Durham University

Durham E-Theses

HIV counselling : ethical issues in an emerging professional role.

TimBond

How to cite:

TimBond (1998) HIV counselling : ethical issues in an emerging professional role. Doctoral thesis, Durham University.

Use policy

The full-text may be used and/or reproduced, and given to third parties in any format or medium, without prior permission or charge, for personal research or study, educational, or not-for-profit purposes provided that:

- a full bibliographic reference is made to the original source
- a https://etheses.durham.ac.uk/id/eprint/985/ is made to the metadata record in Durham E-Theses
- the full-text is not changed in any way

The full-text must not be sold in any format or medium without the formal permission of the copyright holders.

Please consult the full Durham E-Theses policy for further details.

Academic Support Office, The Palatine Centre, Durham University, Stockton Road, Durham, DH1 3LE
e-mail: e-theses.admin@durham.ac.uk Tel: +44 0191 334 6107
https://etheses.durham.ac.uk

HIV Counselling: Ethical Issues in an Emerging Professional Role

Tim Bond

The copyright of this thesis rests with the author. No quotation from it should be published without the written consent of the author and information derived from it should be acknowledged.

Thesis submitted in fulfilment of
the degree of Doctor of Philosophy
University of Durham
1998

1 2 AUG 1998

Abstract

The development of HIV counselling has been one of the major public policy innovations in response to the challenges posed by HIV and AIDS in Britain. This research, using a participative and qualitative methodology, examines how HIV counsellors have conceptualised their approach to the ethical issues associated with their innovatory role. The research takes an overview of two separate phases of fieldwork conducted in 1990 and 1994. The first phase concentrated on establishing the background of self-identified HIV counsellors and how they related to the wider counselling movement which had already developed a distinctive ethic founded on respect for individual autonomy. Their general identification with the wider counselling movement raised issues how this ethic could govern their work with clients affected by HIV. The second phase concentrated on the management of confidentiality within multidisciplinary teams. The results of the research are set within the wider ethical and socio-historical context of AIDS policy development in Britain and explore changes in how HIV counsellors conceptualise ethical issues in the local context of their work. The methodology is that of 'descriptive ethical inquiry' accompanied by examination of how this type of inquiry relates to moral philosophy and social sciences. The method of participative research adopted is consultative and careful consideration is given to how this type of research relates to comparable procedures used in the production of professional codes of ethics.

Key words: 'HIV-counselling', 'professional-ethics', 'descriptive-ethical-inquiry', 'HIV prevention', confidentiality.

Declaration

The contents of this thesis are the sole work of the author, and have not previously been submitted at this or any other university.

Copyright

Copyright © Tim Bond, 1998.

The copyright of this thesis rests with the author.
No quotation from it should be published without the author's prior written consent, and information derived from it should be acknowledged.

Dedication

To

Jan

Acknowledgements

There are so many people who have contributed to this research in various ways. I am particularly grateful to the participants without whom this research could never have taken place. Their generosity in time and effort has been remarkable. The funding provided by the Department of Health and the Northern and Yorkshire (NHS) Executive and the support of their staff has been equally essential.

The progress of the research has been encouraged by my supervisor, Professor Bill Williamson, who had the knack of making succinct and timely observations at critical moments. Other friends and colleagues at the University of Durham, especially Professor Ben Knights (now at Teesside University), Dr Sarah Banks, Centre for Community and Youth Work Studies, Dr Geof Alred, Centre for Studies in Counselling, and Dr Cathy Stark, University of Newcastle upon Tyne, have asked useful and developmental questions in response to earlier drafts, some of which I am still pondering.

Once again, I am grateful to Alpha Word Power, especially Terry Dobson for converting my handwriting into something which is much more easily deciphered, and Peter Hughes, from whom I have learnt so much about desk editing.

The families of researchers often carry a heavy burden due to the frequent absences of one of its members. My family is no exception. Jan, to whom this thesis is dedicated, has endured many absences on Saturdays and Bank Holidays when we might otherwise have been together with our two young children. Zoë, now five years old, has often enlivened the early evening by her running commentary on the production of her 'book' on my office floor, whilst her 18 month old brother has his bath. Sam has treated both Zoë's and my efforts with studied equality by scribbling over both indiscriminately and removing essential crayons and pens without regard to any claims to their ownership, no matter how forcefully articulated.

Abbreviations

ABI	Association of British Insurers
AIDS	Acquired Immune Deficiency Syndrome
BAC	British Association for Counselling
BMA	British Medical Association
BPS	British Psychological Society
CDC	Centers for Disease Control, Atlanta, USA
CDSC	Communicable Diseases Surveillance Centre, England and Wales
DH	Department of Health
DHSS	Department of Health and Social Security
GMC	General Medical Council
GP	General Practitioner
GUM	Genito-Urinary Medicine
HFEA	Human Fertilisation and Embryology Authority
HIV	Human Immunodeficiency Virus
HMSO	Her Majesty's Stationery Office
NACTU	National AIDS Counselling Training Unit
NAT	National AIDS Trust
NHS	National Health Service
PHLS	Public Health Laboratory Service, England and Wales
UKCC	United Kingdom Central Council for Nursing, Midwifery and Health Visiting
UKCP	United Kingdom Council for Psychotherapy
WHO	World Health Organisation

Table of Contents

Abstract i

Declaration and Copyright ii

Dedication iii

Acknowledgements iv

Abbreviations v

Table of Contents vi

List of Tables and Diagrams ix

Chapter 1 Introduction 1

The structure of this research narrative 3

Descriptive ethical inquiry as research 5

General issues about methodology 10

The origins of the research 12

Section 1 Moral and methodological background 17

Chapter 2 The moral arena 18

The anticipatory effects of imminent plague 19

A revival of moral traditionalism 22

'Gay plague' and 'moral panic' 24

The medical metaphors of AIDS 28

The medical discourse on AIDS 31

The moral agenda of AIDS deconstructivists 32

An ethically conflicted setting for the emergence of HIV counselling 36

Chapter 3 Novel challenges: new methodologies? 38

Researching a sensitive topic 39

Locating the research within the extant research methodologies 43

Criteria for relationship between researcher and participants in the consultative process 49

Criteria for readers external to the research process 53

Ethical considerations 60

Integrity of the research process 61

Integrity of treatment of participants 64

On becoming a researcher 67

Section 2 HIV counselling: role emergence and the ethics of ambiguity 70

Chapter 4 HIV counsellors, their role and concerns 71

Literature review 71
In search of HIV counsellors 80
Background to self-identified HIV counsellors 82
Professional background 82
Settings in which HIV counselling was provided 84
Training in counselling 87
Experience of counselling 89
Counselling-supervision 92
The role of HIV counsellor 94
The pattern of work involved in HIV counselling 94
The range of client work involved in HIV counselling 96
The concerns of HIV counsellors 98
Triangulation of sources of information about HIV counsellors 99

Chapter 5 Germs or people: ethical diversity in HIV prevention 102

The method of consultation 102
The personal background of HIV counsellors 107
Division of views about the relationship between HIV prevention and HIV counselling 109
Ethical aspects of role ambiguity 119
Mapping the range 120
Ethical ambiguity for HIV counsellors 122

Section 3 Matters of confidence 125

Chapter 6 Building confidence: Researching confidentiality 126

The changed circumstances for HIV-related services 127
Divergences between the professions over confidentiality 129
Routine disclosure within multidisciplinary teams 129
Disclosures within HIV-related services 134
Application for funded research 137
Selection of research participants 139
Research methodology 145
Understanding the practical management of confidentiality as the basis of ethical mapping 152

Chapter 7 Practical strategies for managing confidentiality in multidisciplinary teams 153

Communications outside the team 153
Disclosure of HIV status for medical referrals 155
Notification of general practitioners 155
Referral to previously unknown providers of HIV-related services 157
Preliminary discussion on no-name basis 157
Provision of community nursing services 158

Interdisciplinary communication within teams....160
Core-group confidentiality....*163*
Agency-based team confidentiality....*166*
Relationship between the two systems....*172*
The dynamic influences in the construction of confidentiality....174
The integration of social workers and counsellors within teams....*174*
The relative moral standing of client groups....*175*
The search for an ethical framework....177

Chapter 8 The ethical underpinning of confidentiality 178
The method of analysis and interpretation....181

Chapter 9 Ethical frameworks explicated 189
Autonomy....*189*
Individual welfare....*198*
Community welfare....*206*
Fidelity....*210*
Relationship between ethical frameworks....213

Chapter 10 Transitions between ethical frameworks 215
The relationship between autonomy and other ethical frameworks....216
Permutation of ethical principles....218
Issues of proximity and integration....223

Section 4 On learning from descriptive ethical inquiry into HIV counselling.... 225

Chapter 11 Ethical impoverishment by professional codification? 226
Comparison of output from professional and research consultations....226
Comparison of processes involved in professional and research oriented ethical constructions....229
The relationship between descriptive and normative ethics....233
The potential contribution of descriptive ethical inquiry within an interactive research methodology....236

Chapter 12 Mapping the ethical domain of HIV counsellors 239
A socio-political context for ethical development....240
The relationship between this research and other research based publications....252
Implications for interprofessional working involving counselling....258
Implications for counselling practice....261
Implications for further research....262

Bibliography 267

List of Tables and Diagrams

2.1 Adult patient groups – USA and UK – September 1989 20

2.2 Medical and stigma models of AIDS 34

3.1 Consultative process 48

3.2 Research criteria for external readers 55-56

4.1 Professional background of HIV counsellors (1990) 83

4.2 Primary role showing secondary role sectors 85

4.3 Types of agency providing HIV counselling 86

4.4 Training in generic counselling 88

4.5 Self assessed adequacy of training 88

4.6 Duration of providing HIV counselling 90

4.7 Responses to different HIV-related issues 91

4.8 Theoretical orientation of HIV counsellors 92

4.9 Counselling-supervision 93

4.10 Reasons for seeking HIV counselling 95

4.11 Main issues raised in HIV counselling 95

4.12 A framework for the provision of HIV counselling 97

4.13 Comparison of normative requirements for HIV counsellors and their known background 98

4.14 Issues that concern HIV counsellors 99

5.1 Ethical discourses quadrant 120

6.1 Ethical basis for routine disclosure of clients' confidences to team members 133

6.2 Background of participants 143

7.1 Two systems for the management of confidentiality 172

7.2 Relationship between the two systems 173

8.1 Distribution of examples by ethical system 187

9.1 Differentiation of ethical frameworks 213

10.1 Gateway criteria between ethical systems 218

10.2 Ethical framework 220

11.1 Comparison of output from professional and research focused consultations 228

11.2 Comparison of ethical consultations for professional and research purposes 233

12.1 The socio-historical events associated with HIV counselling 242-44

12.2 Relationship between ethical stances 1990-1994 250

12.3 Sources of professional ethical discourse 255

Chapter 1

Introduction

> 'What is natural is the microbe. All the rest – health, integrity, purity (if you like) – is a product of the human will, of a vigilance that must never falter.'
>
> Camus, *The Plague*

How do HIV counsellors conceptualise the ethical challenges of their role? This question has preoccupied me over the past eight years and has raised a number of inter-related issues which are considered in this research. My reasons for selecting this topic rather than any other aspect of counselling for this kind of ethical inquiry were originally humanitarian, as I recognised the social stigma surrounding a diagnosis of infection with the Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS) tends to isolate affected people from their usual sources of support: partners, friends and family. From 1984 onwards I had met people directly affected by HIV because of their own HIV-seropositive diagnosis or indirectly affected because of the diagnosis of someone who was socially or emotionally close to them. I had become aware of how often the health status was concealed because of fear of rejection, prejudice and outright hostility. In these circumstances, people with HIV appeared to be in a potentially extreme form of dependency on their counsellors because of their social and personal isolation. The development of an adequate professional ethic appeared to offer an important safeguard against exploitation and would enhance the quality of the counselling being offered, which was becoming more widely available from 1985 as a matter of government policy (DHSS, 1985). As I became more involved in the process of developing these ethics, I realised that they could not be developed in isolation from consideration of the rest of society. Indeed, some of the most acute ethical issues and dilemmas only arose because of the contradictory reactions of different social groups and that the development of any ethic on this issue was influenced by dynamic interactions between different moral

pressures evident in society in general, but also specifically within the construction of public policy around AIDS. For example, there was no general consensus within society about the balance between respecting the rights of individuals affected by HIV and the prevention of the transmission of HIV. Similarly the boundary of confidentiality around the counselling relationship was contentious with clients often requiring high levels of confidentiality at a time when the public wanted to look behind confidential relationships in order to be reassured that they were being adequately safeguarded. The significance of the dynamic influence at work in the construction of professional ethics was the first of a series of issues which I encountered in conducting this research and which in combination explain the distinctive approach that I have adopted.

From the outset, I wanted to prioritise the experiences, perceptions and opinions of HIV counsellors themselves but to consider them in their wider social context. I had some prior experience of constructing professional codes for counsellors on behalf of the British Association for Counselling (BAC, 1988, 1989b, 1990) as a member of their Standards and Ethics Committee and had been impressed by how a consultative process had enhanced the quality of the codes by taking the experience and opinions of a wide range of counsellors into account. This process had generally been well received in the context of a national professional association but raised interesting questions when transferred to academic research. What sort of ethical inquiry would this amount to? What kind of research methodology would be used? How does the outcome of this kind of research relate to the development of professional codes? Each of these questions became highly significant during the research, although subsidiary to the attempt to understand how HIV counsellors conceptualise the ethical challenges of their role. In order to provide an initial orientation towards this research I intend to give some preliminary consideration of the issues which have influenced the structure that I have adopted for writing this research and its methodological orientation.

The structure of this research narrative

The main basis of this research is two episodes of fieldwork conducted in 1990 and 1994 sponsored by the Department of Health and the Northern and Yorkshire NHS Executive respectively. Originally I had conceived of the second research as being methodologically closely related to the first by replicating the same selection criteria and gathering data on a similar basis to facilitate a comparative analysis which charted the ethical development of HIV counselling over several years. However, the rapidity of changes in medical responses to HIV, especially in epidemiology and treatment, in combination with developments in public policy meant that the professional context for HIV counselling had changed to such an extent that a strict methodological replication would have been a considerable constraint on the second phase of the research, would have frustrated its relevance to participants, and would probably not have attracted essential funding and access to participants. Instead, the second phase became an opportunity to proceed sequentially with the ethical issues under consideration by moving from a focus of the HIV counsellors in HIV prevention and implications for respect for the individual autonomy of clients, which was a paramount issue in 1990, to a closely related issue about the management of confidentiality which had become critical in 1994. Taking this sequential approach highlighted changes in the context of each study which needed to be recorded and considered separately because the basis for the longitudinal study is not a sustained working within the same methodology over a period of years but more analogous to social-historical research in which disparate sources of information and interpretation inform the development of an overall interpretation of the period of time under consideration. The progressive unfolding of issues and responses extend beyond the primary focus of examining how HIV counsellors conceptualise their ethics to the subsidiary issues about the nature of ethical inquiry being undertaken, the development of a consultative methodology and consideration of how a research-based construction of ethics compares to the development of statements about ethics in a professional context.

I experimented with several different structures as a means of presenting this multi-layered example of qualitative research. Thematically working through the issues within a conventional framework of literature search, methodology, data collection and interpretation tended to understate the changing circumstances in which ethical issues were being addressed unless the chronology was repetitiously reinforced. More importantly, a conventional structure tended to conceal the gradual and progressive clarification of ethical issues over time and divorced those developments from their immediate context. Instead, I have adopted a chronological presentation which resolved these difficulties and provided an opportunity to focus on issues within their socio-historical setting and within an evolving research methodology. Inevitably, there are some disadvantages in this approach, especially the potential for temporarily losing sight of the overall pattern of what is unfolding. I have attempted to counter this disadvantage by dividing the narrative into four sections. The first section establishes the wider context by outlining the ethical controversy surrounding HIV and AIDS current at the beginning of the research and considering the methodological implications of conducting research in such conflicted circumstances. The next two sections focus on each of the phases of the research. Section 2 reports the research undertaken around 1990 with an emphasis on discovering the social characteristics of people who self-identify themselves as HIV counsellors, their ethical concerns and an in-depth consideration of the relationship between a public health agenda of HIV prevention and a professional counselling ethic of respect for individual autonomy. The management of confidentiality emerges as a related but unresolved issue between different professional roles which became sufficiently significant to be the focus of the next phase of the research reported in Section 3. Confidentiality was at the centre of so many different ethical issues that it proved to be a good basis for mapping the conceptualisation of ethics by HIV counsellors based on research conducted around 1994. The final section draws different themes together and considers the wider implications of the research.. This is the location for

considering a comparison between the process of ethical development within a research context and one leading to professional codification. The research concludes with an overview of the socio-historical context of this research and the discovered ethical conceptualisations.

From these descriptions of the structure it will be evident that the distinctive feature of this research narrative is a perspective which takes an overview of two separate research activities to study issues which would not emerge from either research activity considered in isolation. It is a meta-study of two projects which I have published elsewhere (Bond, 1991, 1995), which were conducted and reported under tight time constraints that precluded the consideration of methodological issues and findings in the depth and detail that has been possible in this account. The research is deliberately exploratory at a number of different levels as the process of investigating ethical conceptualisations has raised a number of methodological issues. I have used the opportunity of producing this narrative as a melting pot for reformulating and expanding my own perspectives on professional ethics.

Descriptive ethical inquiry as research

The overall conceptual framework within which this narrative is set is innovatory, although not unprecedented, and therefore its adoption is exploratory. It is an attempt to explore whether there is a distinctive area of academic interest which lies between the normative discourse which characterises most of moral philosophy, i.e. the exercise of moral judgment based on philosophical reasoning about what *ought* to be the case, and the social scientific and historical studies about what *is* believed to be moral or ethical in specific contexts and used as a basis for interpretation within the relevant academic discipline. The adoption of the term descriptive ethical inquiry is intended to direct attention to the potential usefulness and interest in researching how people conceptualise their ethics within specific contexts as an area of study in its own right. If it were to

become established as an area of academic interest in its own right, it would probably be characterised by its developmental role in enhancing the ethical articulation and explication of specific social groups and an attentiveness to working within the language and conceptual structures created or freely adopted by the research participants. Its major application would probably be multicultural situations where adoption of a normative stance would disadvantage one culture against another and inhibit dialogue across social diversity or in situations where groups or classes of people are confronting new ethical challenges and faced with the task of constructing an ethical response.

The discovery in 1981 of an infectious and largely sexually transmitted disease which was incurable and usually fatal created an extreme challenge in which existing morals and ethics were re-evaluated by many different groups within society. Independently and without any knowledge of each other's work in different countries, Miriam Cameron and I adopted the same terminology to describe our research into how people responded to the ethical challenges associated with AIDS. In Cameron's study, *Living with AIDS: Experiencing Ethical Problems* (1993), she was studying the acute ethical problems experienced by people diagnosed with AIDS because of its life-threatening, communicable, chronic and stigmatising characteristics. In this research, I am concerned with how the holders of an emergent role, namely counsellors, respond to the ethical challenges of working with people directly and indirectly affected by HIV and AIDS. In both studies, we are concerned to focus on the perceptions and experience of participants in our research. We both appear to have adopted the term 'descriptive ethical inquiry' from the same source, a seminal text in biomedical ethics written by Tom Beauchamp and James Childress (1979) and currently in its fourth edition (1994).

Beauchamp and Childress (1979: 8) used the term 'descriptive ethical inquiry' to identify a specific activity, although this activity was not central to their work other than as a source of illustrations for their normative task. In making a clear distinction between

what *ought* to be and what *is* factually believed to be right, they were reiterating a distinction which would be familiar to their intended readership as a characteristic of modern science which shares their assumption that moral judgments cannot be derived from statements of fact (Adams, 1992: 880). However, the emphasis on a logical boundary between statements of fact and value is not universally accepted within philosophy, thus viewed from other perspectives, that which Beauchamp and Childress have defined negatively, can be reframed positively. Two conceptual systems which arguably compete with a scientific understanding of the world are particularly relevant. Phenomenology, which has been seminal in the development of social sciences (Luckmann, 1978) constitutes a major intellectual tradition originated by Brentano [1838-1917] and Husserl [1859-1938], and adopted by Cameron as her preferred methodology. It is a feature of phenomenology that distinctions between statements of value and fact become relatively unimportant as these dualisms are subordinate to the concept of 'intentionality' within which what is perceived, *noema*, and how it is perceived, *noesis*, combine. As a consequence, moral philosophy and social science suffuse each other. Similarly, critical theory and post-modernism emphasise the contingent nature of all cultural construction including claims to scientific or normative authority as being inextricably linked to particular social and historical contexts. Post-modernism is a term which holds no single meaning and historically may represent no more than being in chronological succession to modernism characterised by an earnest belief in progress and confidence in objective and scientific truth. In the context of this research, I shall use the term in ways which follow the analysis by Lawrence Cahoone (1996: 13-19). Methodologically, it is anti-realist in the sense of claiming that knowledge becomes valid not by its relation to its objects, but by its relation to our pragmatic interests, our communal perspectives, our rhetoric and so on. This approach to knowledge creates new possibilities of positive reinterpretation of any phenomena on the basis of representation and construction (as opposed to presence or presentation),

phenomena (versus origin), plurality (versus unity) and immanence of norms (versus transcendence). When applied to moral philosophy by writers such as Jurgen Habermas (1992) in communicative ethics, and Zygmunt Bauman (1993, 1995) in post-modern ethics, both writers prioritise the moral value of dialogue, which suggests that post-modern theory may be particularly relevant to aspects of descriptive ethical inquiry because dialogue is central to this kind of research.

The preceding discussion has attempted to set out in broad terms the relationship between a positive adoption of descriptive ethical inquiry and some different moral philosophical traditions. It is harder to define the relationship with social sciences because although sociologists, anthropologists and others give descriptive accounts of people's moral attitudes and behaviour, they do not characterise what they are doing as 'descriptive ethics'. A negative finding is notoriously tricky to interpret but it is possible to speculate that neither 'descriptive' nor 'ethics' are as central to most social scientific endeavours as they appear to be within 'descriptive ethical inquiry'. Within most social sciences 'description' is usually a transitional activity on the way to an interpretation made within the relevant academic discipline. A noteworthy exception is Clifford Geertz (1973, 1983) who advocated the production of 'thick description' as the research outcome and thus contradicting any notional progression from description to interpretation by emphasising that interpretation is an inherent aspect of any description. Another reason for the absence of 'descriptive ethical inquiry' in the social sciences may be that the explication of ethics undertaken by the people being researched is not seen as significant either because this is an activity which is undertaken by the researcher independently of the research subjects, or the aim of the research is not to produce an explicit ethical discourse but to research public morals which are usually defined more widely to include unspoken social norms and conventions which influence the discrimination between acceptable and unacceptable behaviours. This absence of a pre-existing category of 'descriptive ethical inquiry' in social sciences does not imply that this kind of research is inconsistent with

a social scientific orientation. 'Descriptive ethical inquiry' can be viewed as signifying the application of research methodologies developed with social sciences but directed towards the explicit articulation of ethics by the people being researched as an end in itself.

The use of the term 'descriptive ethical inquiry' advocated in this research does not exclude the possibility that this type of activity may already have been undertaken within the social sciences without necessarily having adopted the terminology. A potential example of this may be Carol Gilligan's study of women's morality, *In a Different Voice* (1983), based on listening to women talk about morality and how it relates to them from which she explicates an ethic of care. The outcome of this research contrasted with the findings of Laurence Kohlberg (1966, 1971, 1985), in which he applied a less interactive and dialogical approach to researching the ethical development of men which initially he assumed to be characteristic of both genders and from which he hypothesised an 'isomorphic parallism' (1971: 224) between the ethic of his male subjects and the principles of justice advocated by the moral philosopher, John Rawls, in *A Theory of Justice* (1971). One of the consequences of Gilligan's research has been to provoke a lively debate between proponents of her discovered 'ethic of care' and an 'ethic of justice' within the normative discourse of applied moral philosophy (Gatens, 1995: 42-57; Tong, 1997: 38-48). This may indicate one of the potential contributions of 'descriptive ethical inquiry' by providing new sources of insight into the morals and ethics in operation in society which may be of interest beyond those directly involved in their construction and explication.

A characteristic of descriptive ethical inquiry as the innovatory and experimental category within which this research is set, is the use of participative social science research methodologies in order to facilitate the explication of ethics adopted by specific groups or classes of people. The use of the term 'descriptive' does not exclude either analysis

or interpretation but both are directed towards the developmental task of explicating the ethics adopted by the participants rather than addressing some external point of reference. As a consequence, the basis of interpretation and analysis would tend to be inductive, which is a characteristic interpretive strategy in much qualitative research within social sciences, rather than deductive which argues from a basic principle to specific examples and characterises most normative discourse within moral philosophy.

General issues about methodology

The task of descriptive ethical inquiry as I have defined it is not to evaluate the relative merits of a particular ethic relative to another but to facilitate the explication of ethical conceptualisations held within specific social groups in identifiable socio-historical contexts. The catalytic or developmental aim is both to help unspoken moral norms and conventions to be made explicit, and thus subject to scrutiny by participants, and to facilitate a dialogue between holding different ethical positions so they can either reach consensus or be better placed to understand what divides them. As such, the methodology is primarily qualitative and participative, and outside both the culturally dominant set of basic beliefs sometimes characterised as orthodox science or 'old paradigm research' (Reason and Rowan, 1981a: xiii) and their qualitative equivalents of positivism and post-positivism (Guba and Lincoln, 1994: 109). New paradigm research incorporates an eclectic mixture of theoretical inspiration including humanistic psychology, phenomenology, existentialism, critical theory and post-modernism (Reason and Rowan, 1981a: xvi-xviii). As such Reason and Rowan (1981: xviii) envisage that researchers working closely with participants will revise and elaborate their methods by the logic of what works and what does not work with human beings in the specific research context within a subject-subject relationship with the field of study. The researcher in new paradigm research has in effect become a '*bricoleur*' a 'Jack of all trades or a kind of professional do-it-yourself person' (Lévi-Strauss, 1966: 71) who produces 'a

pieced-together, close knit set of practices that provide solutions to a problem in a concrete situation' (Denzin and Lincoln, 1994: 2). The organising focus for bricolage in new paradigm research is an emphasis on the interpersonal encounter between research participants in which personal dialogue is fundamental. This will become particularly evident when I consider the criteria for validity in this kind of participative research where I will argue that not only have the criteria selected by Reason and Rowan (1981b) been consistently reiterated in subsequent publications in their emphasis on relationships within the research process but, perhaps surprisingly, they have not been significantly elaborated or extended to consider the relationship between research narrative that is produced and the external reader. I became particularly aware of this absence because of the expectation of participants and funders that whatever emerged from the research ought to be useful to non-participants and the reality that non-participants were seeking preliminary copies prior to publication and afterwards because the research was addressing issues which were perceived as highly relevant to the practice of HIV counsellors. As a consequence I have proposed an extension of the usual criteria from participative research of this kind, which focus on the relationship between the narrative and the external reader (see Chapter 3). However, I am also aware that the outcome of participative research directed towards 'descriptive ethical inquiry' may be disappointing to those who are hoping to be told what they *ought* to do in specific circumstances. The outcome of this research is not directed towards that end. Even were the outcome of the research a clear consensus between participants about what they consider to be their obligations supported by unanimously agreed reasons, this could only be informative but not imperative to the non-participant who would still retain the responsibility for assessing the transferability to another context. If, as seems more likely, the research discovers a number of different positions which have been explicated and refined by dialogue, the descriptive (i.e. non-normative) aim of this kind of ethical inquiry requires an evenhandedness between the different positions that have emerged. In this respect,

descriptive ethical inquiry is fundamentally post-modern and therefore entails the dilemmas about relativism which may be sufficient to be supportive of explorations of moral and ethical plurality during times when that diversity is socially and morally acceptable, but may be insufficiently entrenched and authoritative to provide much protection for stigmatised social minorities in less favourable circumstances. This issue has preoccupied some post-modern ethicists like Zygmunt Bauman (1993) and I will return to his thinking in the final phases of this research narrative.

The origins of the research

I have already stated that my interest in the ethics of HIV counselling started in 1984 but, as many researchers can testify, it requires the creation of a specific opportunity to convert a general research interest into an actual research project, especially in the context of HIV. The high volume of clinical research taking place meant that it was difficult to gain access to participants because of a general sense of research fatigue, as well as their natural wariness about giving access to any researcher who was not endorsed by one of the major agencies. In 1988, I started to let it be known that I would welcome the opportunity to conduct some research around ethical standards for HIV counselling within the British Association for Counselling and elsewhere.

At that time infection with the Human Immunodeficiency Virus (HIV) and the associated opportunistic illnesses sometimes resulting in Acquired Immune Deficiency Syndrome (AIDS) appeared to constitute a major health crisis and threatened a universal pandemic of sexually transmitted life threatening illnesses (Mann and others, 1988). The advent of a previously and largely unknown sexually transmitted disease which was both incurable and life-threatening had major implications for sexual and personal behaviour. The absence of effective cures or preventative vaccines meant that counselling was increasingly being proposed as a key component with national AIDS control and prevention plans in support of information and education programmes and as a *sine qua*

non of clinical management (Green, 1986; Miller, 1986; Pinching, 1986). It was argued that the only effective countermeasure to HIV was behavioural change (Weber, 1988: 11), and counselling was co-opted in Britain as a matter of government policy as early as 1985 (DHSS, 1985) only four years after the first discovery of the syndrome later known as AIDS, and two years after the putative discovery of the causative virus (Gallo and others, 1984). The government policy of requiring counselling prior to voluntary HIV antibody testing and for anyone receiving a positive result was reinforced by evidence given to the House of Commons Social Services Committee considering 'Problems Associated with AIDS' who were:

> ... repeatedly told that the most effective way of providing information and enabling individuals to understand that information and relate it to their own life is through one to one discussion. People coming forward for counselling represent the next stage in the educational process [after public education by leaflets, advertisements and media campaigns]
>
> (House of Commons, 1987)

A comparable emphasis on the development of HIV counselling was being implemented internationally. By 1989, the World Health Organisation's (WHO) training programme in HIV/AIDS had reached health and social services staff in over 80 countries (Carballo and Miller, 1989: 122). The WHO Global Programme on AIDS was strongly influenced by the British experience (WHO, 1990: v) and defined HIV counselling as:

> An on-going dialogue and relationship between client or patient and counsellor with the aims of: (1) preventing transmission of HIV infection and (2) providing psychosocial support to those affected.
>
> (WHO, 1990: 10)

In a paper delivered to the Fifth International Conference on AIDS at Montreal, Carballo and Miller (1989: 119) observed that internationally, there were a number of difficulties in the development of HIV counselling. The absence of any clear professional identity or structure made it difficult to identify and organise those who provide counselling. The lack of clear policies about the content of HIV counselling compounded the difficulties. In particular, confidentiality remained a significant but unresolved issue. They envisaged

that confidentiality would probably have to be one of the cornerstones of HIV counselling, especially in situations where the lack of it could lead to discrimination. On the other hand they recognised that no policies or agreements had been reached about confidentiality because of the intrinsic difficulty of identifying appropriate practice.

In Britain, the difficulties identified by Carballo and Miller were also evident, but were taking a slightly different form. As a counselling movement had developed in Britain prior to the discovery of AIDS, HIV counselling was being introduced into a situation where generic counselling was relatively well established in comparison to most of the world, with the exception of some States in the USA. Counsellors had been organising themselves within a national body, the British Association for Counselling (BAC) from 1977. As a member of BAC's Standards and Ethics Committee from 1985 I was aware of potential sources of conflict between the development of HIV counselling and the generic counselling movement, especially over ethics. The first *Code of Ethics and Practice for Counsellors* (BAC, 1984) was deeply rooted in an ethic of respect for client autonomy. Evidence from the current consultations over the production of a revised version of the code (BAC, 1989b) indicated that respect for autonomy was still the predominant ethical ethos. From this perspective, the two elements of HIV counselling, namely prevention and psycho-social support appeared ethically in conflict. The public health agenda of HIV prevention had the potential for overriding the autonomous wishes of clients receiving psycho-social support as it was understood within BAC. An emphasis on confidentiality was regarded as an ethical corollary to the importance of client autonomy. Confidentiality protected the client's right to act for themselves in a social environment uninfluenced by anything that had been disclosed in counselling. Confidentiality and client autonomy were sometimes viewed as so closely related ethically that they were described by participants in workshops, at that time, as two sides of the one coin. The emphasis on confidentiality in counselling achieved statutory recognition where special provision had been made to maximise the protection of counselling records

from public disclosure if they were required as evidence in criminal proceedings (Police and Criminal Evidence Act 1984 s.12) and in the clinical context of human fertilisation and embryology where information derived from counselling was given additional statutory protection in comparison to medical data (HFEA, 1990, ss. 3.24, 6.25). As someone with a professional and academic interest in counselling ethics (Bond, 1988, 1989) I realised the potential for ethical difficulty and ambiguity in the combination of the preventative role with psycho-social support and how this combination could impact on confidentiality with serious consequences for counsellors and clients alike. These issues became the primary focus of this research because they turned out to be the dominant ethical concerns of HIV counsellors in 1990 and 1994 respectively.

The decisive opportunity for conducting the research arose in 1989 when I was invited to assist Dr John Sketchley, then a researcher at the British Medical Association (BMA) AIDS Foundation, in preparing a research proposal which succeeded in obtaining funding from the Department of Health. Sadly, John Sketchley withdrew from the research at an early stage in planning for its implementation when the funding for his post at the BMA was withdrawn by its sponsors, the Association for British Insurers (ABI). The withdrawal of funding was the result of a dispute between the BMA and ABI about the inclusion on life insurance application forms of questions about HIV antibody testing and counselling. The inclusion of these questions was viewed by the BMA as undermining a major element in the HIV prevention strategy by creating a financial deterrent for people seeking HIV counselling and testing, a view which was substantially justified by subsequent research (Department of Health, 1991a: 35). The withdrawal of John Sketchley was indicative of the levels of social conflict taking place over AIDS at that time and the potential difficulty and unpredictability of the task that I had set myself.

I opened this chapter with a quotation from Albert Camus in which he uses the metaphor of a fictional plague as a setting in which people are existentially challenged. The plague

symbolises the meaninglessness and absurdity of life which had preoccupied him in his earlier writing. By the time he was writing *The Plague* (1947) he had developed a concept of ethics as a rebellion against the absurdity of life. In the novels from this later cycle, Camus advocated the virtues of justice, lucidity, transparency, courage, solidarity and hope (Kockelmans, 1992: 122). During this research I saw plenty of evidence of these qualities in the research participants. But I have deliberately selected a quotation which, at least when taken out of context, is much more ambiguous about how the search for meaning is expressed. The advent of AIDS created a socially extreme situation which evoked comparably extreme responses of courageous generosity, deliberate cruelty and indifference rooted in denial. This range of potential responses increases the significance of clarifying the ethical basis for the work of counsellors and other professions. In the next chapter I will set out some of the ethical diversity which created conflicting moral positions within which HIV counsellors have been obliged to construct their ethics.

Section 1

Moral and methodological background

This section establishes the circumstances in which the research originated. Particular attention is paid to the intensity of the moral debate about HIV and AIDS (Chapter 2) and the implications of this moral conflict for the selection of research methodology (Chapter 3). Additional methodological issues are also considered, in particular the criteria appropriate to evaluating the quality of this kind of *post factum* reflection about experiential and consultative research.

Chapter 2

The moral arena

> A plague is a formidable enemy and is armed with terrors that every man is not sufficiently fortified to resist or prepared to stand the shock against.
>
> Daniel Defoe, *A Journal of Plague Years* (1722)

> The real plague is panic.
>
> Editorial, *Guardian*, 19 February 1985.

The conjunction of 'HIV' and 'counselling' into a single role represents the merging of one of the most morally charged illnesses with a novel way of helping people. From the first reports of seriously ill young men with rare forms of pneumonia, skin cancers and damaged immune systems in June 1981 (CDC, 1981) a battle has ensued for the moral agenda arising from AIDS. Social scientists and specialists in cultural studies have commented extensively on different manifestations of competing moral agendas which permeate the construction of AIDS as a medical and social phenomena. Writing about AIDS in 1988, Jeffrey Weeks observed that,

> during its relatively brief history, it has become more than a ghastly and relentless disease. It has come to symbolise an age where fear, prejudice and irrationality battle against reason, responsibility and collective endeavour. At the moment it is by no means clear which will triumph.
>
> (Weeks, 1988: 10)

As a consequence, HIV counselling was evolving in a moral arena within which different moral approaches were advocated by combatants seeking the supremacy of their view within society in general, and within public health policy in particular. This chapter sets out some of the distinctive features of the different ethical approaches which are presented as a three way division between 'traditional moralists', the 'liberalism' of the medical establishment and the radical moral agenda of the 'AIDS deconstructivists'. Finding a title for the last group has been problematic because, although strongly influenced by the experience and rationale of the politicised gay movement, it represents a wider coalition

which includes members of the women's movement and others who seek to preserve advances in sexual freedom gained over the previous two decades which they saw as threatened by the attribution of moral meaning to AIDS. Alternative titles might have included 'sexual libertarians' but this would have omitted a small number of participants who hoped for a liberalisation of non-prescribed drug use. 'AIDS activists' is a term which has subsequently gained some credibility but is inappropriate to this analysis because it emphasises public activism and protest about public and government policy at the expense of the less publicly known emphasis on deconstruction of cultural perceptions of AIDS. Although it is not a wholly adequate descriptive label of a loose knit and sometimes fragmented coalition, the label 'AIDS deconstructivists' probably best captures their common ground in questioning the moral meaning of AIDS. The contents of this chapter are taking a 'broad brush' or stereotypical approach rather than attempting to locate all the variations within the different ethical stances, a task which would justify a study in its own right. Published sources of information for this analysis are acknowledged. Some information was gathered in 1988-9 by discussions with friends and colleagues who were active in hospital-based and voluntary organisations delivering HIV-related services.

The starting point for understanding the intensity of the moral conflict was the polarising effect of an anticipated 'plague'.

The anticipatory effects of imminent plague

Catastrophic predictions of the future impact of HIV infection on the general population were widely disseminated from the early 1980s. A public information campaign initiated by the government in 1986 appeared to confirm the sense of foreboding that a major catastrophe was imminent. The scale of this campaign was unprecedented outside time of war. Every household was circulated with a leaflet entitled *Don't Die of Ignorance* providing basic information about the transmission of HIV and how to protect yourself.

A television and media campaign continued into the next year which used the image of icebergs, which conveyed the metaphorical message of hidden danger on a larger scale than is visible. At the same time there was growing awareness of the catastrophic impact of HIV in Central Africa where the predominant impact was on young sexually active adults and therefore evidence of heterosexual transmission.

The actual figures of people diagnosed as having AIDS in Britain were relatively low in comparison to other countries. It was the anticipation of much higher figures based on epidemiological predictions which fuelled concern about HIV and AIDS. The comparative figures between the reported incidence of AIDS in the USA and the UK in September 1989, when this research was initiated, partially explain the sense of foreboding.

Figure 2.1: Adult patient groups – USA and UK – September 1989

Patient Groups	USA		UK	
	No.	%	No.	%
Homosexual men	65273	61	2149	82
Intravenous drug misuser	22188	21	72	3
Homosexual male and IV drug misuser	7555	7	37	1
Haemophilia	1014	1	161	6
Received blood	2604	2	44	2
Heterosexual contact	5048	5	123	5
Other/Miscellaneous	3590	3	41	1
	107308	100	2627	100

Source of figures CDC (USA)/CDSC (UK), Johnson (1989: 14)

The figures revealed that the two groups most affected by HIV through self-directed activity were men who have sex with men and intravenous drug users. Haemophiliacs and other recipients of blood products had become infected through contaminated medical treatments. This route of infection could be relatively easily closed by improved protection of the blood supply and therefore was considered to constitute less of a threat. In contrast, self-directed activity constituted much more of a threat, especially when it involved something as instinctive as sexual behaviour or as compulsive as drug use. The anticipated scale of the future impact of HIV depended to a considerable extent on heterosexual transmission. The largest epidemiological predictions assumed an exponential growth comparable to the early patterns of infection in gay men and injecting drug users. A comparison between the known cases of AIDS in the UK and USA appeared to support fears that an exponential increase in heterosexual transmission was imminent. The USA experience suggested 50% of all heterosexually acquired AIDS were transmitted in association with being the partner of an injecting drug user and 6% due to partner of bisexuals (Johnson, 1989: 15). The inexorable and steady rise of heterosexual transmission in the USA appeared to run ahead of but match the early British figures for AIDS. Epidemiologists suggested that it was reasonable to suspect a potentially analogous pattern of transmission with a corresponding growth in heterosexual transmission and this view predominated at a national symposium on the current and future spread of HIV and AIDS sponsored by the UK Health Departments and the Health Education Authority held in late November 1989 (Mann, 1989: 8).

