was sacrosanct. Medical models of care predominated; however, HIV catalysed partnerships between doctors and patients that questioned medical and social models of delivery. Clinicians, with no medical solutions, began talking to patients about choice. Activists, researchers and collective communities began supporting a common agenda and peer-led community development models came to the fore within the context of a cure, or at the very least treatment models, and secondary prevention for people who were HIV-positive.

Jonathan Mann [1] of the World Health Organization commented in 1990:

'... never before, even in the time of the great European plagues, has a health problem catalyzed such a broad rethinking of the health of individuals and society, and therefore also of our social and political systems.'

Self-help services began to flourish outside the health service, although often with financial support from the mainstream. They also became a part of health service referral care pathways. While Body Positive groups may have evolved from 'patient groups' they soon had their own identities and became a vital part of the voluntary sector team, meeting an often previously unmet need. For over a decade, peer-led HIV groups predominated in the UK, sustained by emerging community development policies.

Volunteers also played a vital part in the delivery of services. The risk of stigma or discrimination had an effect of uniting people together in common adversity. During the 1980s, groups of HIV-positive people strengthened and became firmly established. Larger, corporate voluntary sector organisations such as the Terence Higgins Trust and National AIDS Manual also grew during that era. They are still key participants working in partnership and sometimes challenging the statutory sector.

Development of public health medicine

The Department of Health's 'Shifting the balance of power' [2] was a major development within the statutory sector. Public health had long been the domain of medical doctors and infection control predominated. Now NHS staff members were encouraged to acquire a wider understanding of public health. More people were employed to deliver primary and secondary care and to actively use the legislation on community participation and involvement.

This policy shift had economic effects on peer-led community services as funding was reduced and many Body Positive groups closed down. The need for 'patient participation' for people with long-term chronic disease and managing them more efficiently was increasing. However, at the same time, the NHS also faced massive resource constraints that ensured a lack of capacity to support patients.

In HIV care, advances in antiretroviral treatments galvanised the NHS into pan-district commissioning forums that addressed the whole sexual health agenda. To play a part in these forums and be a significant stakeholder, it was important for voluntary groups to shift limited energy and skills into commissioning. This was a difficult move as

most Body Positive groups had little knowledge of sophisticated monitoring and target-setting work.

Body Positive North West (BPNW) recognised the changing paradigm and its potential impact on the organisation's philosophy and adjusted its delivery of services, but also managed to stay true to the original aims and objectives identified in 1986. BPNW's 'unique selling point' is that the whole organisation is shaped by, and involves people who have HIV. The governing documents, the Memorandum and Articles, ensure that the strategic direction from the Board remains in the hands of those directly infected and affected by HIV.

HIV demographic changes

Clearly to anyone involved in this field, there have been major demographic changes in the communities that are affected by HIV. Over half the people living with HIV in the North West live in Greater Manchester. In the North West, gay men account for 53% of those living with HIV and 35% of people accessing treatment and care acquired their infection abroad. Of those who acquired HIV abroad, 70% acquired it in sub-Saharan Africa and 81% acquired it through heterosexual sex, compared with just 13% who acquired HIV in the UK. Two-thirds of all people accessing care in the North West are White: the remaining third consists of people from Black and ethnic minority communities [3].

BPNW operates social inclusion policies actively within the organisation, ensuring that our volunteer base reflects the diverse communities affected by HIV. Service delivery is facilitated by a small core of salaried staff along with a number of volunteers. Approximately 50% of our fantastic volunteers are people who have themselves been service users for at least a year. This group of people work in tandem with a wide variety of agencies from both statutory and voluntary sector backgrounds, thus ensuring pathways for service users are smooth and easily navigable.

Two examples of innovation emerging from 'Patient Participation' and the Positive Self-Management Programme

The Positive Self-Management Programme (PSMP) was developed in the USA for people with HIV-positive status and is rooted in norms that stress self-efficacy and taking on individual responsibility for managing illness.

In 2004-2005 we undertook a case study of a course run by BPNW with the National Primary Care Research and Development Centre (NPCRDC). The course run by BPNW is the Expert Patient Programme tailored to people with HIV. The course, called the Positive Self Management Programme

(PSMP) and the study arose out of the national evaluation of the Expert Patient Programme (EPP) being undertaken at the NPCRDC.

The aims of the first study BPNW conducted were to compare and contrast the delivery, impact and appropriateness of the training materials and to identify and compare the role and value of a voluntary sector agency in mediating self-management support.

