

***"Empowerment"* and self-help
in the care experiences of
people with HIV.**

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INTRODUCTION

This paper reports the findings from the initial phase of a study investigating the "*lived experiences*" of people with HIV and AIDS. I will begin by discussing the context of the study by giving a brief overview of empowerment and by making some connection between these issues and the British political and nursing arena. ⁱ

The aim of the study is to describe the processes and nature of empowerment amongst people with HIV infection. The rationale for the study is to further develop caring practices which may help shape individual survival and promote wellness and longevity amongst those infectedⁱⁱ.

Attitudes of "fatalism" from within HIV/AIDS services may focus on those individuals attempting to make profound efforts both individually and communally to survive. These attitudes have been cited by AIDS "dissidents" and others ⁱⁱⁱ. I do not mean to deny the reality of the progressive disease process, but merely to raise the question about how the majority of services have a palliative/terminal care perspective, rather than rehabilitative, and to ask how should these services be positioned if there are any further developments in treatments, given in the current growing confidence about the "New Virology", the emerging role of UK treatment activism through the Treatment Action Taskforce and the Aids Treatment Project and the new options which are emerging and may suppress AIDS-related infections and sustain low HIV viral load ? ^{iv}.

This study uses in-depth focused interviews to generate discourses ^v connecting "*action, experience and change*" ^{vi} in people's social networks and care interventions. Subjects were recruited using "snowballing" or tracing sampling ^{vii}. The theoretical framework constructs a discourse analysis for evaluating the fields of meaning which lie beyond individuals' use of words and language ^{viii}. This methodology rejects the notion of a representative sample and

defines discourse as "all forms of spoken interaction, both formal and informal" ^{ix}.

BACKGROUND

The context of the study includes the growing literature on empowerment, the British government's response to the HIV epidemic and the current fluidity of health care politics in the UK. Firstly, empowerment has been popularised by the US black civil rights movement during the 1960s^x. The philosophy of AIDS care has been "shaped" by those who are themselves diagnosed with HIV and AIDS and who exercise "*voice in what happens to them*" ^{xi} with the nursing role as enabling or "*to empower*" individuals and their carers ^{xii}. Empowerment has been defined as the power human beings have for "*altering the world and transforming the conditions of their own actions*" ^{xiii}.

Secondly, at the beginning of the HIV epidemic in the 1980s the British government response to HIV and AIDS was slow with the official policy makers quietly conceiving of the epidemic as affecting "*expendable communities*" namely, those of gay men, drug users and African migrants ^{xiv}. The government relied heavily on gays who had pioneered innovative concepts of safer sex and had changed the nature of "*consumer power*" by effecting radical change in the licensing rules for medications ^{xv} as well as ensuring community mobilisation and development against the epidemic ^{xvi}.

A third context is the change in the British health and social care system or "*welfare state*" and especially its flagship the National Health Service or NHS. Since 1984 the NHS has been under

"reform" by successive Conservative governments ^{xvii}. In these "reforms" the rhetoric of self-care and empowerment has maybe had a tangible political utility by concealing or manufacturing a favourable public face behind which sits the reality of the government agenda which is replacing "collectivist" models of welfare provision such as the NHS with the "individualistic"^{xviii}. The agenda is establishing a "template" for a free market US style health care system in the UK ^{xix}. Thus this is our "choice", the new paradigm for Britains's welfare state ^{xx}.

British nursing in the 1980s spawned the "New Nursing"^{xxi} which was seen in the fashionable promotion of "primary nursing", "nursing development units" and "therapeutic nursing"^{xxii}. The partnership and empowerment with patients embodied in and central to this "New Nursing" sought to identify individual needs^{xxiii} but in reality, as services were cut back the concept of partnership was used as a mask by those in health authorities who were government appointed business managers who considered health a material "commodity" which may be bought and sold in a market place ^{xxiv}. It was a leader of a British supermarket chain whom Margaret Thatcher appointed to "transform" the NHS.

FINDINGS

The discourses evident in this preliminary analysis focus on gaining or acquiring information to increase control and autonomy in decision-making and overcoming symptoms, caring, support and outliving one's partners whom have previously died of AIDS, increasing control over the death through euthanasia and coping through the grieving process.

Gaining or acquiring information was a major discourse within the interviews especially relating to the T-cell count or the CD4 count, its meaning, its interpretation and supposed predictive value.

Scepticism was expressed in relation to the correlation of CD4 or T-cell count and progression or prognosis. A common experience was great longevity with a very low CD4 count. The issue of conceptualising what an HIV diagnosis meant was also described as *"difficult to get a purchase on"* and receiving information on the diagnosis of HIV infection was described as a *"burden of a knowledge loaded on you"*.