Some more conservative epidemiological predictions had become available to the government but these were much less publicised, not only because good news attracts less media attention, but probably because they went counter to the prevalent pessimistic view. Although these more optimistic figures were the result of considered scientific analysis, they still had a high level of uncertainty because of a lack of knowledge about the actual incidence of HIV infection in the population which would provide a much more

reliable basis for predicting the future incidence of AIDS. Nonetheless, some epidemiologists were beginning to reconsider the pattern of infection and in 1988 the Cox Report revised the figures downwards. It concluded:

> Continued exponential growth would lead to about 10,000 new cases diagnosed in 1992. While this cannot be totally excluded, there are a number of reasons for expecting slower growth and predictions in the range of 2,000-5,000 are more likely.
>
> (DoH, 1988c)

In 1989, given all that had gone before, these lower predictions seemed less credible than the more catastrophic fear of widespread infection. This level of fear intensified the moral debate that was taking place about AIDS. The imagery of impending 'plague' was metaphorical but not necessarily fanciful.

A revival of moral traditionalism

The discovery of a serious infectious illness which is most frequently transmitted sexually provided an opportunity for a revival of moral conservatism. Prior to AIDS, changes in sexual mores had been a focus of anxieties about social change in the post-war period, but the advent of AIDS appeared to confirm both the validity and centrality of these concerns. A former Solicitor General, Sir Ian Percival, considered the reasons for AIDS to be immediately obvious, because "so many have strayed so far and so often from what we are taught as normal moral behaviour" (*The Guardian*, 22 November 1986). A leading campaigner against the swearing, sexual explicitness and violence on radio and television, Mary Whitehouse, shared these views: "Over recent years homosexuality has been represented as perfectly normal ... But now the laughing is over" (*The Guardian*, 22 February 1985). The AIDS Lecturer and Resource Officer for the Christian Medical Fellowship, Dr Caroline Collier, argued for a mobilisation of the church against the spread of AIDS:

> The church has traditionally had a warning role. From ancient times this has been so, and today the danger comes from a disease spread by one of the most vital urges of the human race, the sex drive. The Christian rules relating to sex, part of the general consensus until

> twenty or so years ago, do give total safety from the new disease of AIDS. The church therefore has a duty to restate these guidelines today.
>
> (1987: 35-6)

These moral views often supported a view that the appropriate response to the threat of AIDS involved overriding individual freedom to introduce compulsory HIV-antibody testing and the segregation of those found to be HIV positive from the rest of the community. Although Collier did not wholeheartedly advocate compulsory segregation, she did envisage it as having advantages to people with HIV as well as the wider community.

> In a segregated situation, sufferers will not feel the isolation which sometimes comes from the secrecy and anonymity which may in mixed communities prevent the full support of a person with AIDS.
>
> (1987: 32-3)

She also argued that an early intervention in the cycle of infection would enable a better level of care to infected people, rather than delaying so that the available resources become spread more thinly across much larger numbers and inevitably subject to tighter financial constraints because of the size of the problem (pp. 86-8). She was concerned to treat all people with AIDS compassionately, as she saw it, because from her religious perspective AIDS is 'not God's judgement on every single individual who catches it .... Christians do, however, see in the AIDS epidemic the hand of God's judgement on a corrupt *society*' (p. 66). Not everyone who took this traditional moral stance was as concerned to maintain a distinction between individual and social blame. Individuals living with HIV and social groups considered most at risk of HIV were vulnerable to being singled out for blame and condemnation. Gay men were particularly vulnerable as the worst affected social group (see figure 2.1).

The stereotypical characteristics of a morally traditionalist approach were the subordination of individual will to an external moral authority construed either in terms of religious faith or tradition. This deference to a moral authority legitimised the exercise

of coercive powers by the State to segregate people with HIV to enforce compulsory testing to identify 'AIDS carriers'. HIV prevention was invariably viewed in terms of the moral value of 'abstention' from sexual 'immorality' and 'drug abuse' with a corresponding emphasis on the positive values of sexual fidelity within monogamous heterosexual relationships.

'Gay plague' and 'moral panic'

Traditional moralists were simultaneously challenging both the liberal medical establishment and the reconstruction of sexual freedom and responsibility by AIDS deconstructivists. One of the ethical arenas within which these opposing views were expressed was in the media. The 'common sense' assertions of moral traditionalists were largely challenged by the medical establishment as non-scientific (Cawley, 1988: ix) and reframed as 'moral panic' by AIDS deconstructivists (Watney, 1987: 39). The assertion of 'science' as a basis for moral liberalism in medicine will be considered later. The adoption of the term 'moral panic' from criminology and sociology in the 1960s is particularly illuminating about the relationship between moral traditionalists and AIDS deconstructivists.

The attraction of the term 'moral panic' to those who wished to question assertions of traditional morality was that it provided a conceptual basis for questioning the normative assumptions of any assertion of tradition and authority. The development of the concept of 'moral panic' rejected the authoritative division of society into insiders and outsiders and instead substituted a concept of society endlessly reforming itself in which moral panics represented resistance to the inevitability of change. The concept was devised around studies of youth culture in the 1960s.

Stanley Cohen (1972: 9) described how societies,

> appear to be subject, every now and then, to periods of moral panic. A condition, episode or person emerges to become defined as a threat to societal values and interests; its nature

> is presented in a stylized and stereotypical fashion by the mass media; the moral barricades are manned by editors, bishops, politicians and other right-thinking people .... Sometimes the panic passes over and is forgotten, except in folklore and collective memory; at other times it has more serious and long-lasting repercussions and might produce such changes as those in legal and social policy or even in the way the society perceives itself.

A few examples of some of the press coverage of AIDS illustrates the attraction of reframing strident moral conservatism as 'moral panic'.

In December 1986, James Anderton, the Chief Constable of Manchester, blamed prostitutes, homosexuals and their clients for the spread of AIDS. In a speech to a national conference of police officers he continued:

> Everywhere I go I see increasing evidence of people swirling about in a human cesspit of their own making ... We must ask ourselves why homosexuals freely engage in sodomy and other obnoxious practices, knowing the dangers involved.

This speech evoked considerable support as well as condemnation. Norman Fowler, the Secretary of State for Health and Social Security, was sufficiently provoked to state that the government did not have time for the luxury of a moral debate about AIDS and asserted the importance of public policy being informed by science. However Anderton's comments represent one of the most vivid responses to AIDS and are consistent with the way that AIDS had been presented in significant parts of the media. From 1983 onwards, there were a steady stream of stories about the 'gay plague', a term widely used in both tabloids and broadsheets. A few of the early headlines exemplify the moral agenda; in the *Daily Telegraph*, 2 May 1983 'Wages of Sin, A Deadly Toll'; in the *Sun* on 8 May 1983 'US Gay Plague Kills Three in Britain'; and in the *People* on 24 July 1983, 'What the Gay Plague Did to Handsome Kenny'.

If the moral message contained in these examples prevailed then it could conceivably justify a recriminalisation of homosexuality which would appear to match Stuart Hall's analysis (1978) that 'moral panics' are the first step in a line of argument towards increasingly punitive state control.

For all these reasons, the concept of 'moral panic' was widely adopted by gay men who were feeling increasingly under attack. Simon Watney and others writing in both gay and academic literature were particularly eloquent in challenging the re-imposition of sexual restrictions on new found freedoms, especially for gay men (Watney, 1987) and sometimes jointly with feminists to defend the sexual freedom of women (Carter and Watney, 1989). Feminists also joined in the resistance to the moral panic in their own right (Patton, 1985).

However, there were aspects of the 'moral panic' about AIDS which troubled Watney and others. The persistence of the panic over many years caused him to suggest that perhaps there were many different panics serving many different causes (Watney, 1988: 57). In his view, the panics are better thought of as a commentary on a range of anxieties characteristic of an industrial society at a particular point in development concerned to protect a familial ideology, rather than the reality of the family life which Watney suggests is beset with anxieties about sexuality in the form of erotophobia, of which homophobia is only one expression. With this modification to account for long-lived panic because of the persistence of an unresolved source of anxiety, his analysis is consistent with moral panics attempting to advance repressive causes. However, it is arguable that the use of panics was even more diverse than he was willing to recognise.

There is some evidence that 'moral panics' were also adapted and converted to support liberal causes. One of the earliest harbingers of the liberal cause was the publication of guidelines by the Royal College of Nursing (Berridge, 1996: 61) which attempted to establish a fundamental principle that no nurse had a right to refuse care to a patient with AIDS. These guidelines were accompanied with one of the highest predictions of the future impact of AIDS. They predicted that there could be a million cases by 1991, if there was a significant spread beyond the homosexual community. As a justification of the liberal policy, it probably backfired by eliciting expressions of public concern and a

tendency to reassert traditional moral values. However, the fear of the future impact of AIDS could also be used to subvert this moral traditionalism and it appears that the possibility of drawing upon a scientific discourse was sufficient to achieve this end within public policy. In order to gain knowledge about the incidence of HIV infection and disease progression, scientists and clinicians needed to be able to gain the co-operation of social minorities in the population who could easily be driven underground by any suggestion of oppressive public policy. Gaining the necessary levels of co-operation was not envisaged as being either straightforward or inevitable, but was more likely within a liberal policy ethos which individual consent, confidentiality and potential advances in treatment and prevention from improved scientific knowledge. In this case, fear of the epidemiological consequences of adopting a coercive illiberal policy was used to justify a liberal public policy. This inversion of the 'moral panic' may explain the paradoxical phenomenon of the public policy controlled by a Conservative government being at its most liberal at the point when epidemiological predictions were at their highest in the mid-1980s and the reassertion of more traditional moral values in AIDS policy in the 1990s as the level of threat is downgraded, especially with regard to the heterosexual population.

Gay men may also have emphasised the possibility of heterosexual spread as a way of sharing responsibility and potential vulnerability across the whole population. It had been suggested in a high level DHSS briefing to a journalist that this amounted to a 'gay conspiracy' to mislead the government into a national emergency response, reported in the *Sunday Telegraph* on 5 June 1988. This briefing may simply have been a governmental attempt to start to regain the moral initiative against the liberal medico-bureaucratic establishment who had been influential in creating the liberal ethos. However it does seem probable that there were many diverse interests in addition to moral traditionalists who sought to argue for developments in policy on the basis of variations of the 'moral panic' engendered by high epidemiological predictions of the impact of AIDS.

The medical metaphors of AIDS

The moral conflict about AIDS was also evident in the moral valences associated with a diagnosis of AIDS. No illness is wholly free of moral value. Within linguistic philosophy it is accepted that 'illness' is a value laden concept with 'ill' and 'healthy' symbolically analogous to the most basic values of 'good' and 'bad'. The strength of these evaluative connotations varies with context. Generally speaking, the evaluative component increases where the scientific or physical causes of illness give way to social factors, for example a diagnosis of physical illness relative to psychiatric illness (Fulford, 1995: 154). The evaluative connotation may transfer between illnesses over time. Susan Sontag, in a moving essay about her experience of cancer, wrote about the negative metaphors implying shame, and the accusatory aspect of metaphors intended to encourage the patient to fight her illness (Sontag, 1988).

> Twelve years ago, when I became a cancer patient, what particularly enraged me ... was seeing how much the very reputation of this illness added to the suffering of those who have it.
>
> (Sontag, 1988: 12)

The reputation of illnesses is relative and can be supplanted by the discovery of yet more terrible illnesses.

> In recent years, some of the onus of cancer has been lifted by the emergence of a disease whose charge of stigmatisation, whose capacity to create spoiled identity, is far greater. It seems that societies need to have one illness which becomes identified with evil, and attached blame to its 'victims', but it is hard to be obsessed with more than one.
>
> (Sontag, 1988: 16)

Brian Redhead, the journalist and broadcaster, speaking about his lifelong involvement in the hospice movement at the Grubb Institute in 1988, observed that no amount of public education had done more to improve the attitudes to cancer than the arrival of AIDS.

The moral valences of an illness are not merely relative one to another, like physical in comparison to mental illness, or cancer to AIDS. The moral status of an illness can shift according to the dominant generic discourse in which it is being considered.

Although medical diagnosis of an illness is not value free, it is relatively less value laden than a forensic judgment. The granting and withholding of some medical diagnoses may determine whether the moral connotations are enforced legally. For example, the use of illegal drugs may be viewed as antisocial behaviour for which the moral disapproval ought to be expressed in the criminal law and any transgression subject to punishment. However a diagnosis of 'addiction' weakens the individual's responsibility for the illicit behaviour and may be used to completely excuse someone from the forensic process or as a mitigation in sentencing. In these circumstances 'medicalising' a particular behaviour weakens but does not eliminate altogether the ascribed moral associations. The withholding or giving of the diagnosis determines whether someone is a morally irresponsible 'drug fiend' or a 'victim', a morally passive category and an admission of personal inadequacy (Kennedy, 1981: 5-6). A medical diagnosis frequently diminishes, even if it cannot eliminate, the negative values associated with illness. Most diagnoses limit the patient's responsibility for the consequences of the illness. They place the patient temporarily in a morally neutral zone excluded from personal responsibility for the consequences of the illness. To "be under doctor's orders" is a socially and morally acceptable reason for breaking personal commitments. This protection can be weakened by the suspicion of a feigned illness; 'bad faith' undermines the social protection. The protection may be weakened in other ways.

In some instances, a medical diagnosis may be too weak to protect someone from moral opprobrium. Venereal diseases are so strongly linked with sexual immorality in the popular mind that medical diagnosis alone is insufficient to enable people to come forward for treatment. Special provisions for protecting the confidentiality of patients are required in order to reduce the incidences of such illnesses by encouraging voluntary self-referral combined with a system of 'contact tracing' to draw people into treatment who might not otherwise overcome their sense of moral blame, whether ascribed by themselves or others.

A person diagnosed as having AIDS is as vulnerable to moral blame as anyone with a venereal disease. The typical protection from moral judgment provided by a medical diagnosis is eroded unless the general moral attitude to the way in which the disease was caught can be challenged. One approach is to exclude some people from the moral battle by arguing their moral innocence in the acquisition of their illness. People infected by medically prescribed treatments for haemophilia, blood transfusions, perinatally infected babies and children, all have a strong claim on being excluded from the morally charged debate and taking on the moral mantle of 'innocent victims'. The 'innocence' of those infected by blood products was recognised by the courts and by the government who agreed to make a special welfare fund exclusively available for people within these categories to be distributed by the MacFarlane Trust. The term 'innocent victim' has the effect of creating moral distance from others who are conversely implicated as 'guilty carriers', which attributes both personal responsibility for catching the infection and blame for its future spread. Homosexuals and injecting drug users would fall within these categories. Susan Sontag writes of the shame of AIDS:

> With AIDS, the shame is linked to an imputation of guilt; and the scandal is not at all obscure. Few wonder, Why me? Most people ... know (or think they know) how they got it. It is not a mysterious affliction which seems to strike at random. Indeed to get AIDS is precisely to be revealed as a member of a certain 'risk group', a community of pariahs.
>
> (Sontag, 1988: 25)

The intensity of the moral debate in the 1980s was not merely the result of a disease which evoked,

> all the features of a traditional morality play: images of cancer and death, or blood and semen, of sex and drugs, of morality and retribution. A whole gallery of folk devils have been introduced – the sex crazed gay, the dirty drug abuser, the filthy whore, the blood drinking voodoo-driven black – side by side with a gallery of 'innocents' – the haemophiliacs, the blood transfusion 'victim', the new born child, even the 'heterosexual'.
>
> (Plummer, 1988: 45)

The symbolic weighting of bad and good served to mark out the moral boundaries of a particular culture and either to establish a degree of closure on a particular social order and entrench the categorisation of some as deviant and deserving of stigma.

The medical discourse on AIDS

The stereotypical discourse on AIDS within the medical literature makes no explicit reference to morality. There is a seemingly deliberate avoidance of the use of moral language so that 'facts' are overtly privileged over 'values' in an ethos of neutrality. The subject matter is 'objectified' even when it invites either a moral or personally subjective response. It is as if the independent objective observer stance taken within the positivist scientific tradition excludes any comments on the social and personal factors. For example, a veneriologist observed,

> Cases of gonorrhoea have declined among homosexual men in London (Weller et al., 1984). Rectal gonorrhoea has decreased which suggests that patients may be modifying their sexual behaviour ...
>
> (Forster, 1986: 69)

A genito-urinary specialist writing about sexual activities which would probably outrage moral traditionalists explains their relative decline in popularity in terms of medical risks and an assumption of a causal link between knowledge and behavioural change.

> Insertion of the finger or a fist or arm through a dilated anal sphincter – known as fisting [and other activities described in the same style] ... have all become less fashionable. They were never as popular in the UK as they were in metropolitan parts of the USA ... Fisting has the danger of tearing the anal sphincter or rectum present every time, except, perhaps, when used by those experienced in this form of sex.
>
> (McManus, 1989: 231)

Epidemiologists talk of human behaviour with equal detachment from any moral judgement. An international seminar to discuss 'Future Trends in AIDS' (HMSO, 1987) was conducted in an ethos of moral 'neutrality' and personal distance from the consequences of any changes in epidemiological predictions or the behaviours giving rise to these adjustments. The prevailing sense of moral dissociation and personal detachment

extended to medical disciplines involved in psycho-social consequences of AIDS, such as psychiatry (Dilley, 1988), but was most evident in those disciplines which concentrate on the physical symptoms or physiology of illness including urology where the patient becomes invisible in scientific accounts of cause and effect. This medical detachment contrasts with the moral commitment of both the 'moral traditionalists' and 'AIDS deconstructivists'.

The moral agenda of AIDS deconstructivists

The moral agenda of AIDS deconstructivists is probably most apparent in presentations made at an annual series of conferences on social aspects of AIDS held at Bristol Polytechnic from October 1996 (Aggleton and Lomas, 1988) and in the proceedings of a conference on 'Taking Liberties: AIDS and Cultural Politics' held at the Institute of Contemporary Art in March 1988 (Carter and Watney, 1989). The movement was Anglo-American and involved academics and journalists who provided a rationale for the practical peer support of people with HIV and an HIV education and information campaign especially within the gay urban communities of New York, San Francisco and London. Representative texts include Cindy Patton, *Sex and Germs: The Politics of AIDS* (1985), Dennis Altmann, *AIDS and the New Puritanism* (1986), and Simon Watney's *Policing Desire* (1987), but their views were probably more widely disseminated through the gay press and other radical publications. The moral agenda was to deconstruct any moral association of AIDS with sexual oppression or reversal of sexual liberalism in conjunction with an assertion of the value of mobilising the minority communities to provide care for themselves. AIDS was not simply to be stripped of all moral metaphorical associations and to be viewed as an illness like any other, but provided an opportunity to redefine the ethical value of acceptance of sexual diversity and the corresponding obligations for consenting adults to protect themselves from any potential health risks. Some comparable arguments were also made on behalf of acceptance of non-prescribed

drug use. A parallel concern to protect the newly won sexual freedom of women in general following contraception and especially the contraceptive pill was evident. However, the main focus was on protecting and advancing the sexual freedom of gay men and lesbians. Community initiatives to provide education to enable people to protect themselves from all related health hazards and to befriend people who were adversely affected were advocated as the morally responsible way of responding to the promotion of healthy individuals and communities. Many voluntary agencies concerned with HIV and AIDS in Britain were developed within this ethical ethos and represented the practical application of this ethic which had its origins in activities prior to AIDS. The London-based Gay and Lesbian Switchboard and National Friend had already been distributing health information about hepatitis B which could be sexually transmitted and offered support to people who knew themselves to be carriers. The advent of AIDS gave greater urgency and priority to the health aspects of supporting gay people, but it also intensified debates about remedicalisation.

If the primary goal of the AIDS deconstructivists was to counter the arguments of moral traditionalists, this goal was sometimes concealed by divisions of opinion about remedicalisation. In his presentation at the first 'Social Aspects of AIDS' conference, Ken Plummer (1988: 24) was equally critical of both the 'medical' and 'stigma' rhetorics of AIDS which he viewed as monopolising contemporary thinking. He summarised the two approaches diagrammatically.

Figure 2.2: Medical and stigma models of AIDS

	Medical model	Stigma model
Focus	Body/organic	Behaviour/lifestyle
Mode of conceptualisation	Scientific	Moral, political, theological
Mode of explanation	Germ-based	Evil, sin, choice, responsibility
Mode of management	Clinical	Segregation, discrimination, exclusion

(Plummer, 1988: 24)

He argued, following Illich's (1975) classic polemic 'Medical Nemesis' that medical intervention can be damaging in three ways. Clinically, medical intervention can make situations worse and be fatal. Socially, the role of medication is extended wider and wider into social experience. Culturally, too much dependency is created and there is a paralysis of healthy responses to suffering, impairment and death. He laments the absence of a corresponding gay critique of medical rhetoric and points to the major challenges coming from the alternative holistic health movement (p. 26). These views are deeply held and represent a significant reservation about the role of medicine which was characteristic of some of the AIDS deconstructivists. However, this view was not universal. An alternative response to the threat of remedicalisation was to develop a distinctive gay-orientated health programme within the health service in large urban centres. This difference in response to the threat of remedicalisation created considerable divisions within voluntary sector organisations about whether to collaborate with sympathetic clinicians and scientists. Those who rejected collaboration with conventional medicine were also most likely to emphasise self-empowerment strategies to individuals and groups. Radical self-help books which favoured this view (e.g. Spence, 1986; Tatchell, 1986) rarely mentioned counselling. This omission suggested that the role of counselling

was excluded from the radical agenda and might well be at the centre of the conflict over remedicalisation.

However, counselling was not without its supporters. The Terry Higgins Trust was founded in 1982 by the friends of the first man known to have died of AIDS in Britain. They had been appalled at the manner of his hospital care. He was reported to have been double barrier nursed and to have died in considerable fear compounded by his isolation. His friends established the Trust to gather funds to sponsor medical research. The founding group was replaced a year later by a more professionally and administratively experienced group including a representative of the Gay Medical Association and Tony Whitehead who developed a close collaborative working relationship with Donald Acheson, the Chief Medical Officer. The transition to a more middle class organisation with closer relationships with government and clinicians was symbolised by renaming the organisation the Terrence Higgins Trust. In 1985, the Department of Health funded its first counselling organisers.

In 1988 in a speech at the Institute of Contemporary Arts, Whitehead asserted:

> ... instead of pulling the rug from under the government, we said 'Yes, we must do something. We must strengthen the voluntary sector ... Our immediate response to the tragedy of AIDS has been to rush off to hold people's hands at bedsides. We have not taken our fight out onto the streets as has happened in the United States ...'
>
> (Whitehead, 1989: 108-9)

In 1984, the strengthening of the voluntary sector had seemed to Whitehead and others to have been a higher priority and a better prospect for delivering significant help than campaigning in the streets. It is possible that too high a campaigning profile might have compromised the confidentiality sought by most recipients of services. A great deal was achieved invisibly by using gay networks rather than, as Tony Whitehead regretted in 1988, by forging a broad base for support.

> Looking back I recognise that we should have tried to forge a broad base of support. Not just with either gay people, or those involved in drug-related work, but across the entire

> spectrum of British politics. We relied on community contacts, and on the sympathy of individuals, but we had not taken in the fact that AIDS requires a coherent political analysis.
>
> (Whitehead, 1989: 109)

Whatever the regrets with hindsight, the Trust was swept up in responding to urgent social needs in 1984 in collaboration with medical services and was strongly committed to counselling.

The potential sensitivities around counselling within an ethos of self and group support may be symbolically represented by the arrangements for the location of Body Positive, a self-help organisation which developed within the Trust before it developed its independent existence. When it relocated to Philbeach Gardens in London in the late 1980s, a counselling organisation known as the Red Admiral Trust was located next door so that it was readily accessible to members of Body Positive but not necessarily identified with that organisation.

An ethically conflicted setting for the emergence of HIV counselling

Three major ethical stances were evident within the ethical arena in which HIV counselling was being constructed. This account has outlined some of the distinguishing characteristics and forms within which each had developed. The development of the ethical ethos applicable to HIV counselling would be significantly affected by which of these ethics eventually dominated. A moral traditionalist view would co-opt counselling to a moralising agenda. A medical ethos would tend to favour moral 'neutrality' over matters of sexual orientation but would tend to be more directive about the advisability of specific sexual behaviour based on scientific knowledge of risk of transmission and to the health of the patient. An AIDS deconstructivist view would either reject counselling in favour of other forms of self- help and community based support or might adapt counselling as an additional response within that tradition. In the late 1980s, it seemed that there was real doubt about which of the first two would prevail in the longer term

in public policy. The current public policy ethos was within the liberal tradition based on individual consent rather than coercion as evidenced by the Department of Health endorsement of 'non-moralising' HIV counselling, freely available testing facilities, and needle exchanges for injecting drug users (Berridge, 1996: 117-21). However, there were considerable pressures to modify this policy towards the moral traditionalist position. These substantial forces included the strength of opinion of some of the opponents to the liberal policies and their ability to attract the support of the popular press, the Conservative character of the Government of the day and the unforeseeable impact in future developments of medical impact and knowledge. Internationally, there were examples of more coercive responses to AIDS involving compulsory segregation and confinement in countries as diverse in their political traditions and attitudes to sexual liberation as Cuba (Miller, 1991: 56) and Sweden (Wolfe, 1989: 242). The potential for altering the ethical *status quo* appeared to add to the intensity of the moral debate. However, the construction of HIV counselling would not simply be resolved at the interface of moral traditionalism and medical ethics. Counselling was also being constructed within the cross currents between medical ethics and the AIDS deconstructivists, the latter being prominent within the communities most affected by AIDS and therefore might be considered to be most influential with potential clients. The potential range of views about the appropriate ethic to be applied within HIV counselling meant that ethics could reasonably be expected to be a source of conflict and ambiguity for HIV counsellors. As such, the construction of an appropriate ethic was likely to be contentious and a source of potential sensitivity for any participants in this research. The adoption of an ethic was not only a personal or collective stance about the moral significance of HIV and AIDS, but also entailed a political agenda within a fiercely fought and conflicted political arena.

Chapter 3

Novel challenges: new methodologies?

'The student is forced out into the uncertainty of all things, upon which the necessity for commitment then bases itself. Study must again mean taking a risk ...'

Heidegger (cited in Reason and Rowan, 1981: xvii)

The aim of this research is to study the ethical conceptualisations of HIV counsellors as they are constructed over time. In the general methodological considerations identified in chapter 1, the research was identified as descriptive ethical inquiry in which a participative methodology that encouraged dialogue was a fundamental feature. However, there were more immediate issues to be considered in conducting the research before the nature of the participative inquiry could be defined in more precise terms. Major features were the high levels of uncertainty at the outset of this research about:

- whether HIV counsellors would be willing to participate because of the sensitivities of their role and the research topic;
- what would emerge from the research process because of the invisibility of HIV counsellors who appeared to be working in isolation and in conditions of considerable secrecy which made it hard to anticipate issues and views; and
- finding a methodology (with associated research ethic) which would be acceptable to both research participants and academic review.

This chapter considers each of these uncertainties in sequence because of the necessity of linear progression in this kind of writing, whereas the lived experience was that these sources of uncertainty were more closely related within an interactive cycle of initial uncertainty and gradual but progressive resolution. It required positive strategies to convert uncertainty into defined issues, goals and decisions and then to live with the risk of commitment. The main factor present throughout the research was its self-evident

sensitivity, which has been the decisive issue around which other decisions were organised.

Researching a sensitive topic

During the preparatory phases of both cycles of fieldwork, the exact nature of any sensitivities could only be anticipated as informed guesses which were partially corroborated by soundings with known HIV counsellors. There was always the potential for unforeseen sensitivities to emerge during the implementation of research but it seemed highly desirable that as many as possible of the sources of vulnerability were anticipated and taken into account in the choice of methodology. Lee and Renzetti (1993: 5) suggest that the sensitive character of a piece of research appears to inhere less in the topic itself and more in the relationship between that topic and the social context in which the research is being conducted. However, this opinion assumes that a distinction between the research subject and the social context can be sustained and is less appropriate to subjects where a dynamic interaction between these elements is the focus of the research, as in this instance. For potential research participants, the sensitivity of the subject matter could be experienced simultaneously as personal unease about how to resolve uncertainty about an ambiguous ethical issue as well as contextual vulnerability to criticism by clients, colleagues or within the wider community. A commitment to publish reports of the research created the possibility of the research itself placing a sensitive issue in the public domain. (The ethical implications of protecting the privacy of participants for the integrity of the research are considered towards the end of the chapter.) During the preparatory phases, the following sources of sensitivity were anticipated.

(a) The research was taking place in a context where fear of HIV infection fuelled prurient public interest and potentially could result in greater vulnerability for counsellor and client.

(b) Counselling services were in competition with each other for funding and could have their future prospects diminished by adverse or controversial research findings.

(c) As providers of a new service, HIV counsellors would be inserting themselves into already established multidisciplinary teams or networks and therefore may already be the focus of conflict or resistance.

(d) Many services would probably only have started within 18 months prior to the first fieldwork because of the availability of funding. An unknown number may only have been at the point of starting or struggling to establish themselves. In both cases, being at the inception of a new service could enhance a sense of vulnerability and impermanence.

(e) Many HIV counsellors were thought to be working in personal isolation from others in the same role. It seemed reasonable to anticipate that they were probably feeling simultaneously unsupported by the absence of a collective identity and might quite reasonably be ambivalent about the outcome of any collective process which could either affirm or contradict individual experience and opinion.

(f) The distinction between counsellor and client was not a tightly boundaried one. Anecdotal evidence and my own personal observation suggested that many people became involved in HIV counselling because of the personal experience of the impact of HIV on someone close to them or more directly because they were themselves HIV positive. Two factors increased the probability of the latter. Some clinicians from medicine and nursing were known to have been transferred from providing invasive treatments to offering counselling as a way of excluding the risk of HIV transmission in clinical settings and allaying public fears. Health workers with HIV were extremely vulnerable to public exposure. Prior to the research, a court injunction had been required to prevent tabloid newspapers from publishing

the identities of doctors with HIV on the basis of information leaked by a national health employee (*X v. Y, 2 All ER 648*). It was important that this research did not provide an alternative and perhaps more legitimate route to the same information. Regardless of the real possibility of media intrusion there was also the potential for amplifying personal vulnerability by bringing together people with contrasting personal experience which included of those who knew their HIV status to be positive, those who did not know their HIV status but who feared that they were positive and those who knew themselves to be negative.

The combination of all these different sensitivities constituted a substantial threat to the viability of the research, thus an extreme form of research sensitivity as defined by Lee and Renzetti:

> '... a sensitive topic is one that potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding and/or dissemination of research data.'
>
> (1993: 5)

A number of strategies were adopted to manage the sensitivity of the topic following preparatory discussions with known HIV counsellors and representatives of the funders of the research. These included:

(a) maintaining a focus on 'good practice' as examples for less developed services and perhaps with an implicit challenge to some established practices rather than seeking to expose or publicise poor practice. 'Good' in this context carries both connotations of 'ethical' and 'competent' although for the purposes of this review the emphasis is on the former. This focus on 'good practice' also carried with it an expectation that the research would be developmental and the process would act as a catalyst for good practice rather than concentrating on an evaluation of present practice.

(b) adopting a policy on terminology appropriate to the field. Language about HIV and AIDS had become symbolically charged with associations and affiliations so that the choice of terminology would be an important factor in the attitude taken by potential participants. Dr John Sketchley (1990) prepared a briefing paper on the significance of terminology about people with HIV and AIDS based on his experience of research for the British Medical Association Foundation for AIDS. In the paper he suggested that *'AIDS carriers'* was firmly rooted in the moral panic still evident in the popular media with a deliberate focus on the threat posed to others at the expense of any awareness of the person with the virus. *'AIDS victim'* and *'AIDS sufferer'* implied passivity which contrasted with the collective and self-help mentality of many initiatives. The use of AIDS as the generic term for people affected was also problematic because it represented a specific late phase in the disease progression in which HIV infection was the only constant. For all these reasons the slightly cumbersome phrase *'people affected by HIV'* was usually adopted to include those who knew themselves to be infected, or considered themselves at significant risk of infection, or were affected by the infection of someone close to them. This generic phrase included all those likely to approach counselling services including the *'worried well'* who continued to believe that they were infected by HIV in spite of negative test results or not having been exposed to the known routes of transmission. *'People living with HIV'* or *'... infected by HIV'* were considered acceptable labels for people with a sero positive diagnosis. The adoption of this terminology was intended to convey as accurately as possibly that the research was being conducted from the considered perspective of looking outwards from the personal experience of having or working with people living with HIV rather than as an independent and detached research. The aim was to signal from the outset a basis for empathy rather than sympathy in which the participants' perspectives and meanings would be the subject matter of the research.

The briefing paper was made freely available to members of the steering panel appointed by the Department of Health and to anyone who assisted with the research process in the 1990 fieldwork and continued to influence communications in subsequent research.

(b) My own previous background in the gay movement, and having worked in a progressive regional unit for alcohol and drug addiction were not concealed from participants and funders and communicated as seemed appropriate, taking care to minimise any sense that people with other backgrounds such as haemophilia were excluded. This socially inclusive stance was underlined by the selection of group facilitators and rapporteurs for the first phase of the research. They were recruited from a range of backgrounds including health education, the women's movement, voluntary organisations, etc., so that there was a reasonable probability of participants finding some social proximity within a socially and professionally diverse research team.

(c) Research participants were encouraged to be actively involved throughout all phases of the research in what was originally envisaged as collaborative research. The collaborative focus was intended to maximise a sense of participant control with the consequence of a corresponding diminution of personal threat. A subsidiary aim was to enhance the catalytic effect by sharing the ownership of the research with participants so that they had a degree of personal commitment to implementing any 'good practice' which emerged as desirable from the research.

Locating the research within the extant research methodologies

The desirability of a collaborative approach to the research was endorsed in both phases by the funders (including the Steering Panel appointed by the Department of Health to oversee the quality of the research conducted in 1990-91) and by informal soundings

with potential participants. This appeared to provide a basis for making a preliminary choice from within the plethora of research methodologies which constitute qualitative research. This diversity of methodologies is distinctive of qualitative research (Bryman, 1988: 50-61; Crabtree and Miller, 1992: 3-6; Miles and Huberman, 1994: 5-8; McLeod, 1994: 76; Mason, 1996: 13-5; Denzin and Lincoln, 1994; Patton, 1990: 87-9). Maximising the involvement of participants throughout the research process, the emphasis on participant led perceptions of ethical issues and the developmental focus pointed towards an approach which combined an emphasis on the experiential, phenomenological methods and action research. The most obvious choice was new paradigm research as devised by Peter Reason and John Rowan which combined all these elements within an overall paradigm of critical theory (1981a: xvi-xviii). However as the research unfolded it became apparent that consideration of other factors pointed away from too rigid an adoption of new paradigm research which created a need to define the relationship of the adopted methodology with new paradigm research and to consider the implications for the selection of research criteria.

Other factors which qualified a commitment to new paradigm methodology included the following:

(a) The importance of a sense of group identity and interaction between all participants as co-researchers in the optimal forms of new paradigm research would suggest limiting the number of participants to relatively small numbers. Instead both the exploratory and developmental aims of this research suggested the desirability of maximising numbers of participants. Larger numbers increased the range of experience available to the research thus extending its exploratory field. Similarly, increasing the numbers of participants would advance the developmental aims of the research by maximising the opportunity to contribute to the research and

hopefully creating a correspondingly large pool of people committed to its practical implementation.

(b) HIV counsellors tended to be geographically scattered outside central London. The commitment to a geographically wide ranging research project covering England and Wales in 1990 would create obstacles of travel time and expense in a research methodology which usually emphasised face to face interaction. Other methods of interaction using telephone and correspondence would tend to make the researcher the focal point of communications and therefore undermine the sense of everyone interacting on an equal basis as co-researchers by creating a distinction between participants and researcher.

(c) The practical reality of the limitations on time and energy that any individual participants could offer to the research. The high levels of commitment required in truly collaborative research like human inquiry groups (Heron, 1996: 49-50; West, 1996: 350) would exclude many potential participants who could only make a limited commitment. This exclusion would be most likely to affect those with the most experience working in the busiest settings whose views might be particularly informative.

(c) The range of expectations of the actual participants about their level of involvement appropriate to this kind of research. Reflection on the combination of the background of the words brought together in the role title 'HIV counsellor' indicates the conjuncture of potentially two opposing academic traditions, namely science and phenomenology. The medical developments based on increasing knowledge about the nature of HIV and its effects were largely derived by traditional science founded on variations of positivism. On the other hand, the psycho-social focus of counselling probably attracted participants who were diverse in their intellectual orientation and more influenced by the development of

theoretical alternatives to traditional science. These different theoretical orientations would probably be associated with different expectations of the level of involvement and influence on the research by researcher and participants. Participants who adhered to the sciences would tend to expect to be able to limit their contribution to data generation and probably expect a clear demarcation between researcher and research subject. In contrast, participants who were already familiar any kind of participative research were more likely to be open to the possibility of participants extending their involvement in the research process to interpretation and creating the research narrative, although they might still be constrained in their potential commitment by practicalities.

In order to equalise the degree of influence of participants on the research process, it became increasingly apparent that a methodology which lay between, on the one hand, wholehearted collaboration between researcher(s) and participants (the ideal of new paradigm collaborative research), and on the other hand, a remote researcher with the entire responsibility for the research (characteristic of traditional scientific research) was required. This became all the more apparent when the criteria for validity of new paradigm research were considered.

In many ways the criteria for assessing the quality of new paradigm research have remained remarkably consistent from 1981- 1994 (Reason and Rowan, 1981b: 239-50; Heron, 1988; 40-59; Reason, 1994: 327). The characteristic emphasis on an interpersonal collaborative and experiential encounter in which researcher and participants share equal responsibility as co-researchers creates an emphasis on validity as more personal and interpersonal rather than methodological. It is difficult to envisage the quality of interpersonal interaction being achieved without a strong sense of group cohesion. As the first research phase involved 118 participants divided between four regional locations in England, with each group meeting for one day, it is clear that the level of cohesion

between all participants falls short of that envisaged in new paradigm research and that the core researchers acted as the common factor between a series of different groups. Again in the later research, the emphasis was on the researcher acting as a link and communicator between different established interprofessional groups rather than the research itself generating a new collective and cohesive group within which the research process is undertaken. The term coined for this research process was 'consultative' rather than 'collaborative' in which it was envisaged that participants, collectively and individually, would be involved throughout the research process by systematic and strategic consultations but without necessarily taking direct responsibility for the creation of the collective experience, its interpretation, or the writing of several drafts of the report. Each one of these activities would be a responsibility of the researcher(s) undertaken in consultation with participants. The consultative cycles of each of the two research activities can be represented diagrammatically (see diagram 3.1).

Diagram 3.1: Consultative process

Research activity	1990	1994
Data collection	Group consultations in which notes of meetings summarised to participants for checking and correction.	Individual interviews in which putative problems and interpretations discussed with interviewees.
Data interpretation	Process of interaction supported by correspondence and telephone conversations with relevant participants.	
	Early written drafts were circulated for comment especially by those whose information or views had been influential in the writing of particular sections	
	Oral presentation of the research outcome to a significant proportion of those who had participated in the research for comment, discussion and critical review prior to preparing final draft.	
	Final drafts circulated to corroborate, amend or veto any quotations by the person concerned.	
	Publication of reports (Bond, 1991, 1995) with free copies to all participants who are invited to continue to offer comments and enter into discussion.	