Methodology

All written documents from the course were analysed, with all participants being interviewed before and after the course. The degree of interaction and disclosure in the groups during the course was assessed, and how the group acted to aid its members was explored. The points of importance to the participants were also identified, with the goals and action plans noted. Two PSMPs were run at BPNW during a 4-month period in late 2004 and early 2005. A total of 32 participants attended the courses and 37 pre- and post-course interviews were completed with separate interviews for course conveners.

Key points that emerged from the study were the importance of the voluntary sector provision as opposed to sole statutory sector provision. Programmes such as EPP and PSMP that are placed in voluntary organisations increase the likelihood of producing active, engaged, self-managing citizens; effectively 'patient participation'. This provides evidence for the suggestion that self-care support resources could be very effectively directed at helping voluntary organisations develop pathways for people with newly diagnosed long-term conditions. These pathways could then be integrated into the advice and care provided by the NHS and Social Services.

Another key point that emerged from the study was that outcomes from the course were dependent on the individuals' starting points with people with the lowest self confidence benefiting most. The study also identified that PSMPs may represent a democratising shift in patient care.

The Baobab Group at Body Positive North West

BPNW provides services to many people from diverse communities living with and affected by HIV. In the past 2 years there has been a steady increase in the number of Black Minority Ethnic (BME) individuals affected by HIV. This group of people often face stigmatisation, social exclusion, isolation and discrimination.

Following the studies in 2004–2005 BPNW undertook an ethnographic observational study in 2006–2007 as Action Learning Research to explore how an anglicised version of an American course delivered by a voluntary organisation was received by a

group of people with HIV who originated from sub-Saharan Africa and were seeking asylum.

Two main issues emerged. Those from sub-Saharan Africa articulated norms and values that differed significantly from the philosophy of individualism that underlies the PSMP. This shows that clear differences are needed in current public health approaches as they differ from successful approaches to people from the sub-Saharan Africa. Secondly, service users also identified urgent social problems and the need for welfare and social support, neither of which the course attempted to cover. We suggested that these two factors help explain why learning self-management skills was not seen as a priority for this cohort of people managing their HIV status initially in 2005–2006.

BPNW formed the Baobab group in 2005 to address the conclusions reached after this research. The group was named after the baobab tree, a well-known symbol of community gathering, consultation, discussion and arbitration. The current aims of the group are to support Africans infected and affected by HIV/AIDS through regular meetings, advocacy, advice and information, as well as the traditional services available at BPNW.

Initially, the Baobab group emphasised support for male members of BME who traditionally had been reluctant to access services; however, it was soon realised that both men and women wanted a service that gave access to all.

It would be understandable for some female participants to have a high level of mistrust of male participants as many became infected with HIV through rape. They have also experienced sexual trauma, loss, bereavement, war and conflict in their countries of origin and are now refugees and asylum seekers. However, the safe and supportive environment within the group lessened the impact of what could have been a threatening and stressful situation. Also, often lone parents, women felt it would benefit children to be involved in a group with representation from all ages and genders within the African community to provide appropriate role models for children and families. In addition, male participants had concerns that their culture was being dissipated through long-term residence in the UK and felt they could have an important role in strengthening and reinforcing their own cultural identities and perspectives.

During the weekly meetings members share knowledge and concerns around their lives in the UK and have become instrumental in steering the aims of the group for the future. Many members have become volunteers within the agency as they have a considerable range of professional skills and expertise. By sharing experiences, the Baobab group has acted as a 'surrogate' family.

Patient participation

In reviewing patient participation, a complex array of situations has to be taken into account such as the need to explore individual notions of power and control. However, these case studies cannot be divorced from the impact of social systems that can reinforce power imbalances. Collectivism is also a key dynamic in communities taking charge for themselves and this is evidenced when individuals share issues and develop common goals.

Directives such as the Department of Health Expert Patient Programme have been operational in this country since 2002 [4]. EPP demonstrates that self-empowerment for people with chronic long-term conditions has a significant effect on self efficacy [5] and, subsequently, on an individual's health status. Investment in prevention and secondary prevention that does not rely on the bio-medical model but develops social models, such as EPP, moves towards greater patient control. Prior examples of engaging with communities contrast with these attempts to secure sustained health gain through local people and patients. The idea is that they develop and drive the agenda initiated together by front line workers, modifying its direction and gradually becoming involved in policy development as key and equal stakeholders. Within this model, the gap between communities and the services that they use are supposed to be narrowed and become seamless as the vision of joined-up working turns into reality.