The vagueness of the T cell count and the so-called "objectivity" of having a quantitative measure applied to one's prognosis seemed major issues as it did not fit easily with the reality experienced. Health professionals were described as *"gatekeepers of the knowledge"* and were described as *"in control of that"* and who functioned by inspiring doubts instead of imparting skills for competence and confidence.

The ability of being able to act on knowledge was cited as important for proactive management of AIDS-related conditions and health promoting strategies to prevent progression; this appeared to question the absolute value of the CD4 measure in determining individual's prognosis. Trying to grasp what was going on through self-education was an important theme as well attempts to make sense out of the medical diagnosis and taking decisions on *"one's own back"* in order to try and achieve this.

Discourses relating to HIV antibody testing focused on partners attending for testing together

and the shared meaning a shared positive result may have. There was also a sense that after a partner's death from AIDS, whilst seeking testing and testing HIV positive gave an added meaning to one's own life after the partner's death. Support was a major discourse throughout the interviews whether it focused on giving support for dying partners, partners who had died, other friends and loved ones or receiving support.

Services were in relation to support, coordination and both personal and geographical boundaries. The effect of the emerging health care market featured in both terms of how much choice over hospital admission and clinic attendance would be possible and what is the reality in levels of primary health care service provision. Structured and proactive approaches were suggested including the "*signposting*" of individuals into services and development of awareness of what is available, what are the choices and how to access it. Therapies discussed ranged from antiviral drugs such as AZT, ddI, ddC and antibiotics to alternative and complementary therapies such as shiatsu and massage.

Surprise and relief at being treated with "respect" was evident. It was apparent that expectations were of prejudice and discrimination with prior experiences shaping an inability to trust from previously being seen as just as a "*homosexual*" which is an experience one individual described as never leaving him. There was also surprise at health care professionals expectation of improvement and or for expectations of "get better" from an AIDS-related illness with and key sentence "*you don't have to die because you're HIV positive*".

There was evidence of experiences which had the potential for either negative or positive outcomes; these may be termed "thresholds" of empowerment^{xxv}. Hope inspiring strategies were

evident from professionals who were *"taking an interest"* and encouraging *"me to come along with them"* developing feelings of being *"boosted"* through encouragement to take positive steps to help improve one's health. This was also in the context of decision-making by the professionals for the patient. Good medical practice was perceived as behaviour which was extending *"far over and above"* what should have been done. The benefits of attending a local integrated service as opposed to a large HIV centre were that there was time to *"think it over while you are there"*.

Prejudice against "HIV counselling" was expressed due to the perception of HIV counselling services as predatory, *"closing in for the kill"* and the offence and deceit experienced by offers of counselling when practical support and advice was needed.

Managing orthodox and alternative medicines focused on shiatsu and massage. Massage was seen as a *"priority"* as its *"one of the few people who touches me"* and the *"only person who touches my body"*. The issue of gay men receiving support from our own social networks was linked to a concept of the gay community and its mobilisation in the face of danger. This was discussed almost as a comradely experience unique for gay men with parallels in other communities.

Lack of personal space was reported in relation to inappropriate emotional behaviours from nursing staff at the bedside prior to dying with touching from the nursing staff as *"heightening the emotional intensity .. rather than coming to you with strength and the full practicalities and with genuine support"*. HIV & AIDS was seen to be instrumental in *"making public of a private thing"* in terms of having to put up with such intrusive behaviour from nurses because

you have HIV and your partner is dying.

Dying, euthanasia and bereavement were major discourses. Death was referred to as the "*unavoidable reality*" of AIDS with "difficult questions" to be asked by the patient and "*difficult answers*" not readily forthcoming from health professionals. The progression in AIDS was referred to as the "*Deterioration programme*". A common experience of AIDS of multiple loss was referred to as the "*erosion of support mechanisms*". Medical and nursing hostility to answering any questions on euthanasia were experienced. Lack of faith in Living Wills meant that medical staff could still have power over this part of life even where an individual stated his preference for death, and euthanasia over life, as he was experiencing nothing to left to live for.

DISCUSSION

This preliminary analysis has revealed discourses of empowerment of significance for people diagnosed with HIV and AIDS. Further analysis is required to describe further discursive practices and uncover meaning not manifest at a surface level. Of significance are individuals searching for information seen are important for decision-making about health promoting behaviours and strategies for control of living and dying, including control over the dying process and choice of when to die independently of doctors.

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NOTES

- i. This paper draws on seven respondents experiences of care from fourteen completed interviews.
- ii. A fundamental contradiction in the experience of AIDS remains the dearth of rational hope inspiring discourses even with the documented increasing numbers of HIV antibody positive people either surviving with AIDS or non-progressing. This has been commented on by Larry Kramer and others.
- iii. This is also reflected in early nursing discourses surrounding the use of intensive care units for individuals with Pneumocystis or with an AIDS diagnosis. Within the such discourses there is often struggle with a deterministic and fatalistic view of HIV and AIDS and those affected which may have more relation to medical or extreme christian positions on "homosexuality".