Conceiving of the research process in these terms raises issues about two critical interfaces between the researcher and participants within the research process; and the research narrative and external readers. A straight forward transfer of the criteria of new paradigm research from a collaborative to a consultative research process could not be assumed. Within new paradigm research, at least in its ideal form, the co-researchers have direct personal experience of the entire research process which is founded on and validated by their interaction. Hermeneutically, they are the originators, authors and recipients of the research narrative. Consultative research follows a parallel process but the inherent division of responsibility between researcher and participants requires different methodological procedures in order to maximise the quality of the consultative

process for those aspects of the research developed outside the collective interaction. These criteria also define the relationship between participants and the resultant research narrative that is produced. The developmental aims within this version of consultative research envisage that the research narrative will be read by a wider audience than the participants. In both phases, the research was funded in order to produce a research narrative which would influence the practice of others working in closely-related contexts and similar roles. This draws attention to the desirability of devising research criteria which are appropriate to assessing the quality of the research narrative for the external reader who, unlike the participant, will not have direct experience of the research process and for whom issues of validity may not be adequately encapsulated with the communication of the interpersonal process. I will consider each of these interfaces in turn.

Criteria for relationship between researcher and participants in the consultative process

The aim of the criteria for the relationship between the researcher and participants in consultative research is to maximise the quality and meaningfulness of any interaction within the research process as the means by which data, interpretation and report are generated. The criteria generated for 'new paradigm research' are arguably a useful starting point because they have been devised and tested over time to maximise the learning from interactive experience. A systematic comparison of three sources of criteria representing the model at its inception, a mid point and more recent explanation (Reason and Rowan, 1981b: 239-50; Heron, 1988: 40-59; Reason, 1994: 327) have been selected as the basis for distilling the key criteria for the face to face interaction within the consultative process, which are:

(a) Creating the circumstances conducive to a collaborative encounter with experience (Reason, 1994: 327) in which attention is given to both reflection and action, individually and collectively (Reason and Rowan, 1981b: 247-9; Heron, 1988: 44).

In consultative research this requires attention to a range of circumstances in which the consultative encounter takes place including a conducive and appropriate physical setting, the use of appropriate ground rules in facilitated group encounters to maximise individual safety and quality of participation. The ground rules adopted for group consultations throughout this research were:

(i) All participants should know who is present at the consultations with essential background information about place of employment (and/or venue for providing HIV counselling), role title.

(ii) Personally identifiable information should be restricted to the consultation in which it is disclosed as the basis for managing confidentiality. Any subsequent disclosures of personally identifiable information in further consultations or publications should only take place with the consent of the person concerned.

(iii) Each person is responsible for their own participation. The constraints of time provide a context for the exercise of this responsibility in which the aim should be to provide an equality of opportunity for each other to participate. Silent participants are encouraged to make contributions. The garrulous are encouraged to be more selective in their contributions. All participants may offer the appropriate encouragement or make observations about the pattern of participation.

(iv) The sensitivity of the subject matter, with its potential for personal vulnerability, entails a corresponding responsibility on everyone to provide sensitive support to each other and to respect differences in experience and opinion. It is considered evidence of a positive consultative dynamic where deeply held differences of experience and opinion can be expressed and discussed.

(v) Consultations should take place in circumstances where the focus of the consultation is clearly indicated in the briefing to participants by the thematic title and any supplementary structure within the consultation (which should be minimal and negotiable within the parameters of the theme).

These ground-rules are particularly pertinent to face to face consultations. Where facilitators were used in 1990, they were briefed on these ground rules which were also made freely available to all participants throughout the research. With some modification they are also relevant to communications by telephone and correspondence.

(b) Attentiveness to issues of 'critical subjectivity' which informs participants' judgments and high quality discernment of key issues is a fundamental basis for the research without which meaningful dialogue would be frustrated. Two major threats to critical subjectivity need to be actively considered and addressed throughout the consultation process. *'Unaware projection'* as an individual defence against anxiety generated by the research process and *'consensus collusion'* as a collective defence represent two ways in which critical subjective and intersubjectivity can be distorted (Reason and Rowan, 1981b: 244; Heron, 1988: 51-3; Reason, 1994: 327). The quality of the facilitation of the consultative process and its attention to group dynamics and processes is particularly significant.

(c) The key questions for the consultative process are 'Is it right?', 'Is it useful?', 'Is it illuminating?' (Reason and Rowan, 1981b: 243). Consideration of these issues provides the basis for the developmental or catalytic aims of the research.

(d) Transparency in the relationship between researcher and participants takes on an extension of meaning in the shift from collaborative to consultative research. Transparency in the relationship between the researcher and participants within the totality of the research process is required. In face to face interaction, I cannot

exclude myself from being influential within the research process. My own subjective perceptions influence the achievement of (a) to (c). In common with all participants I share the socio-historical context of the research in which certain values and ways of viewing the phenomena are privileged over others. Maximising transparency over the researcher's own orientations and offering these as a subject for discussion at appropriate moments both models a way of interacting which accepts the worth of different views between participants and provides participants with information which enables them to influence the orientation of the research. Challenges, modifications and affirmations of each other's views are all valuable within the consultative process.

As the consultative process envisages that many significant tasks will be undertaken by the researcher away from the participants, especially the drafting of the written report, it is necessary to be as transparent as possible about how this task will be undertaken prospectively and to be accountable to participants retrospectively. Again the interpersonal aspects of this process are significant. I know that there were times when I found it hard to remain non-defensive when someone or a group questioned the basis for what may have been a hard won passage in a draft or to listen to someone who may feel strongly that a particular point of view has been omitted. However, the researcher's manner of responding is as important as the context of the response to the sense of influence that participants feel able to exercise during process and correspondingly their commitment to influencing the outcome. In some instances several rounds of consultations were required before either points of difference were sufficiently clearly defined to be acknowledged or a resolution into a single point of view was achieved. The consultative process may lower the demands on participants in terms of attending face to face interactions in comparison to fully collaborative research but in my experience, there is a

corresponding cost to the researcher in administering and responding to cycles of consultation undertaken by correspondence and telephone.

Validity in the relationship between researcher and participant in consultative research, like 'new paradigm research', is primarily personal and interpersonal with additional methodological considerations to manage transparency between researcher and participant for those elements of the research conducted outside the collective face to face interaction.

Criteria for readers external to the research process

The criteria appropriate to the internal consultative process cannot be an adequate substitute for consideration of criteria appropriate to the relationship between the research narrative and the external reader within consultative research. The external reader is by definition outside the consultative process and is encountering a narrative which mediates the consequences of that direct experience between researcher and participant. As a consequence, the external reader's focus is not so much on the interpersonal but on the relationship between the narrative and the reader's experience of it, and how the narrative relates to the subjective experience and opinions of that reader.

This way of viewing the relationship between the research and the reader is significantly different from the way in which validity is conceptualised in traditional sciences. The traditional scientific criteria for validity are intended to support claims of generalisability and place responsibility on the researcher for demonstrating that these have been met. It is assumed that the researcher and reader share an ontological assumption that reality exists and can (to a greater or lesser extent) be known, and that the researcher's attention to criteria consistent with associated epistemological and methodological considerations reveals aspects of that reality. In contrast, locating this research within the general paradigm of post-modernism erodes a clear distinction between ontology and epistemology because both are value mediated through their construction within a social

and historical context by those who interact within that 'virtual' or historical reality (Guba and Lincoln, 1994: 110), including the researcher and participants in the research. The purpose of the research is no longer directed towards generating propositions about reality discovered by a detached and objective researcher writing about objectified subject matter. The purpose changes to creating a chain of interactive and dialogical relationships which culminates in the relationship between narrative and external reader with the aim of enabling the reader to be better placed in apprehending a plastic reality and by a combination of reflection and action to influence that reality. However, there is currently no consensus in the academic community about which criteria are appropriate to this task (Lincoln, 1995: 275) and the inherently fluid nature of the ontological and epistemological assumptions associated with critical theory suggest that any agreement would always be less stable than those associated with traditional sciences. (This is not withstanding the diversity of theory (Harré, 1981: 14) and practice (Mitroff, 1974: 79) within science which result in corresponding adjustment in research criteria.) In these circumstances it is tempting to abandon the search for criteria, but to do so undermines the basis of the paradigmatic commitment to communication as the basis of reality, and to challenging socio-historical assumptions about reality. The crises of legitimation (i.e. agreement about appropriate research criteria) and representation (i.e. whether it is possible to capture lived experience) cannot be ignored but invalidate the search for criteria only if the criteria are assumed to entail some form of ontological reality rather than a much less ambitious indication of a commitment to a dialogical process within a particular socio-historical context. In the spirit of the latter, I decided to compare three different approaches to research criteria written from viewpoints broadly consistent with a critical theory paradigm. The sources are derived from different academic contexts. The criteria proposed by John McLeod (1994) for 'Listening to stories' are specifically devised for conducting counselling research and encompass a wider range of qualitative methodologies than those usually associated with critical theory. In contrast, Joe

Kincheloe and Peter McLaren (1994) were specifically rethinking the implications of the historical development of critical theory for contemporary qualitative research. Yvonna Lincoln (1995) was describing what she considered to be 'emerging criteria for quality in qualitative and interpretive research'. Each of these analyses have been reorganised in Diagram 3.2 around key themes identified as thematic criteria.

Diagram 3.2: Research criteria for external readers

Thematic criteria	Kincheloe and McLaren (1994: 138-57)	McLeod (1994: 97-101)	Lincoln (1995: 275-89)	Others
Credibility	Credibility of portrayals of constructed realities	Experiential authenticity of material Systematic consideration of competing explanations Sufficient conceptualisation Triangulation Testimonial validity	Involvement of academic community as arbiter	Verisimilitude and truth (Denzin, 1997: 10-13)
Relational qualities	Internal/external reciprocity	Negotiations with informants Testimonial validity Credibility of researcher (reflexivity)	Critical subjectivity/ reflexivity Reciprocity Sharing prerequisite of privilege	Reciprocity (Rowan, 1981: 167-71) Sharing prerequisite of privilege (Reinharz, 1979)

Positional transparency	Declaration of socio-political affiliations		Positionality Attentiveness to who speaks for the dispossessed	
Transformative effect	Catalytic validity	Catalytic validity		Catalytic validity (Lather, 1991)
Transferability	Anticipatory accommodation	Clarity and comprehensiveness of research procedures Sufficient contextualisation		Naturalistic generalisation (Stake, 1994: 240)
Attentiveness to wider significance of human experience			Sacredness Ethical concerns Ecological concerns	Sacred and spiritual character of science (Reason, 1993: 273-283)
Replication		Replication		Replication (Reason and Rowan, 1981b:250)

(a) **Credibility:** the aim is to produce research which holds credibility with all readers in terms of experiential authenticity. John McLeod (1994: 98-101) suggests a variety of criteria to enhance conceptual credibility in terms of openness to the possibility of alternative explanations, triangulation between different elements of the research, and evidence of the validation of participants. The crisis in representation unpicks the assumption that reality can be truthfully, faithfully and accurately captured (Denzin, 1997: 10) and as a consequence the correspondence between verisimilitude and the truth cannot be assumed. Following Todorov,

Denzin draws an analogy with the construction of detective novels to illustrate the relationship between verisimilitude and truth.

> In a murder mystery, the murderer must appear to be innocent, and the innocent person must be made to appear guilty. 'The truth has no verisimilitude, and the verisimilitude has no truth' (Todorov, 1977: 86). The end of the narrative must, of course, resolve the tension and contradiction.
>
> (Denzin, 1997: 11)

It follows that it adds to the credibility of the research if the compatibility between verisimilitude and the truth (i.e. the map and the territory) is not too readily assumed and periodically examined. This is the researcher's responsibility. The external reader should be in receipt of sufficient information of sufficient quality to evaluate the compatibility between verisimilitude and truth, both within the narrative and by reference to personal experience.

(b) **Relational qualities:** The research process is so closely akin to humanistic and phenomenological psychology, that sound relations with participants supported by insightful and discerning awareness of their subjectivity is essential and should be evidenced in the research account. The criteria described in the previous section are an elaboration of this criteria.

(c) **Positional transparency:** There is only the semblance of neutrality within this research tradition. There is no value free position in the construction of narrative although the author(s) may adopt a position of denial to minimise anxiety created by questioning values or be unable to explicate values which are normative within that phenomenological field. The difficulty of discerning our individual and collective values in our cultural and sub-cultural contexts suggests that simply declaring known predispositions may be only a partial response to this criteria. Sufficient biographical information should be included to enable someone from outside the author's culture to search for unacknowledged values or socio-political affiliations. Denzin (1997: 12) explains the relationship between the political and

the textual aphoristically, "... a text is always a site of political struggle over the real and its meanings. Truth is political, and verisimilitude is textual."

(d) **Catalytic or transformative effect:** This criteria assumes that the validity of the research is enhanced by evidence that it has been of sufficient significance to have transformed the individual/collective narrative of participants in ways which can be described within the research narrative. An interactive research process which produces no discernible change would be vulnerable to scepticism about the choice of topic, management of the research process and/or accuracy in the research narrative. Lather (1993) has a distinctive approach to the issue of criteria which are not fully considered here. She holds a particular view of catalytic validity from within the feminist tradition in which she emphasises the degree to which the research facilitates those it studies to an understanding of their world in order for them to transform it (Lather, 1991). From this perspective, the transformative effect for participants is essential and the transformative effect on external readers is optimal.

(e) **Replication:** The research should be described in such a way that it can be replicated. The production of a different outcome does not necessarily undermine any of the research, especially if the divergences can be linked to the inevitable differences in the subjective experiences of researcher(s) and changes in context. Reason and Rowan (1981b: 250) construe any such differences positively as a contribution to 'binocular vision'. The corollary of this is that the absence of differences with such contextually sensitive research may indicate methodological flaws.

(f) **Transferability:** The external reader should be placed in a position where the encounter with the research narrative assists him/her with the construction of knowledge – a process identified by Stake (1994: 240) as *'naturalistic*

generalisation'. In contrast, Kincheloe and McLaren (1994: 151-2) locate their preferred terminology, *'anticipatory accommodation'*, within a psychological understanding of cognitive processing by adopting Piaget's notion of accommodation. This suggests a capacity in the reader for discerning points of similarity and difference between the research narrative and the reader's experience and a capacity to take these into account in anticipating the application of the research to situations within their experience. They suggest that this construction of generalisation is much closer to the way people function than the more traditional understanding based on external validity in scientific discourse. An obvious implication of this is that readers should be provided with sufficient contextual information and clarity about research procedures in order to be able to make anticipatory accommodation(s).

(g) **Attentiveness to the wider significance of human experience:** It is a feature of the human imagination that it can construct narratives which place human experience in a wider context of the sacred, spiritual, ethical and ecological (Lincoln, 1995: 284). The wording of the preceding sentence deliberately leaves open whether the imaginative narrative is the totality of its significance or whether it is a mechanism for discerning, however imperfectly, some other reality. Out of the prime movers in new paradigm research, Reason (1994: 334) is most critical of post-modernism in the forms which seem to him excessively nihilistic and over-intellectualised. Along with Heron (1992), another founder of 'new paradigm research', he would argue that reality can be at least partially discerned through primal experience which is present prior to culture. There is an analogous ambivalence in constructions of ethics (which is one of the catalytic aims of this research) about whether ethics are primarily to be understood as an aspect of social psychology or indicative, however imperfectly, of ontological foundations.

These criteria are not of the kind which must be fulfilled totally such that any deviation or omission would invalidate the entire research. They constitute an orientation towards the research task which takes into consideration both the research participants and external readers. The impossibility as a human being of consistently sustaining intense sharing characteristic of reciprocity (Rowan, 1981: 167-8) which are optimal relational qualities or achieving total positional transparency is inevitable, given the contingencies of human experience. A commitment to the criteria throughout the research may be more important than any attempt at precise evaluation of what are essentially unquantifiable.

Ethical considerations

I approach the topic of ethical considerations with some trepidation. A number of potential problems could frustrate what must be a brief and focused consideration of this fundamental topic.

(a) The potential scale and volume of considerations: A descriptive ethical inquiry into the experience of qualitative researchers, including the participants in this research as co-researchers would constitute another piece of research and one that could be undertaken to advantage but it is not the task in hand. It is therefore essential that the focus of this section is restricted to the specific ethical issues associated with this research.

(b) The topic 'ethical considerations in conducting ethical inquiry' has the potential for generating a sequence of ever receding conceptual loops, analogous to the effect of holding two mirrors almost parallel to each which produces sequences of ever diminishing but almost identical images.

In order to avoid both dangers I have decided to circumscribe this section quite tightly and to structure it within two subheadings which address the primary ethical issues in conducting this research.

There are as many different ways of constructing ethics as there are different ethical systems which must run to many hundreds. However, there is one primary function of ethical considerations regarding qualitative research which is to enhance and protect the integrity of the research. Integrity is directed towards two foci, namely the research process itself, and the treatment of participants in the research. I shall divide the available space between these two inter-related issues.

Integrity of the research process

Attentiveness to the criteria for the quality of the research is in itself an ethical requirement as protection of the integrity of the research. In making this statement I am assuming that ethics do not stand outside the post-modernist perspective. The explication of relevant criteria represents a component in the construction of the research narrative and establishes the ethical ethos. This is particularly important in an experiential research paradigm of the kind used in this research where there is no clear separation of process from findings because of the interactive structure between researcher and research subjects. Clarity about the criteria for the relationship between participants and researcher constitutes an important element in establishing the relationship between the narrative and the process which the narrative depicts. Therefore it is surprising that relatively little attention is given explicitly to ethical considerations within new paradigm research. Ethics are fragmented and scattered in the first text (Reason and Rowan, 1981a), not indexed in the follow-up volume (Reason, 1988) and thus unsurprisingly omitted altogether from an international review of participative inquiry (Reason, 1994). I cannot reverse this neglect in one short section but there are two major issues which seem to be directly relevant to both consultative and participative research alike. The first is quickly disposed of because it becomes a non-problem by definition but the second is substantive.

(a) Reactivity: In a traditional stereotypical scientific methodology with physical and some kinds of social research, reactivity between the research and the researched

represents a contamination of the research process (Bryman, 1988: 112-3). Too much information about the nature of the research in advance of conducting it, even to obtain informed consent, could be considered the equivalent of having 'dirty test tubes' because of the possibility that research subjects might attempt to behave in the way that they anticipate that the researchers are looking for. Technically known as 'observational reactivity', it is readily apparent why some psychologists have been tempted to withhold information or to deceive participants about the nature of the research (Kimmel, 1988: 28). Reactivity is much less of a concern in experiential research which would encourage a consistent attitude of transparency between researcher and participants. In experiential and action research, the 'subjects' are viewed as partners in the research process. To dupe them would be to undermine the very processes that one wants to study (Punch, 1994: 89). The kind of justification which might seem to justify deception within other research paradigms to avoid 'reactivity' have no place within experiential and consultative research.

(b) Differentiating levels of influence, power and control within the research process: The ideal in new paradigm research is full collaboration or co-operation between all participants as co-researchers on equal terms (Heron, 1981: 154-5). However the reality may be rather different, as evidenced in the two source books (Reason and Rowan, 1981a; Reason, 1988). This deviation from the ideal is viewed as a weakening of methodology but, so far as I could discover, is not considered as an ethical issue. However it seems to strike at the integrity of the research unless there is clarity about what elements are truly joint and therefore fully collaborative, those elements which are consultative with an element of power and interpretive authority resting with the main researcher, and those elements which are predominantly the result of the researcher's work on her own without further consultation. It seems to me that ethically, all these variations are justifiable in their own terms. What is

unethical is to present one category of activity as though it belonged to another with the consequential misrepresentation of power and control in the research process. I have been particularly aware of this dilemma in this research because as a retrospective review of two separate research projects there are several different kinds of narrative being fused into a single account.

Research relating to the fieldwork conducted in 1990 and 1994 was subject to extensive consultation up to the publication of the official reports (Bond, 1991; 1995). There is a sense in which the consultative process extended beyond their publication as feedback continued to be received, which although not resulting in any revisions of those publications, has been taken into account in this rewriting of those research narratives. Some aspects, especially chapters 9 and 10 on ethical frameworks, are the result of continued analysis and interpretation but have not been seen in their present form by a majority of the research participants, although a significant minority have been consulted. The lapse of time and transfer of staff to new circumstances frustrated attempts at a fuller consultation. Perhaps most significantly the consultative process has been sequential rather than continuing across the two projects because although there were some participants in common, most participated in only one project and in the rapidly moving world of AIDS many are no longer contactable, usually because of changes in employment, but in some significant instances due to illness or death. Therefore the closing chapters are a personal reflection which, although shared with a small number of participants for comment, are essentially my personal reflections. I do not consider that this either invalidates the narrative or makes it unethical so long as clarity about the levels of collaboration and validation are maintained. In another sense, I have been so immersed in the material and consultative process that even when I am speaking personally, my own narrative has been transformed by the research process towards becoming a representative of the intersubjective experience and dialogue that occurred within the research. This has been particularly apparent when I have spent long periods

immersed in transcripts and contemporaneously recorded notes which are sometimes several years old and have attempted to discuss my findings with participants whose memory of what occurred is filtered through present concerns and therefore cannot be assumed to be in the same social and historical context.

Integrity of treatment of participants

The ethics of the treatment of participants in qualitative research is an obvious major issue and is the main focus of most treatments of this topic. There are obvious parallels with the ethics for counselling and therapy about maximising research participant autonomy and the avoidance of abuse or exploitation. The main protection for participants in collaborative/ consultative research must be:

- informed consent based on written information about the purpose of the research, the expectations of participants, the intended output from the research (i.e. types of publications) and at least two points of contact so that participants can raise any concerns or grievances.
- clarity about confidentiality.
- the integrity of the researcher(s) supported by membership of an academic and professional community able to challenge and support the intellectual and facilitative aspects of the research.

The importance of these aspects of the research increases with the sensitivity of the topic. Sieber (1993: 19-20) relates sensitivities arising from the cultural context of the research such as the exposure of minority groups to public gaze to those arising from the needs and fears of participants. Approaching this research from the perspective of an espoused 'conservative' personal morality or misrepresenting the struggle to enhance ethical standards by over-emphasising deficiencies in current practice would constitute examples of insensitivity in each of Sieber's categories.

One way of reducing sensitivity was to maximise confidentiality about the personal identity of research participants. It was relatively straight forward to avoid deliberate breaches of confidence without participant consent but much more problematic over less direct breaches. (For the purposes of this discussion disclosures authorised by a participant's consent are by definition, consensual communications and therefore not considered breaches of confidence.) A full range of breaches of confidence would include:

- **deliberate disclosure:** such disclosures might be justified or viewed as ethically (and legally) *defensible* where there are other considerations, such as the protection of others from immediate physical danger, which takes priority over confidentiality. A variation on deliberate disclosure arises where appropriate disclosures are being made, e.g. between researchers, but in circumstances which are *reckless* with regard to being overheard or to giving unauthorised access to sensitive documents. Avoidance of reckless disclosure has included ensuring that personally identifiable information is not left in cars, in case of car theft.

- **constructive disclosure** arises when someone considers themselves obliged to reveal confidential information, usually about themselves, in order to avert some other ethical danger. It was difficult to envisage how constructive disclosure would occur within this research but examples were provided from clinical practice. A nurse who was storing used 'sharps' in her car wrapped in newspaper under the seat created circumstances in which someone with HIV felt obliged to reveal his health status because of his concern that her children or herself might be accidentally cut and infected. Other examples were essentially of the same kind and arose from the need to challenge poor practice.

- **inadvertent disclosure** might arise due to unforeseeable circumstances which *overwhelm* all reasonable precautions like a burglary directed at obtaining

information. Fortunately, this did not occur although during the course of the research one participating counselling service was burgled seemingly to discover the HIV status of some clients with prominent public roles and another agency discovered that phone calls on cordless phones were being scanned by a disgruntled client. A variation within this category is *deductive* disclosure which has remained a major concern throughout the research and extended beyond the research to the protection of my own clients' privacy. The difficulties of protecting the identity of people with HIV in areas of low incidence from deductive disclosure are greater than in areas of high incidence where there can be the anonymity of the crowd. Comparable difficulties arise in writing research about a relatively small and identifiable group of people like HIV counsellors where gender, location or simply mannerisms of speech evidenced in quotations may be enough for someone to deduce the identity of a specific individual. For these reasons a great deal of care has been taken to ensure that all publications of this research have been scrutinised and cleared by people vulnerable to deductive disclosure. Material likely to prove sensitive which could not be adequately anonymised or approved by the person concerned has been omitted.

As a researcher I considered how I would respond if I encountered circumstances in which I felt obliged to breach confidentiality in order to protect others. For example, if I discovered HIV counsellors who were directing clients towards the blood transfusion service as a way of obtaining their HIV status and to avoid the stigma of being seen in clinics for sexually transmitted diseases. This kind of practice would constitute a threat to the safety of blood transfusions because of a period, usually 3 months, between infection and the production of testable antibodies, when the blood is infectious but may not be detected as such. Fortunately, situations of this level of seriousness did not arise. I had decided that I would attempt to resolve dilemmas of this kind with the person(s) concerned directly and if that failed would seek confidential advice from specialists in public health and infectious diseases. A few less serious issues were resolved by directly

contacting the person concerned. Instead I found one aspect of my own practice over confidentiality being challenged by health advisers.

As a counsellor who sometimes worked with students, I was well aware of their desire to avoid compromising their future employment prospects by becoming known as someone who considered themselves vulnerable to HIV infection. In common with a number of student counsellors and others in gay counselling and befriending circles, I suggested the possibility of using false names when seeking an HIV antibody blood test. Unfortunately, staff in clinics reported that patients are seldom very imaginative in choosing fictitious names and will often use the name of a real person known to them with all the consequent potential for confusion and embarrassment if that person later attended that clinic. It was a salutary lesson in the difficulties of foreseeing all the inadvertent consequences of attempts to protect confidentiality in such a sensitive area. Clinical experience suggested that simply withholding the name was the best way of simultaneously signalling a concern about confidentiality and obtaining the desired protection.

On becoming a researcher

The sub-title of this concluding section to this review of methodological issues is a deliberate adaptation of Carl Rogers' title to his seminal text *On Becoming a Person* (1961) in which he provides a personally reflexive account of the experience of being a therapist. I would like to conclude with two succinct reflections on the implications of this methodology for me as a researcher.

The catalytic effect of conducting this research has spread well beyond the ostensible subject matter, the ethics of HIV counselling, to an expanding appreciation of methodology, partially captured in this chapter. Over a series of years I have exposed myself, more so than I would otherwise have done, to the seemingly random and

meaningless consequences of the wanderings of a microbe which has resulted in tragedy for those that it has touched and made extraordinary demands on those who cared for those living with HIV, especially in the early 1980s when to get involved meant unknown physical dangers and the risk of social ostracism. I have observed and listened intensely to the ethical dilemmas associated with one particular role involved in responding to this health crisis and I am left with a profound sense of wonder at the resourcefulness, courage and capacity to transform the absurd into the meaningful that I have seen in other people. Ethics is an imperfect and partial representation of a much larger picture about the search for the meaning of life but as a consequence of this research I have a much richer sense of the value of life. I have been challenged existentially by the consultative research process in ways that I doubt a less personally involving research method would have achieved. At this stage in the research I can see the benefits but there have been times when I have also felt despair and grief over the pains and losses that I have witnessed and sometimes experienced personally when I have heard that yet another participant in the research has become ill or died. In some ways this parallels my experience as a counsellor when I deliberately open myself to making an imaginative leap into someone else's pain and, as with counselling, I have had to look beyond myself to the support of colleagues in supervision and personal therapy to make this possible. Experiential research into such painful areas is far more personally demanding than these few words can capture. The reward is bitter sweet because personal change involves both loss and gain in profound ways which have transformed my life and would require a more heuristic account than is appropriate to this research. One of the consequences was that between the two phases of the research I re-evaluated my own sexuality and started the long term commitment to raising a family. This changed my relationship with some participants and on occasions I discussed the implications explicitly with participants who perceived a social distancing between us.

My final observation is the congruence between my experience as a researcher and as a counsellor. There is a reciprocity between these roles which I experience quite positively. My sense of congruence between roles is due to commonalities in methodology and the emphasis on relationship rather than the subject matter. Indeed, it is possible to experience considerable discontinuity between oneself as therapist and researcher even when researching counselling. Rogers reflected on his own sense of personal schism between being a 'tough-minded fact finder in the psychological realm' endeavouring to discover the meanings which science can give to therapy which contrasts with himself as a therapist 'entering into a personal relationship' (1955: 267). Rogers considered that he was viewing two aspects of the same phenomena and that his scientific endeavours where to test his personal subjective experience against the intersubjective experience of others by scientific methods which he argues were themselves ultimately dependent on and informed by subjective experience (1955: 274-77). In some ways the diversity of methodology between positivism and phenomenology used by Rogers allows a more thorough triangulation between different aspects of his experience which is an opportunity lost in my sense of methodological congruence. Nonetheless, I hope to demonstrate such research need not be less rigorous or systematic. A corollary of this research enterprise is that there is the opportunity of exploring how far the criteria for quality in consultative research are transferable to counselling – but that would constitute a separate piece of research.

In this chapter I have considered general methodological issues which apply throughout the thesis. Issues which are specific to particular phases or activities are considered in their context. For the management of group consultations see pages 102-7 and a modification of induction analysis is described on page 148-51 and pages 181-6.

Section 2

HIV counselling: role emergence and the ethics of ambiguity

The wider social conflict about the moral implications of HIV and AIDS indicated in the previous section raises corresponding questions about the ethical orientation of HIV counselling. In this section, I consider the background of HIV counsellors and an overview of the ethical issues which concern them (Chapter 4). The following chapter gives particular attention to HIV counsellors' perceptions of the fundamental choice between a public health ethic of disease prevention or an ethic of individual autonomy.

Chapter 4

HIV counsellors, their role and concerns

Establishing a description of who is the subject of the research is fundamental to establishing the research context. Without this information, a study of descriptive ethical inquiry is devoid of social context and no matter how interesting the ethical component, the utility is diminished by being unable to answer the question, 'Whose ethic?'. In this research, establishing background information about people who identify themselves as HIV counsellors takes on additional significance. Although it had been government policy that counselling should be offered to everyone seeking an HIV antibody blood test and available to anyone receiving a positive result (DHSS, 1985) very little was known in 1989 about how this requirement was being implemented either at a national or local level. At a meeting attended by representatives of key statutory and voluntary services, where the idea for this research was originally conceived, an ad hoc collation of individual knowledge about HIV counselling from around the country took place. The minutes of that meeting held at the National AIDS Trust (NAT), a charity founded to co-ordinate and support the development of HIV services by the voluntary sector summarised the collective views of those present as, 'health professionals were unclear about what counselling is and what counselling can do' (Davies, 1989). In a private conversation with Andrea Kelmanson, the deputy director of NAT, she expressed the view that the bringing together of HIV and counselling represented the merger of two areas of activity which were both newly established and ethically underdeveloped with considerable potential dangers to counsellors and clients alike.

Literature review

The available literature was little more illuminating either about the nature of HIV counselling or the appropriate ethics. A database search of the AIDS Database of the

Bureau of Hygiene and Tropical Medicine, References for General Practitioners Database and the Department of Health and Social Security Database conducted early in 1990 generated 90 substantial articles, policy documents and books making reference to HIV counselling. Closer examination of the articles revealed that they mostly tended to be fairly vague about exactly what as meant by HIV counselling beyond an opportunity to consider HIV prevention and psycho-social care with people concerned about their health status. These articles usually included rhetorical assertions about the importance of HIV counselling, assertions which received scant attention in comparison to detailed updating medical knowledge. Evaluations of the impact on HIV counselling based on British experience were most exceptional although positive about the effectiveness were based on small numbers (Broadbent, 1987). Internationally, evaluation studies were also rare but an American study of the use of brief counselling to reduce AIDS risk in intravenous drug users also reported positive effects (Gibson and others, 1989).

The overall impression created by the articles was that in comparison to the rapid progress in medical knowledge, HIV counselling was at a much earlier phase in its development in terms of the level of sophistication in identifying, discussing or researching specific issues. Some early articles focused on the difficulty of recruiting nurses to care for AIDS patients in London hospitals, thus drawing attention to the need for staff support and training (Sherman, 1985a) leading to the development of a National AIDS Counselling Training Unit (NACTU) at St. Mary's Hospital, Paddington (Sherman, 1985b). However, four years later, a psychiatric nurse was still complaining about the lack of British research or knowledge required for the development of services (Thomas, 1989). Reference to the absence of research is a recurrent theme throughout the articles. Nonetheless, there were many personal accounts of using counselling in diverse settings which appeared to support the positive view taken by authors of the potential usefulness of HIV counselling. A community nurse (Wolf, 1988), a health visitor (Broadbent, 1987), and a GP (Heley, 1987) all wrote positively about providing community based counselling

characterised as providing non-judgmental empathic support to individuals or groups of patients. However, these positive accounts, based on what are in effect individual case studies, may not have been representative of the generality of experience. Surveys of patients' attitudes to GPs revealed that concerns about a GP's negative attitude (King, 1988) and doubts about confidentiality and competence would deter them from informing their GP if they were HIV positive (King, 1988; Mansfield and Singh, 1989). Early surveys of GPs' attitudes tended to confirm that concerns about confidentiality were well founded (Rhodes and others, 1989; Natin, 1989). For these reasons, there appeared to be a tendency amongst substantial numbers of people to bypass primary care and to seek medical care from specialist out-patient clinics (Helbert, 1987).

One of the major sources of HIV counselling were genito-urinary medical clinics who offered much higher levels of confidentiality than were possible in general practice. Their experience of counselling was almost certainly under-represented within published articles especially as these published articles indicate problems of coping with the large volume of counselling following media campaigns in 1986 and 1987 (Beck and others, 1987) rather than specific considerations about the practicalities of counselling. It was known that a major study based on transcripts of HIV counselling around testing was in progress but the preliminary reports of this work were not yet available (Silverman and Peräkylä, 1990). In comparison, many more articles were available about HIV counselling of haemophiliacs who had become infected through contaminated clotting agents used in their treatment (Miller, 1989; Miller and others, 1989a and b) although many of these articles are based on experience within the same hospital unit. Articles about counselling drug users (Faltz, 1988; Gibson and others, 1989; Stimson, 1988) suggested that the quality of the available counselling was quite variable. Counselling pregnant women with HIV infection also features in the articles (Bury, 1989). A case is also presented for the provision of counselling in residential institutions including prisons

(Curran, McHugh and Nooney, 1989) and community homes (Nitaback and Richards, 1988).

The contribution of the voluntary sector to HIV counselling was evident especially through London Lighthouse, a hospice founded in 1988 to provide care for people with HIV (Bartholomew, 1987; Lowry, 1988; Wilson, 1988), the Terrence Higgins Trust (Green, 1987; Hockings, 1989) and the Mildmay Mission Hospital (Moss, 1989). The development of telephone helplines which also provided counselling (Hills, 1987; Melville, 1987) were evidence of the potential significance of the voluntary sector and in contrast to the charities just mentioned, the helplines were not exclusively London based.

This review of a selection of the available articles suggests a considerable expansion in the range of services provided in a wide range of settings to a wide range of client groups. There are many reasons why the range of published articles cannot be considered representative of the totality of activity in the field. The absence of articles specifically referring to gay men (the social group most adversely affected by AIDS) in comparison to haemophilia where the numbers are smaller must be considered significant. The relative absence of articles on HIV counselling in genito-urinary medicine does not reflect either the government policy that HIV counselling should be offered in respect of the antibody test for which these clinics are the main source, or the observation in the Monks Report (DH, 1988b: 3) about the additional workload created by the provision of HIV counselling. Nonetheless the articles indicate a burgeoning of HIV counselling in the late 1980s and that sufficient experience would have been generated in individual settings to make a more comprehensive review worthwhile. In the context of this study, it is noteworthy that there had been no evidence of attempts to identify ethical issues associated with HIV counselling. The inclusion of considerations of consent and confidentiality with regard to GPs was not usually replicated elsewhere (a noteworthy exception is Sketchley,

1989: 361) and possibly precluded by the generally favourable rhetoric advocating the provision of HIV counselling.

Four longer publications specifically about the management of psychological issues and/or HIV counselling are noteworthy because they are not constrained by the brevity of articles. Although none of these longer texts are research-based, they are all written by practitioners who were already prominent in the field of counselling therefore informed by personal experience with the strong implication that they were describing how HIV counselling ought to be practised. *The Management of AIDS Patients* is a collection of individually authored chapters written from the perspective of medical clinical management which includes consideration of psychological issues associated with AIDS (Miller, 1986a and b) and the counselling of people who are sero-positive (Green, 1986). As both authors subsequently expanded these contributions I will consider their views shortly. However, one chapter on 'Hospital counselling: structure and training' (Green and Miller, 1986) indicates a medical view of the relationship between HIV counselling and other forms of counselling. The contents of their recommended training programme for HIV counselling consists of a combination of medical information, information giving about homosexual lifestyles and haemophilia with a problem-solving approach to counselling skills delivered over two days (p. 193). They consider this an adequate training to develop the appropriate skills and observe that some experience in counselling others is clearly an advantage. However, they caution that:

> This is not the same thing as having a formal counselling qualification. Many professional counselling courses teach skills which confer little advantage in this context. Some schools of counselling use approaches in which the counsellor is trained not to give advice, clearly a disadvantage in this field.
>
> (Green and Miller, 1986: 188)

This view appears to characterise the next two publications to be considered. David Miller expands on the psychological pressures of *Living with AIDS* (1987: 136 pages) from a cognitive behavioural viewpoint in which he advocates positive strategies to

overcome or at least minimise the high levels of uncertainty and anxiety associated with the diagnosis. Writing as a senior clinical psychologist he favours a structured approach to self- help which he assumes will also be supported by counsellors who only receive incidental mentions as members of the clinical team (p. 32). John Green is both the co-editor with Alana McCreaner and substantial contributor to *Counselling in HIV Infection and AIDS* (1989: 321 pages) in which the medical clinical perspective remains dominant so that the provision of counselling is not restricted to trained counsellors but regarded as

> something which anyone who is working, in whatever capacity, with people affected directly or indirectly by HIV and AIDS not only can do *must* do.
>
> (Green and McCreaner, 1989: ix)

However, the emphasis on informed consent throughout the book makes this clinical co-option of counselling more of a challenge to the emergence of a distinct role for HIV counselling than to the ethics of autonomy which characterised the ethics of generic counselling nationally (BAC, 1984). Uniquely, this is the only book to consider ethical questions as a distinct area of interest relevant to HIV counselling. Kenneth Boyd (1989) concentrated on how the general importance of consent to all patients is amplified in the context of HIV in order to maintain public co-operation and trust in services (pp. 304-5). The importance of confidentiality (p. 306), the health professional's ethical duty to treat people with HIV (pp. 307-8), her objections to voluntary euthanasia (pp. 309-10) and the substitution of an emphasis on honesty and mutual care as the basis for human relationships rather than traditional sexual morality are all considered (pp. 310-2), albeit briefly. The therapeutic orientation of the book tends to be pragmatic but informed by cognitive behavioural and systemic theory, probably reflecting the background of John Green as Chief Clinical Psychologist at St. Mary's Hospital, London and the contributors. However, the absence of any gay perspective or critique of an exclusively clinical viewpoint of counselling is surprising as Alana McCreaner was then the head of NACTU

which was widely regarded a coalescence of gay or self- help with counselling and advisory functions (Berridge, 1996: 73) and therefore had the potential for more radical critiques of the medical agenda. Other contributions, particularly from Janet Green (1989: 238-47), the administrator of counselling services at Terrence Higgins Trust and by Tom McManus (1989: 224-32) a specialist in genito-urinary medicine about male homosexual behaviour omit any references to the socio-political dimensions of gay experience. Before I consider the significance of the absence of the gay critique I will complete this review of books taking a distinctly clinical perspective by reference to Robert Bor, a district AIDS counsellor and senior psychologist, and Riva Miller, a district AIDS co-ordinator and senior social worker, both of whom were attached to the Haemophilia and Haemostasis Unit at the Royal Free Hospital, London. In *AIDS: A Guide to Clinical Counselling* (1988a: 127 pages) they adopt a systemic orientation associated with family therapy which they applied in the context of haemophilia and extended to work with other patient groups. The distinctive feature of this book is long lists of questions indicating the sorts of topic and style of intervention expected of HIV counsellors. The authors assume that HIV counsellors may be non-specialist incorporating counselling with any professional role (p. 1). A recurrent theme in the questions is an exploration of the client's position within a wider network of relationships in order to determine the possibility of mobilising appropriate social support.