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Developing user involvement in HIV services in London

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In recent years attention has been focused on the greater participation of health service users in the identification of health service need, service design, and delivery and service evaluation. This approach attempts to improve communication between health professionals and the health communities they serve in order to deliver more effective services. The establishment of user groups in HIV services has been one approach by which clinicians have attempted to establish ways that service users could help in the improvement of clinical services. This paper describes the process in the involvement of service users in the work of the North East London Sexual Health and HIV Clinical Network (NELNET) and the establishment of a network-wide user group called Patient's Voice. The paper discusses factors and challenges that must be addressed before meaningful user involvement in HIV services can be established.

Introduction

The UK Department of Health encourages users of the NHS to be actively involved in all aspects of service provision, including decision-making and planning processes and for healthcare providers to welcome the contribution of users' opinions [1-3]. In the management of chronic conditions such as HIV disease, user involvement is particularly important as it can improve communication and understanding between health professionals and the community they serve and helps them to develop services appropriate to the needs of that community. The process also aims to engage the expertise of the patients and increase the self-confidence of service users resulting in better self-management skills and a more collaborative relationship between service user and provider (the 'expert patient') [4-6].

Experiences of involvement for HIV service users

Effective user involvement has been difficult to achieve in NHS services such as those for diabetes and mental health, and in HIV services it has been particularly problematic. The evaluation of HIV services has often been limited to the use of anonymous surveys in an attempt to identify areas

of the service that need attention, without being able to tap into the service users' experience and views through any other means [7].

Sexual health services are unique as few people wish to announce publicly that they have a sexual health problem and fewer still that they have HIV disease. Service users may also be reluctant to discuss services normally associated with their personal life and particularly around issues of sex, sexuality, infection, illness and death. People with HIV, who are already stigmatised, have a particularly strong need for confidentiality and may worry that confidentiality would be compromised by participation in user involvement [8,9]. In addition, some healthcare professionals have been reluctant to implement any changes that disturbed the traditional power relationships between users and service providers [9].

In her article, Bruton [9] outlines a successful model of user involvement in the HIV clinic in Brighton. Reflections on the model that was developed concluded that there are barriers to user involvement from both clinicians and service users. Disclosure issues were concerns from the perspective of service users and lack of experience with the philosophy behind user involvement was an issue for clinicians. The paper emphasised the need for an ongoing commitment to the process from both service users and clinicians as it takes time for its benefits to be seen. The notion of the 'stropky patient' was drawn on: a stropky patient is one who is empowered and able to talk to clinicians and managers about concerns and who expects to be taken seriously.

A National AIDS Trust report [10] highlighted several barriers to user involvement including: users' lack of skills and confidence; insufficient trust that the NHS would give authority to users to make a meaningful contribution; and the difficulty of creating user involvement that is truly representative of the patient group. The report emphasises the commonality of HIV and the shared issues among people affected such as the needs for appropriate medical and social support, accessible clinic times, support from clinical staff to build confidence, and awareness of stigma and how it affects access to services.

Clients' needs and personal circumstances influence the criteria used to judge the quality of services and users will have conflicting opinions about healthcare provision [8]. This emphasises the challenge of establishing how representative are the different views that will necessarily exist in any group of service users and also the importance of reaching out to marginalised groups whose voices will be even less strong. People from sub-Saharan countries constitute a very large proportion of HIV service users, particularly in London, and there are many challenges involved in ensuring that their voices and experiences are heard [10-12].

Establishing user involvement in North East London: the consultation process

Consultation with service users about their perceptions of how clinical services are organised and delivered is often difficult. Clinicians in London who are part of NELNET and professionals working in the sector organised a consultation event in 2006 to ask service users their opinions and perceptions about services they received: what they would like to influence or change in these services, and what were the ways in which they might do this. The event aimed to give service users examples of successful user involvement models in HIV services. Speakers from existing user involvement groups outlined how they had organised themselves and their experiences of being involved in the process. Participants in the consultation process discussed these issues in small and large groups and had the opportunity to share their opinions, perceptions and ideas of influencing the services provided to them.

The event was widely advertised in five clinics in east London by posters and leaflets and clinical staff were asked to promote the event to their patients. The event was scheduled for the early evening; crèche facilities were offered and refreshments were available.