The issue has been cited by many AIDS dissidents including Duesberg and more recently Maggiore. The UK support group Continuum have also questioned this belief and so have the UK "Equilibrium" magazine to a lesser extent. This is reflected in the position of many current UK HIV and AIDS services and their lack of rehabilitative focus which occupies a lesser agenda than "palliative care" or death and dying discourses.

- iv. See King (1996) who calls for HIV health promotion and prevention work to be informed by the "new virology" and how policies and practice are to be influenced by the medical arena which is "..being transformed, as many clinicians feel increasingly confident that their interventions can have a dramatic impact on the equality and quantity of life of people with HIV". There is also a call here for better treatment information which in the UK is lacking with virtually no staff time in organisations devoted to this aspect of

secondary prevention work. The discourses generated so far in this study support this view. King asks the questions "What does it therefore mean for safer sex if the prospect of a cure had moved into the realism of the possible ?"

v. Grace (1991) defines discourse as referring "primarily to language, but including other significations such as images or gestures, which are part of a particular field of activity such as "health promotion". "Discourse" is used instead of "language" because discourse connotes the actively political and strategic role of words and how they are connected to form sentences and construct meaning. This differs from understandings of "language" that imply universal and fixed linguistic structures and meanings for words. An analysis of discourse is concerned with discovering how and under what conditions words and phrases have specific meanings and what can be learnt about the politics underpinning the structuring of a particular at a given historical moment".

vi. Gilbert, N. (1993) *Researching Social Life* chapter 1.

vii. Davies et al (1993); James et al (1994).

viii. Bandler & Grinder (1982).

ix. See Potter & Wetherell (1987), chapters 1 and 8.

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Research ethics approval was granted by two London Health Authorities for access to patient groups through community sites in north London. The audiotaped open-ended interviews are transcribed verbatim. Written consent was obtained prior to interview and for copyright.

x. See Solomon (1986).

xi. See Scott (1994) page 40.

xii.Scott (1994).

xiii.See Giddens (1991).

Empowerment also comes from the relationship of individuals to established authority and from direct community participation or mobilisation in politicised campaigns. It is difficult to "unravel" or measure empowerment. Thus empowerment remains a useful tool for the rhetoric of policy makers

xiv.Watney (1994) The Practices of Freedom chapter 2.

xv.See Berridge (1996) chapter 8 for discussion of the licensing of AZT.

xvi.See Weeks & Hollland (1996) chapter 8 on the UK community response to HIV and AIDS.

xvii.The reforms were fuelled purely by a right wing Conservative agendas moving away from the egalitarian and altruism enshrined in the socialist philosophy of the service following the Second World War.

xviii.Grace (1991).

xix.This produce one tier of service for those who can afford to pay for their own private health care and a "public" system which is over stretched and under-resourced but is still "free at the point of delivery" for others unable to afford the private "option".

xx.This "template" is now so ingrained as our future, following the last seventeen years of Conservative government, that even a prospective incoming Labour government (once called "socialist") aims to "**reform**" the welfare system through "stakeholding" as the welfare state cannot stop poverty, limits people's "independence" and is not "**cost-effective**" (Blair, 1996).

xxi.See Salvage (1986) for the discussion of "New Nursing". It is interesting how institutions and practices are reinvented as something different but similar. Current political discourse talks about the British Labour party as "New Labour".

xxii.Whilst there were benefits to such developments The New Nursing only arose as a result the Conservative governments ideological rethink of health care and the "growing" financial cost of an apprenticeship style of professional training for nurses enshrined within the "Old NHS" with its altruistic and socialist trappings.

xxiii.See Salvage (1986).

xxiv. See McStravic (1988)

The British nursing authorities misjudged the push for professionalisation and provided new university based courses and let care assistant training transfer to hospitals, which is changing or "deconstructing" British nursing. "New Nursing" with its consumerist rhetoric of "empowerment" and "partnership" was only a professionalising strategy, and one which is failing to "transform" nurses relations with the public, as services are cut and all over the UK nurses employed on lower and lower salaries for the same work; whilst greater and greater expectations are raised by government health charters which promise the public improved access to services.

xxv. I am defining "threshold" as "about to begin or experience" (Pocket Oxford Dictionary) as there appeared to be an openness about the way such experiences were reported and the choice of words.

Giddens talks about **fateful moments** as "phases when people may have recourse to more traditional authorities ... mark a period of re-skilling (re-acquisition of knowledge and skills) and empowerment"(Giddens, 1991).