One distinctive feature of the four longer texts just described is that they are dominated by the experience of clinical psychologists in comparison to the range of professions contributing articles. The reasons for this domination are not clear but might be speculatively attributable to greater emphasis on research within psychology for career progression than in most other non-medical therapies, a degree of active strategic planning about the new opportunities that AIDS presented to a profession (Cooper and Bender, 1987) and their co-option into the management of some of the more clinically psychologically demanding situations like chronic anxiety and dementia which conferred

a status to pronounce on more mundane psycho-social aspects of HIV. The relative disdain for HIV counselling as a specialist activity would not be inconsistent with a more general professional competition for territory between the psychologists and counsellors, but there is no direct evidence for this in any of these HIV-related publications.

The commitment to a non-specific and generalised definition of HIV counselling is also characteristic of these publications and is a view which is specifically criticised by the fifth extended publication to be considered within this literature review. This publication is very different in purpose and content from those already mentioned. In a report commissioned by the Department of Health to study the current provision of *Advice, Support and Counselling for the HIV Positive*, Robert Chester, a Senior Research Fellow at the Institute for Health Studies at the University of Hull, specifically commented on the absence of a clear definition of HIV counselling and the inadequacy of too broad a definition for policy development.

> In the present context, it is a source of some difficulty that in the AIDS milieu the term 'counselling' is used in a variety of senses, and that activities which are analytically distinct are conflated under this single term [i.e. prescriptive and directive advice, health education, support, training activities, non-directive counselling as understood by the British Association for Counselling]. The problem with these different understandings is that mandatory requirements for counselling in association with the HIV antibody test are liable to be differently interpreted by different people. Claims that counselling is provided are therefore not self-evident in meaning and may lead to misunderstanding.
>
> (Chester, 1988: 7, S.2.2.1)

He also reported a greater diversity of sources of counselling, in terms of counsellor background, settings and ethos required by specific groups than was evident in the clinically oriented books but consistent with the review of articles. Chester's observations open up the possibility of a significant discrepancy between the assumptions informing normative accounts of clinical practice and the diversity of opinion and practice evident in a descriptive and interpretative study.

Chester's report also draws attention to the contribution of gay men's experience of self-help and support to the development of sophisticated self-provisioning (s. 5.2.1) and

on the basis of this experience to the development of services in the voluntary sector (ss. 9.3.1-7) and, not withstanding some reservations about the acceptability of these services to other social groups affected by HIV because of their 'gay ambience' (s. 9.4.1), he takes a very positive view of their achievements. This view contrasts with both the articles and books where this gay experience is almost totally invisible. The gay contribution is much more evident outside counselling literature. For example, books by Christopher Spence (1986: 64 pages), a founder of London Lighthouse, and Peter Tatchell (1987: 171 pages), a gay activist, are passionate in their advocacy of peer support and draw on ideas of co-counselling but make no explicit reference to counselling. This omission of counselling appears to be considered and deliberate. When I discussed the relative absence of the gay experience in the HIV counselling literature with Simon Watney, a radical gay author committed to the conceptual deconstruction of AIDS (1987, 1988, 1989) at a conference 'Taking Liberties' (March 1988), he viewed counselling as largely irrelevant to his concerns and, at best, a benign form of the medicalisation of an essentially social challenge.

A systematic consideration of the available literature suggests that not only is the role definition of HIV counselling in dispute but that potentially significant views based on the experience of gay men in providing psycho-social support are largely absent or unacknowledged probably because of the concerns about remedicalisation of homosexuality described in chapter 2. The diversity of the field in terms of client groups, settings in which counselling is provided, and cultural ethos is also evident. The combination of these observations suggests that the role of HIV counselling is disputed and that the literature raises more questions than it answers. Following Chester's example, it may be that questions about the role of HIV counsellor and the background of people taking that role would be best answered by themselves. Their answers would also establish the social context of the descriptive ethical inquiry.

In search of HIV counsellors

Civil servants in the AIDS Unit at the Department of Health were aware of the significance of Chester's observation and its implication that a mandatory service ought to be more tightly defined to establish acceptable parameters of service provision within public policy. They indicated a willingness to provide substantial funding to discover the current state of HIV counselling and the views of HIV counsellors about ethical and quality issues. They shared a concern that the study should be as inclusive of the range of HIV counsellors as possible and that it should be devised to maximise the development of the field of activity and that as a consequence research participants should have as much of a sense of ownership of any recommendations as possible. The view was expressed that it was unlikely that recommendations would lead to mandatory changes. It was considered that a sense of commitment to them by practitioners was their best chance of coming to fruition. A consultative research model was supported as being most likely to achieve these aims. In line with common practice, the Department of Health wanted to delegate responsibility for the management of the research and selected the British Association for Counselling (BAC) to undertake this role as an organisation which was not prominent or partisan for the world of HIV and AIDS and hopefully therefore acceptable to the widest range of practitioners.

From a strictly policy point of view, it appeared that they had doubts about an exclusively medico-clinical approach to counselling and were therefore open to the possibility that choosing BAC to manage the project might add weight to an alternative point of view to enrich the debate and enhance standards. An inclusive approach to the incorporation of the full range of positions and experience around HIV counselling was considered important by both the civil servants and the steering panel.

Deciding the basis for recruitment of participants in the research was a priority. Doubts about the parameters of the field, represented by Chester's broad and narrow definition,

and the background of HIV counsellors themselves indicated that self- selection by participants recruited by advertisements in counselling and AIDS-related journals and using networks around involved voluntary organisations would maximise the involvement of the full range of the field. The only criterion adopted for self-selection was that they should consider themselves as providers of HIV counselling without necessarily holding the formal role title of 'HIV counsellor'. The sensitivity of the research meant that it was difficult to predict the take-up of opportunities to participate. The possibility of a low take up seemed very real at the time. The sensitivities outlined in chapter 3 might have acted as a considerable deterrent. Alternatively the project might be viewed as having taken the sensitivities sufficiently into account to provide a relatively safe arena to address some of the associated issues. In the event just over 200 people expressed a serious interest in participating in four consultation days to be held in Leeds, Bristol, Birmingham and London during May 1990. Priority was given to ensuring the attendance of at least one person from each point of delivery of counselling, usually an agency or organisation but also included a few private practitioners. (The method of consultation and structure of the days is discussed on pages 102-107) As a prior condition of attendance participants were asked to complete an extensive questionnaire which provided a considerable amount of information about the role and background of those who considered themselves to be HIV counsellors. 142 people attended consultations including 15 people as independent observers from the Inspectorate for Social Services, the Central Council for the Education and Training of Social Work and the Department of Health and members of the steering panel, all of whom agreed to be bound by the ground rules for the consultation process. Some observers were present only at plenaries in order to provide maximum privacy for the small group discussions. 112 questionnaires were received at or shortly after the consultations. A further 6 were obtained by following up participants by letter and telephone which represented 100% of those with some experience of HIV counselling. Six participants were in the early stages of developing

counselling services and attended because of the developmental aspects of the consultancies but did not consider themselves able to complete the questionnaire and are therefore excluded from the total of HIV counsellors. Three were excluded because they categorised themselves exclusively as trainers and therefore unable to answer many of the questions about experience and supervision in ways which distinguished generic and HIV related work. Overall 118 people identified themselves as HIV counsellors and provided most of the requested information. Of these the majority were female (76/118; 64%)

Background to self-identified HIV counsellors

Professional background

The professional background was considered to be the role with which participants identified with themselves and was cross checked against their record of training and any references to professional affiliations or professional regulation. A small number of participants were contacted by telephone to clarify ambiguities. Five participants were recorded as unknown because of ambiguities in their responses and difficulties experienced in contacting them.

The professional background of HIV counsellors is very varied. There were 14 different professional backgrounds. The first five of these accounted for 85% (100/118) of respondents.

Table 4.1: Professional background of HIV counsellors (1990)

Counselling	34
Health Advisers	23
Nursing	20
Social Workers	17
Psychologists	6
Clergy	3
Probation Officers	2
Befriender	2
Doctors	2
Home support worker	1
Lecturer	1
Salvation Army	1
Youth Worker	1
Not known	5
	n = 118

This distribution of professions appears to corroborate a suspicion that the published literature does not represent the diversity of occupational background of the field. The literature over-represents the contribution and perspectives of psychology relative to at least four professions. This corroborates the earlier observations based on a comparison between articles and books (pages 76-9). On the other hand, a comparison with the literature suggests that the contribution of GPs to pre- and post-test counselling may be under-represented in the consultations. When I discussed this with a GP member of the steering panel, he considered that the pressures on GPs with re-organisation of the funding of their services would deter attendance. He also thought that GPs who were knowledgeable about counselling or HIV would probably prefer to refer patients to genito-urinary medicine for counselling because of limitations of their time and to avoid

potential conflict of roles as GPs also complete reports for insurance companies and employers. GPs who lacked knowledge about counselling would probably not consider the consultations worth attending, especially as many GPs had not knowingly encountered someone who was HIV positive.

It is probable that some of the 5 unknowns either had professional/occupational roles which they considered irrelevant to HIV counselling or in some cases had none and had become involved because of their own experience of sexuality, haemophilia, drug-use or HIV status. A sense that either their response would be irrelevant, or personally sensitive, would be consistent with the low response rate to follow-up enquiries.

Settings in which HIV counselling was provided

HIV services were known to be provided in both the statutory and voluntary sector. The voluntary sector had taken on its traditional role in British social policy of pioneering new services (Hill, 1980: 155-7; Green, 1989a: 238) and were often initiated by people who had been directly affected by HIV and were therefore culturally closer to service users (Altman, 1986: 91). The prominence of the voluntary sector with regard to AIDS was a matter of public policy as a 'respectable out' for government ministers who preferred to avoid talking about sexual and drug-related transmission routes in the media or who wished to avoid any appearance of support for homosexuality, promiscuity or drug use as contradictory to the official emphasis on 'family-values' in Conservative Party ideology.

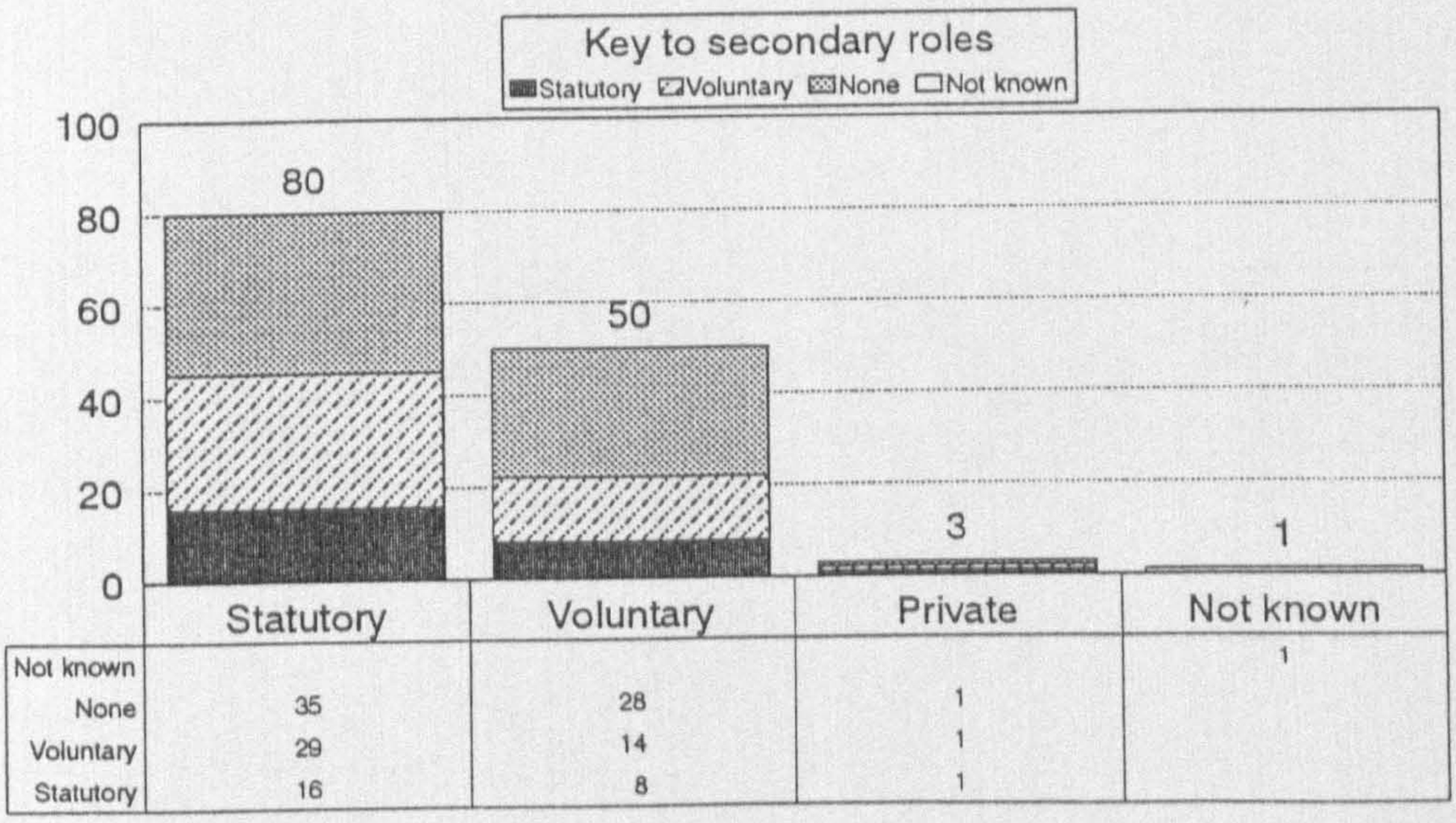
> Ministers needed to be shielded from inappropriate and possibly damaging involvement in public discussion of intimate sexual matters while at the same time giving the appearance of intense involvement in, and concern for the issue.
>
> (Berridge, 1996: 123)

The creation of the National AIDS Trust (NAT) to co-ordinate and develop the voluntary sector response was one aspect of the 'respectable out'. For a brief period between late 1989 and early 1991 I was able to observe a considerable amount of co-operation and

communication between the NAT and the AIDS Unit in the Department of Health as the executive arm of government. It was unknown how far this collaborative relationship and policy making level extended down to service delivery. Thus discovering the extent of the distribution of HIV counselling between the statutory and voluntary sector holds a particular significance with regard to HIV.

Analysis of 117 responses to the questionnaire (one was unknown) indicated that significant numbers of HIV counsellors had a main agency in which they provided HIV counselling but were also involved in additional settings. The distribution of primary roles between statutory, voluntary (i.e. 'not for profit' or charitable) and private sector (i.e. 'for profit or fees') is represented in the bar chart in diagram 4.2.

Diagram 4.2: Primary role showing secondary role sectors



The analysis indicates that:

- 57% (69/118) provide counselling in more than one setting;
- 36% (29/80) who provide counselling in the statutory sector also have a secondary role counselling in the voluntary sector;

- 24% (8/34) who provide counselling in the voluntary sector also have a secondary role in counselling in the statutory sector;
- the role of the private sector appears to be much less significant as a source of HIV counselling but where it exists 2/3 also counsel in other sectors.

The total picture is one of the predominance of the statutory sector as a source of HIV counselling, probably because most testing takes place in clinical settings but this is supported by a significant contribution from the voluntary sector. There is a substantial amount of movement between the sectors with 31% (37/118) of HIV counsellors providing counselling in both the statutory and voluntary sector.

An examination of the addresses of the main setting in which counselling was provided revealed that HIV counselling was being provided from 22 different types of agencies. The main outlets for HIV are listed in diagram 4.3.

Diagram 4.3: Types of agencies providing HIV counselling

	No. of HIV counsellors	Hospital based	Community based
Genito Urinary Medicine (NHS)	25	25	
AIDS support services (vol. sector)	22		22
Social Services (local authority)	16	5	11
Nursing (medical)	10	2	8
Drugs Treatment Units (NHS)	9	6	3
Drug Support services (vol. sector)	8		8
Health Education	5	5	
Psychology services	4	4	
Counselling services	4	3	1
Nursing (psychiatric)	2		2
Prisons	2		2
	107	50	57

Other outlets represented singly included gay support services, HIV hospice, HIV co-ordination, homeless support, pregnancy advisory service, probation service, school advisory service, higher education, psychotherapy services (NHS), Salvation Army and youth work. The division between hospital and community based services is weighted towards the latter (57%, 67/118).

Training in counselling

As counselling is probably not innate (Feltham, 1995: 9) and requires training and education, it appeared an important aspect of the participants' context to know how much training they had received. Anecdotal evidence suggested that in some instances HIV counsellors were simply allocated the role by a process of 'ascribed instant expertise'. For instance, one HIV counsellor had approached me for support because he had been given 72 hours notice of transferring from nursing duties to becoming an HIV counsellor and had been sent home with two books to read over the weekend. It was important to know whether this was a representative experience.

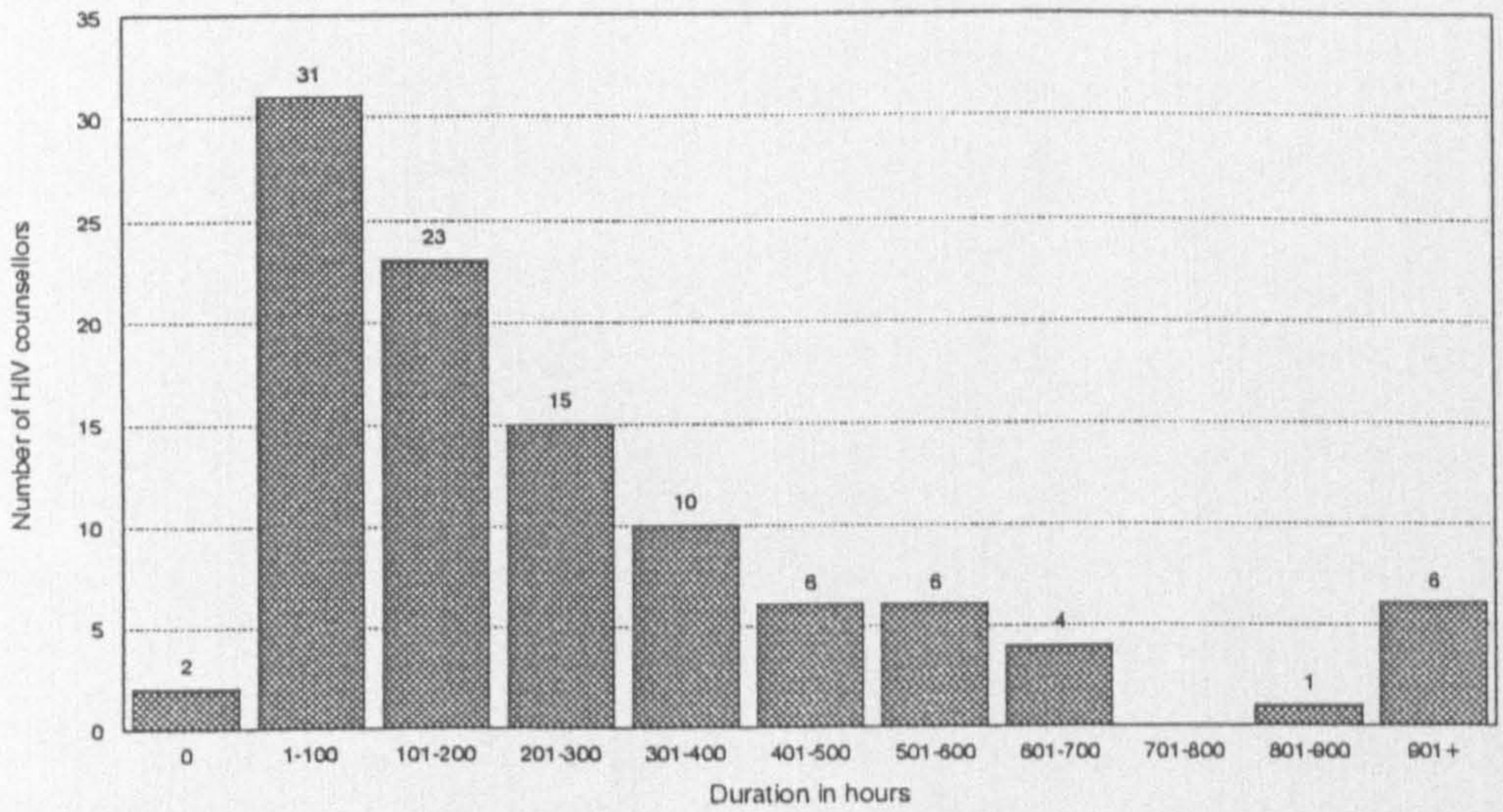
It was possible to calculate the total training in counselling in hours with a reasonable degree of certainty for 88% (104/118) of respondents. Obviously incomplete, ambiguous and inconsistent answers were omitted. The assumption was that the replies related to course contact time excluding meal breaks and out of course work as this is the usual basis for these calculations but it is not universal. Therefore even after the elimination of indeterminate responses, these figures have to be treated as indicative of a broad pattern rather than detailed precision. Nonetheless they are informative about the background of the participants.

The pattern of training is represented graphically in diagram 4.4.

The graph indicates a considerable range of length of training between 0 and 1620 hours.

The arithmetic average is 257 hours (26,775 ÷ 104). The median average is similar but

Diagram 4.4: Training in generic counselling



the modal average is considerably shorter in the 1-100 hours range. A closer examination of this 1-100 hours band reveals a considerable range between 12-19 hours and an arithmetic average of 53 hours. Participants were also asked to indicate their sense of the adequacy of their training on a four point scale. When the self assessed level of adequacy of training is plotted against duration (see table 4.5) it would appear that a self-assessed adequate training lies within the 101-200 hours band and when levels of inadequacy are taken into account, it would suggest an average adequate training in the upper level of that range.

Table 4.5: Self assessed adequacy of training

Adequacy for counselling	Duration of training in hours											
	0	1-100	101-200	201-300	301-400	401-500	501-600	601-700	701-800	801-900	900+	Total
Very adequate			2	1		2	2	1		1	5	14
Adequate		17	15	10	7	3	4	2			1	60
Inadequate	1	8	3	2	3	1						18
Very inadequate				1								1
Totals	2	31	23	15	10	6	6	4		1	6	

However training is only one aspect of a counsellor's background and arguably needs to be considered in conjunction with experience which is how accredited status is awarded by the British Association for Counselling (BAC, 1989a) and the United Kingdom Council for Psychotherapy (UKCP, 1993).

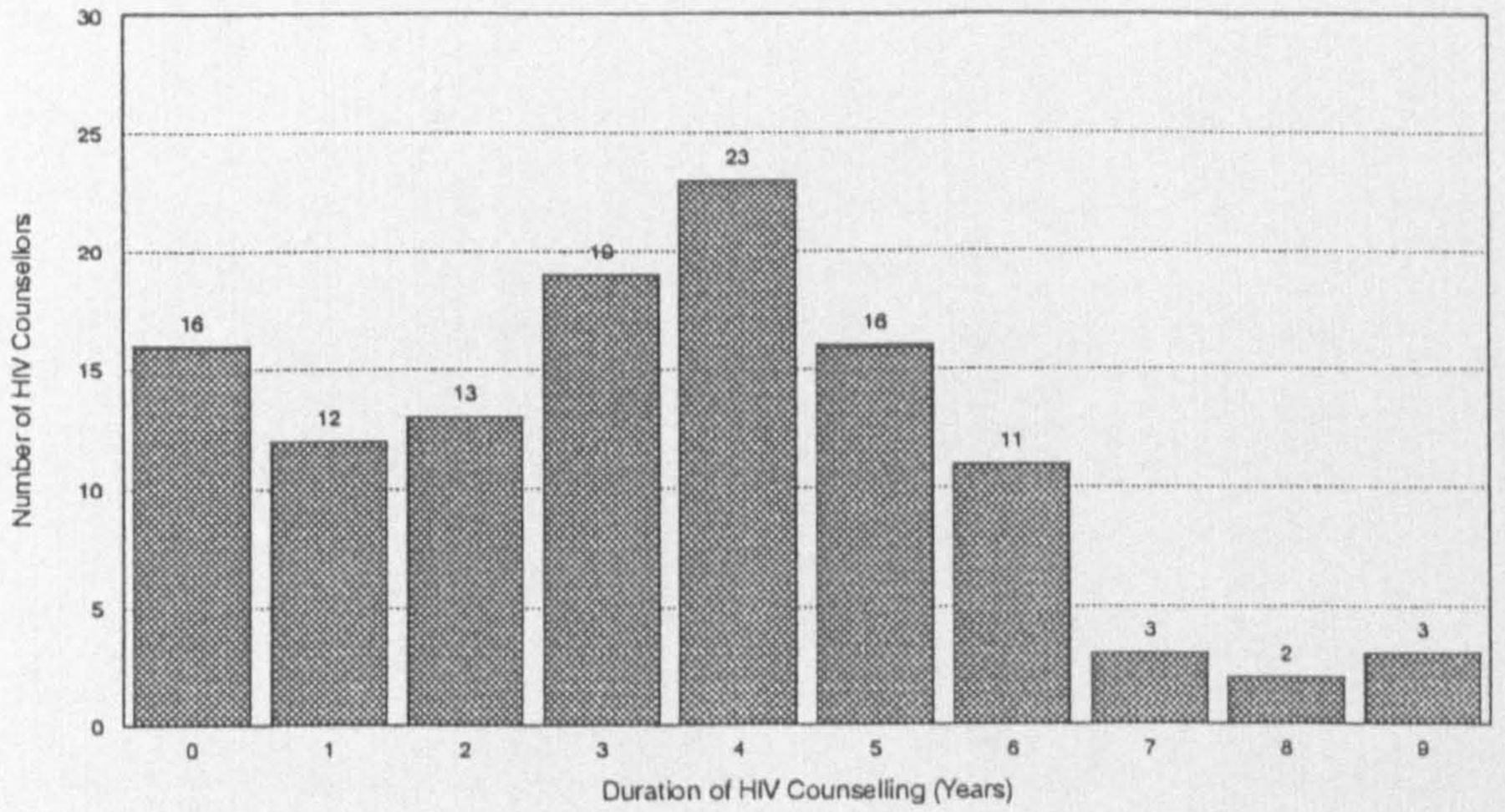
Experience of counselling

Participants in the consultations were asked to provide a summary of *all* their counselling experience in chronological order. From this it was possible to calculate both the duration of their generic (i.e. non-HIV-specific) counselling and their experience of HIV counselling.

Sufficient information for the calculations about duration of generic counselling experience was provided by 113 HIV counsellors. The arithmetic average was 10.75 years with a considerable range between 2 months and 32.4 years. The median was 9.5 years. The distribution over years was reasonably even with an exceptional peak of 12 counsellors with between 4 and 5 years experience. The depth of experience is indicated by 50% (56/113) of participants having generic counselling experience which predated the discovery of AIDS in 1981. However there were also relatively inexperienced counsellors with 4 having less than one year and 8 with between 1 and 2 years experience, making 12% (13/113) with less than 3 years experience.

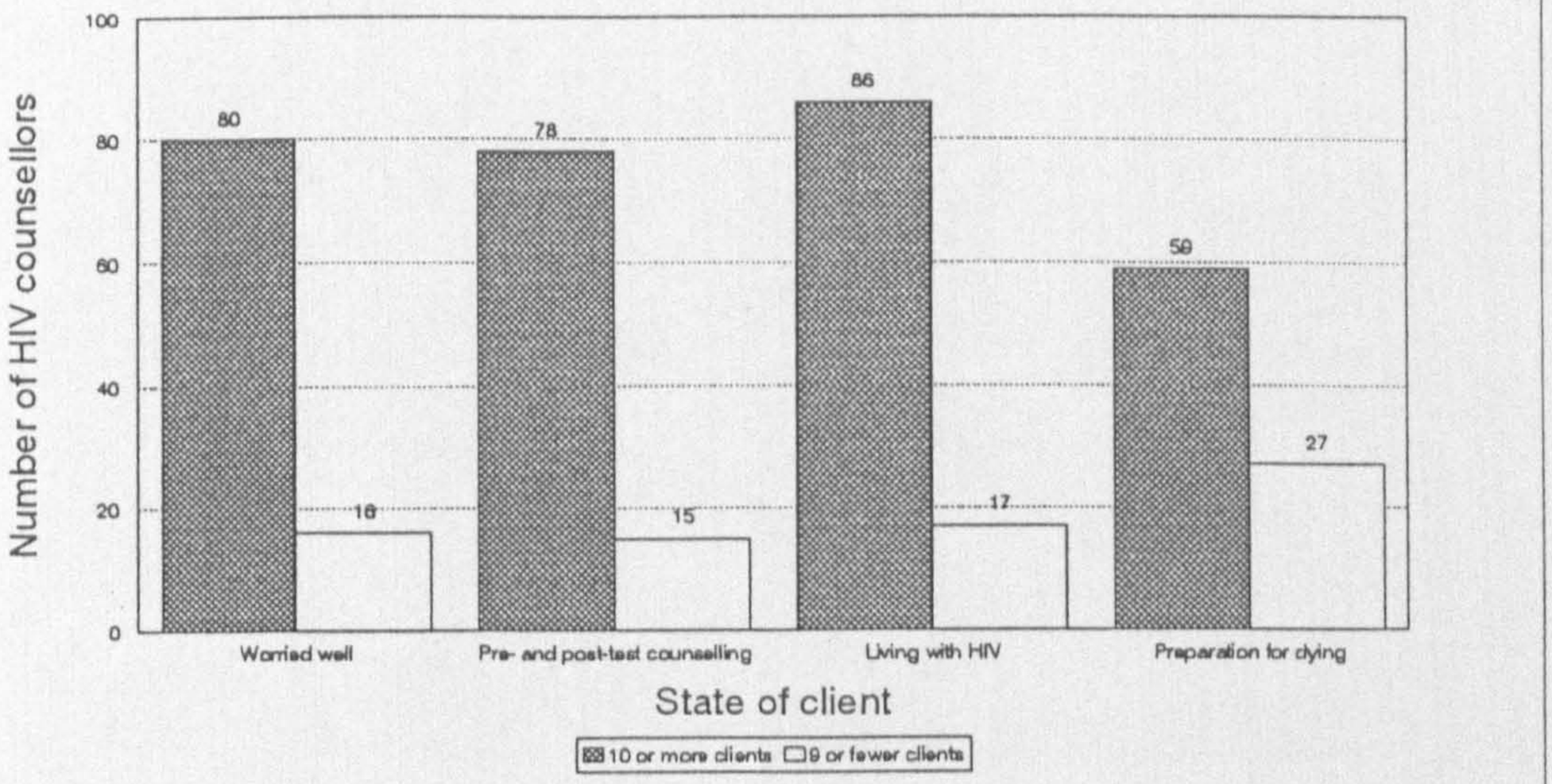
Some participants had HIV-related counselling experience which went back to the origins of HIV in 1981 (Diagram 4.6). However the median was between 2 and 3 years and the modal average between 3 and 4 years. The arithmetic average was 2.9 years. The peak with between 3 and 4 years experience probably represents an increase in recruitment following the mandatory requirement that HIV counselling be provided in 1985 when allowance is made for a delay in converting policy into practical implementation.

Diagram 4.6: Duration of providing HIV counselling



However, duration is only a crude indication of experience unless the nature of that experience is taken into account. The typical progression of HIV from being asymptomatic and well, often over many years, to a period of chronic illness with increasingly serious episodes and a terminal phase means that there is the potential for most of the counselling experience being with those who are asymptomatic and well which would usually be an optimistic phase, sometimes referred to as the 'golden days', when someone experiences life intensely with a heightened sense of mortality but without the negative effects of illness. This would generally be considered less emotionally demanding of a counsellor than working in the later phases. Similarly, pre-test counselling and working with the 'worried well' might be considered be less demanding than working with asymptomatic HIV positive people. Therefore HIV counsellors were asked to indicate the range of their experience which is represented diagrammatically in Diagram 4.7. The diagram distinguishes between working with up to 9 clients and 10 or more.

Diagram 4.7: Responses to different HIV-related issues



The diagram illustrates that many counsellors may have experience of relatively small numbers of people, usually under 10 in all categories but the intensity or duration of that experience cannot be gleaned from these figures. The increase in HIV counsellors who have seen 10 or more people about preparation for dying in comparison to those who have seen fewer than 10 is difficult to interpret but it would be consistent with people who are HIV positive relying upon peer support whilst they are asymptomatic and turning towards professional counselling in the terminal phases.

HIV counsellors were also asked an open question about their preferred theoretical orientation for their counselling. They were asked to identify this either by the usual name for the model or influential writers. Their response indicated a strong preference towards non-directive counselling emphasising either the counsellor-client relationship (person-centred) or problem-solving (developmental eclectic) which between them accounted for 51% of the classifiable responses (Diagram 4.8).

Diagram 4.8: Theoretical orientation of HIV counsellors

Counselling model	Number of HIV counsellors	% of 118
Person-centred (Rogers)	43	36
Developmental Eclectic (Egan)	22	17
Gestalt (Perls)	14	12
Systemic Therapy (Bor, Miller)	10	8
Psychodynamic	9	8
Dying and Bereavement (Stedeford, Kubler-Ross)	7	6
Cognitive behavioural	6	5
	N = 111	92

Counselling-supervision

The emotional burden and professional responsibility for counselling people with HIV is likely to be considerable and therefore requires some form of support. In generic counselling this is usually provided by counselling-supervision (Bond, 1990) which is non-managerial (BAC, 1990) involving a combination of personal support, professional development and monitoring standards (Proctor, 1988). Ongoing and regular counselling-supervision is considered an ethical requirement for counsellors by the British Association for Counselling (BAC, 1984). Knowledge of the extent to which HIV counsellors receive supervision and from whom provides an indication both of how supported they are and their relationship with the wider counselling and therapeutic movement. For example, a low incidence of independent supervision would probably indicate the development of HIV counselling independently of the wider counselling movement.

All HIV counsellors were asked to indicate the amount of supervision received over the previous month, whether it was from a manager, colleague or someone independent or

work setting and whether it was one to one or in a group. The range of permutations was considerable so I shall consider them in broad categories with satisfaction levels where these views can be discerned.

Table 4.9: Counselling supervision

	No. of HIV counsellors	Average hours over last month	Satisfaction			
			Too much	About right	Too little	Don't know
No supervision provided						
None	44			7	1	
One to one						
Independent only	16	3		10	6	
Manager only	13	3		10	3	
Colleague only	6	2.5	4	2		
Combinations of one to one supervision						
Manager and independent	4	2.75		4		
Manager and colleague	3	5		2	1*	
* received 8 hours in last month.						
Group only						
Group only	6	4		2*	4+	
* Received 6 hours each + Received 3 hours each						
Combination of group and one to one						
Group and manager	9	8	1*	6		2
Group and college	11	7		7	4	
Group and independent	6	7		6		
* Received 15 hours supervision						

The diversity of the supervision arrangements is noteworthy. Of those who received one to one supervision, regardless of with whom, about 3 hours was considered 'about right' but groups required slightly longer, 4 hours, to be considered 'about right'. Combined group and one to one required considerably longer, an average of 7 hours to achieve the 'about right' rating. Some caution is required in interpreting these results because they

are divided across such a wide range of categories that the numbers in each specific category are small and no attempt has been made to correlate satisfaction levels with level of difficulty, volume of counselling being undertaken or prior experience or training.

Those who reported receiving no supervision provide intriguing levels of satisfaction. A review of supplementary comments on questionnaires and some follow-up inquiries by telephone suggests that some of those who considered no supervision to be 'about right' considered that they had good peer support on an informal basis from colleagues. However, there were those who expressed considerable concern about not receiving supervision for both personal and professional reasons. The existence of 37% (44/118) who are not receiving any formal supervision represents a significant minority working outside the usual professional expectation for counsellors. On the other hand, 55% (65/118) had at least gone some way to adopting a non-managerial form of supervision which would be considered acceptable in the wider counselling movement.

The role of HIV counsellor

Two approaches were adopted in building up a picture of the role of HIV counsellors. The first was an attempt to discover the pattern of work by asking HIV counsellors to volunteer to keep a summary of their work in a prescribed diary format. The second was to analyse all references to different types of activity and to devise a matrix representing the diversity of the work. These two activities took place independently of each other and cannot be correlated.

The pattern of work involved in HIV counselling

A record of the counselling sessions provided by 33 counsellors who volunteered to keep a diary of their counselling during September 1990. The counsellors worked in a variety of settings including GUM clinics (10), Social Service Departments (5), Drug and Alcohol Units (5), voluntary self-help agencies (3), Psychology Departments (2),

Training Unit, GP, Probation, Community Project, Haemophilia Unit, HIV Unit, Hospice and military family support service. An anonymous record of 843 sessions was made in which 904 individuals were seen (some sessions included working with couples or groups). Most of the clients were male (69%: 627/904).

The counsellors were asked to give a brief indication of the main issues raised in the counselling. From these it was possible to identify the use of HIV counselling by three main client groups.

Table 4:10: Reasons for seeking HIV counsellling

Client group	Number of sessions	% of 843
People who are HIV negative or unknown status	261	31%
People who are HIV positive	432	51%
Carers (partners, family, volunteers & professional helpers)	150	18%

Table 4.11 below shows the most frequently recorded issues.

Table 4.11: Main issues raised in HIV counselling

Issue	Number	(% of 843)
Arising from change in health status	398	47%
Pre-test counselling	139	16%
'Worried well'	53	6%

An analysis of the reasons why people sought HIV counselling services reflected this pattern, with the greatest demand for services by people who were HIV positive, and who were either recently diagnosed HIV positive or else experiencing illness of various degrees of severity (48%: 408/843). Pre-test counselling was a major part of the work of counsellors in GUM clinics and Drug Dependency Clinics.

The range of client work involved in HIV counselling

The value of developing a matrix to distinguish different tasks subsumed within HIV counselling had been demonstrated by Chester (1988: 25a) and indicated the potential diversity of the work. An analysis of the responses to the questionnaire from which references to different tasks relating to HIV progression formed the basis for preparing a draft matrix which was refined by consultation with experienced HIV counsellors. The version published in the official report (Bond, 1991: 17) omitted one category (S) which has been added to this matrix (Figure 4.12). The diagram represents the different elements of an integrated provision of HIV counselling to which many service providers aspired.

The critical feature of the diagram is that HIV prevention work is not given a specific recognition within the matrix but is subsumed within a client-focused system of categorisation. As a result of contributions from Shamil Wanigaratne, a clinical psychologist at James Pringle House, I had explored the possibility of including boxes about 'basic HIV prevention' and 'relapse prevention' (Bond, 1991: 72; Wanigaratne and others, 1994) but it was clear from wider consultations that this would have been viewed as a misrepresentation of the general experience of providing HIV counselling. The relationship between the ethics of psycho-social support and HIV prevention was so contentious for ethical reasons that they are the subject of the next chapter.