Thirty people indicated that they were interested in attending; however, only 10 people actually attended. Reasons given for not attending were that transport and/or translation was not provided (8), inconvenience of the time of the event (3), other commitments (3), concerns about confidentiality (1) and other reasons (5).

Participants were asked to discuss eight questions within small groups and then to feed back their discussions to the larger group. Notes were made of their feedback. The questions addressed were:

1. How do you tell someone in your clinic/service about things you are happy/unhappy about?
2. How do you feel these comments are acted on?
3. What are the current barriers to service user/patient involvement?
4. How do you feel services are tackling these barriers?

5. What would you like to influence in your current services?
6. How would you do this?
7. How can we change things to improve involvement for HIV services in North East London?
8. How should we prioritise this?

Evaluation

Participants were asked to evaluate the consultation meeting by completing a questionnaire. The questionnaire contained four questions:

1. The most useful topic we talked about this evening was ...?
2. The topic that we talked about that was NOT useful was ...?
3. Was there something we did not talk about that you consider important?
4. Is there anything else you would like us to know about the issues we have discussed this evening?

Participants also had access to a graffiti wall on which they were invited to record any other thoughts they had had about the discussion that was not captured in the discussion or the evaluation.

Views about clinical services and signposting

Participants reported that generally they were happy with the clinical services they accessed but there were specific issues about which they had concerns. They agreed that the length of the consultation time they had with their physician in particular was inadequate. They thought that there is an increasing pressure on HIV services due to the increased number of patients and that this is reflected in less time for them individually.

'Doctors have not enough time - a 15-minute appointment is not enough time to discuss everything.'

'When you call them [clinical staff] they don't call back.'

Difficulties with adherence to medication were highlighted and participants felt that not enough help was offered to them. This highlighted a wider issue of access to mental health services.

'More help is needed to help with adherence to the medication.'

'There needs to be greater communication and emphasis on the psychosocial aspects of [antiretroviral] adherence.'

'It is difficult to find the right professionals to address psychosocial problems.'

'Access to mental health services needs to be improved in terms of speed.'

They considered that clinics need to be more flexible in the way that services are delivered particularly with regard to opening times and home delivery of medication. They thought that more people are now in employment due to the success of antiretroviral medication and that 9-to-5 clinic appointments that eat into the working day are inconvenient.

'Clinic opening times need to be more flexible – opening later and at weekends.'

'I talked to my consultant about home delivery [of medication] and how more convenient this would be for me but nothing happened.'

Suggestions about improvement

The education of staff groups about the aims and philosophy of user involvement and providing the practical resources to make user involvement work was emphasised as it would be naïve to expect that staff might not feel threatened or challenged by service users with whom they are used to a traditional professional/patient relationship.

'Train medical students at an early stage before they pick up negative attitudes towards people with HIV.'

'Better information for service users to signpost all services and professionals and provide better information about how to access them.'

'Encouraging clinical staff to talk to patients about service user involvement.'

Service user views about the way forward

Practical suggestions were made in order to support user involvement. These included travel issues (booking disabled transport facilities to collect and deliver people home), accessibility issues (stairs, ramps, toilet facilities), travel expenses, crèche facilities, language support, appropriate meeting environment and secretarial support.

'Ask the network to support a service user forum by providing a venue to meet, travel expenses, crèche, refreshments, stationery costs.'

Service users might also require training in order to help perform their roles, for example how to set up and run meetings, the functions and duties of roles such as Chair and Secretary and how minutes are taken and distributed. Participants addressed this issue and suggested:

'Service users who want to be involved need training and support.'

'Training and support for service users who want to be involved.'

It is important that the service users can see that their contributions have an influence on what service-provision decisions are made. This

demonstrates the need for consultation with the service providers about the available options regarding involvement to ensure that the one chosen will suit the needs of the user involvement group and the service providers. One participant suggested:

'Recruit a service user representative to the Clinical Network board.'

The outcome

As a result of the consultation, the service users decided that their participation was essential in the work of the clinical network board. Two service user representatives are now on the board. They are supported by named clinicians who act as champions for user involvement and who support the representatives in practical ways such as briefing them in advance about the context and history of issues. The representatives are currently being invited and encouraged to get involved in the work of various professional groups, for example they have been invited to liaise with mental health professionals to explore how mental health services might better meet the needs of service users.