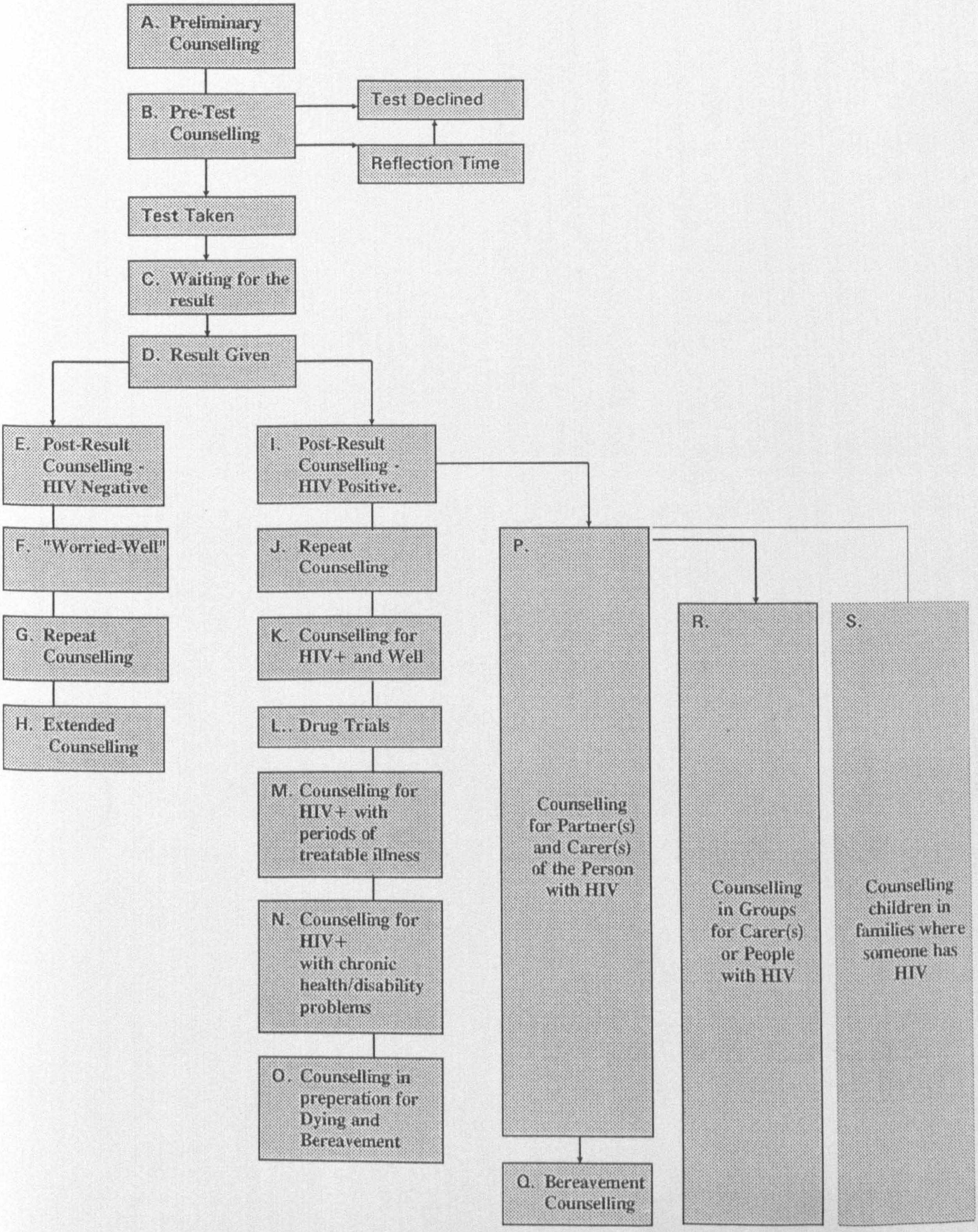


Figure 4.12: A framework for the provision of HIV counselling

The concerns of HIV counsellors

The concerns of HIV counsellors are probably best understood in the context of the divergence between the normative requirements for HIV counselling evident in the leading current texts (Miller, Webster and Green, 1986; Miller, 1987; Green and McCreaner, 1989) and the known background of participating HIV counsellors. The picture is complex and multifaceted but can be represented diagrammatically (Diagram 4.13).

Diagram 4.13: Comparison of normative requirements for HIV counsellors and their known background

	Normative requirements of key texts	Background of HIV counsellors
Professional background	Dominated by clinical psychology and medicine	Divided between counselling, health advising, nursing, social work
Settings	Mostly envisaged as statutory and clinical	Mixed between statutory and voluntary with significant collaboration between sectors
Training	Brief training of two to five days considered adequate (i.e. 12-30 hours)	Average training is 257 hours with a minimum self-assessed adequate training of 150-200 hours
	Formal training in counselling which excludes advice is disadvantageous	Preferred models are client-led and non- directive, i.e. person-centred, developmental eclectic
Experience	Some experience of HIV counselling advantageous	Generally high levels of HIV counselling (average of 3 years) with considerably higher level of generic counselling (average 11 years)
Non-managerial supervision	Not mentioned	55% receive regular non-managerial supervision averaging 3-4 hours per month
Overall conception of HIV counselling	Opportunistic	Structured around needs associated with health status and the support of others closely involved

It is evident that for all the factors for which information is available, HIV counsellors are generally much more grounded in the generic requirements for counselling than those required for HIV counselling as defined from a medico-clinical perspective. The ranking of general concerns, that they wished a Department of Health sponsored report to consider, tend to point towards a tension between the medical and counselling perspectives of HIV counselling with a strong tendency towards wishing to consolidate the latter perspective. Three-quarters (75%: 88/118) of participants provided a total of 195 different responses in advance of the consultations. These were clustered around four broad themes.

Table 4.14: Issues that concern HIV counsellors

Need for adequate supervision and support	56
Clarification of relationship with colleagues (e.g. role definition, confidentiality)	48
Need for adequate training	38
Status of HIV counselling inadequately recognised	24
	n = 166

Other issues included need for better networking between counsellors (6), recognition of specific client groups (6), updating of HIV-related knowledge (5) and a number of idiosyncratic/unclassifiable concerns (12). The general trend of these concerns is invariably towards a greater recognition of the 'counselling' component of HIV counselling.

Triangulation of sources of information about HIV counsellors

In this chapter, three distinct sources of background information have been considered. The literature constitutes two of these sources because of the divergence between the

cumulative themes derived from articles which suggest a diverse range of background and perspectives within HIV counselling in comparison to the homogeneity of the medico-clinical perspective of the major texts. A detailed exploration of the background of HIV counsellors who self-selected themselves to participate in the project and who were recruited under open-ended criteria suggests that cumulative findings from articles about the diversity of background is closer than the extended texts to the background of the counsellors. In contrast to both the articles and extended texts, HIV counsellors are generally much more experienced in generic counselling and more closely affiliated to the general counselling movement by training and supervision than is evident in any of the literature.

One issue stands out as unresolved. In the only substantial research about the practice of HIV counselling, Chester (1988) makes reference to the influence of the experience of gay men in providing mutual support for each other on the development of HIV counselling in the voluntary sector. This is not directly evident in the HIV counselling literature, especially the longer texts, but examples of self-help literature (Spence, 1986; Tatchell, 1986) indicate a use of counselling and therapeutic literature as a source of ideas but without any significant reference to the use of counselling directly as a means of support. This mutual lack of acknowledgement of each other's contribution in the development of HIV counselling and gay mutual support implies a degree of conflict in the perceived socio-political agenda between the politically active gay movement and the development of HIV counselling. Issues considered in chapter 2 point to a determination by some gay activists to resist the remedicalisation of homosexuality, an aim which they attributed to the rhetorics of medicine and stigma (see page 34) developed by Plummer (1988). However there is no reason to suppose that all gay men would share the view that a co-operative relationship with medical culture and practice would inevitably be disadvantageous to gay men's capacity for mutual support or collective self-determination. This issue remains unresolved. The involvement of gay men and

representatives of other groups affected by HIV in the provision of HIV counselling might have become clearer if questions had been asked about the personal, as distinct from professional, background of participants in the research. The sensitivity of such information precluded this kind of question as a possible option. It would be an indication of the level of personal frankness and quality of the consultation process if this kind of information were to be disclosed in face to face contact with other participants.

Issues of individual and collective self-determination for counsellors and clients alike are starting to emerge as a fundamental issue with significant ethical implications. On the basis of their background it would be reasonable to anticipate that counsellors might take a different point of ethical reference from a medical or public health perspective. Whether or not this is the case and how they construct their ethical stance on this fundamental issue is the subject of the next chapter.

Chapter 5

Germs or people: ethical diversity in HIV prevention

The relationship between HIV counselling and HIV prevention appeared to be a defining issue in identifying the ethical position of HIV counsellors. The ethic of public health might reasonably be expected to prioritise the reduction in transmission, whereas those HIV counsellors who adopted the prevailing ethic in the generic counselling movement might be expected to prioritise working within the parameters of respect for client autonomy.

The method of consultation

This analysis of the participants' perceptions of HIV prevention as an issue and their associated ethical positions is based upon a systematic review of all the reports and correspondence associated with the consultations conducted in May 1990 in Leeds, Birmingham, Bristol and London at which 118 people who completed the questionnaires referred to in the previous chapter were present. Planning the structure of these days had itself required preparatory consultations with known HIV counsellors and the Department of Health Steering Panel. A possible approach which had been favoured by some was to adopt a highly open-ended form of consultation based on techniques associated with the Tavistock Institute and the Grubb Institute. In practice this would have meant the consultation opening and closing with a large group event at which everyone was present with people divided into 3-4 smaller groups in the intervening period to reflect on 'good practice in HIV counselling' as the focal theme but how each subgroup defined that task would be devolved to them. It was also envisaged that there would be a system whereby members of the subgroups could issue questions to other groups for their consideration. It was envisaged that the facilitator's role would be largely to comment upon and perhaps

interpret the group processes rather than the content. Each group would also be provided with a rapporteur who would note the content of the discussion, the associated emotional climate, and any points of agreement or unresolved conflict. Tape recording the discussion for transcription would have produced a richer source of data with the potential for direct quotation unfiltered through the process of rapportage. There was a consensus amongst those consulted that this would be inhibiting to participants and that a system of rapporteurs checking their observations with group members would be more likely to create the circumstances in which participants felt able to communicate freely and to voice both professional and personal concerns in circumstances which had unavoidable risks to them because of the unpredictable responses of other participants. The sacrifice of direct access to the content of the discussion through transcribed tape recordings was considered a preferable loss to the research than running the risk of creating such anxiety about being recorded to invalidate the discussions through individual 'unaware projections' or collective 'consensus collusion' (Reason and Rowan, 1981b: 244; Heron, 1988: 51-3).

As will be apparent this approach had been developed in some detail in terms of a draft programme, a specification for the kind of accommodation required, and draft briefings for facilitators. However, during the preparatory consultations I became increasingly uneasy about several aspects of this method of consultation. I noticed that people who already had prior experience of unstructured group meetings with a process-oriented facilitator tended to be positive, although a few had significant reservations based on previous "bad experiences". A few expressed concern about whether such an open structure would be sufficient to contain the potential for strong emotions evoked by the losses associated with HIV and AIDS or conflict of views which would be likely to be deeply held. In their opinion, a great deal would depend on the quality of the facilitation. These all seemed well founded observations about the proposed method of consultation and potentially manageable. However I noticed that potential participants with little

previous experience of unstructured groups sounded sufficiently apprehensive that they might be deterred from attending or inhibited in their participation. I also had some prior experience of facilitating a consultation of this kind for the Central Council for Education and Training in Social Work in 1988 concerning the implications of HIV for residential child care and had observed how this approach was counter-cultural to participants unfamiliar with this deliberate abstention from structuring group discussion.

The use of structure had been a subject of interest from the mid 1980s (Bond, 1986) and I was aware that it was a recurrent issue in the history of social groupwork (Shaffer and Galinsky, 1974: 286) which was thought to influence both the process and content of the discussions. Views ranged between two poles represented by those who believed that eliminating (or at least minimising) formal structure exposed the group process in revealing and informative ways whereas the opposite pole was represented by those who considered the absence of structure represented a distortion of the way people behave in groups and contaminated the discussion. Variations of these views were represented by corresponding diversity in practice. My own experience of facilitating a consultation about an HIV-related topic suggested that the facilitator's focus on process issues had a corresponding effect on the content of the discussion which encouraged the disclosure of deep feelings evoked within the group and especially about AIDS rather than perceptions about issues external to the group. Although this was unknown to me at that time, a group analytic approach had been adopted by Angela Malmos (1990) to consultations about AIDS, the account of which concentrates on the deep feelings of fear and anxiety associated with AIDS and how this affected group functioning. These findings would tend to support my own observations. The task of this research required a different balance between process and task in which the former was addressed not as the focus of the research but to provide sufficient safety to minimise the inhibitions created by the sensitivity of the subject. The use of structure and facilitation style should be sufficient to direct participants' attention towards the task but in an open-ended way. As a

consequence I adapted a theme-centred interaction approach (Cohn, 1971) to structuring the day in which the small group sessions were each given a theme as the focus for discussion with the potential for participants and facilitators to suggest variations in group structure and activity within those sessions where it would help to address the theme. The ground rules listed on pages 50-51 (chapter 3) are also influenced by this group work model.

The preparatory consultations suggested a number of core areas of concern, about the nature of counselling, training, supervision and support, the effect of counselling on 'at-risk behaviour', and the consumer/client view of counselling. These themes were chosen in advance of the completion of pre-consultation questionnaires but have a sufficiently close correspondence to the issues which concerned HIV counsellors to suggest that these preparatory consultations and especially the views and experience of the steering panel were creating a sound basis for the research planning. It was clear that this modification to the original proposal considerably reassured potential participants unfamiliar with unstructured group process and redirected their attention to the subject of the consultation rather than its methods. This account represents the bare bones of a decision-making process which, although somewhat different from the route taken by David Morgan (1988: 11-15) in his development focus groups as a strategy for market research, reached a not dissimilar end result. It is also worth noting that the literature associated with new paradigm research is relatively silent on issues of structure and focus and their practical implications in collaborative group research. The outcome of these preliminary consultations was the following programme circulated to participants in advance.

9.45 Arrival and registration (Participants)
(Briefing of facilitators and rapporteurs by myself and answering questions about written information circulated in advance)

10.15 Plenary with everyone present: Introduction to the day by myself.
(Aim of research; structure of day; ground-rules; house keeping)

10.35 Consultation on HIV counselling

12.30 Lunch (provided)

1.30 Consultation on either training,
or supervision and support of counsellors

2.45 Tea

3.05 Consultation on either the effect of counselling on 'at-risk behaviour'
or the consumer/client view of HIV counselling

4.20 Plenary for comments and observations to everyone present

5.00 End

All consultations were made in four smaller groups with usually eight to ten participants present and a facilitator and rapporteur. Participants made their own choice of alternatives in the afternoon consultations.

An evaluation undertaken by BAC administration indicated a high level of satisfaction with the way the consultation process worked in practice with 33% (39/118) reporting they had found the day 'very useful' and 58% (68/118) 'quite useful'. A consistent feature in the comments of those who found it 'quite useful' was a desire for more time in the small groups. 4% (5/118) reported that they had not found the day useful and the remainder (5%: 6/118) did not complete the form.

An analysis of views about HIV prevention, the subject of this chapter, is based on a review of the entire consultation because it was a recurrent theme throughout the day and not merely confined to the consultations about the effect of counselling on 'at-risk behaviour' although those consultations were particularly informative. In the analysis I

will start by setting out the range of views elicited before considering their implications for the conceptual mapping of the ethics associated with HIV counselling.

The personal background of HIV counsellors

Chapter 4 concluded with a question about the significance of the absence of reference in the literature about HIV counselling to the contribution of gay men in providing health education and support within their own community. It was also suggested that the level of disclosure about personal information by participants would be an indication of the extent to which the consultative process had managed to overcome the obvious sensitivities of the topic. When planning for the sensitivity of the research subject, it was anticipated that some HIV counsellors would know themselves to be HIV sero-positive. This proved to be the case. Some were quite open about their status, others asked that their identity be omitted from the rapporteur's account and a few contacted me outside the consultation. There may well have been others who chose not to disclose their status. On the basis of definite disclosures with some allowance made for 'off the record discussions' which are counted as one person but may have involved more than one disclosure, it appears that between 15 and 20% of the participants knew themselves to be HIV positive. Sadly this estimate also approximately corresponds to the known deaths of participants by 1997. It appears that there may well have been an approximately equal number who were closely involved in the care of someone, usually a partner, family member or friend. It is very difficult to be precise about these figures but when involvement in buddying and befriending is taken into account it appeared that at least half and maybe more participants had significant personal experience of HIV independently of the role of HIV counselling. There were many disclosures of gay relationships (male and female) and some disclosures of injecting drug use and haemophilia, but it is not possible to quantify these with any certainty. Personal sexuality, drug use and health conditions were less likely to be recorded by rapporteurs, as

acceptance of a diversity of sexual orientation and social background was normative within the consultations.

One of the consequences of so many participants having either direct personal experience of belonging to a social minority strongly associated with HIV/AIDS was a recurrent criticism of stigmatising clients and the stress on services based on tolerance as a minimum standard or preferably a positive acceptance of social diversity as the optimum standard. A frequently expressed view was the importance of providing counselling in ways which were acceptable and accessible to specific client groups. Some accounts of what this might involve were based on personal experiences of being a client and a number of challenges to conventional views of counselling were offered. Some gay HIV counsellors who were active in their own local community spoke about how the gay community tended to be a relatively small and socially distinct community in which a counsellor would inevitably meet gay clients in other social settings. In these circumstances, the boundaries between acquaintance, client and friend could not be defined by social distance in ways which might be appropriate for a more disparate social network characteristic of 'straight' society. Counsellors specialising in drug addiction and prostitution spoke against too rigid a way of defining 'formal counselling' in terms of counselling offered by appointment which was incompatible with working with people whose own lives were unstructured and sometimes characterised as 'chaotic'. In these circumstances, the emphasis needed to be on the availability and accessibility of the counsellor and working opportunistically especially in outreach work within the community. Some young haemophiliacs spoke about their experience of feeling patronised or infantilised in services based on responding to the family as a unit. Conversely some women spoke about the conflict of emotions and values they experienced working with clients in the same age range as their own children and how hard it was to sustain a distinction between a parental and counselling relationship. The recurrent theme across all these disclosures was how becoming involved in HIV

counselling had posed personal and professional challenges which frequently provoked a review of accepted beliefs about counselling and to this extent compounded the sense of role ambiguity. There was a perception that the voluntary sector was more encouraging of personal reflection and self disclosure by counsellors than more clinical settings where an ethos of personal detachment might make consideration of personal issues less culturally acceptable. The levels of personal disclosure during the consultations suggested both that the research ethos and a significant proportion of participants favoured addressing personal issues as a source of personal values and role clarification. However, this personal exploration was perceived as insufficient by itself to clarify the relationship between HIV counselling and HIV prevention but it appeared to justify a commitment to discussing the issue in terms of people and personal impact rather than focusing on 'germs' and 'disease'.

Division of views about the relationship between HIV prevention and HIV counselling

The preventative task as a component of HIV counselling was invariably viewed as some form of behaviour modification which reduced the risk of HIV transmission, which might be total abstention, risk minimisation (e.g. using condoms in penetrative sex, sterilising injecting equipment) or substituting a lower risk activity in place of a higher risk (e.g. mutual masturbation in place of penetrative sex). In comparison, counselling was a more fluid concept as will become apparent in the analysis. This ambiguity in the views about counselling meant that the demarcation between different viewpoints was not always clear.

The relationship between HIV prevention and HIV counselling was a recurrent issue throughout the consultations and was widely recognised as a source of concern. There were four possible views that these two tasks were:

(a) incompatible

(b) compatible but with modifications or limitations to counselling in order to prioritise the prevention

(c) compatible but with modifications or limitations to prevention in order to prioritise the counselling

(d) wholly compatible.

The aim of this analysis is not to quantify the adherence to particular viewpoints but to explicate the conceptual basis and ethical implications of the different positions. As reported at that time the most widely supported view was a degree of modification to HIV prevention to protect the counselling role (Bond, 1991: 68) but there was clear evidence of some support for the other possible positions. Set out below is the declared conceptual basis for each of the positions. Within each category there were a variety of reasons for adopting that position.

(a) Incompatibility of HIV counselling and HIV prevention

(i) *The counsellor's non-directiveness over the content of the counselling*

This viewpoint was crystallised by a participant who asked 'is the counsellor there for the client or to help the client meet someone else's agenda?' She emphasised the client's right to control the agenda within counselling and the counsellor's openness to the possibility that the client may have more urgent concerns than HIV prevention. She would not exclude HIV prevention issues raised by a client but appeared to support a strong differentiation of the two tasks as most protective of the ethic and process of counselling. She was asserting the individual client's control of the content of counselling against the public agenda of HIV prevention.

(ii) *The necessity of directiveness in HIV prevention*

In reaction against references to respect for client autonomy sometimes based on assertions about client-centredness in person-centred counselling (e.g. Rogers, 1977; Mearns and Thorne, 1988: 17) or the codes of ethics and practice for counsellors (e.g. BAC, 1984, 1989b), it was sometimes posited that there was a need for giving directive advice based on current scientific knowledge about the transmission risks. One person, with a tone of exasperation, commented that the prevention of a health crisis was more important than 'professional niceties' with the implication that HIV prevention was paramount whenever there was incompatibility with 'non-directive' counselling. These views broadly correspond to the medical-clinical approach evident in some of the literature.

(iii) *Moralising to prevent HIV transmission*

On the basis of 'love the sinner, not the sin', a few religiously motivated participants spoke, quite courageously in the context of the prevailing group norms, in favour of compassion and support for people with HIV but that the impact of the disease would be reduced by a return to traditional moral values. If these views were applied to counselling (which was undisclosed), they appeared to be distancing themselves from both the prevailing views of non-advisory HIV counselling and non-moralising HIV prevention. The moralising of both prevention and counselling can be viewed as either a way of reconciling the two activities or as a radical critique of the general way in which participants approached this issue. I have construed it as the latter and therefore allocated this view as indicating the incompatibility of HIV counselling and prevention as conceived by most participants.

(b) Compatible but with modifications or limitations to counselling in order to prioritise HIV prevention

(i) *Pre-set agenda and use of information-giving*

Two major modifications to counselling were frequently disclosed in the context of pre-test counselling which included an expectation on the part of the counsellor that some of the available time would be devoted to HIV prevention and what the client needed to do to avoid the transmission of HIV. This would involve using some of the available time for information-giving about medical information, about the test, transmission routes, potential consequences of being tested (e.g. life insurance, employment) and preparation for test result. These topics were sometimes suggested as a fixed agenda for pre-test counselling. The arguments in favour of these modifications to a wholly client determined agenda for counselling without information giving were that in view of the prevalence of negative test results this might be the only opportunity to ensure the dissemination of adequate HIV prevention information because only people with positive results were usually seen for post-test counselling. On at least two occasions facilitators suggested that this way of working was not counselling as it was understood with BAC but the 'use of counselling skills' i.e. the use of skills derived from counselling but applied within another role (BAC, 1988). How far the persistence of wanting to modify counselling to incorporate substantial amounts of information giving represented an ignorance of this distinction or constituted a deliberate challenge to current views of generic counselling was unclear. The justification for this view was usually the individual client's need to be adequately informed.

(ii) *Compliance with pressures to breach counselling confidentiality within inter-disciplinary teams*

Some counsellors complied (with varying degrees of willingness or covert resistance) with expectations that the content of counselling sessions be made available, usually through shared records, with colleagues in interdisciplinary teams. One of the justifications for the expectation and compliance was the opportunity this afforded to reinforce HIV prevention messages by colleagues.

(c) Compatible but with modifications or limitations to HIV prevention in order to prioritise the counselling

(i) *Emphasis on staying within the boundaries of the client's agenda*

Pre-test counselling restricted the agenda to that wanted by the client, perhaps after a discussion of what topics might be included. HIV prevention would be addressed only in so far as the client wished. The counsellor's viewpoint was one of working as closely as possible to the prevailing ethic and methodology of generic counselling and/or being mindful of establishing a sufficiently trusting relationship as the basis for future counselling especially in the event of a positive result. A parallel argument was offered for post-test counselling and on-going psycho-social counselling of people affected by HIV by emphasising the importance of building an on-going relationship. In many ways this position was not so different to those who argued for the compatibility between health education and counselling based on a shared ethic of autonomy but the position was justified exclusively by reference to counselling standards and ethics.

(ii) *The confidentiality of counselling within inter-disciplinary teams*

The confidentiality of most counselling sessions was routinely protected from automatic disclosure to colleagues in multidisciplinary teams even if this reduced the opportunity of colleagues to reinforce HIV prevention. This stance was based on respect for client autonomy (thus disclosure with client's consent was considered ethical), the importance of the trust between counsellor and client, and the experience that some other professions disclosed information about clients more freely within their own profession or setting and that as a consequence it could not be assumed that the sensitivity of information derived from counselling would be respected.

(iii) *Harm minimisation rather than total prevention*

One modification to the concept of 'prevention' was not to regard it in absolute terms which would imply total and persistent abstinence from a behaviour which carried the risk of HIV transmission but the achievement of modifications in behaviour which lowered the risk of transmission (e.g. using condoms in penetrative sex, or sterilising injecting equipment or using a needle exchange). An enduring substitution of a minimisation strategy might be considered more effective than a short-lived abandonment of a high risk behaviour. The ethical advantage of this position was perceived as avoiding moralising, usually viewed as incompatible with counselling, but permitting a range of outcomes, maximising client autonomy and building upon current knowledge of transmission.

(iv) *HIV prevention which excluded testing*

This research was taking place at a turning point in the attitude of gay men and their organisations towards antibody testing. Initially there had been

considerable resistance because of the psychological distress caused by a positive diagnosis without any commensurate health gain because of lack of any cure or initially improved treatments. A few counsellors, largely working outside London or larger regional centres included within their counselling a tendency to discourage people from being tested and to encourage them to take all the precautions that were known to reduce HIV transmission as they were the same behaviour changes whether they were sero-positive or negative. This ethic was criticised as being outside the usual ethic of autonomy and defended in the interests of the welfare of the client. One facilitator wrote, about the dissension in his group "over the issue of whether people should be encouraged to undergo testing on the basis of early intervention both of counselling and of a medical nature. This was most enlightening for me and certainly taught me not to assume that every Health Authority is as well-resourced as London or Brighton on the issues of HIV testing, health care provision and so on".

(d) Compatibility between HIV counselling and HIV prevention

(i) *HIV prevention defined positively as health education*

Participants and one rapporteur qualified in health education challenged the prevailing view about the degree of incompatibility between counselling and prevention. It was asserted 'Counsellors have a health educational role' and that within health education and counselling there was a much greater 'links and overlap' than participants appeared to realise. Clarification of this viewpoint directed my attention to the shared liberal values of counselling and health education.

Within health education and counselling there exist a range of views about the standing of health as a value. From one viewpoint, health is merely

instrumental in achieving autonomy, so it is ethically consistent to argue that 'individuals have the right to act as they want unless they are harming others', that is a 'negative freedom' limited only by a principle of harm. However, within health education ethics it has also been argued that the value 'health' is not only instrumental but integral to the concept of autonomy so that 'if a person knowingly pursues a lifestyle which is destructive of his or her health, this cannot count as an expression of autonomy unless other values are involved ... health is *a* value, not that it is a supreme value. But since it is *a* value it always ought to be one regulator of autonomy behaviour' (Downie, Fyfe and Tannahill, 1990: 150). This analysis places greater emphasis on the health educator to interact with people positively (rather than neutrally as implied by 'negative freedom') so that they are best placed to exercise their autonomy informed about the consequences for their health, permitting a degree of persuasion but excluding indoctrination or deception (Campbell, 1990: 23). By analogy, it was suggested by some participants that most models of counselling are not neutral with regard to autonomy but have associated values which favour specific ways of exercising autonomy as more healthy than others in terms of self and relationships. For example, 'the process of becoming' in person-centred therapy (Rogers, 1967: 108-24) or substituting the ego where the id once was in psychodynamic therapy (Freud, 1962: 115; Stevens, 1983: 138) conveys a value of healthier (and conversely unhealthier) states of autonomous being. The incorporation of a value of 'health' in both health education and counselling, it is argued, provides a shared ethical base and reduces, if not eliminates, any incompatibility between HIV prevention and counselling, in which autonomy is the dominant ethic. It was also suggested that this construction provided the best basis for validating a counsellor's involvement in activities such as boosting a client's

self-esteem or imparting social skills to negotiate safer sex. A comprehensive explication of the practical opportunities implied by this view for HIV counsellors can be found in the official report (Bond, 1991: 69-70). For the purposes of this analysis, the ethical orientation is the key feature and was evident in another line of argument explicitly based on a counsellor-led assessment of the client's best interests rather than an ethic of autonomy which incorporates values about health. This is considered next.

(ii) *Behaviour exposing self to risk of HIV infection viewed as evidence of mental distress*

One therapist entered into heated exchanges with another participant who probably advocated the next viewpoint in this category. The therapist stated that, 'He saw high risk behaviour as a symptom of psychological distress', He viewed this behaviour as one way in which someone might feel alive (perhaps to alleviate depression) or as a response to a whole series of difficulties which stem from early life. In his view, this did not legitimise crude attempts to counter 'high risk behaviour' but lowered its status as truly autonomous behaviour. This line of reasoning appeared to owe much to the psychological determinism which is characteristic of Sigmund Freud's approach to psychotherapy (Payne, 1991: 75; Banks, 1995: 55). From this perspective, therapy and HIV prevention were ethically and professionally compatible, even if it required caution and skill to effect both.

(iii) *Both HIV prevention and HIV counselling rooted in an ethic of radical autonomy*

This view was predicated on a combination of scientific knowledge about HIV and an ethical view which devolved responsibility for HIV prevention to each sexually active adult to protect themselves. It was based on two

observations that (a) an awareness of the limitations of testing, especially the possibility of a period of three months when someone might be infectious but without having produced the antibodies which would produce a positive result, and (b) that probably many sero-positive people had not been tested and did not know their status, therefore it was argued that therefore there was an ethical duty to inform and support people in protecting themselves and that each adult was responsible for their own protection. Notions of coercively preventing someone known to be positive from infecting others were seen as irrelevant and unethical. There were no limitations to adult autonomy with other adults. The appropriate response to knowledge about a potential risk of infection was disseminating information and education supported by counselling, all based on a concept of radical autonomy. This ethic provided a justifiable basis for extending the conventional role of the counsellor into information-giving and counsellor-determined agendas. This position was strongly associated with a resistance to scientific evidence and language around 'at risk' behaviour as it could obscure the social significance of such behaviour – e.g. 'science refers to the rupturing of mucous membranes during anal intercourse but the socially constructed debate around "buggery" is much more relevant to people who engage in these acts .... Many people engage in high risk acts for no other reason than they like to do so' [in disagreement with the reasoning of the therapist referred to immediately above]. When asked if imparting information was 'counselling', he believed that the two could not be separated.

The multiplicity of views on the relationship between HIV prevention and HIV counselling made this one of the most conflicted and fraught topics during the consultations. Facilitators frequently commented on this being the most difficult issue raised during the day. Divergence of views was compounded by personal fears of being

hypocritical which led some participants to disclose their own struggle to modify behaviour and how difficult it was to sustain changes; fear of one's past catching up with oneself was a factor disclosed by a former injecting drug user who did know his HIV status; professional vulnerability of working in agencies with contrary policies or no policies on HIV prevention also added to the general sense of vulnerability and difficulty which characterised discussions on this topic. It was the issue which most clearly exemplified the role ambiguity of the HIV counsellor. I do not think that anyone had anticipated the diversity of ethical positions associated with this ambiguity. In the report I coalesced this diversity into two broad positions in favour and against the compatibility and contribution of counselling to HIV prevention (Bond, 1991: 67-70). In this account I have disaggregated the views to provide a clearer basis for the ethical analysis.

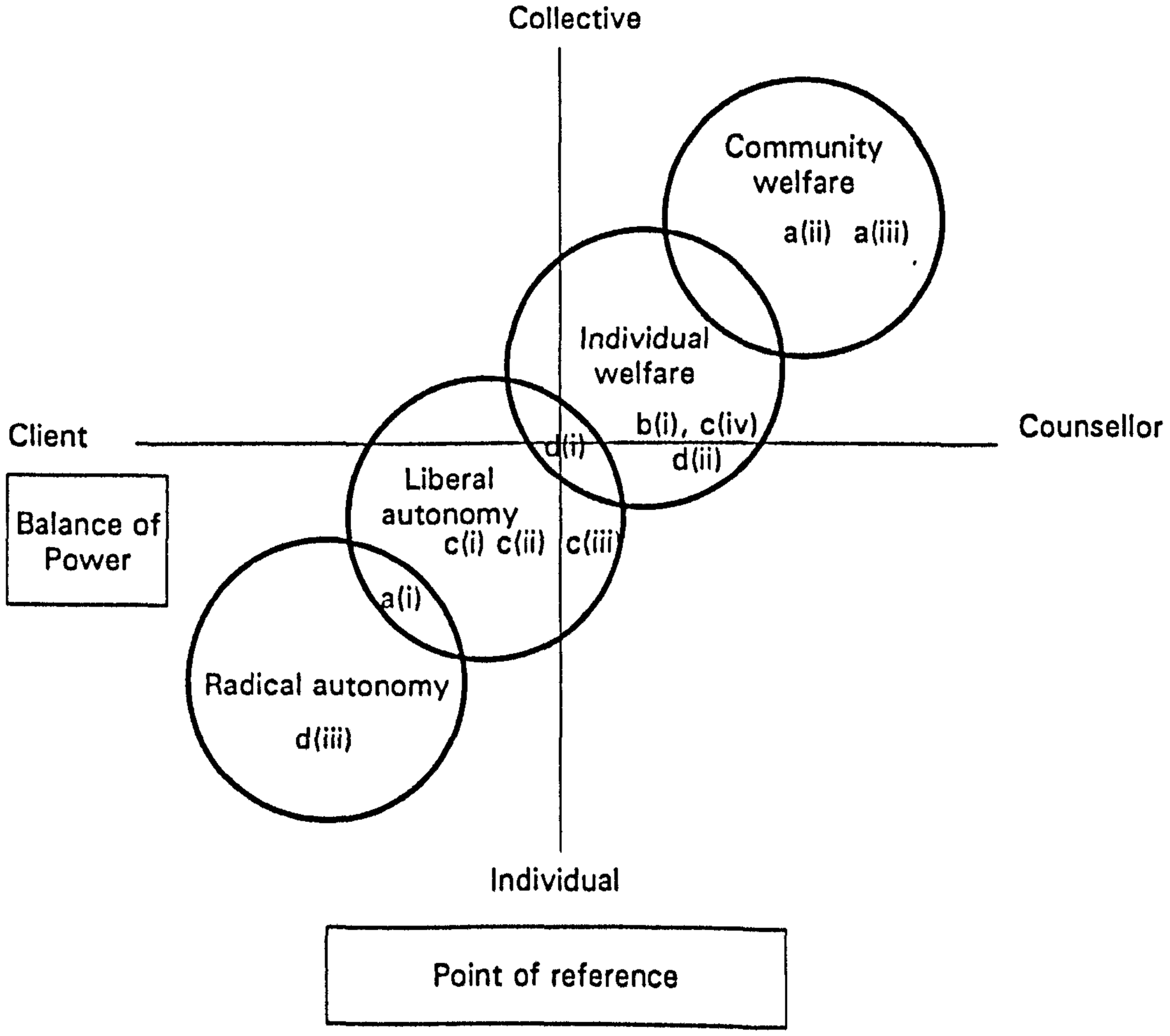
Ethical aspects of role ambiguity

The use of the term 'ethical' in this context would be misleading if it is taken to suggest that participants were advocating firmly established ethical positions supported with entrenched principles. This was not the case. The debate was generally expressed in terms of values derived from personal and professional experience in which the dominant form of expression was sociological and psychological. In this respect, the discussion may have been complicated and to some extent frustrated by a lack of adequate terminology and conceptual framework in which to describe the other dimension of the debate. This is probably a reflection of the relatively underdeveloped ethics of counselling at that time. The experience of conducting this research was one of the sources of motivation for me turning my attention to an extended consideration of counselling ethics (Bond, 1993). However, this research is based on data and interpretation which predates that publication and is committed to being descriptive of a particular state of affairs within a specific context.

Mapping the range

The identification of a number of distinctive viewpoints about the relationship between HIV counselling and HIV prevention conveys the state of ethical ambiguity associated with the role of HIV counsellor. The ambiguities which can be construed as differences in views about autonomy which can be plotted on a quadrant in which one axis represents the balance of power between client and counsellor and the other axis depicts the ethical point of reference from individual to collective. When the twelve distinctive positions are plotted on the quadrant, a number of ethical stances became apparent ranging from radical autonomy to community welfare (see diagram 5.1).

Diagram 5.1: Ethical discourses quadrant



Radical autonomy envisages a highly individualised form of autonomy unconstrained by any principle of harm because the responsibility for preventing HIV infection is devolved to each individual to protect themselves. The counsellor's duty to the client is to provide the basis for someone protecting themselves.

Liberal autonomy prioritises the individual over the collective autonomy but this is limited by a principle of 'harm to others'. As a consequence the counselling ethic is constructed as non-directive and non-moralising which limits the counsellor's full use of HIV prevention strategies to varying degrees so that there is a degree of overlap between radical autonomy at one end by exclusive attention on counselling and individual welfare at the other by the incorporation of a value of health into the ethic of autonomy.

Individual welfare represents a change from client assessment of own autonomy to a more counsellor based view of the client's welfare or best interests, usually taking into account the client's autonomous wishes but these are not paramount. There are degrees of movement between the power of client and counsellor which provide the overlap between liberal autonomy and community welfare.

Community welfare represents placing the collective good over and above individual good. Two main ways in which this might occur were identified. First, a public health ethic rooted in a medical rhetoric might justify a shift from what might be experienced as paternalism inherent in individual welfare to individual coercion in the perceived interests of the wider community. Second, moral traditionalism would justify a remoralisation of both the relative 'neutrality' of medical rhetoric on HIV and of counselling itself. Both these positions were mentioned most frequently as one's opposed to by participants rather than avoided. Both positions would legitimise a higher level of directiveness than individual welfare might justify up to and including coercion or segregation.

Ethical ambiguity for HIV counsellors

This analysis of the range of positions *vis-a-vis* HIV counselling and HIV prevention draws attention to the range of expressed ethical ambiguity present in the role of self-selected HIV counsellors in 1990. In many ways, this represents a more profound challenge to the role of HIV counselling than a wide and narrow role definition identified by Chester (1988) and discussed on pages 78-81 At the heart of the ethical ambiguity is a dispute about the basis for working with people affected by HIV. It might reasonably have been anticipated that narrowing the focus might have reduced role ambiguity by eliminating some of the variations. In particular, it might have been supposed that there would be a resolution between the tendency for counselling to be a more prescriptive and directive process in medical settings than would be the case for the British Association for Counselling (Chester, 1988: s. 2.2.1). Instead the fundamental variation of positions with regard to HIV from radical deconstruction antagonistic to medical rhetoric at one extreme to moral traditionalism at the other, extended the potential range of positions within counselling. The wider debate within the moral arena (chapter 1) is evident within HIV counselling at this early stage in its development. The conceptual map of ethics is wide ranging as a consequence.

One of the aims of this research was developmental. After further consultations on this issue, it was possible to recommend an approach to HIV counselling which represented the substantial majority view that the respect for individual autonomy (variously construed) set some limitations on the HIV preventative role undertaken by HIV counsellors but operating within an ethic of autonomy permitted a wide range of possible activities. Even as late as 1997 I am still receiving requests for permission to photocopy this section of the report as it is still seen as professionally useful and was perceived as emerging from an open consultative process. However from an academic perspective I

was left with a number of intriguing anomalies which invited further consideration if the opportunity arose:

1. Closely associated with the ethic of autonomy is the management of confidentiality. The structure of the consultations and limitations of time highlighted this as a recurrent issue in the relationship between HIV counsellors and their colleagues in multidisciplinary teams. At the end of this research cycle it was an issue which was viewed as being of critical importance, for example confidentiality was often suggested as the first thing counsellors need to be trained in with regard to HIV, and yet least resolved. The perceived tension was between a medical and counselling approach to confidentiality. My pragmatic response was a plea for mutual understanding in the differences between how counsellors and doctors manage confidentiality necessitated by the difference in their responsibilities, working practices and relationships with colleagues, supported by a similar plea from Hilary Curtis, the administrator of the British Medical Association Foundation for AIDS (Bond, 1991: 47-8). How HIV counsellors perceived their responsibilities in potentially extreme situations, such as when faced with someone deliberately or recklessly placing others at risk of infection, entailed considerations of autonomy and confidentiality and had not really been explored in this research. On the other hand it seemed possible that a methodology and conceptual framework had been developed in this phase of the research which might be useful in understanding these unresolved aspects of confidentiality.

2. This research highlighted the dynamic influence on the construction of role boundaries and ethics of the values and experiences imported by the counsellors as people on the one hand, and the potential influence of social policy on the other. A follow up study would provide an opportunity to compare the influence of two specific socio-historical contexts on and within HIV counselling so that the dynamic

interaction of different factors in the construction of ethics might become more apparent.

The opportunity for follow-up research concerning confidentiality about HIV within multidisciplinary teams arose in 1994 and is the subject of the next section.

Section 3

Matters of confidence

Confidentiality is a critical issue for HIV counselling which requires both practical management but also takes on different levels of significance according to the ethical orientation of the counsellor. This section explicates the conceptualisation and implementation of both these aspects of confidentiality concluding with a differentiation between a variety of approaches to the ethical domain of HIV counselling.

Chapter 6

Building confidence: Researching confidentiality

The choice of confidentiality as an ethical issue which would advance the mapping of the ethical domain of HIV counsellors was based on a number of factors. Firstly confidentiality had been identified in the earlier study as a critical issue around which there were unresolved differences especially between a medico-clinical and counselling approach to HIV-related services. A greater understanding of the nature of these differences holds out the possibility of adding to the explication of ethical diversity. Secondly, it appeared that the immediate practical implications of confidentiality for the relationship between service providers and users and for relationships between different members of the same multidisciplinary teams would ensure that participants would be likely to have developed clear views about their chosen ethics on this subject. As a topic in an ethical mapping exercise, it had the advantage of being one around which participants are likely to have experienced difficult issues and understanding how these are resolved would provide clear examples of the ethical stance that had been adopted. Thirdly, the choice of a topic which was ethically unresolved and recognised as important would tend to maximise the motivation of research participants within the consultative process.

However, it could not be assumed that this research would simply pick up where the other research had left off. A gap of four years is significant in a rapidly developing and fluid situation such as the response to a health crisis. This research would need to take account of the new circumstances and to be informed by the available literature. I shall review each of these in turn before considering their implications in the refinement of the research methodology.

The changed circumstances for HIV-related services

The social context of HIV counselling changed considerably during the interval of four years between the research reported in section 2 and fieldwork for this section. Uncertainties about the future incidence of HIV infection had diminished. The downgrading of the potential scale of HIV infection predicted in the Cox Report (Department of Health, 1988c) had been established by large scale screening of anonymous blood samples obtained during routine testing and treatment of other conditions (Burridge, 1996: 232). This initially controversial procedure confirmed that new HIV infection was predominantly occurring amongst gay men and injecting drug users. Better procedures in the preparation of blood products protected haemophiliacs from new infection but a significant number of people infected prior to the introduction of these safeguards continued to need HIV-related services. Heterosexual transmission was occurring but on a much smaller scale than seemed likely in 1990, and the threat of widespread heterosexual transmission typical of many other countries had largely evaporated in Britain. The distribution of HIV infection was unevenly spread across the country with the highest density of infection occurring in inner London and to a lesser extent in large urban centres in the regions. Most regional health authorities outside central London remained areas of low incidence of HIV. This downturn in the threat posed by HIV was interpreted differently according to the interpreter's own viewpoint. It could be viewed as an exemplary success for a public information and education programme supported by widespread testing and counselling. Alternatively, it could be viewed as the inevitable outcome of an exaggerated health threat, where the exaggeration of the threat of a heterosexual epidemic was attributed to gay men wishing to avoid becoming seen as a reservoir of highly stigmatised illness or the re-medicalisation of homosexuality. The political ethos in which public policy was being decided had moved markedly in the latter direction.

Senior politicians responsible for health within a Conservative government were known to wish to move towards a more traditional moral agenda than the liberal ethic based on individual autonomy and confidentiality. Virginia Bottomley, who was generally recognised as being sufficiently knowledgeable about AIDS to speak without briefing, started to support the development of policy in favour of a national provision of contact-tracing for HIV in the same way that had been established for other sexually transmitted diseases. Although contact tracing for HIV had been implemented on a local basis in some areas it was not widely used. Contact tracing had been opposed by the 'AIDS policy community' for practical and ethical reasons. Burridge (1996: 255-6) summarised the practical reasons as a recognition of the difficulty entailed in tracing many of the sexual contacts of gay men over a number of years, the resource implications, the ethical reasons concerned the enormous personal implications of a positive test, and the ethos of confidentiality around the original infected case. The widespread reporting of Roy Cornes, a 24 year old HIV-positive haemophiliac, in June 1992 appears to have provided the stimulus to overcome any established resistance to a national policy. Cornes was reported to have been directly responsible for infecting four girlfriends and indirectly his baby son as well as placing the children of former girlfriends at risk. The absence of any contact-tracing was much criticised in the media and by some professionals. On ministerial initiative, national guidelines for contact tracing were published in December 1992 (Department of Health, 1992; Coyle, 1993). At about the same time, Brian Mawhinney was reported by a civil servant as attempting to overthrow single-handedly the policies of harm minimisation over illicit drug use supported by the medico-bureaucracy in favour of abstinence and moral counselling (Burridge, 1996: 259). This hard-line approach to drugs appeared to be favoured by the new Home Secretary, Michael Howard. A shift in policy towards active moralising coincided with progressively removing ring fencing from drugs and AIDS-related funding and a general downturn in funding available for both areas of work.

Other changes were also taking place with implications not only for HIV-related services but also for the whole of the health service. Following the publication of a White Paper *Working for Patients* (DH, 1989) and the NHS and Community Care Act 1990 which was implemented in 1993, there was a general shift away from services provided in hospitals to services delivered in the community with the responsibility for the development of these services placed on local authorities. Both voluntary and statutory agencies were invited to compete in providing community based services within a new market place ethos organised around service providers who tendered for contracts allocated by purchasers. The early 1990s was a period of considerable structural change within the NHS.

Divergences between the professions over confidentiality

A systematic examination of the available published statements for the caring professions involved in providing HIV-related services suggested that management of confidentiality had also been changing, partly in response to the demands of delivering HIV-related services. An examination of the general principle of confidentiality within multidisciplinary teams reveals how practice had been evolving gradually over time before the advent of AIDS and that AIDS-related responses are an extension of those trends. I shall consider the background to both these observations whilst paying particular attention to divergences between the professions.

Routine disclosure within multidisciplinary teams

Current guidelines for both medicine and nursing emphasise individual patient consent as the basis for disclosure of confidential information with multidisciplinary teams (BMA, 1993b: 39-40; GMC, 1993b: 26; UKCC, 1992: s. 10). Nursing explicitly acknowledges that this standard may not always be practicable and permits implied consent provided that patients already understand that such information needs to be made available to others

involved in providing care (UKCC, 1987: 6). In medicine, the decision about when other team members need to know confidential information about a patient rests with the doctors who lead the team. The doctors concerned are responsible to ensure that patients are informed about circumstances in which information is likely to be shared and that patients have an opportunity to object (GMC, 1993b: 26 para 79). Consent may be assumed in the absence of objection. This represents a significant change in policy over confidentiality from earlier practice. In 1954, the British Medical Association voted against modifying its rigid policy of complete secrecy in all circumstances with the sole exception that a doctor might warn others against possible venereal disease infection (Phillips and Dawson, 1985: 121). An increasing list of exceptions exercised at the discretion of the doctor and the widespread assumption of consent to permit the sharing of information with others directly involved in providing care for patients resulted in a vigorous debate in Parliament during the passage of the Police and Criminal Evidence Act 1984. Opinion was divided about whether medical communications and records could be regarded as sufficiently confidential to merit the additional safeguards of being treated as 'excluded material' under the proposed legislation (Mason and McCall Smith, 1994: 18-19). The occurrence of this debate is indicative of how any relaxation of confidentiality, even for well-defined reasons, can be construed by politicians and the public as an abandonment of confidentiality. In the event, medical records were deemed sufficiently confidential to require the legal safeguards ascribed to 'excluded material' within criminal investigations. However the subsequent increased accessibility of records to non-clinical staff for analysis by auditors and health managers has raised the question of how confidential is confidentiality with regard to medical records? At what point do either the number of individuals or different classes of people having routine access to records defeat the concept of confidentiality?

Similar questions have been raised about the development of confidentiality within social services. There has been a long tradition of confidentiality being conceived as inclusive

of more people than the client and an individual social worker. When a client discloses secret information, it is on an implicit or explicit understanding that the information communicated will be available to the social services agency (Biestek, 1961: 125). The co-ordination of services within the agency and accountability to local authorities has taken a higher priority than professional autonomy over client confidentiality. This tendency was reinforced by the emphasis on the co-ordination of services in the Seebohm Report (HMSO, 1968) which resulted in the amalgamation of specialised services into a single generic department in the early 1970s. The report extended the networking of information. Other issues have continued this trend. In particular, the prominence of social services in the prevention of child abuse has required further revision of internal practices and co-ordination between agencies under the policy known as 'Working Together' (Department of Health, 1991b). The combined effect of these and other factors has contributed to an emphasis on confidential information belonging to the social services agency rather than the person to whom it was disclosed (Thomas, Noone and Rowbotham, 1993: 65). Ownership is interpreted as securing a right of access to confidential records by other members of the same agency. This contrasts with a distinction between 'ownership' and a 'right of access' which characterises clinical professions such as nursing (UKCC, 1987:8). However, this distinction may be of greater theoretical than practical significance in terms of internal staff because access to confidential information within social services is not automatic and is based on similar criteria to those of nursing, i.e. especially 'a need to know' (Thomas, Noone and Rowbotham, 1993: 36). However, 'ownership' of confidential information in social services is the basis of a legal authorisation to disclose information within the welfare network of different agencies without the consent of the person concerned (Department of Health, 1988a: paras 16-20). This is different from the usual practice with regard to confidences held by health care staff which would be restricted to the agency in which the information has been disclosed unless the explicit consent of the person concerned has been obtained for subsequent

disclosures. Therefore within social services a distinction was made between personal information and health-related information, and the latter should only be circulated to other agencies with the consent of the originator of that information, usually a doctor or someone authorised by a doctor (Department of Health, 1988a: para 10c). The development of community care may have eroded this distinction because of associated trend towards the routine exchange of information between agencies, including the use of joint computer databases to obviate the need for formal case conferences (Department of Health, 1991b: s.4).

These recent developments have their origins in the vision of the Seebohm Report (HMSO, 1968) which urged social service staff 'to see themselves not as a self-combined unit, but as part of a network of services within the community' (para 478). Implicit within this construction of social services was a rejection of anachronistic ideas of confidentiality and the acceptance that 'confidential information is exchanged freely, otherwise the work could not be done properly (para 657). This antipathy to confidentiality within social services has been periodically criticised (BASW, 1983: 12; Dawson, 1983: 55; Family Rights Group, 1987). Similar concerns about the management of confidentiality within social services in the United States have been captured in the phrase 'the right to nose' rather than a 'right to know'.

The practice of psychologists has generally been to emphasise the client's consent as a prior condition to disclosures to colleagues with the exception 'that when working in a team ..., they shall endeavour to make clear to recipients of services ... the extent to which personally identifiable information may be shared between colleagues ...' (BPS, 1993: 3 para 4.3). The vagueness of 'endeavour' leaves open the possibility of assumed consent in the absence of objection. It is also unclear what would constitute a sufficient obstacle to transform an ineffective endeavour at informing clients into the status of acceptable practice. In contrast, counsellors are required to 'work within the current

agreement with their client about confidentiality' (BAC, 1993: 6 para B.4.3). The term agreement implies explicit informed consent and no provision is made for routine personally identifiable communications with colleagues without explicit consent.

All professions recognised in their published guidelines that confidentiality need not be absolute. They envisaged exceptional circumstances in which legal obligations or conflicting ethical principles such as the need to prevent serious harm to others may override the duty of confidentiality. The probability that such situations might arise in connection with HIV/AIDS meant this aspect of confidentiality would merit careful consideration in the research.

Diversity in the routine management of confidentiality within team settings is evident from this analysis. The differences can be summarised diagrammatically:

Diagram 6.1: Ethical basis for routine disclosure of client's confidences to team members

Profession	Minimum basis for communications to team members	Client control	Professional control
Medicine	absence of objection	low	high
Nursing	implied consent	low	high
Social Work	agency policy	very low	very low
Psychology	psychologist endeavours	low	high
Counselling	client consent	high	low

The diagrammatic representation emphasises the differences in level of control exercised by particular professions relative to their clients. Social workers and their clients share an absence of control which is held by the agency and ultimately the Secretary of State in central government who holds the power to issue mandatory directives (Local Authority Social Services Act, 1970 s. 7). In comparison, doctors and nurses exercise

much higher levels of discretion but are accountable to their statutory regulatory bodies who have the power to withdraw their professional registration. Psychologists hold similar powers and are accountable to the disciplinary procedure of the British Psychological Society which has the power to removed chartered status. In contrast, the clients of counsellors exercise a much greater degree of control and counsellors are required to seek their consent. However, as a profession unregulated by statute, the client has less potential for an effective resolution of any grievance over a breach of this requirement.

Disclosures within HIV-related services

The advent of AIDS in the early 1980s prompted professions to review their policies over confidentiality for this area of work because of the associated amplification of contradictory pressures for heightened confidentiality and greater disclosure.

People affected by HIV were especially insistent on wanting high levels of confidentiality because of the social climate of moral panic and fear of infection. This created a significant force against general trends towards freer communications of confidences between professions. Equally there were pressures for greater openness by the public who wanted reassurance that they were being adequately protected from infection. Sometimes these demands went much further than a threatened loss of confidentiality. At the height of the moral panic, there were demands for the compulsory testing of everyone and enforced 'separate living' for those found to be HIV positive (Collier, 1987: 87). The decline of these views may be an indication of the extent to which service providers walked the tightrope of providing sufficient confidentiality to enable the treatment of people with HIV and a successful HIV prevention programme, whilst at the same time communicating enough information to the public to offer sufficient reassurance. Clinicians were under particular pressure and had the additional need to

provide for members of their own professions who became infected with HIV as well as protecting the public from any transmission of HIV during the course of their treatment.

General policy about confidentiality to HIV had been strongly influenced by the precedent of the National Health Services (Venereal Diseases) Regulations 1974 (S.1, 1974, No. 29 amended by s. 1 1982/288). This requires that a health authority, "shall take all the necessary steps to secure that any information capable of identifying an individual obtained by officers of the authority with respect to persons examined or treated for any sexually transmitted disease shall not be disclosed with two exceptions of notifying a medical practitioner or the employee of a medical practitioner working under his direction, or for the purpose of such treatment or prevention.

This had resulted in a series of statements with regard to confidentiality about HIV which would have implications for multidisciplinary team work. In medicine, the patient's right to refuse disclosure of HIV status to other health professionals, including GPs has been reasserted, even if this is at the expense of receiving optimum treatment (GMC, 1993a: 4). Both doctors and nurses are in receipt of guidance about how to respond to clinicians who are infected with HIV which also asserts their right to personal confidentiality unless their non-compliance with safety requirements compromises the protection of the public (GMC, 1993a: 2; UKCC, 1994: 5). The general tendency in published guidance has been to reduce the level of professional discretion over the management of threshold confidences in favour of a service-user's consent within clinical settings.

There have been two published references to differences in practice between the professions over HIV-related confidences. The first concerns the role of social workers within genito-urinary medicine (GUM) in a discussion document published by the Central Council for Education and Training in Social Work (CCETSW). Terry Thomas and others (1993: 30-1) emphasise the statutory requirement that the boundary between GUM and social services is observed and suggest that potential clients for the social workers

are informed about the different practices over confidentiality between GUM and social services where information is more freely circulated so that the patient can give informed consent to (or refuse) the referral. The second reference relates to the relationship between counsellors and clinicians based on the research reported in the previous section (Bond, 1991: 47-8). In this instance, it might have been expected that the clinical move towards a greater emphasis on a patient's explicit consent in HIV-related services might have eliminated differences in practice between the medico-clinical ethos and counselling. However the experience reported by HIV counsellors suggested that differences still remained. The reasons for this discrepancy were not explored in the earlier research, and, if they still applied, would be an important topic in this research.

Although not directly related to confidentiality, a comparable difficulty had arisen between doctors and nurses over requirements for informed consent for HIV-antibody testing. In medicine, the requirement for informed explicit consent prior to testing had been asserted (GMC, 1993a: s.13) but this requirement is qualified.

> Only in the most exceptional circumstances, where a test is imperative in order to secure the safety of persons and other than the patient, and where it is not possible for the prior consent of the patient to be obtained, can testing without explicit consent be justified.
>
> (s. 13)

Special provisions are also made for the testing of children where the process of parental consent might be distorted by the possibility of having been the source of infection. In these circumstances the doctor must decide in the best interests of the child patient (s. 14). In contrast the guidelines issued to nurses by the Registrar stating the position of the United Kingdom Central Council for Nursing, Midwifery and Health Visiting stated simply that 'Informed consent is regarded as essential prior to such testing' and stressed the nurse's potential liabilities if they personally take blood specimens or if they co-operate in obtaining such specimens without consent (UKCC, 1994: s. 16). The only exception that is envisaged is that it is in the patient's best interests and where it has not

been possible to obtain consent (s. 17) or in anonymous screening of residues of blood samples taken for other purposes (s. 18). These exceptions represent a more stringent set of requirements for nurses than doctors. Within any grievance procedure, it is usually easier to justify the protection of third parties than the best interests of a patient as grounds for overriding a requirement for explicit and informed consent by the patient.

It appeared that no specific guidance had been given to psychologists or counsellors by their respective professional bodies with regard to HIV-related information.

The analysis of published guidance to the relevant professions suggested that the differences between clinical professions and counselling would have narrowed but may not have been eliminated. The management of confidentiality by social services departments was quite distinctive and managed under a separate set of principles which were largely independent of the consent of the client or professional autonomy of the social worker.

Application for funded research

My application for funding to conduct this research contained a brief synopsis of the previous section in this chapter. The application to the Northern Regional Health Authority (shortly to become part of the Northern and Yorkshire NHS Executive) was specifically to conduct a follow-up study to the 1990 research project. The aim of the research was to discover how confidentiality about HIV was managed within multidisciplinary teams. This topic was of particular interest to the regional health authority because they wished to fund some developmental work on a topic which was viewed as increasingly sensitive in a shift towards community- based services. They hoped for a discussion document which would ensure an exchange of information about good practice within the teams and which would be useful for the training and induction of new staff in HIV-related services. My interest was multi-faceted and included:

(a) an opportunity to revisit an issue which was left unresolved in the earlier study concerning the differences in practice over confidentiality between clinicians and counsellors. Anecdotal evidence suggested that in some health authorities professional differences remained over confidentiality;

(b) the possibility of an in depth study of confidentiality which was not only a theme which pervaded HIV-related work but was also a recurrent issue in HIV-counselling specifically and more generally in counselling;

(c) the multidisciplinary focus of the study would provide a greater sense of the evolving meaning of 'counselling' in HIV counselling;

(d) the opportunity to examine the way professional ethics had been constructed within a defined location and period of time; and

(e) the opportunity to continue to refine a consultative methodology applied to descriptive ethical inquiry.

For all these reasons, the opportunity to research the question *'How is confidentiality about HIV managed within multidisciplinary teams?'* was both an attractive and exciting prospect and one which had the potential for enhancing services to people affected by HIV.

Once again, funded research was providing me with an opportunity to gain access to data which would not otherwise be available. The endorsement and active support of Robert McEwen as a senior administrator within the regional health authority seemed certain to ensure a higher level of willingness to participate than would have been the case had I been undertaking this research in a personal capacity or funded from outside the sphere of AIDS. The endorsement of a major funder and organiser of services seemed likely to counteract to a reasonable degree any reticence to participate arising from the sensitivity of the subject, for the proposed project had been scrutinised in advance by the regional

health authority which had also consulted a panel of eminent practitioners in the field. It also seemed probable that this might be a last opportunity to conduct this kind of research within a specific focus on HIV because of the impending removal of ring-fencing and the probability (which proved to be the actuality) that this would be the last allocation from ring- fenced money for HIV-related research. All these circumstances combined to make this an important opportunity which required the systematic consideration of a number of issues before I could bring the research to fruition. In particular the selection of research participants and a research methodology required particular attention. I will consider each of these in turn.

Selection of research participants

The research topic raised two immediate issues relating to the selection of a range of multidisciplinary teams to be studied and the selection of participants from within those teams. These issues related to geographical spread and the range of professional background of participants.

The funding required that the research be undertaken within the boundaries of the Northern Regional Health Authority which broadly covered the north of England from the Scottish Borders southwards to Kendal on the west coast and Teesside on the east coast. The major conurbations were Tyneside, Wearside, Teesside and Carlisle. One possibility would be to spread the study across the teams to be selected from a wide range of locations. However I decided against this. It seemed to increase the potential for informed dialogue within any consultative process if teams were selected who regularly interacted with each other. This approach might also be expected to benefit the research as a number of different accounts of the same issues or incidents could be collected, which would help to differentiate participants' perceptions. The quality of the research would be further enhanced by minimising the danger of a schism emerging between avowed and implemented ethics, that is a gap between what people say they do because

that is what they think that they ought to do and what they actually do (Silverman, 1997: 18) because of the cross checking between practitioners. Another reason for concentrating on a defined geographical area was the concentration of most of the region's specialist HIV-related services within a ten mile radius of Newcastle city centre, and as a consequence in an area of low incidence of HIV, most of the experience and expertise was concentrated within these teams. This does not mean that there were no other units and teams with substantial experience elsewhere in the region but they were more scattered and less likely to be working in regular contact with other teams in their area. Newcastle was at the hub of HIV-related services in the region and therefore more likely to be the point of referral for more complex and difficult issues which might also yield the most interesting ethical issues.

The choice of a geographical region which was the focal point of services made it much easier to ensure that all the major teams with significant commitment to HIV-related work were involved in the research. These included genito-urinary medicine (sometimes also referred to as sexually transmitted diseases), haematology (involved in the treatment of haemophilia), infectious diseases, alcohol and drugs dependency, medical social work and clinical psychology. All these services were predominantly hospital-based but with growing responsibilities for the provision of services in the community. In addition it seemed important to include a slowly growing number of community nurse specialists, HIV co-ordinators in social services, primary health care and voluntary (i.e. 'not-for-profit') organisations specialising or with extensive experience of HIV-related work. In total it was possible to identify and involve thirteen teams with particular responsibilities for aspects of HIV-related services.

The second issue concerned the range of professional backgrounds of participants. The research topic about confidentiality within multidisciplinary teams suggested the desirability of extending the range of participants beyond those who identified themselves

as HIV counsellors working within the ethics of the wider counselling movement so that a dialogue could take place between people with different professional roles and allegiances present within the multidisciplinary teams. Developments in the provision of HIV counselling in the interval between the earlier research and this phase also pointed in this direction. The vision of creating an integrated HIV counselling service providing a wide range of services, as indicated in diagram 4.12, and working within a narrow definition of counselling had not become a reality. Instead, HIV counselling was a role undertaken by people with a range of professional backgrounds and as a consequence often viewed as an inter-professional role to which individuals contributed different levels of skill and commitment. There were those for whom undertaking the role of HIV counselling was their major commitment and specialism, but they were largely confined to areas with a high incidence of HIV. In areas with a low incidence, like Tyneside, a commitment to working within a more narrowly defined approach to HIV counselling would usually arise because someone had already specialised in providing counselling or psycho-social support for a wide range of clients and transferred that way of working to HIV-related work. However, the attention to issues around the narrower and wider definitions of HIV counselling evident in the earlier research had also had some impact on the way that many providers of HIV-related services appeared to have incorporated a distinction between formal counselling and counselling skills in the way that they offered counselling. For example, a doctor or nurse working with someone requiring assistance with a difficult decision about her preferred course of treatment might well attempt to resolve this by an informal incorporation of counselling skills within the consultation but might alternatively set aside time to offer counselling on a more formal basis. The level of formality in terms of explicitly agreeing to offer time, attention, or respect to another person for the purpose of counselling would usually be sufficient to satisfy the narrower definition of counselling adopted by BAC (BAC, 1985). The kind of issues addressed in the context of HIV would usually include issues of consent, HIV education and prevention

as well as psycho-social support. In the context of HIV-related services, formal counselling was not only being provided by specialists in counselling but was also provided by specialists within other professions as a sub-role but not necessarily within the ethical principles adopted by national organisations like BAC with regard to confidentiality or supervision. This research was therefore taking place within a complex developmental stage with regard to the role of HIV counselling in which it was desirable to include participants primarily committed to working within the narrower definitions of HIV counselling as well as those who viewed HIV counselling as an inter-professional responsibility and formally adopted a counselling role occasionally within another professional role. This range of backgrounds gave the best prospects of maximising the inter-professional dialogue. This could be interpreted as a significant change in the professional orientation of participants with regard to counselling which would need to be kept in mind in making comparisons between this study and the previous one and in considering the implications of this phase of the research for the generic counselling movement. However, it would be misleading to exaggerate the implications of this difference because in the earlier research the clearer differentiation between counselling and counselling skills had not necessarily been achieved but was merely aspired to as a way of increasing the recognition of the contribution of HIV counselling and as a basis for arguing for the adequate training and supervision. The inclusion of five participants from the previous study in this research also meant that the basis for comparison was integrated, as far as possible, within the research participants. As in the previous research, the criteria for selection were theoretical rather than randomised or representative. The main difference within the selection process was that participants were pre-selected rather than self-selected.

The final selection of participants was based on devising a grid which plotted the professional background of potential participants known to the regional health authority against membership of interdisciplinary teams. This document has been omitted from

this account because it would be possible to deduce the identity of particular individuals especially from the smaller teams. Teams varied in size between 20 full-time staff and an unpaid co-ordinator supported by a few volunteers. However it is possible to indicate the range of professions spread across the teams in table 6.2. For completeness I have also indicated the gender of participants which were divided almost 50-50 between the sexes.

Table 6.2: Background of participants

Primary role	Number	Gender (Female)
Medic	6	1
Nurse	5½ [A]	4½
Health Adviser	2 [B]	1½
Social Worker	4½ [C]	4
Clinical Psychologist	3	1
Counsellor	1	1
Co-ordinator of Voluntary Sector Services	3 [D]	–
Total	25	13

Notes:

A. Includes one combined nurse/health adviser

B. Includes one nurse/health adviser and voluntary sector services co-ordinator/health adviser

C. Includes one social worker/voluntary sector service co- ordinator.

D. Includes two voluntary sector service co- ordinators who combine role with social work and health adviser respectively.

All split roles are counted as ½ and a single role as 1 unit to indicate the proportion of roles.

As a general principle I intended to interview at least two people from other than the smallest teams and at least three from the largest teams. The duplication of roles held by some individuals (see notes to table 6.2) meant that one individual could sometimes speak

from their experience of working in two teams. Some roles, like clinical psychology and social worker, could involve working within three or more of the relevant teams at any one time.

In practice, the selection procedure continued alongside the fieldwork. An initial selection accounted for about one third of participants considered likely to hold strategic positions within networks within and between teams. All participants were asked to suggest other people who might be involved in the research. Many of these suggestions coincided with selections which could well have been made in advance but this procedure was considered more consistent with the consultative ethos of the research. It was also valuable in confirming or contradicting my own impressions of existing lines of communication and did generate some valuable suggestions which would not have occurred to me.

During the selection procedure I primarily concentrated on the spread of professions and representation of teams rather than individual involvement in counselling because it was already known that all potential participants had experience of HIV counselling and were likely to have had experience of offering HIV counselling as a sub-role. It was only as the final choices were being made that I sought to ensure that participants would include some who worked within the narrower definitions of formal counselling. Seven participants held primary roles with a major commitment to delivering psycho-social therapy but might not necessarily identify themselves as a counsellor to clients (for example the social workers provided family and solution-focused therapy, and clinical psychologists who used a variety of therapies). One participant worked exclusively as a counsellor within a person- centred humanistic tradition but not exclusively with HIV-related problems. In terms of counselling-related training six participants held post-graduate qualifications in which therapy or counselling had been a component and one post-graduate qualification was exclusively in counselling. At least three participants

had received in excess of 100 hours training in counselling skills. About a third of the participants (8½/25) held professional roles within the psycho-social therapeutic field.

Research methodology

One of the aims was to refine, or at least to try some modifications to, a consultative methodology. The selection of participants clarified some of the issues that would need to be taken into account. These were: (a) maintaining a meaningful level of consultation with a group of participants, many of whom were self-evidently already facing considerable demands on their time as senior members of clinical teams; (b) managing the increased sensitivity of the research theme as I was researching the very strategy by which professionals managed personally sensitive information about clients and the research required a degree of frankness between each other which might have been precluded by inter-professional sensitivities; (c) identifying a methodology for data interpretation which was consistent with a consultative research process but capable of assisting with the analysis of 'slippery' and ambiguous information, and (d) defining the relationship between the consultative process and researcher-led analysis. Each of these aspects of the research required separate consideration.

(a) Maximising the participant involvement in the consultative methodology

Although it seemed less of an issue for participants than for myself as researcher, I had experienced a strong sense of responsibility for sustaining the consultative process in the previous research. After the initial consultations the responsibility for encouraging communications between participants appeared increasingly to rest on myself. Some of this was unavoidable. It was appropriate that I initiated correspondence, telephone calls and circulation of drafts but the collective experience of the consultative process was becoming progressively invisible to many participants. Metaphorically, I was becoming the hub at a centre of many

spokes and increasingly holding the knowledge that defined the rim of the metaphorical wheel. Ideally, it would be better to start and end the consultative process with a collective experience but realistically, the level of funding available would not permit this. Instead, I decided that on this occasion I would work progressively from the hub towards identifying the rim which would become apparent to all in a culminating consultation. This seemed to satisfy several needs simultaneously. It would follow a research programme in which the research process was more closely co-ordinated with the sense of progressive discovery which would be tested collectively and hence might be better at motivating participation within the consultative process. It also eased potential issues around confidentiality by enabling me to meet people individually (or in pairs where there were close working relationships) which seemed a more likely way of discovering and responding to any inter-professional, inter-team and inter-personal sensitivities that might exist. It seemed self-evidently self-defeating to expect these to be disclosed within the group settings which may be the source of issues requiring confidentiality.

The overall structure of the research was therefore designed to work progressively from fairly open-ended interviews, through a phase of analysis largely conducted by myself but in consultation with participants by phone and correspondence, followed by a presentation of preliminary findings to all (or at least most) participants with an opportunity for group discussion at that presentation and individual feedback before the final report was written.

The broad themes for the initial interviews were given to participants about 7-10 days in advance. (Other research experience in clinical areas had suggested that this was an optimum time span. Longer notice would fall outside the short- term focus of this setting. Much shorter notice ran the risk of being swamped by the

emphasis on responding to urgent client needs as they arose on a day to day basis.)

After an initial phone call to establish someone's willingness to participate, a letter was sent out setting out the contents of the interview in the following terms:

> **"Management of Confidentiality for HIV-related Work in Inter-disciplinary Settings**
>
> Thank you for offering to participate in this research. I would be grateful to hear your views about the management of confidentiality concerning the communication of:
>
> 1. personally sensitive information about patients between team members, e.g. when is consent to disclosure assumed and/or when is a patient's permission required? Do all professions manage confidential communications in the same way?
>
> 2. HIV-related information when referrals are made to other units, e.g. automatic disclosure of HIV status and method of infection or criteria for deciding what should be disclosed?
>
> 3. information about patient services provided to other organisations who fund or oversee services, e.g. does accountability and auditing raise issues about confidentiality and can these be resolved?
>
> 4. disclosing a patient's HIV status to other people, perhaps sexual partner, to prevent HIV infection, e.g. criteria used for making decision and how this is accomplished? Who is responsible for the decision?
>
> 5. suggestions about other people to be interviewed.
>
> The examples provided in topics 1-4 are only suggestions to help provide a focus. If you consider that there are other issues which are more important, I would wish to concentrate on these."

Initially, I envisaged that I would accumulate the experience of conducting all the interviews before communicating any preliminary findings in order to ensure equality of opportunity to influence the consultative process. In practice, I found this to be too great a constraint on the consultative process and tended to create an ethos of research-led questioning rather than each interview being a consultation in its own right. After the fifth interview I adjusted my interviews to share tentative views about patterns that seemed to be emerging. This adjustment benefited both the consultative dynamic and the quality of analysis. As a safeguard against any particular viewpoint dominating at a particularly formative moment in the research, I attempted to ensure that the sequence of interviews moved between different professions and teams.

The interviews were taped and transcribed in order to provide a more direct access to the content of the interviews than had been possible in the earlier research.

(b) Managing the sensitivity of the research subject

If the research structure and process worked well, I could reasonably anticipate that, in addition to all the potential sensitivities considered in Chapter 3, I would hold information given in confidence which could be used to inform the research but not disclosed directly to other participants. This realisation caused me to reflect on the management of confidentiality within the research process. From these reflections and discussions with participants often focusing on specific examples I came to realise that breaches of confidentiality are not all of the same kind and fall into the different categories outlined in Chapter 3 (see pages 65-6). I became particularly aware how there were parallels within this phase of the research between the challenge experienced by practitioners in protecting individual confidences from service users within an area with a low incidence of HIV, and the challenge for myself in protecting confidences given in a context where all the participants had some knowledge of each other. In both circumstances, the risk of deductive disclosure required constant vigilance in combination with sound and routinised procedures. Within the research this often meant that I had to be careful to seek explicit consent to published quotations and to circulate drafts which lacked the required consent 'blacked out'. Avoidance of deductive disclosure created quite an administrative burden.

(c) Matching the method of analysis with a consultative process.

In 'new paradigm research' the research process and the collective interaction of the participants are largely one and the same in a joint process of discovery of inter-subjectivity which is most evident in human inquiry groups (West, 1996). The consultative process disaggregates the fusion of research and subjects into

co-researchers sufficiently to raise the issue of who chooses the interpretative methodology and how is this communicated to other participants where the consultative process is unable to unravel the material because of its complexity or other constraints. This became a real issue in this research because of the slipperiness and fluidity of the subject matter. Discussions throughout the consultative process were probably the most important way of testing and validating ideas generated by participants and myself. Outside the consultation process, I considered that I needed some form of additional conceptual framework to assist in the development of categories and interpretations because I was gaining a sense of the emerging overall patterns ahead of the collective experience of participants. It seemed to me that the adopted methodology needed to be easily communicable to participants; evenhanded between participants (that is not unduly favouring one approach to reality, or knowledge) over another; and one which would facilitate dialogue between participants. The choice was tested in discussion with participants and progressively worked through content analysis, grounded theory to analytic induction.

Analytic induction was not an obvious choice, partially because it is omitted from most current texts on qualitative research methodology (Patton, 1990; Crabtree and Miller, 1992; Moss, 1992; McCleod, 1994; Miles and Huberman, 1994; Mason, 1996) and receives only scant mention in others (Bryman, 1988: 81-3). Another major disadvantage relates to the reason why it has fallen into disuse. Analytical induction is strongly associated with the scientifically-oriented phase of sociology characterised by George Herbert Mead and Florian Znaniecki within the Chicago School. It was devised as a method for the exhaustive examination of cases in order to prove universal and causal generalisations (Manning, 1991: 408). This claim that 'all A is B' is based upon a procedure of progressively refining a statement of principle until no exception can be found. One exception is sufficient

to refute the principle. As the method is a combination of induction and falsification, the approach falls within the paradigmatic category of postpositivism as classified by Guba and Lincoln (1994: 110). It has been criticised from within that paradigm by Glaser and Strauss (1965: 5) as an example of sociologists who 'overemphasize rigorous testing of hypothesis and de-emphasize the discovery of what concepts and hypotheses are relevant for the substantive area being researched'. Irving Goffman (1971: xvi) also dismissed the scientific claims of postpositivist scientists by suggesting that, 'A sort of sympathetic magic seems to be involved, the assumption being that if you go through the motions attributable to science then science will result. But it hasn't.' Peter K. Manning (1991), in a seminal essay on analytic induction, points out the inadequacy of the method to justify claims to 'understand, predict and control events' not least because the analysis invariably retrospective and untested prospectively (p. 416) and elicits 'meaning' rather than 'causality' (p. 418). Nonetheless Manning is positive about its being 'a viable source of data and concepts' (p. 423) and its capacity for constraining the researcher to attend to concept development and revision of those concepts (p. 419), qualities which take on added value within a consultative process.

As I reflected on Manning's analysis, it became apparent that, freed from its origins in scientifically oriented sociology, analytic induction was a method that could be redeployed into a number of different contexts and that some of its distinctive procedures could take on a different purpose within participative research. The characteristic emphasis on progressively reformulating rebuttable principles until all exceptions are incorporated, had originally been devised as a falsifiability test to validate scientific generalisation. However, within consultative research the progressive modification of principles provided a readily comprehensible and demonstrable explanation of the process of analysis which might otherwise have remained invisible to participants. It was a process which had the potential for

considerable levels of transparency between researcher and participant. Invitations to participants to consider whether the latest formulation of the encompassing principle included their experience and opinions helped to focus the dialogue and to draw in voices which might otherwise have been excluded. In other words, a procedure devised for scientific falsifiability is transformed into a strategy for maximising communication between participants. It also had other potential benefits. When the researcher is working away from participants, the search for exceptions becomes a commitment to attempting to hear all the contributions to the dialogue taking place within the research process. When working with ambiguous subjects like the ethics of confidentiality, the dual attention to the entirety of the information provided by participants and a commitment to accounting for all the variations within it provides a useful discipline in creating a comprehensive description, which (following Geertz, 1973; 1983) must inevitably incorporate analysis and interpretation in its presentation. Sometimes, it may be necessary for the researcher to make imaginative leaps beyond the explicit contributions of participants in order to create a conceptual framework to account for apparent diversity (see chapter 7) or to infer what is otherwise implicit (see chapters 8-10). Analytic induction provides both a justification for such imaginative leaps in order to be comprehensive as well as an inbuilt caution against over- extending the imaginative leap beyond that necessary to incorporate exceptions and accomplishing the research task. When applied to participative research, these leaps in imaginative conceptualisation will not only be critically scrutinised by participants, but may also be valued as catalytic and developmental in the construction of a new collective conceptualisation to have emerged from a process of dialogue.

Understanding the practical management of confidentiality as the basis of ethical mapping

One of the particular challenges in researching confidentiality is the ambiguity of the language. A participant in the research with experience of working across several teams in both the statutory and voluntary sector observed:

> A great deal is just implied ... at times there is a danger of there being an acknowledgement that there is a shared view of confidentiality between agencies, and in fact I think that is far from the truth. It does seem to have different meanings for different people, even within the same profession, I think, people can hold onto different strands of confidentiality.

This inherent ambiguity in the terminology challenged the consultative process by requiring a constant attention to the meaning of terms which might at first sight seem clear but by the context and intent of the user moved between ethical systems. For example, two phrases '*need to know*' and the service user's '*best interests*' were used frequently but clearly carried significantly different ethical valences depending on whether the service user or provider determined the application of the criteria. Actual examples derived from personal experience were often the best way of clarifying the meaning conveyed by the user of the term. As a researcher I was seemingly constantly mentally noting 'who holds the power' but to be continually asking questions of this kind might have turned the consultation into interrogation.

The practical focus of the consultations served both the needs of the participants in terms of the potential usefulness of the research outcome and the researcher in terms of clarification and generating interesting examples from which an ethical position might be induced. The next chapter concentrates on the practical management of confidentiality and establishes the working context from which the conceptualisation of confidentiality set out in the following chapters has emerged.

Chapter 7

Practical strategies for managing confidentiality in multidisciplinary teams

Practical strategies for managing confidentiality became an obvious starting point for explicating the associated ethical conceptualisations. The discussions with participants in the research usually reflected their practical interest in the management of confidentiality. As practitioners, they tended to describe their ethical stances in terms of its practical implications and with minimal encouragement would provide examples, suitably anonymised to protect the identity of any client and also, on occasions, the identity of colleagues. The contents of this chapter have been the subject of a full consultation process into which induction analysis was incorporated. As it was particularly useful in developing a description of the management of confidentiality within interdisciplinary teams, I will defer discussion of its application until later in the chapter. In comparison, the practical strategies for disclosures outside the team were relatively straight forward and make a useful starting point, as well as providing insight into the circumstances within which the multidisciplinary teams were working.