The service users themselves decided to establish a network-wide group that they call 'Patient's Voice'. This group aims to consult as widely as possible about service users' views on existing services and how they might be improved. Patient's Voice also seeks to empower service users by encouraging a different relationship between them and their treatment centres. This encourages users to become active and informed partners in care by facilitating skills such as assertiveness, questioning and positive self-management. There are two elected co-chairs, one of whom sits on the Network board, and they are supported by professional practitioners who act as PPI champions within the Network.

The Patient's Voice group plans to develop consultation mechanisms with service users at a local clinic level. Not every service user wants to be involved in Patient's Voice but some may wish to offer their opinions and perceptions about their local service. The challenge will be to develop a strategy to seek these opinions and find a useful mechanism to keep local service users informed of developments.

There are also plans to meet African women's groups to encourage participation in Patient's Voice from this section of the community. African people may be unfamiliar with NHS services and are often confronted by language barriers. This power imbalance can negatively influence whether they feel able to be involved and also the content of their responses.

Discussion

For NHS services, user involvement seems like a seductively easy way to harness the expertise of

patients in order to deliver better services and to ensure patients are informed and fully engaged with their treatment. However, meaningful user involvement is a process and not a single event and requires that HIV services invest time and energy. For busy clinicians this might be experienced as burdensome. However as the London HIV Strategy [13] prioritises patient-led and patient-centred services it is essential that HIV services prioritise user involvement as a critical part of the design and delivery of services. This requires meaningful engagement from clinicians, commissioners and health managers to ensure effective user engagement that will improve the experience of care for people using HIV services.

Integrating the principles of self-management of chronic conditions by empowering people at all levels of PPI supports people with HIV to become more actively involved in the planning and delivery of services. It places chronic disease management and PPI within the remit of specialised services although it is a key objective in the commissioning of all services. By establishing effective clinical engagement in user involvement, a patient's experience is placed at the heart of service delivery [13]. It also delivers the key objective of 'Commissioning a Patient-led NHS' [14] of strengthening commissioning and placing clinicians and patients at the heart of the NHS.

The model that NELNET has adopted and the progress achieved by Patient's Voice aims to deliver user involvement in the planning, commissioning and delivery of services within North East London. We need to learn from the experience of other services, both HIV and non-HIV, and recognise that barriers exist to user involvement. Achieving our vision is an ongoing process that requires sensitivity to the needs of the individuals and communities who engage in user involvement, without making false promises or raising expectations. Recognising that service users are a knowledgeable resource to be valued and respected is key to success.

It is important to remember that this process requires people living with HIV to be part of a long-term process that demands time and energy. It is also inevitable that the people involved will sometimes feel unwell and not able to continue their commitment. This presents a challenge to the sustaining the process in the long term. Patient's Voice has suggested that using new technology

such as blogs, texting, podcasts and social networking sites may facilitate user involvement by sharing and seeking information that service users find easy and acceptable.

This article has highlighted the some of the challenges in establishing meaningful user involvement in HIV services in the NELNET. We believe we have learned from these experiences and approach user involvement with a better understanding of the complexity of the issues and the need for careful thought and reflection about the issues that emerge and their potential solutions.

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Clinical mentoring in a post-conflict environment: improving access to HIV testing in the Sanitary District of Kibuye, Burundi

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There is a French saying in Central East Africa 'Il faut beaucoup de sang froid pour aller aux Burundi, parce que c'est chaud Politiquement!'

This loosely translates to English as 'You must be brave to travel to Burundi because of the explosive political situation.' In fact, this was regularly quoted to us by Rwandans, Congolese and Burundians on our travels throughout the region. This is indicative of the situation that might be expected when travelling to such a volatile part of Africa during its slow transition to peaceful government. It is worth remembering that Burundi and its neighbours are part of the Great Lake Region, a region made infamous by the conflicts that have devastated it for more than 12 years.

In August this year, I volunteered with the International Centre for Equal Healthcare Access (ICEHA) and HealthNet TPO for 6 weeks, as a clinical mentor in the Sanitary District of Kibuye, which is a small rural community half an hour from Burundi's second largest city, Gitega. A driving force for this adventurous trip was my curiosity and interest in post-conflict reconstruction, particularly capacity building of healthcare infrastructure. It was also advantageous that I am a bilingual French speaker with a keen passion for Francophonic Africa.

My main motivation to volunteer with ICEHA was that I admired their philosophy, especially their commitment to strengthening local HIV/AIDS expertise by the transference of clinical skills. Their principal ethos of knowledge transfer is achieved by healthcare professionals from developed countries sharing their experiences and knowledge with their developing-world colleagues with the objective of improving patient care.