Communications outside the team

There was agreement between professions and all teams about the procedures for communications outside teams whether these were to individuals or other teams: the informed consent of a person affected by HIV was required. This would usually be explicit consent regardless of the kind of agency being contacted, usually as a referral to obtain services for someone.

> If I'm making a referral for anyone with HIV, we would have their permission ... So if I'm referring them to [a named consultant in another team], we would have their permission. If I'm referring them to housing, we would have their permission.

Medical referrals would almost always be made on the basis of informed consent.

> But I think that if you are referring outside the team, then it has to be done with the patient's explicit or implicit agreement, 'You know, we need to refer you for your hernia operation. You realise that I will need to raise the risk of transmissible viral infection with the surgeon.'

The main exception to making referrals with consent related to people who were too ill or who lacked the capacity to consent for other reasons. Provided the person concerned was capable of consent, any objection to the referral would be respected, even if this diminished the quality or level of care provided.

A manager in a voluntary organisation viewed the process of obtaining a consent to making a referral as a two stage process:

> In terms of information going out to external agencies, we would say to the client, "We feel that you're at a stage now that you need to access perhaps these range of services .... Do you feel that that is the case? " and have a discussion .... Once we agree ... we would then go on to the next level and say, "Right, this means that in order for us to effectively access those services, there is going to be a need to divulge information. This is the sort of information that we will divulge, if you agree". We will also put fences around the boundaries of how much further we can go if we need to go, without referring back. And that is constantly negotiated with the client.

It was considered good practice, in most circumstances, to restrict what was disclosed to the information necessary for the provision of the required service. In most situations, the transmission route by which someone had become infected with HIV would be considered irrelevant and withheld. In many circumstances a distinction could be made between medical and personal information which needed to be disclosed. However, participants reported referrals which indicated the existence of a wide range of practice from minimal disclosure (below that required for the service requested) to unnecessary total disclosure of everything known to the referrer. Neither of these extremes were considered appropriate. The former could involve the person concerned in unnecessarily having to duplicate giving information, whereas the latter was considered a breach of confidence. These examples of 'inappropriate practice' were attributed to agencies outside the network of teams included in this research and were probably associated with agencies who were new to this field of work.

Disclosure of HIV status for medical referrals

It was not always considered appropriate to disclose HIV status for non-medical referrals. This contrasted with the much stronger requirement to disclose HIV status for medical referrals because this was considered important information in deciding the most suitable treatment, and for staff safety. There was disagreement about this latter point with some people arguing that universal precautions against transmission were the most appropriate and sufficient protection for staff. In order to obtain clarification, I contacted three consultants who were recommended as having treated people with HIV and being sympathetic to their needs. Two were surgeons and one was an oncologist. They were asked about the disclosure of HIV status when people were being referred to them. They were unanimous in stating that HIV status should be disclosed as it would affect decisions about the optimum treatment and any assessment of potential complications to be avoided. Risk to staff was also a factor in some invasive procedures. These risks could be more effectively minimised in the light of definite knowledge. A co-ordinator of a voluntary organisation described the reluctant acceptance of a client that it would be necessary to disclose HIV status for these kinds of referrals.

> He went to his GP for referral and basically his GP said that we would have to tell any doctor that he was HIV because of the risk of operation and stuff like that .. and he was very annoyed at that but if you're seeking services, maybe you have to accept some disclosure.

A consultant considered that this was an issue of building trust:

> We need to use the services of a lot of specialist departments ranging from ENT, general surgery, gynaecology and I have not come across refusal to provide the basic information. But I think you've got to develop an atmosphere of confidence on the part of the patient group that there is not unnecessary dissemination of irrelevant information.

Notification of general practitioners

In most medical referrals, the patient's GP would, as a matter of routine, be informed of any diagnosis and treatment. In the case of HIV infection, this routine disclosure may be a cause of concern to patients receiving hospital based treatments because of the

transfer of information about their status into their community, even on a confidential basis. Some may have specific concerns about the attitude of the GP, other members of their family being treated by the same GP, relatives on the practice staff or uncertainty about the level of confidentiality expected of non-clinical staff living in the same community as the patient. For all these reasons, it was accepted that patients had an ultimate veto to informing their GP when seeking HIV-related services. Nonetheless, if it was possible to find a way round a patient's concerns, it was considered desirable that a patient should have a GP who was fully informed about his or her health status. In order to achieve this end, patients could be informed about sympathetic GPs in their area. Alternatively, telephone communications to a GP or writing to his home (with his consent) had been used to by-pass relatives and acquaintances of the patient working in the practice. The desirability of having a fully informed GP increased when someone became symptomatic but was generally considered sufficiently desirable to justify discussion with the patient regardless of state of health and attempting to find ways of informing a GP which were acceptable to patients.

The notification of GPs became more complex if a patient was referred for medical treatment from one HIV-related service to another. Generally consultants have a duty to inform GPs. In the context of receiving referrals of HIV positive patients, the three consultants involved in this study emphasised the benefits to the patient of having a GP who is fully informed of a patient's health status. Whilst they would respect a patient's wishes, this raised the question of how a restriction on disclosure should be communicated when making the referral. Oral communications were considered appropriate in some circumstances but written communications marked on the outside 'Personal and Confidential' were strongly recommended to ensure that it was opened by the addressee only and that a record of the patient's wishes existed.

Referral to previously unknown providers of HIV-related services

The increasing number of people with HIV infection and the changing circumstances of those who have developed health problems means that there is a continual need to draw in new service providers who are previously unknown to the provider. This complicates the process of obtaining an informed consent to the referral. The referrer needs to know about the protection of confidentiality and the kinds of services available in order to be able to pass on this information to the person being considered for referral. This is the basic information upon which he or she will make informed consent or refusal of the service. Without well-founded reassurance about confidentiality, many people affected by HIV would prefer to continue without a service even if the need was urgent. One strategy was widely used to overcome this problem.

Preliminary discussion on no-name basis

Anonymous exploratory discussions about potential referrals were typical. A voluntary organisation co-ordinator stated:

> I guess the kinds of things I would do initially would be to phone up the agency I'm referring to on a no name basis and say, well in this hypothetical situation with person X, what kind of service do you think you can provide ... I might be asking, you know, whether their staff have had specific training around HIV, confidentiality and so on and so forth ... I would then go back to the client and say, 'Well, you know, this is what they say they can offer, this is the level of information that they require, this is how much extra benefit that will be involved in passing on the HIV status ...' I guess its a sort of cost-benefit analysis really ... But I think the very crucial thing is the informed consent of the client.

Discussions with schools were regarded as particularly sensitive and usually forbidden by parents. The following was given as an example of the effectiveness of preliminary discussions on a 'no-name' basis in the most sensitive of circumstances:

> I mean most people would say they didn't want the information given to the school about their child. One mother said that she would allow that information to be given if I would get a solemn promise from the headmaster that it would only be him and one other person that would have that information ... So what I did was actually rang up and said to the headmaster that, you know, I have a child who's a pupil in that school. I have some information about the child which is medical information, and I've got permission to give it to him only and one other person if he felt that was necessary. Could I, you know, have any kind of assurance that if this information was given, that that would be where it would be retained? And he said, 'I would be glad to give you that in writing actually' ... I went to the school and I talked

> to him, and of course he did know what I was going to say ... But I do know for a fact that there was only him and the child's main form teacher [who knew], and it worked very, very well, extremely well. The child got what he needed from the school, and the school were prepared when the child died, which was another important aspect. And that confidentiality was absolutely maintained.

Anonymous preliminary discussions would usually take place with a senior member of staff, e.g. a consultant, or senior manager in a local authority or voluntary sector organisation or a person with an HIV designated role such as a co-ordinator of HIV services. The seniority of the person consulted was viewed as an essential assurance that what was promised with regard to confidentiality would be delivered. It also minimised the need for additional people to know the confidential information. Typically an agency's usual reception or intake procedures for non HIV-related problems were bypassed and became involved, subsequently, only if this was an essential part of the service.

Provision of community nursing services

There was some evidence that good practice over restricting referrals to those supported with informed consent might have the unintentional effect of delaying the delivery of community nursing services until an unnecessarily late stage in someone's illness. A nurse specialist advocated the inclusion of a community specialist within the regional centre so that patients could learn about the available services at an earlier stage. She explained:

> About eighteen months ago, I received a phone call from a Community Staff Nurse asking if it was OK to supply a urinal to an HIV-positive patient.
>
> I visited the home to make an assessment .... I found an extremely distressed and exhausted mother, whose son had only limited mobility, had chronic diarrhoea and incontinence, and was very ill and emaciated. There had been no input from Community Services as they were unaware of our existence, and the patient and his family were unaware of what could be offered.
>
> Within a few days the situation was under control by supplying aids such as commode, incontinence pads, wheelchair, etc.. Visiting by the Specialist Community Nurse, initially twice daily, offered support and security to the mother and patient and enabled an anticipation of needs and prevention of future problems.
>
> We actually carried on nursing that chap for a further nine months until he died at home in his own bed, which is what he wanted. In the terminal stages District Nurses were visiting six times over 24 hours. His mother kept stating 'If only I'd known this service was available earlier'. She wrote to the Health Authority speaking of this wonderful service that had enabled her son to die at home.

I feel this is an example of what actually happens because of secrecy rather than confidentiality. It is only natural that those infected should be hesitant about who should know their diagnosis, and indeed this is a very important area for post-test counselling and the patient may need some guidance. Lay-people will be unaware of the roles of health-workers.

The situation could be improved by including the identified Community Specialist Nurse on the multi-disciplinary team in the early days of contact with the Regional Centre. Their additional community training, experience and local networking skills will offer a different perception to those trained and working only in the acute sector.

There needs to be a more healthy balance so that provision of care does not become control of care. It is important for improved HIV care provision that both community and the acute sector constantly evaluate their practice and improve upon it. Only meeting patients in terminal stages means lost opportunities for an improved quality of life at home.

Hospital nursing staff were aware of the difficulties of obtaining consent at a sufficiently early stage:

> So unfortunately, you know, there are times when I've wished a nurse to be far more involved at an earlier stage, but I haven't been able to get that consent from the person and if you can't do that, what do you do?

The involvement of community specialists in hospital based teams, bound by confidentiality to the team, was suggested as a way of increasing patient trust and knowledge about the services available to them. Joint training events involving hospital and community based staff were also suggested as ways of enhancing a mutual knowledge of what each service could provide.

This contrast of views between hospital- and community-based nursing staff was a serious matter of professional, but seemingly not personal, conflict. Both people spoke passionately about the implications for their role and the implications for their capacity to deliver the best possible service. The hospital-based nurse with responsibility for liaison with other services was strongly influenced by her need to retain the trust of her patients if she was to help them return to the community. The community-based specialist was aware of the potential for unnecessary suffering that could be the price of decisions based on social vulnerability and nervousness about the trustworthiness of staff who were as yet unknown to patients. This conflict of views appeared to represent a major boundary line in service delivery which had both practical and analytical significance. It suggested both staff and patients viewed hospital- and community- based services as significantly

different and that this might be a possible basis for understanding the differences over the management of confidentiality within teams working in these types of agencies.

Interdisciplinary communication within teams

In many ways, it was not surprising to discover a high degree of consensus about the ethical basis for managing disclosures across the boundaries of multidisciplinary teams. Agreement on this issue was viewed as fundamental both to maintaining a team identity and to explaining a critical boundary in the management of confidentiality to patients and clients. The ethical divergences identified in the literature search (see pages 129-37) seemed much more likely to create significant differences in practice with regard to disclosures made within multidisciplinary teams. However, from relatively early in the interview process, it became apparent that there were differences in practice but that these did not correspond to divergences between professions but related to other, as yet unidentified factors. From interview six onwards I was progressively reformulating and testing rebuttable principles to account for the divergences and this analytic process was presented for comment at a subsequent collective consultation. The following account of how the rebuttable principles were progressively modified represents a gradual abandonment of accounting for variations according to professional allegiances and a search for a more meaningful representation. The process was complicated because participants often had only partial knowledge of the basis for disclosure within teams of which they were not a member but also drew attention to exceptions within their own team.

The process started with:

1. ***Rebuttable principle 1: Variations in the disclosure of confidential information within multidisciplinary teams are attributed to professional differences which correspond to the relevant published ethical principles.***

   As a number of participants questioned or indicated doubts about the adequacy of their relevant professional guidelines and some followed the approach of other professions, this principle was revised.

2. ***Rebuttable principle 2: Variation in the disclosure of confidential information within multidisciplinary teams are attributed to individual modifications and elaborations of the relevant published ethical guidelines.***

   This principle was closer to what was being communicated but seemed to suggest a more individualistic approach than was evident. It also missed the basis around which some common patterns within teams might be organised.

3. ***Rebuttable principle 3: Variations in the disclosure of confidential information within multidisciplinary teams related to the composition of the team in terms of professional mix.***

   Comments on this tended to support the view that the characteristic professional mix within a team was significant in understanding divergences in practice over confidentiality but was not the critical issue. For example, contrary to the literature review (see reference to Thomas, Noone and Rowbotham, 1993 on page 135), special provisions had been made within social services for social workers working with people with HIV to conform to the higher standards of confidentiality associated with genito-urinary medicine.

4. ***Rebuttable hypothesis 4: Variations in the disclosure of confidential information within multidisciplinary teams related to the context of service delivery and***

especially whether services were delivered within an agency-based or community-based setting.

This was significantly closer to the experience of participants but drew attention to exceptions, especially teams delivering community-based services who adopted an agency-based strategy for managing disclosures of confidential information within the team. There were also exceptions within teams so that a liaison person between agency and community-based services might not fit the general pattern of communication within the team. Consideration of these exceptions produced a final version of the principle which was accepted as accounting for the diversity of practice at a collective consultation.

Final principle: Two broad patterns for the management of confidentiality within multidisciplinary teams have been identified as agency-based and core-group to which most team members would adhere, although variations within teams do occur to allow for the application of professional judgment in exceptional circumstances or to enable team members responsible for liaison to work across the two systems.

This final version was considered precise enough to form a conceptual basis for organising the detailed description of the two systems, which follows, as well as encompassing known exceptions and variations within each system.

A critical factor which appeared to distinguish different approaches taken within teams was the sense of heightened vulnerability of people with HIV who were living in the community. For example, although hospitals could not be assumed to be wholly free of prejudice, any inadvertent or deliberate disclosures of someone's HIV status would be likely to have less serious repercussions and could, if necessary, be challenged under hospital and professional guidelines. In other words the practical consequences of any adverse consequences aroused by any internal breach of confidentiality in hospital was relatively circumscribed in comparison to the community where the outer limits of the

expression of adverse reactions were defined by the criminal law and required the co-operation and adequate resourcing of the police in order to make these effective. Dissemination of someone's HIV status in the community could have dire consequences.

Two co-ordinators in the voluntary sector provided examples of the dangers experienced by people with HIV unless they are protected by confidentiality from public prejudice and animosity:

> (a) We've had clients that have had houses burned down. We've had one who was beaten up when it was overheard in a chemists queue, that the prescription was for HIV. The chemist refused to dispense medication, and it was overheard in the queue, and the person left the shop and he was followed by others and beaten up.
>
> (b) I'm certainly aware of situations where people have been subjects of serious harassment from neighbours, people have had to move away from the area due to graffiti written on doors, bricks through windows, kids getting harassed at school ...

Awareness of this vulnerability of people with HIV had resulted in a fairly uniform pattern of management of confidentiality when delivering services in the client's home or making use of local community services such as day centres. As there was no established terminology for describing this system of managing confidentiality, they have been labelled as 'core-group confidentiality' which applied to community-based services, as distinct from 'agency-based confidentiality' which included hospital and some community-based agencies.

For ease of comparison key features of each system are listed in the same order and have the same identifier. After setting out key features of each system I shall present a comparison in diagrammatic form.

Core-group confidentiality

The typical circumstances in which core-group confidentiality would arise were related to the provision of a complex 'care package' responding to the social, physical or psychological needs of someone living in the community. A stereotypical situation would be someone whose health was deteriorating to the point that they needed a combination of assistance with domestic chores, some nursing care, and adaptations to the home to

assist with mobility and a warden alarm system to call for assistance in emergency. Medical care would usually be provided by a local general practitioner supported by regular out-patient appointments. The total 'care package' would usually be co- ordinated by either a community nurse specialist or a social services co-ordinator or both depending on the balance of needs of the person with HIV. These co-ordinators often combined a basic counselling role with holding an overview of the services being provided. Specialist counselling services for psychotherapeutic issues might form part of the total 'care package' to be provided by a psychologist or counsellor from the voluntary sector.

In these circumstances, core-group confidentiality was characterised by:

(a) Free exchange of confidential information about someone affected by HIV would be restricted to a few core staff within a team providing services to a particular person. The core-group might include the person(s) responsible for co-ordinating or managing the service provision and the key workers with most frequent contact with the person concerned. The other team members would have access to such information only as needed to deliver specific services.

(b) Teams were transitory often with unique combinations of team members brought together to provide services for a specific person affected by HIV as determined by the requirements of individually designed care packages.

(c) The main focus of the management of confidentiality was to prevent leakage of information into the community in the context of services often being provided in the person's own home which increased both the risk of accidental disclosures and the seriousness of any breach of confidence to the person concerned. Unlike in areas with a higher rate of HIV infection, where there can be anonymity through numbers, in areas with low rates of infection the risk of deductive disclosure was a particular concern.

(d) Agreements about confidentiality permitted free disclosure of confidential information within the core team only. It was expected that these communications would occur rather than be a theoretical possibility. The importance of obtaining explicit agreement based on informed consent was stressed.

> I think it is important that you recognise that people have choices really, about who knows what information about them, and that assumed consent shouldn't be taken for granted, really ... I always discuss with the patient what it is we're looking at setting up and who needs really to know what within that team.

This meant that explicit consent would be sought in situations where consent might be assumed to exist within an agency-based team.

> My own feeling is that I probably bend over backwards in consulting at all stages because, even if ... if the source is critically ill and can't be bothered, and is too weary, or recovering from surgery ... you have to say to the person, "Look, I know you're not very well today, and you haven't much strength, but I just want to tell you ... " If you know them well, "Would you like me to have a word with so and so to see if perhaps we could do this". That person knows what's being planned and where they're at and their centrality is acknowledged ... even if the source is very ill or anything else, you know they've been consulted and people know what's happening.

(e) Limitations on who could be told and what could be disclosed within the team, especially outside the core-group, based on consultations with the person with HIV, were routine because of the emphasis on working within explicit informed consent.

(f) The person receiving the services was responsible for deciding which categories of information about health status and personal circumstances should be communicated to whom.

(g) The person receiving the service was helped to make decisions about the management of confidentiality based on his or her own assessment of *'need to know'* and *'best interests'*. The person concerned was encouraged to take as much responsibility as he or she wanted over the management of confidentiality.

> The need to know basis, I think, in my head is designed around the negotiation between myself and the client.

(h) Members of core-group teams could expect to have different roles in different care packages and therefore varying levels of access to confidential information about the person receiving a service. In one case, someone might be a core-group member

with full access to information, but have only a peripheral role in another care package so that quite basic information is not disclosed to him or her. A diagnosis of serious HIV-related illness may be concealed by descriptions such as 'serious illness', or 'terminal illness'. Some roles do not usually require knowledge of HIV status so that this information is disguised or withheld, e.g. someone fitting a special aid or alarm system in someone's home.

(i) All the examples of this system of managing confidentiality were involved in providing community based services usually involving staff from more than one agency. Sometimes this was the preferred system within a single agency such as a voluntary organisation or a primary health care team with the result that staff within an agency had different levels of access to information about someone affected by HIV.

Agency-based team confidentiality

Agency-based team services were most likely to arise when someone who was HIV positive was experiencing multiple problems which typically might involve health care from several staff and psycho-social support. Clients or patients seeking services by appointment whilst living at home would not necessarily be regarded as immediately requiring the services of a team although this was viewed as a theoretical possibility depending on the level and combination of needs. For example, someone who was asymptomatic HIV positive attending for routine medical check-ups by a specialist in infectious diseases would be unlikely to see any other member of the team or even to be discussed within the team unless some complicating factor arose which required the involvement of others. Nonetheless, the consequences of HIV are unpredictable so most team-members were mindful of the possibility of needing to involve other team members some time in the future. In contrast, in-patient care would invariably involve teams of staff drawn from different specialisms and often rotating on a shift basis.

In these circumstances agency-based team confidentiality was characterised by:

(a) All members of the team having a theoretical access to confidential information about someone affected by HIV.

(b) The members of the team being clearly identifiable by all participants so that there was a clear distinction between who was within the team and who was not. Membership was usually described in terms of people providing face to face services to patients or clients. The support staff providing secretarial, administrative and reception services were included within the team by implication or explicitly when they provided services exclusively to that team. However, this meant that some support staff were viewed as having an ambiguous relationship with a team.

(c) The main focus of the management of confidentiality was to prevent leaks outside the team. Close and co-operative working relationships between genito-urinary medicine, infectious diseases, and alcohol and drug related services were frequently reported. However, these were each seen as distinct teams for the purposes of confidential communications with different procedures for communications within the team and between the teams. This restraint was not because of any mistrust of the management of confidentiality by other teams but was an expression of the concern to keep the trust that someone affected by HIV has already placed within the team. Trust was viewed as hard won and easily lost. Although only genito-urinary medicine was legally bound to maintain a high level of confidentiality by the National Health Service (Venereal Diseases) Regulations 1974 (S.1 1974, No. 29), all other units including social services and voluntary organisations had adopted this as their standard. The confidence of staff in their ability to maintain confidential information within the team had a considerable influence on their readiness to share information with colleagues of the same and other disciplines.

(d) Practice varied over the levels of expectation that confidentiality existed between the team and client rather than individual worker and client. These differences in

expectation produced different practice at the point of entry into receiving a service from a team and the extent to which a client would be informed about the degree to which he could influence the disclosure of confidential information within the team. Three variations were identifiable:

(i) a non-negotiable and explicit prior condition of receiving a service – for example, in-patient care in an alcohol and drug treatment centre where this condition applied to everyone regardless of HIV status;

(ii) an implicit assumption which could be challenged and negotiated by individual patients/clients – for example, out- patient clinic offering regular screening to asymptomatic people with HIV;

(iii) an explicit and negotiable agreement about communications within teams – for example, counselling sessions about the impact of HIV on personal relationships or other topics not directly related to the primary function of the team so that this arrangement would be more likely to arise in haematology and infectious diseases units than those working with drug dependency where personal relationships are viewed as fundamental to the work of the unit.

Someone receiving a service under the terms of (i) and (iii) would be clear about the nature of the confidentiality on offer because the topic was raised routinely as part of the induction to receiving a service. In contrast, someone receiving a service within (ii) would be much less clear about the management of confidentiality between team members.

(e) Variations in the practice of the induction of clients to services broadly correspond with differences in how confidentiality was managed within teams. However, the exercise of professional judgment could produce a subsidiary set of variations as exceptions to the general protocol over confidentiality.

Two factors were explicitly mentioned in examples where team members had consciously decided to withhold information from colleagues in contravention of the usual practice.

(i) Material of a personal nature to the client with no direct relevance to the work of the team: A doctor offered the following observation:

> If it was something that seemed of no particular relevance but the patient just wanted to raise it with me. It may be in the form of a confession or some way of alleviating some anxiety in that individual. That's fine. That would be treated in confidence, but I think it would depend on judgment. That would be an unusual situation ...

(ii) Material likely to adversely affect relations between the client and other team members which is of no direct relevance to the work of the team: Examples of this included a veneriologist withholding a previous history of sexual diseases; a psychologist retaining information about previous mental illness; and a social worker not disclosing that a client was being investigated for child abuse.

In each case the withheld information was considered significant to the person holding it, but of a kind which justified deliberate withholding.

(f) No general distinction could be made between health and personal information with regard to confidential disclosures within the team. Both kinds of information were considered necessary to ensure that the person was treated as a whole person in medical settings. For example, both a consultant in infectious diseases and a social worker in that team spoke strongly in favour of the need to communicate about both medical and social factors between professions in order to ensure a holistic approach to care. In alcohol and drug-related work, both personal and medical information were equally important to the provision of the best quality of service for the patient. The recognition of the benefits to patients in sharing information across professional boundaries was an important motivation to inter-disciplinary working.

(g) Actual access to information about someone affected by HIV by other team members was not automatic in the teams considered in this study. Too free a communication of information between team members was considered undesirable by some interviewees.

> I am quite concerned that in some units I have visited that there is an automatic disclosure to other members of the team, and I don't think that's thought through.

A number of criteria were offered for deciding when it is appropriate to disclose confidential information between team-members. *'Need to know'* was considered important. This was usually defined as a need to know in terms of providing services to the person concerned but, especially, might include a consultation about how to resolve an ethical dilemma over such matters as confidentiality, a decision which would usually involve consultations with senior team members. *'Best interests'* referred to the interests of the person affected by HIV rather than the recipient of the information or the team. A restriction on subsequent disclosures remaining within the *'purpose for which the original disclosure was made'* was also referred to but this appeared to be of limited significance in the context of interdisciplinary communications within teams as all disclosures were usually viewed as seeking the services of that team. Routine decisions about disclosures on the basis of *'need to know'* and the person's *'best interests'* were often made in consultation with the person concerned, although not always. The existence of a prior agreement about confidentiality being restricted to the team did not automatically exclude the person concerned from being consulted about disclosures between team members. The decision about when to disclose and what to disclose was referred to as an 'art rather than a science' by several participants. In addition to the criteria already mentioned, other factors were evident or expressed as illustrations of these criteria.

The *health status* of someone affected by HIV would be an important factor in determining 'best interests' and who would 'need to know'. For example someone

who is asymptomatic and living an independent life and attending infrequent outpatient appointments to monitor health status would usually be consulted before disclosures were made to team members other than those already directly involved in providing services. This contrasted with someone who had multiple medical and social needs receiving residential care where the exchange of information between team members was essential to providing continuity of care between shifts and to co-ordinate different kinds of services. In these circumstances, a patient's consent to disclosure would be more likely to be assumed. Similarly, staff access to records varied according to the person's perceived need for services.

> It is unlikely that anybody who is not clinically dealing with that person will ever access the case file. So if a client is an out-patient client, they will tend to be seen by certain individuals within this team but the information about their status will not be available to the rest of us. That will not be discussed ... However, if somebody comes into a kind of broader clinical setting, like if they're admitted as a resident, then all the nurse team that is dealing with that client would know about that, and that would be discussed quite freely at clinical team meetings, [and at] the review. So it will depend on the sphere within which the client's operating basically.

The *sensitivity* of the information to the person concerned would also be taken into account in deciding who should know and the circumstances in which it was appropriate to make disclosures. Ward rounds, team meetings, case conferences were all mentioned as being inappropriate for the disclosure of some information.

> Its very interesting, you see, because sometimes ... if people think something is truly secret, then they'll have conversations with one of the team in private and it won't ever get discussed at the multi-disciplinary team ... So clearly people don't think that that multi-disciplinary team ... is ... appropriate for some bits of information, and partly that might be just because of its size.

The *practicalities* of limited time and the availability of the person concerned were also mentioned as factors in deciding the extent to which patients or clients were consulted about disclosures between members of a team.

(h) Staff who had multiple roles distinguished between seeing people as individuals who had been referred to them as personal patients or clients independent of the team, and those people who were receiving services from the team. They actively

monitored the boundaries between these different aspects of their work. When seeing people referred for a personal service, their consent would be sought before disclosures to other team members. Thus the transfer from an individual to team based service was treated rather like a referral to another agency (see next section).

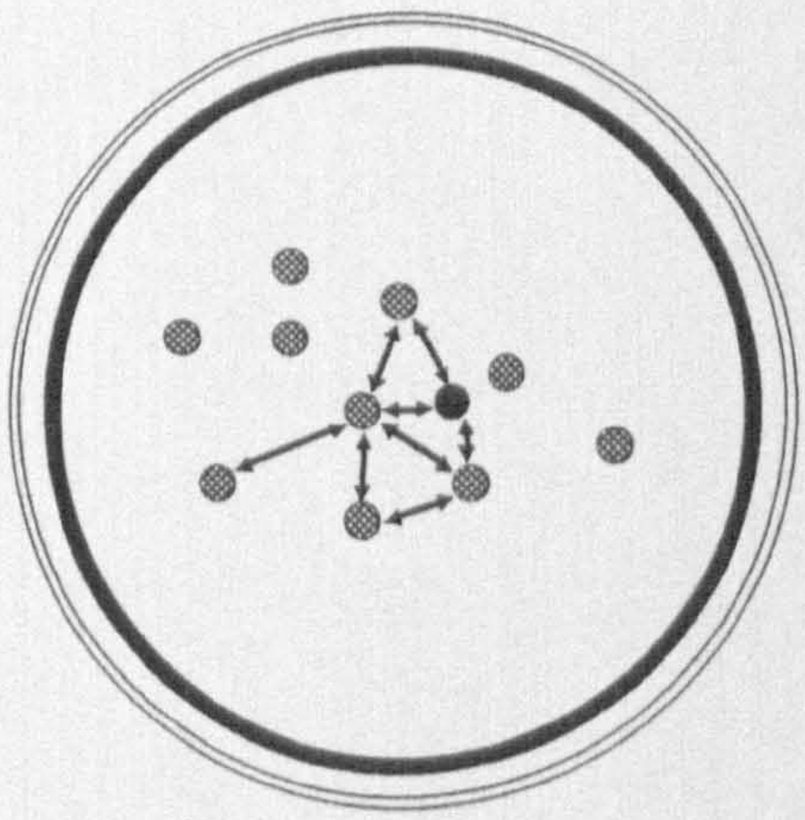
(i) Examples of this system of managing interdisciplinary communications within teams were found within hospital based teams, some primary health care teams and some voluntary organisations.

Relationship between the two systems

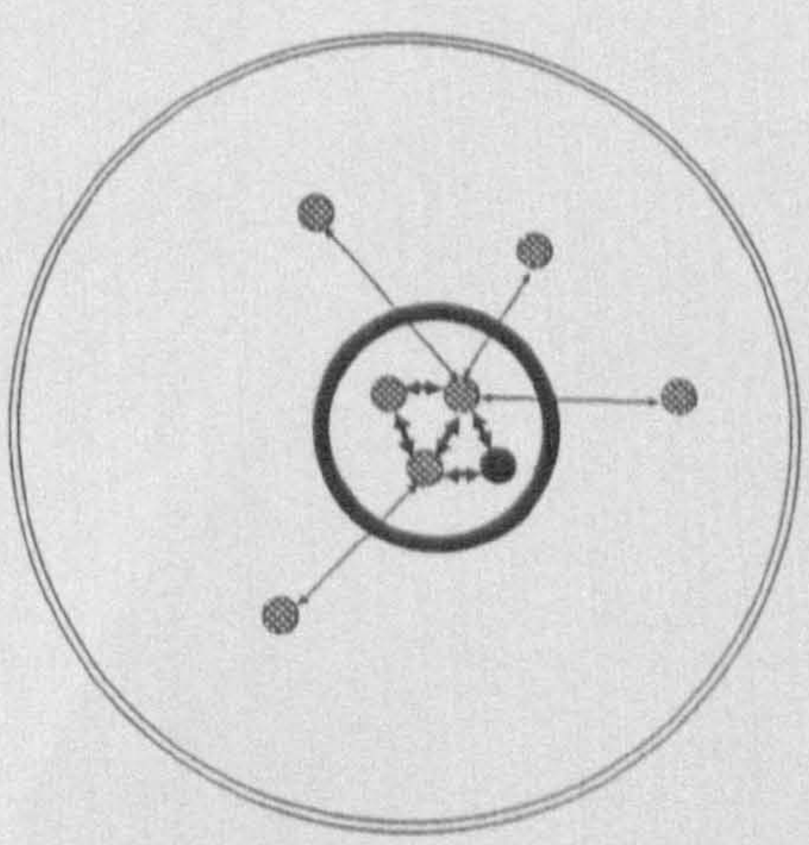
The two systems of confidentiality produced different patterns of disclosure of confidences about clients within teams. These have been represented diagrammatically – see diagram 7.1. The most noticeable feature is the position of the boundary of free-exchange of information relative to other service providers.

Diagram 7.1: Two systems for the management of confidentiality

Agency-based team confidentiality



Core-group confidentiality



Key

- Patient/Client
- Individual team members
- Boundary for free exchange of confidential information
- Boundary of Team
- Full disclosure possible
- Limited disclosure

The key elements of the two systems have also been represented in diagram 7.2.

Diagram 7.2: Relationship between the two systems

Core group confidentiality	*Agency-based team confidentiality*
Characterised by: 1. Active involvement of client in agreement about who knows what information.	Characterised by: 1. Agreement with client that confidentiality is maintained within team/agency. *Variations:* Agreement was implicit/explicit and strict prior conditions/negotiable.
2. Full information about client's circumstances was restricted to a core group of service co-ordinators, and/or managers, and/or key workers.	2. All staff have theoretical access to information. *Variations:* dissemination of confidential information varied according to practical realities, and interpretations of 'need to know' and in client's 'best interests'. Criteria might be decided by professional judgment or client choice.
3. Selected information was disclosed to particular service providers on a strict interpretation of 'need to know' and 'best interests' in consultation with client.	
4. The main focus of the management of confidentiality is to prevent leaks to the community even if this restricted disclosure between team members.	4. The main focus of the management of confidentiality is to prevent leaks outside the team.

The main feature which becomes apparent in the condensation of data essential to the construction of a diagram (such as diagrams 7.1 and 7.2) is the range of variation evident within agency-based team confidentiality in comparison to core-group confidentiality. These variations could simply be regarded as indicative of an area of evolving or unresolved practice which had not yet progressed to a more orderly resolution. However, there seemed to be sound reasons for questioning whether this was an adequate explanation of whether some other significant constructions of meaning and intention were present which were capable of clearer articulation.

The dynamic influences in the construction of confidentiality

It is apparent from the discussion so far that confidentiality is a fluid construction capable of many variations in its constituent elements so that it is adapted to social context and the aims of confidante and recipient of information. The sensitivity of confidential information is such that its management has the capability of enhancing or undermining the acceptability of a service to potential users. This realisation pervaded the reasoning of all the research participants. The particular sensitivities around HIV amplify a tendency towards creating certainty and predictability in how confidentiality is managed with regard to referrals outside the team. It seemed reasonable to ask why such considerations had not created a comparable predictability and certainty within teams. The complexity of the interaction between the practical requirements of specific roles and functions in combination with personal preference was a frequently offered reason. Notwithstanding the plausibility of this explanation, I became interested in two aspects which were referred to by some participants.

The integration of social workers and counsellors within teams

The literature search suggested that the boundary between the type of confidentiality required for sexually transmitted diseases and the less well defined protection of confidentiality within social services agencies should be managed by seeking the client's informed consent (see pages 130-33). One of the consequences of this approach would have been to exclude social workers from the routine functioning of agency-based inter-disciplinary confidentiality. They would, in effect, be treated as if they were external referrals. A corollary of this approach might well have been a refusal by people affected by HIV to accept assistance of social services. These disadvantages were avoided within the teams involved in this research by creating a protective cloak of confidentiality about HIV-related services within social services with the consequence that social workers could be more easily integrated within the teams as fully functioning members.

The combined weight of the desirability of integrating some social workers within teams and the sensitivities of potential clients was sufficient for the social services department to work creatively with its statutory requirements.

The literature search suggested that the greater emphasis on informed client consent within HIV-related services would reduce the distance between medico-clinical and counselling approaches to confidentiality (see page 137). This was generally viewed by participants to be true of the integration of formal counselling within specific services. However, this observation must be qualified by the observation that there were differences in views about the ethical significance of informed consent between counsellors and across all the professional roles so the overall picture was more akin to the 'dovetailing' of mutually complimentary views between individual team members rather than a uniformity of views within any single profession or between professions. The tensions evident in the management of confidentiality in the earlier research were much less apparent in this research and less likely to be attributed to differences between professional groups.

The relative moral standing of client groups

One potentially major issue remained unresolved because of the limitations of resources and time to resolve a considerable diversity of opinion and perceptions within the consultative process. Some participants and myself wondered whether the moral standing of different client groups *vis-a-vis* each other influenced the extent to which agency based team confidentiality took into account client views. For example it might be anticipated that the non-negotiable prior condition of confidentiality between the client and the entire team would be more likely to be applied to clients perceived as having low moral standing in comparison to clients of higher moral standing and who were identified with a more trustworthy social group. Stereotypically, haemophiliacs and children with HIV might be viewed as 'innocents'; gay men as winning moral respect by their collective responses

to HIV; heterosexuals of either sex might be judged by the transmission route; and, injecting drug users would be viewed as having low moral standing because of illegality, dependency undermining their perceived autonomy and the characteristically 'chaotic' or, less pejoratively, 'unpredictable' nature of their use of services. Although some participants disclosed some form of preference for working with one client group over others, this preference was not expressed in moral terms. Some participants, especially among those primarily working with people with HIV in combination with drug dependency, thought that stereotypical moral evaluation was a factor which needed to be countered if their clients were to regain greater control over their lives. They reasoned that any moral evaluation by social group could become self-fulfilling and create a sense in clients of being 'damned if they progress and damned if they don't'. This preference for treating clients as individuals sometimes co-existed uneasily with agency policies which tended to apply to all clients, regardless of individual characteristics. The multiplicity of factors other than moral-standing which influenced the development of agency policy meant that it proved impossible to identify general patterns which accounted for all the exceptions. These other factors included:

(a) client independence/dependency on services associated with physical and/or mental health and maturity in terms of age and experience;

(b) the practicalities of the kind of flow of information required by the team to perform its primary task;

(c) established customs and practice developed prior to the advent of HIV.

The most that could be concluded was that stereotypical moral standing was not perceived as a general issue and that many factors influenced whether client-team confidentiality was a strict requirement or negotiable within agency-based systems of confidentiality.

The search for an ethical framework

The consultative process had progressively helped to identify and describe how the main elements of the management of confidentiality about HIV was managed within multidisciplinary teams. Professional allegiances were largely abandoned in favour of team identity and patterns of confidentiality determined by the context of the work and its aims. However the clearer these configurations became, the more I wanted to explore whether there was another way of viewing all the interview material which could cast a clearer light on the existence of differences of opinion about the ethics of confidentiality within reasonably coherent strategies for the management of team confidentiality. The next chapter is an account of the search and discovery of differences in the conceptualisations of the ethical challenges created by confidentiality.

Chapter 8

The ethical underpinning of confidentiality

The practical management strategies described in the previous chapter reveal a diversity of practice according to the context in which the HIV counsellor is working. Context appeared to be a major factor in the choices made by counsellors and other providers of services but was almost certainly not the only factor. During the interviews I usually experienced a sense of the integrity of the person I was interviewing and a coherence between my sense of that person and their opinions which extended throughout the interview and continued throughout the consultation process. As I reflected on this I started to question whether it was possible to explore this coherence in more precise terms and in particular to identify some of the ethical concepts which underpinned this felt sense of consistency and integrity.

Answering this question posed different methodological challenges from the previous chapter. The practicalities of the management of confidentiality were explicit throughout the interviews. In contrast, any underpinning ethical framework tended to be implicit and appeared difficult for interviewees to express directly. Interviewees were generally able and willing to talk about their specific approach to confidentiality in terms of value statements which tended to be brief, abstract, and expressed in general terms. Examples of this kind of response are 'being trustworthy is important to me', 'my belief is giving people the opportunity to take responsibility for their own lives', 'personal and professional integrity' and 'balancing between someone's privacy and their need for the best possible care'. These value statements represented an ethical orientation, a priority around which ethical decisions were organised, but did not explain why one value was chosen in preference to another; or, more importantly, explain how the value came to be expressed in one practical approach to confidentiality in preference to any other. This

contrasted with the confidence and detail in which the practical implementation of confidentiality was discussed. It was as though the conceptual linkage between values and practicalities existed at an unspoken level perhaps in the form of what has been categorised as 'tacit knowledge' (Polanyi, 1958; 1967). When considering ethical problems and dilemmas, it is the unspoken nature of 'tacit knowledge' that is arguably most problematic because it eludes scrutiny.