Unlike other established programmes offered by ICEHA, this project was a pilot involving a new partner on the ground, HealthNet TPO, a Dutch NGO involved primarily in countries experiencing conflict or that are in the process of post-conflict reconstruction. HealthNet TPO had established links with the Provincial Ministry of Health in order to reconstruct the health needs of the population in Kibuye. This included improving the testing and treatment of malaria and tuberculosis, as well as improvements in both maternal and child health, and increasing access to HIV care.



Top: Entrance to the Kibuye Hospital. **Above:** Workers and community members at the Health Centre of Buraza in an IDP camp.
Inset: Ursula Harrisson.

The Sanitary District consisted of one hospital at Kibuye owned by the Methodist Free Church and 11 health centres, one of which was run by the Catholic Church. Kibuye Hospital had an extensive set of services including one maternity wing, two theatres, internal medicine and a healthcare centre that provided outpatient services. The hospital and health centres served a population of around 200,000 people including a number of camps for internally displaced persons. The hospital was clean, in good working order, and had running water and electricity. With the exception of the resource-limited setting, the situation was not that dissimilar to that of the UK because all the staff were well versed in the prevention of occupational exposure of HIV and other blood-borne viruses, and infection control. Standard practice included the provision of a wide array of antibiotics, anti-malarial drugs, mosquito nets and medication for

the treatments of common parasitic diseases. However the hospital was unable to provide testing for HIV, syphilis, and other blood-borne viruses. In response to the need to achieve key aspects of the Millennium Development goals, the Burundian Government determined that access to free healthcare was essential for all children under the age of five, pregnant and post-natal women, and those requiring family planning and HIV services. Consequently, there have been some health improvements, particularly in the numbers of women attending healthcare centres for their deliveries and the number of children under five receiving immunisations. The hospital had an ambulance service that was able to travel throughout the district in cases of emergencies and also provided a nutritional programme for the financially destitute and other vulnerable people.

At the start of the programme it was noted that, initially, three out of the 11 health centres were offering HIV testing. Unfortunately, prior to our arrival, testing had stopped at two centres, including the one at Kibuye hospital, for more than a year. This seemed to be the result of reports not being submitted to the Provincial Ministry of Health who would then have provided the equipment needed for testing. The reason for the centre at Buhoro being an exception, and continuing to receive its testing equipment was that it was funded and sponsored by the Archdiocese of Mushasha (Catholic Church). My partner clinical mentor, Dr Andrea Low, and I spent the first couple of weeks, with the help of the NGO, negotiating with the Ministry of Health for the provision of HIV rapid-testing kits. This was an essential pre-requisite before we could start mentoring staff on testing. Once this was achieved we began testing patients at Kibuye hospital, and travelled throughout the District teaching nurses how to perform rapid testing, pre/post test counselling for HIV, and how to send the monthly reports. This promoted maximum coverage of the area and facilitated determining future HIV care to be undertaken at Kibuye hospital by the local doctor. In fact, once word spread that testing had recommenced at the hospital, we soon found a seemingly inexhaustible queue outside the testing-room door. This highlighted that the community really wanted and needed this facility, and reinforced the importance of developing an enduring service for the future. To ensure sustainability, we trained the district nursing supervisor and doctor in rapid-testing skills, enabling them to go out to refresh the nurses' skills and knowledge on rapid testing, counselling and reporting, once rapid testing kits were rolled out to

the District's health centres. Additionally, we actively participated in ward rounds, and triaging in the Outpatient department, signalling to both nursing and medical staff which patients would benefit from HIV testing. An integral part of our role was to provide education and mentoring to the staff on the recognition of opportunistic infections and on the use of prophylaxis until antiretroviral therapy was made available by the Ministry of Health.

This was one of the best experiences in my life and if I was asked to go back tomorrow I would do so without hesitation. I felt that this was an invaluable experience because it taught me much about living and working in a culturally different environment and gave me the opportunity to develop my skills in managing a programme in a resource-poor setting. I met some of the most committed people in the world, who wanted to expand their knowledge of HIV and AIDS care. I am not going to mislead you; we did have our ups and downs. Burundi is not for the faint-hearted. There are limitations to what you can do; accommodation is very basic and you do not have the freedom of movement that you would expect on other volunteering missions. Weekends are limited to Bujumbura, with its many hotels and beaches, or Rwanda. Going to the Democratic Republic of Congo right now would be dangerous to say the least! However, if you feel like an adventure and rubbing shoulders with some of the friendliest, laid-back people in Africa – Burundi should be your destination of choice. In spite of limitations in what we could do because of time and other constraints, we still felt we had achieved our goals and provided the partner on the ground some new ideas in order to improve HIV care in that sector. I always like to end with a highlight and lowlight. The highlight for me was meeting President Pierre Nkunrunziza on his state visit to the hospital; the lowlight – just the sheer size of some of the cockroaches!

Doctors, nurses, and other HIV healthcare providers are needed to be clinical mentor volunteers in resource-poor settings around the world. More information is available at www.iceha.org or by emailing: volunteer@iceha.org

More information about HealthNet TPO is available at: www.healthnettpoug.org

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NHIVNA Update

Season's Greetings from all at NHIVNA

■ The first announcement is now available for the 10th Annual Conference. The conference will be held in Glasgow 26–27th June 2008. The programme is very exciting with many excellent speakers and topics. There are also scholarships available to help student nurses, junior nurses and senior nurses attend. Further information on the conference, abstracts and the scholarship applications is available on the NHIVNA website (www.nhivna.org).

■ Membership renewals have been sent out recently and after the 14th December we will be having a lucky draw for five free NHIVNA memberships. All those who renewed their membership before 14th December will be included. The winning names will be announced by 18th January 2008.

■ We recently had a meeting with the web designer overhauling our website. This was very productive and hopefully you will see the results of this very soon. To ensure the new site is active and very much alive we need contributions from members for the members-only section. Ideally, we are looking for HIV-nursing-related guidelines and protocols. If you would like to submit please contact: jacqueline@mediscript.ltd.uk

■ Planning has begun in earnest for the programme for next year's study days. We will soon be releasing details of locations, dates and their contents. Please check the website for the latest information as it becomes available.

Sheila Morris, Chair

Call for Papers 2008



National HIV Nurses Association

HIV Nursing welcomes all articles, editorial letters, case reports and other contributions which would be of interest to healthcare professionals working in the field of HIV.

If you have recently completed a dissertation for a degree, set up a project that has improved the service of care for your patients, or done some interesting research, let us know.

As professional nurses, one of the best ways to raise our profile is by demonstrating innovative work that improves the lives of patients, family, and staff within the domain of HIV care.

HIV Nursing aims to provide a forum for those at the forefront of caring for people affected by HIV and is intended to provide a medium of communication on issues relating to HIV care. Readers' contributions are highly valued.

If you wish to contact **HIV Nursing** please email: hivnursing@mediscript.ltd.uk
or send items by post to:

The Editors, HIV Nursing, Mediscript Ltd, 1 Mountview Court, 310 Friern Barnet Lane, London N20 0LD, UK

The themes for next year's issues will include:

Issue 8.1 Research

- Practical help on how to develop research
- Research in practice
- Applying theory to practice
- What is good science?
- Guides to aspects of research: statistics

Issue 8.2 Focus on the Competencies: Health Promotion

- Diet
- Cardiovascular health
- Recreational drugs
- Sexual health
- Guides to aspects of research: how to judge good research

Issue 8.3 Focus on the Competencies: Treatment

- Nurse prescribing
- Adherence
- Treatment in developing countries
- Managing side effects
- Guide to blood test results

8.4 Focus on the Competencies: Assessment

- Assessing patients
- Issues around HIV testing
- HIV and poverty
- Gender and HIV
- Identity

HIV NURSING

Instructions to Authors

1. **Manuscript submission:** Articles to be considered for publication and other correspondence relating to the journal should be addressed to:

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Articles are accepted on the understanding that they have been approved by the Editorial Board and may be subject to revision. One hard copy of the manuscript should be supplied together with an emailed version.

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Wu AW, Rubin HR, Mathews WC *et al.* Functional status and well-being in a placebo-controlled trial of zidovudine in early symptomatic HIV infection. *J Acquir Immune Defic Syndr*, 1993, **6**, 452-456.

Rolfe G and Fulbrook P. AIDS dementia complex. In: *HIV Neurology* (Brew BJ and Harkins R, eds), Oxford University Press, Oxford, 1998, pp71-79.

Royal College of Nursing. *New Horizons in Clinical Nursing*. Royal College of Nursing, London, 1975.

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