In this chapter, I seek to transform 'tacit knowledge' into 'explicit knowledge' in order that such knowledge can be more directly accessible to HIV counsellors and that the 'felt-sense' of ethical coherence is susceptible to scrutiny and justification. If this can be achieved, it would represent a qualitative improvement in the construction of professional ethics for HIV counsellors. Firstly, the development of an explicit ethical framework increases the quality of the involvement of counsellors in the development of ethics. The creation of a language and terminology is a fundamental tool in the active construction and control of any knowledge (Bernstein, 1971: 47). Secondly, the credibility of any ethic which is capable of explanation and analysis is enhanced. From some viewpoints of ethics, the ability to combine reflection with practical action is fundamental to a credible ethic. From this perspective, a combination of values and knowledge (conceptual framework) with action (practical implementation) are essential. The absence of one or more of these elements is a significant weakness. Jean Paul Sartre (1969) considers these issues in terms of 'bad faith'. If reflection and action are compartmentalised from each other the resultant ethic is 'bad faith' because it involves a pretence of a 'value-free' or purely technical ethic. This is not the position of the HIV counsellors under consideration because they are clear about their values and action but less articulate about the knowledge (i.e. reasoning) which in combination with values amounts to reflection. As a consequence, they only partially satisfy the criteria established by Sartre as indications of 'good faith'. As the participants were selected on the basis of their sound reputation in their field of work rather than as moral philosophers, it is reasonable to expect an

emphasis on the practical rather than ethical reasoning but if it turned out that it was impossible to discern rationale(s) within the tacit reasoning between values and action this could represent a normative weakness which, in the terminology of Freire (1972: 75-6), would constitute a bias towards 'activism' (which is action without reflection as opposed to 'verbalism' which is reflection without action). The notion of the fusion of reflection and action in ethics has a long history in moral philosophy and has been referred to as 'praxis', a concept which can be traced back to Aristotle. Although I intend to remain within the parameters of descriptive ethical inquiry which, I would argue, is of academic interest in its own right, it is worth highlighting that the findings may and probably will have normative implications.

Although, it is generally accurate to state that participants left the conceptual framework between values and actions largely unexplained, there were some references made by some counsellors to written authorities to explain or justify a particular viewpoint. These included guidelines which usually contained a mixture of public policy and law relevant to a particular professional role, for example, the UKCC guidance on confidentiality (UKCC, 1987) or in-house documents and policy statements developed by voluntary organisations. Without exception there were no references to ethical systems described by moral philosophers or ethical systems in the terminology of moral philosophy. There were a few references to practical ethics written specifically for professionals, for example Bloch and Chodoff (1991) *Psychiatric Ethics*, and my previous publications for HIV counsellors (Bond, 1991), and for counsellors in general (Bond, 1993). If it had been available prior to the research I anticipate that some would have made reference to a forthcoming publication, *Building Confidence*, by the Standing Conference on Drugs and Alcohol (SCODA, 1994) as some had participated in a consultation during its preparation. These references indicate the sources of ethical guidelines used by participants. However, the relatively low number of references of this kind suggested that published codes, guidelines and texts were of limited use and, at best, constituted a

source of knowledge which appeared to be of limited relevance to the specific situations encountered by HIV counsellors. There were no references of any kind which suggested that the framework for someone's ethical stance was encapsulated in an existing publication or that any existing publication provided an adequate terminology for discussing these issues. Some participants expressly hoped that this research would contribute towards the on-going development of a terminology and conceptual framework for the management of confidentiality about HIV within this network of practitioners. The contents of this chapter constitute an extension of this process beyond the funded work of the project and therefore are not included within the official report (Bond, 1995).

The method of analysis and interpretation

One of the reasons why it has not been possible to include the contents of the next three chapters within the published finding of this research is the amount of time required to conduct this kind of analysis in comparison to the time limited basis of the funding and the natural life of any consultation process. As with the previous research the dialogue with at least some of the participants has extended beyond the funded life of the research. Their persistence has been invaluable. My own persistence was due to a strong sense that in the interview transcripts, fieldnotes and subsequent consultations, that I was in possession of a possibly unique opportunity within my lifetime to build on the focused experience of HIV counsellors and other HIV-related roles which might advance the understanding of both HIV counselling and interprofessional ethics. The abolition of ring fenced funding meant any opportunity for further studies in this field was unlikely to occur.

Conducting this phase of the research outside the full-blown consultation phase progressively required a shift in emphasis from consultation to periods when I relied on systematic induction as the basis for formulating new concepts and ideas, followed by bursts of consultation with available participants. As will become apparent, in the final

phase I became more creative in generating interpretative possibilities but in each case tested these interpretations against rebuttable principles which were progressively refined by comparison with the totality of the recorded data, in which I periodically immersed myself, and discussion with participants whenever the opportunity arose.

The emphasis in conducting the descriptive ethical inquiry remained as focused as possible on the context and time of the original consultative process. Subsequent changes and developments are not taken into account. However, insights developed with the benefit of hindsight have not been eliminated or ignored.

An example of how the process of analytic induction was applied to this stage of the research may be informative. The starting point was usually a rough definition of the problem under construction. In this example, it was 'the identification of the ethical framework(s) underpinning the management of confidentiality'. The first hypothesis was usually phrased to account for a substantial part of the data within a secure interpretation of that data, but phrased to exaggerate its interpretative relevance to the rest of the data. I found that this approach, both in the consultations and when working on my own, would direct attention towards exceptions which were required to refine the original hypothesis. With each subsequent adjustment, the reformulated principle was becoming closer to the material it interpreted and so the discrepancies and exaggeration diminished. Bryman (1988: 83) describes induction analysis 'as a highly stringent approach to analysis of data in that the occurrence of a single negative case is sufficient to send the researcher off to reformulate the problem'. One of the consequences of this rigour in this research was the tension between the necessity to generate new categories in order to accommodate exceptions and the opposing pressure to avoid an excessive number of categories by redefining the category to contain a greater range or depth. The apparent complexity of the material existed in tension with the simplification required for meaningful

consultations and ease of applicability in the working environment. The working out of this tension is evident in the development of the following rebuttable principles:

1. ***Rebuttable principle: The ethical management of confidentiality about HIV is exclusively based upon respect for the principles of autonomy.***

   This principle was selected as a starting point because it was so readily apparent in the interview material. At least three interviewees, two health advisors and one nurse specialist worked exclusively within an ethic founded on client consent. A substantial majority of interviewees also recounted examples of regarding client consent as paramount. As will become apparent in the description of the ethical system of autonomy, the question arose about whether being willing to overrule client consent in order to protect others from infection constituted a subdivision within the ethic of autonomy or a new category of ethic. The answer to this question determined whether a new category of ethics was required. I based the categorisation on whether the focus of ethical concern remained with the autonomy of the client or represented a refocusing on some other feature of the client's interests or on a point of reference other than the client.

   The protection of others from HIV infection is clearly one of the most acute dilemmas for workers in this field. It became a defining or critical instance around which other ethics became apparent. There were those who took the view that it was in the best interests (or conversely least harmful) to actively intervene even if that meant breaking confidentiality and thus overriding the autonomous wishes of the person concerned. Some believed that they were acting in the best interests of the client. Others acted out of a sense of responsibility to the wider community. These differences in points of reference established a basis for identifying two other ethical systems, respectively individual and community welfare.

Other critical instances were examined around suicidal intent, attitudes to enforced tests or treatment, counselling children, the mentally ill and physically dependent. In each case the examples could be contained within the three ethical systems in which the following ethical commitments were paramount:

1. autonomy
2. individual welfare
3. community welfare.

As a consequence the first principle was revised to accommodate these divergences.

2. ***Rebuttable principle: The ethical management of confidentiality is exclusively based upon any of three ethical systems, namely autonomy, individual welfare and community welfare.***

This adjustment to the principle accommodated a large part of the identifiable ethical thinking explicit or implicit in the resolution of ethical dilemmas. However, it is one of the principles of inductive analysis, that the principle should be modified each time when even a single incompatibility is discovered. Closer examination of some of the critical instances identified that there were a relatively small number of situations where the ethical commitment was focused on the trust in the relationship between counsellor and client. Initially it had been easy to lose these examples within the autonomy category because of the attention given to the client views but the terminology of negotiation rather than consent, attention to honouring trust and a focus on the relationship were all indicative of a shift in perspective which I labelled 'fidelity'. The principle was revised again to accommodate this fourth ethical system.

3. ***Rebuttable principle: The ethical management of confidentiality is founded exclusively on any one of four ethical systems which prioritise respect for***

individual autonomy, promoting individual/client welfare, maintaining good faith between service provider and recipient or promoting the welfare of the community.

This restatement of the principle appears to be comprehensive in that all the ethical frameworks are accounted for. No-one has been excluded from consideration. There are no further ethical systems implied within the data that I could detect. However, the principle as stated does not capture the extent to which any individual may resolve different ethical dilemmas by reference to more than one ethical system. There are a small number of ethical purists who appear to confine themselves totally to one ethic but they are exceptional and were occasionally criticised by others who adopted a more eclectic approach as creating problems for themselves. The principle also fails to capture the ambiguity of some practical strategies which might be compatible to more than one ethical system. For example, an emphasis on the desirability of individual consent was compatible with all four systems but had different status within the systems. It was paramount in an ethic of autonomy, and important but not paramount in ethics of individual or community welfare. In an ethic of fidelity, client consent was necessary but not sufficient because the ethical focus is on a mutuality of ethical responsibility between service provider and client and thus better described in terms of agreement.

A final version of the principle was produced in order to capture these complexities and subtleties in the relationship between the different ethical systems.

Final principle: *The management of confidentiality about HIV was best explained by adherence to one or more ethical systems founded on the principles of autonomy, individual welfare, community welfare or fidelity respectively. Some practitioners took a purist adherence to a single ethical system. However, it was commonplace for individuals to move between these different ethical systems according to specific*

circumstances relating to the client and the setting in which the service was being provided. Some ethical principles in the management of confidentiality were ambiguous and spanned one or more ethical system within which they may serve different purposes or hold a different ethical priority.

A careful and systematic re-reading of all the transcripts of the interviews generated no further discrepancies between the principle and data. The principle achieved a high level of support from those participants who I was still able to consult.

The distribution of examples of the ethical systems could be plotted diagrammatically.

Table 8.1: Distribution of examples by ethical system

Interviewee	Ethical System				
	Autonomy (A)	Individual welfare (B)	Community welfare (C)	Fidelity (D)	Combinations
1		2	5	1	
2	6				
3*	1	3	3	1	
4	2	1			2 (BD; BD)
5	2				
6	1	1	1		
7*	2	7	1		2 (ABC; ABC)
8	7	2	1		1 (BD)
9	3				
10	4				
11	1	4			
12	3	1			
13	2	1	1		
14	3	1		1	
15	4	1			
16	1				
17	3		1		
18	1				
19	1		2	1	
20		1		1	
21	1	4	1		
22	3	2		1	
23	4				
Totals	56	31	16	6	5

* Interview with two interviewees simultaneously.

Table 8.1 records the distribution of examples of the different ethical systems across the interviews. The distribution indicated the predominance of an ethic of autonomy amongst the participants in comparison to other ethical systems. It is also apparent that interviews

were variable in how much information they revealed about the ethical orientation of the interviewer. Sometimes this was due to a lack of clarity or completeness in the interview material due to either the participant or researcher. More typically, it was due to the subject matter raised by the interviewee within the loosely structured interview format. Many issues and dilemmas which concerned interviewees were equally applicable to all the four ethical systems. For example, recurrent concerns about avoiding deductive disclosure in an area of low incidence of HIV, the trend away from hospital-based to community care, changes to the funding arrangements for HIV-related work and the desirability of consultative and complaints procedures are arguably equally applicable to all four ethical systems and thus do not form the basis for discriminating between ethical frameworks.

A small number of examples were particularly informative. There were thirteen instances of the interviewees referring to ethical conflicts in terms ascribed to two or more ethical systems. Eight of these were resolved by interviewees in favour of a distinct ethical orientation (6 autonomy; 1 individual welfare; and 1 community welfare) and are included within the figures for those systems. Some of these will be referred to later as being particularly informative of the elements within ethical dilemmas and relationships between systems. Five were resolved in ways which were compatible with two or three systems. For example, it was possible to seek and obtain consent to something which the counsellor considered to be in both the client's and community's best interests, e.g. training in safer sex. Again they provide interesting examples which have informed the development of descriptions of the different ethical systems.

From this analysis, it is possible to develop more complete descriptions of each of the ethical systems which is the subject of the next chapter.

Chapter 9

Ethical frameworks explicated

Four ethical frameworks, identified by a combination of inductive analysis and checked by follow-up consultations, will be described. A composite depiction of each one has been constructed by combining individual contributions from participants. Whenever possible I have included passages from the interview transcriptions. These have been chosen as representative of an aspect of thinking or practice associated with a particular ethical framework.

Out of respect for participant anonymity which was promised at the outset of this research I have stripped the quotations of personal identifiers and randomised gender references by the toss of a coin. Throughout most of the analytical procedure, each quotation was coded so that it could be relocated and reviewed in context within the transcripts. These codes have been removed in the final drafting phase in order to minimise the risk of deductive disclosure.

Autonomy

The value statements most strongly associated with an ethic of autonomy emphasised 'client choice', 'informed consent', 'control over own life', or the 'patient's wishes'. Underpinning these non-specific assertions of values is a general and paramount commitment to enhancing and maintaining the capacity of clients to control their own lives in their own way. For the interviewee this was frequently indicated by an explicit commitment to seek the client's wishes and to consider themselves bound by those wishes.

> I think it is important that you recognise that people have choices really, about who knows what information about them, and that assumed consent shouldn't be taken for granted.

> Making contracts with people. I don't know whether its a sign of old age, but I am very much into contracts with people. I think it ... makes the work with clients very focused and

> actually brings more out of clients ... I really feel that it is important to go to the source [i.e. client] and not assume anything.

This emphasis on explicit consent precludes duplicity.

> ... and one thing we certainly would never do is go behind peoples' backs and provide information without the person knowing ... its something that we certainly would not do, and we won't. And I think that may limit our funding.

The level of formality with which the client's wishes are accorded varied. For most, an oral affirmation of their wishes seemed sufficient. Some referred to making a note in official records. In one of the above examples the term 'contract' was used with the implication that the client held the power to opt in or out and to contribute to the contractual terms.

Respect for a client's wishes extended over a wide range of issues:

(a) Explicitly obtaining consent to communications within teams was characteristic of an ethic of autonomy.

> The usual framework is when somebody comes to see you as an individual and wishes to discuss something which they regard as sensitive and specific to themselves and don't want you to divulge it to anybody else. In those cases, of course, you have to be guided entirely by the patient and it would be quite wrong to divulge that information to anybody else.

The phrase 'need to know' is a client-determined criterion within the ethic of autonomy.

> ... I always discuss with the patient what it is we're looking at setting up and who really needs to know what within that team. And I always, if I feel that the team need to know the diagnosis, I always get the consent of the person first, and discuss why I think they should know.

> ... but the need to know basis, I think, in my head is designed around the negotiation between myself and the client. So if somebody comes to me and says, I need ... care at home, and we would discuss, well okay that might mean fifteen different people in your house in any one week. That's fifteen people to know your status who might let it drop ... but in terms of looking after you ... it would be better perhaps if they

> knew because of getting you to the right bit of the hospital at the right time if you needed to.

(b) Informed consent was paramount within an ethic of autonomy with regard to testing, treatment, and the client's right to refuse treatment.

> ... And within HIV testing, of course, you're raising the advantages and disadvantages of testing and being impartial, completely impartial so that they would make their own decision.

or financial support,

> ... And of course, sometimes you have patients who do not want to be tested after counselling, and you know very well that they may be at risk, and in that case all I can do is to go along with what the patient wants, you can't force them into being tested ... [even though in haemophilia there are] quite sizable compensation funds that the government has made available ... So people could lose out on benefits by not being tested.

Client consent to or refusal of treatment was touched upon as an issue associated with the management of confidentiality. An ethic of autonomy would imply a commitment to respecting a client's wishes not only over whether or not to receive treatment but also the associated communications.

(c) It is usual practice for the providers of hospital based services, especially medics, to make automatic communications with the general practitioner which raised particular issues for medics committed to individual autonomy. There were different ways of resolving a potential conflict between professional norms and an ethic of autonomy. One interviewee considered the issue to be straight forwardly a matter of client/patient consent.

> Most of our cohort of clients ... [have] given permission to communicate with other health care physicians. There are obviously the handful who do not permit us to communicate with general practitioners altogether, and that, therefore, is clearly identified whenever letters are written to the referring surgeon that no information is passed onto their health care physician. I mean, if people do not permit us to write to health care physicians, to their general practitioners, it is clearly identified.

Another medic working with a different client group took a different viewpoint and achieved what he believed to be in the best interests of the patient by forward planning and offering the ethical dilemma at a point when the patients could make autonomous choices.

> ... from a medical point of view ... confidentiality should be straight up. So I tell them, if they're negative, I prefer to tell their GP, but if they're negative I'm happy to cope with that [i.e. a refusal of consent to inform the GP]. If they're positive I do want their GP to be informed. If they don't want their GP [informed], if they think they're unsympathetic, I ask them would they consider changing to a GP before we take the test. So I really go into that before I take the test and I haven't had a problem with it. They've all agreed to tell their GP [at] once, if they are positive ... I think the most important thing is to deal with it before you take the test. If you take it and then you have to deal with it and they say, 'I don't want my GP to know', I think you're in a terrible ethical dilemma.

(d) Clients expressing serious suicidal intentions constitute a particularly acute ethical dilemma for counsellors, which can be resolved in different ways according to the ethical viewpoint of the counsellor. A declaration of suicidal intent constitutes a critical incident which differentiates between ethical frameworks which prioritise either the client's autonomy or the professional's commitment to the preservation of life in the interests of the patient (see pages 203-4). Suicidal intent was a recurrent topic in the interviews often raised by the interviewee spontaneously, but if this did not happen I raised it as a topic to gain a sense of the ethical position of the interviewee on this topic as a reference point for understanding other dilemmas which might be more ambiguous.

> [It is important] to actually find out how serious that [suicidal] intention is, and then to work from there ... discussing what the circumstances around that are, how clearly someone has thought out how they're going to do it, whether they've thought about it before, whether they've attempted it before, looking into all the surrounding issues, and then discussing how then to carry forward from that including involving other people ... out of specialty, such as psychiatric staff ... And so far I haven't had anyone, nor have my colleagues, who has said, 'No, you can't communicate that any further' ... It has always been that that has been brought into the conversation ... because there has been some desire for something to be done ... on one occasion the psychiatrist came .... [and after seeing the patient] ... came out saying, yes, you're quite right, she is suicidal and she's going home. That was her choice. I haven't seen her since. I don't have any knowledge that she did carry out her threats ...

Iee: ... All I can give is a personal view that, I think ... it comes back to the sort of difference between, I guess, myself and others, about the nature of suicide and ... [what] suicide means mentally ... and its an abnormality of mind, and it is not something that you could actually stand back and say 'this is not a rational decision by this person'. I think there are circumstances where people can make decisions about that, and I guess its about making a judgment over what criteria they are using and whether they are capable of making that decision in the circumstances. There may be occasions when ... take the individual who is terminally ill ...

Ier: So you'd feel able to discuss it with them, but suppose they still insisted, and said, yes, I've thought about that, I don't want a hospice, I want to die at home in bed in my own time.

Iee: Personally, I would be glad to respect that.

The distinction between suicidal intentions by someone with a good prospect of a reasonable duration of health and a reasonable quality of life and those immediately faced with terminal illness and a diminishing quality of life was important to another interviewee. The willingness to intervene to prevent suicide in the former situation falls within the ethic of individual welfare whereas respect for the suicidal wishes of the terminally ill falls within an ethic of autonomy.

I think that the context of the suicidal [intent] is very important to me. Certainly if you're in a situation of palliative care, then what we're actually talking about are degrees of control and ... if you're talking about palliative care, you're talking about an individual who's moving towards some kind of solution for themselves ... I perceive the nurse's role as, once again, an empowering and facilitating role in helping that person come to some kind of accommodation with themselves and their situation. Thinking in terms of breaking up of a relationship or a recent diagnosis ... I think AIDS and HIV science is at such an early stage that we are obliged to intervene. If that means formal psychiatric intervention if people are acting out in some way, then so be it, because ... we all know of people who have been ten or eleven years diagnosed and are still healthy, and are still contributing greatly to the world. I don't know what's going to happen in the next ten years in terms of cure and ... I think we have to act. It's a different situation if people are terminally ill.

The following exchange between interviewer and interviewee in one of the less forthcoming interviews indicates the extent to which someone would go to offer, suggest and persuade someone to obtain help to alleviate the causes of suicidal intent, short of overriding someone's autonomy.

Ier: Have you given any thought ... to how you might respond to it if you picked up that, say, one of the people was suicidal or one of your carers suicidal perhaps?

Iee: ... If I think they were suicidal then I would ... be trying to help them first myself, but then trying to open it up to a wider ... In fact ... I'd be sort of saying, you know, maybe a trip to the GP. If that doesn't work I would be trying to look for other avenues, other areas of help. I mean, obviously if it was suicidal because of the practical things about caring, then what we obviously would do to find members of the group, if this was allowed, to go in and do some of the practical things to actually lighten the load somehow. I mean, that's what we are hoping to be able to get around to doing.

Ier: Right, surely. Now suppose these didn't resolve it. That the person says, I'm not going to talk to my GP. I don't trust him. There's nothing this group can do, or you've done all you can, and it still hasn't resolved it, a likely scenario.

Iee: Right.

Ier: Would you consider going behind a person's back to get outside help.

Iee: No.

(e) Respect for a client's control over who knows confidential information about their medical condition would be maintained even if this was to the disadvantage of other members of the family or the family as a whole.

> ... And we see that with families as well, when people are not allowed into the secret. Yet as professionals, you don't have a lot of influence to change things ... I did a lot of work with a father who has two children ... he died about a year ago now, and we were working up to that. He hadn't actually shared the information of his status with his own family for a lot of years. He actually carried that himself, so he ... didn't tell his parents or his brothers or sisters, and they found that hard, when they did get to know ... and he was working towards [telling] his two children, and in fact we'd got to the stage where he said he couldn't do it himself but I could do it ... and then he died before that was done, and you know, the family they just put the shutters down and said you will not [tell] ... and as a professional in that scenario, and a part of the team here, we had no influence because that family was saying ... no way will you do that.

This scenario contrasts with the stance taken towards the protection of young people's interests as a paramount priority within the ethics of individual and community welfare (see pages 204 and 208). However, the ethic of autonomy is not necessarily always in favour of the adult with parental responsibilities. There were examples of a young person's wishes over confidentiality taking priority over those of the family. In the next extract, the interviewee reflects on the difficult transition of having been involved with the family over many years and how the control of confidentiality gradually passes from parents to the maturing young person.

Iee: ... children have always come with their parents until a certain age, right, and that has continued on past the age of consent in many cases ... then suddenly, I am my own man, thank you Jack, and you just stay down there mother where you belong.

Ier: At what age is that officially?

Iee: Seventeen. Officially. I would say probably, about sixty percent of the fellows here have been fine, but forty percent haven't been and it is very, very difficult when the door is closed on the parents who have always been part ... of [i.e. involved in] the medical problems ... helped them to resolve them, and then they don't know what's going on. And of course they always, after every clinic appointment, every three months, they go back home ... Well what did he say today? Nothing, I'm fine. Well, you know, [how] was your T-cell count? Absolutely fine. There's no way they're going to tell them what it was. Well did you get your tablets changed? No, everything was okay. So what you imagine might have been said is horrendous if you're that parent. And of course, quite often they ring me. I know that you can't tell us and I know he hasn't given you permission, but is he all right? Is he telling the truth? And of course I do quite often say to the young fellows, if I said to you that I would tell your mother if there was something really wrong, what would you say to me? Well you probably would anyway, wouldn't you? But one or two categorically would not let you do that. Again, its a case of working through it and saying, you know, if you don't tell, this is what might happen or whatever. But it is very difficult that changeover, from a boy wanting to leave everything to his parents to do and then ....

(f) The circulation of letters about clients in order to make referrals or obtain additional services required special consideration within an ethic of autonomy. Not only was the client's informed consent required to the letter being sent (even to routine letters to GPs – see above) but some considered that it was important the client saw the content and made the final decision about whether it was sent. For example, life insurance companies often required reports about clients.

> ... dealing with any outside body, apart from the usual GP letter, [the routine practice] is that the information is sent to the patient to read in his own home, and if he wishes, then to pass onto the insurance company.

(g) The prevention of harm to others, especially unknowingly being exposed to the risk of HIV by the client, constituted another one of those critical issues which differentiated the underpinning ethical framework. Some took a robust view of adult autonomy and the responsibility of each adult to protect themselves.

> This is a very callous way of looking at it ... but every sexually active adult (I know some people are more powerful in their sexual relationships than others) but basically

every sexually active adult does have responsibility to keep themselves safe in the 1990s.

... and at the end of the day if they say 'I don't care a damn and I'm out to infect everybody, you're on a very difficult wicket ... certainly when I did [i.e. ran] my first awareness training ... people within our own department who were not dealing with HIV were aghast at what I was saying, that at the end of the day, we're all responsible for ourselves and you can't be your brother's keeper. If it's a youngster, of course, you have a child protection issue. That's quite different.

An ethical corollary of this view is the acceptance by the counsellor of a responsibility to ensure, whenever possible, that the other person at risk of infection has sufficient information and education in order to recognise the sexual or other health risks and how to protect themselves. Respect for individual autonomy was not merely an excuse for inertia or passivity on the part of the counsellor. The danger posed to others required activity and created ethical responsibilities. These responsibilities were alternatives to the duty to warn characteristic of individual, and especially community, welfare ethical frameworks.

> If we're talking about consenting adults, my bottom line is that it's each individual's responsibility to protect themselves and I would see my responsibility, if I was in contact with two people and I knew one was HIV positive, and I knew that there was a possibility that they were going to either share a syringe or have unprotected sex with the other one ... in general terms I would not see it as appropriate for me to tell the other individual the HIV status. I would see it as my responsibility to make as sure as I could that the uninfected individual had full knowledge in general terms about the risks of unprotected sex and sharing injecting equipment, but ultimately, if .... they then decide that they're going to take that risk, then I see that ultimately as their responsibility, not anybody else's, including the person with HIV.

The avoidance of a responsibility to warn third parties to the counselling relationship was regarded by some as a professional ethic rather than one which extended into personal friendship.

> to be honest, I am talking as an employee of [named agency]. If it was a situation outside of work where my knowledge of the person's HIV status was through personal friendship ... I'd have to feel less bound to be confidential.

One interviewee warned that even with all these safeguards for respecting individual autonomy, events could take unexpected turns to the disadvantage of the client.

> I would always ask the person to tell them himself. If they wouldn't do that, I will suggest that I will do it with the person, and ... there was one where I told him a while ago he was positive. He wouldn't tell his partner and ... we agreed that he wouldn't have sex with her, because he didn't want to suddenly produce a condom ... until he assimilated it himself first, and then we did it [inform the partner] ... she didn't handle it well at all, she ran and told the next door neighbour and told everybody ... She came in and I had a chat with her, but she went off it ... they split. I don't know if we could have handled it any differently.

The critical incidents resolved by reference to an ethic of respect for individual autonomy combine to suggest adherence to an ethical framework in which respect for individual autonomy was the paramount ethical concern with a wide range of applications. The emphasis is on respecting the self-government (the literal meaning of autonomy). In the context of HIV and AIDS where it is considered that adults are capable of protecting themselves from the transmission of HIV, the concept of autonomy is sufficiently robust to envisage that any responsibility to prevent harm to third parties could be discharged by the provision of information and education. In this way, the usual limitation operative within the principle of autonomy is transcended by the assumption that each competent adult is responsible for their own health as an aspect of their autonomy. From this viewpoint the reckless and possibly deliberate exposure of others to HIV may not be regarded as a sufficient reason for considering that a limitation to the principle of autonomy has been reached. This view was not universal and it was clear in a number of interviews that when someone considered that they had encountered the limitations of autonomy because of the perceived threat to the autonomy of others or the lack of a capacity for autonomy in an individual, they moved to another ethical framework. The predominance of the ethic of autonomy suggested that this was the ethical framework from which most participants considered their ethical responsibilities in the first instance.

Individual welfare

An ethic of individual welfare is characterised by prioritising the welfare of the client. Respect for individual autonomy is part of this ethic but it is not a paramount ethical concern and is subservient to an assessment of the client's best interests. This ethic was referred to in many situations.

(a) In the context of the multidisciplinary team, it is assumed that it is in the best interests of the client that confidentiality rests with the team rather than between any individual team member and the client.

> The situation with [named agency] is that we say to clients that information you give us is confidential within this project. In terms of HIV we work very much on a need to know basis so that there will be a file and there will be named members of staff who would generally be allowed access to that file. But in the absence of those staff it may be that other members of staff would have access. So basically, in terms of what we're saying to clients, is that boundaries of confidentiality are [within] this project. But that's not to say that if I'm working with a client, I would automatically be sharing all the information with all the other members of staff. We'd only do that on a need to know basis.

Similarly, in another team,

> The way we manage this is that confidentiality is to this agency. I certainly feel that there are so many ... management problems in making confidentiality specific to certain individuals. It's too difficult to actually deal with, and my preferred option, and also that of the agency, is to make it team confidentiality ... as a team issue, a clinical team issue. So that that information is common knowledge and freely available to all clinical workers.

The existence of a prior condition of confidentiality between the client and the team (rather than the individual service provider and the client) is potentially ambiguous. It could be construed as either within a form of qualified autonomy or within an ethic of individual welfare. Consultations with participants following this analysis suggest that the allocation of a prior condition of confidentiality exclusively to the ethic of individual welfare is occasionally contentious and may be surprising to some. My reason for doing so is that whenever I have pressed people for

explanations about why they have adopted team confidentiality, it is invariably an assertion of a professional view of what is ethically desirable over individual client wishes. The reasons offered for this assertion are varied. Some assert that this practice maximises the quality of the service to a client by providing the benefit of a seamless service between specialisms within a team, avoids unnecessary repetition of emotionally painful personal histories, and creates a system of confidentiality which is most complementary to multidisciplinary working. In other words, confidentiality vested in the team rather than individual counsellors is viewed very positively by the professional as benefiting the client. Sometimes these reasons existed alongside more negative evaluations of the trustworthiness of some categories of client or their capacity to work within individually based confidentiality. For example, counsellors working with drug addiction were ensuring that they were well placed to respond to those clients who were considered manipulative (perhaps to obtain extra drugs) or too chaotic to work within individual confidentiality. Some participants expressed the view that drug-taking in association with HIV was an indication of a more dependent predisposition in clients in comparison to politically empowered gay men concerned to protect their lifestyle. Similarly dependence might arise from illness or immaturity, in which case team confidentiality was sometimes considered more appropriate (but not invariably).

The boundary between individual and team confidentiality was not absolute and in some instances the prior condition of team confidentiality was a condition which could be rebutted at the initiative of a client. An individual client could request and would be granted individual confidentiality or limitations on team confidentiality.

> Obviously being given information in an individual way does create problems, it makes it very difficult to record it anywhere. But yes, patients do set limits on our communication ... and we obviously accept that constraint.

(b) Within a system of team confidentiality there were variations in how the ethic of individual welfare was implemented. In some contexts, usually in-patient hospital units, some interviewees considered that there was a positive ethical duty for team members to communicate with each other.

> ... I tend to look upon the care of that particular individual as being multidisciplinary. Each member of the team has a role to play, and the best effective way of providing that care is that each member of the team has to communicate with each other. If I don't get information from, for example, a social worker about particular aspects then I, as the leader of the team, would not be able to actually give him the best care. I mean ... care of the particular individual as a whole person.

However, the duty to communicate to other team members could be qualified by professional judgment of the 'best interests' of the patient.

> ... I have chosen not to share information with other multi-disciplinary colleagues within this hospital ... about a child protection matter ... Within the hospital, we didn't think it was necessary that they should be involved at this stage until lots of [inquiries] had been made [i.e. child protection investigation closer to completion] ... and as it didn't relate particularly to that person's [HIV] care ... and [I] was anxious about how they would respond to that information and how they would then respond to the client.

There were other examples of someone withholding information about a client's past mental illness and another protecting information about previous sexual diseases as being irrelevant to current care and potentially divisive between the client and other team members.

One team leader spoke about his concern about a recent increase in what she considered to be inappropriate humour within a team which might seem to suggest that HIV and AIDS was less serious than it was.

> I think that the self defence of humour actually kind of exacerbates that [sense of HIV being something apart – happening to others]. It makes it more likely that people will be regarded as other ... [with] the implications of dehumanising, or makes it more likely that confidentiality issues won't be taken seriously.

The same interviewee also believed that too free an exchange of information within teams was contrary to the best interests of the clients and in common with several others advocated criteria for deciding whether a communication within a team was ethically appropriate. She advocated information should be available only to people directly involved in the care of that person and who had 'a need to know' in order to carry out their role. The phrase 'need to know' was a recurrent qualification of the duty to communicate within teams.

> It would be on an absolute need to know basis in order to provide a quality and a good service. And even where there is a need to know, a discussion would take place [? with the patient and involved staff ?] about who exactly that would involve, how the information would be stored, who would have access to it, and it would be gone into quite clearly before any action would be taken.

This quotation indicates the inherent ambiguity of 'need to know' between ethical systems. It is undeclared with whom any discussion would occur. I have inferred from the wider context of this quotation that this would not be exclusively with the client concerned but would involve professional colleagues making an assessment of the availability of other services and the needs of the client, hence I have inferred that the discussion takes place within an ethic of individual welfare. If the discussion were exclusively with the client (and/or anonymised with colleagues) it would be better classified within the ethic of autonomy.

The following extended example reveals the potential difficulty of deciding when the 'need to know' basis for communication arises. At least initially, there were differences in view between a social worker and the interviewee about the child's best interests over confidentiality.

> We were put into a position where a particular piece of information came to us about a child ... [which] concerned the child's interactions at school. The parent was dying [in a complex situation] ... So we first of all spoke to the social worker concerned and made them aware of the situation. The response that they gave us left us feeling ... that the matter wasn't being addressed to our satisfaction, and ... [that] the child in our view would be put at more serious risk. So we then spoke to the manager of services within the authority ... The social worker then got to know that we had done that and reacted quite badly, saying that we had abused the information about the child

> [by disclosing it in] ... another environment without the child or the guardian's knowledge or consent, and that ... we had destroyed the confidentiality and credibility of that particular individual. Our response back to that was twofold. First of all we have a responsibility under the Children's Act and we felt very clearly that there was something going on here that would certainly be to the detriment [of the child], and we had to use our own judgment, and rightly or wrongly we stood by that and we accepted the faults of that process. But secondly, we had taken that decision in the light of the parent was very open about their own status, it was an open secret, had regularly been in the tabloid press. In fact how the teacher had come to contact us was that they had seen an article in one of the papers with a picture of the parent and they put one and one together and got two. [The teacher] realised then that that parent's child was in their class, that there were emotional problems going on with that child, and that teacher was seeking support and didn't know how to access any support. Subsequently after all that people got together and started communicating, but it was the fact that we had dared to, in the eyes of the social worker, who is actually a very good social worker ... do something that in their eyes they say undermined the confidentiality, whereas in fact every child in that school was quite well aware of this child's parent's diagnosis.

A recipient of referrals for counselling and other forms of support commented on the diversity of practice around 'need to know'.

> Well, I think a lot is around the subject of the need to know basis, and that some would give a full and comprehensive history of a client, if, say, in a referral situation whereby one agency would give us a date of diagnosis, they'd give a mode of transmission, they would tell us all the details of the family household, and its not entirely sure whether or not that information has been elicited from the client with their knowledge to pass that on, whereas other agencies are very cagey and will give us the bare minimum details in terms of the referral of just a name and address, and then you find out everything from there on, and there's no shades in between.

With this awareness, the interviewee proposed two further conditions to a 'need to know' communication.

> Everyone, I think, likes full information ... there's no getting away from that. The more you know, the more you are informed. But we do realise there are difficulties about some of the sensitive information that can be passed on, so my personal view is that any information that is passed on to myself, and ... our agency would aim to hold this ourselves, that we would pass on information that is only relevant to the purpose for which it is needed, and there is an obtained consent from the person involved about the information that is passed on.

The clarity of these two conditions appeared to be more apparent than real because the participant later observed that the issue of consent within a system of individual welfare need not always be explicit.

(c) Within an ethic of individual welfare, it would be sufficient to override explicit instructions about confidentiality in order to be able to offer life saving treatment.

> Iee: ... but say for example we had a woman for whom we did a cervical smear, and it showed casting over of the cervix, now it may be that patient defaulted ... we always try and persuade the patient when we're doing a smear to allow us to send a carbon copy of the smear to the GP. Now it may be that the individual says no, they don't want the GP to get a copy because they don't want the GP to know they've been here [GUM clinic]. Now in that situation, if we got a result like that, we'd contact the patient and hadn't got any response, then I would certainly write to the GP and say, we had this smear result. Now that is not doing it with the patient's consent but it's such an overwhelming situation which is potentially eminently treatable but is potentially fatal without urgent treatment, and I think I'd be justified in doing that.
>
> Ier: So that might be an example where best interests would override patient's consent.
>
> Iee: Yeah, that's right. So ... We're not totally rigid here, and that's a situation which we apply. I think its unlikely to apply so much in the HIV scenario, but certainly I suppose there are situations where it could be relevant.

Two examples of the application of individual welfare to self harm were explicitly raised by counsellors. The first related to counsellors holding medically-relevant information about the client such as mixing prescribed and non-prescribed drugs or countering proposals for inappropriate but well-intentioned care arrangements.

> ... the only real times I can remember actually choosing against the patient's wishes to tell the doctor something that they told me and they didn't necessarily want me to tell the doctors, things like if they're taking some other drugs and are clearly influencing their medical condition but they've told me and they've asked me not to tell the doctors, or, for example, if people have had relationships with other patients and I find out they are both in-patients, and somebody's suggesting that they share a room because they're a bit short of beds or something, and they've only just become ex-lovers a couple of weeks ago or something, you know. Hang on a minute, that might not be the best thing.

The second concerned suicidal intent (one of the issues which differentiated between an ethic of autonomy and individual welfare – see pages 192-4). The ethic of individual welfare had resulted in the development of a suicide prevention strategy advocated by several interviewees.

> ... If we're talking about somebody who's actively expressing the desire to kill themselves ... I would envisage immediately, a team that involved their consultant, their social worker, their psychologist, and probably somebody from the neuro-psychiatry team, and their carer/family whoever, and setting up agreements

> about whether its an admission to a psychiatric ward or whether its care at home, and getting something actively on the road, that its called a suicide prevention strategy, that everybody knows what they're doing.

This contrasted with someone else who generally followed the line of suicide prevention but considered that this might not always be in the patient's best interests and could be unethical with a person who is close to death.

> I was certainly carrying one recently where we were going for discharge of a patient and I knew that when he got home he would kill himself, because he told me ... that was difficult actually because ... to be honest I didn't tell the physician. It didn't happen actually, the guy died in the hospital, but he was in here thirteen weeks and I think that a lot of it was suicide prevention and wrong.

This quotation is significant because it indicates an ethical boundary and criteria in the interviewee's thinking which would generally favour an ethic of individual welfare as justification to intervene to prevent suicide except where the best interests would require reassessment because of an imminent deterioration in quality of life or death itself.

(d) Incapacity to make autonomous decisions for oneself was recognised by most interviewees as grounds for using an ethic of individual welfare even if that was not the usual ethical framework adopted by that interviewee. A variety of different forms of incapacity were offered as examples. Physical deterioration to the point of unconsciousness, HIV related dementia and acute severe mental illness were referred to by many interviewees. Children were also considered by some to require decisions within an ethic of individual welfare because of their immaturity, especially if issues around protection from abuse were involved. Child protection issues were widely considered to override the young person's autonomous wishes either in the best interests of the individual child (i.e. individual welfare) and/or to enhance the well-being of society (i.e. community welfare). Child protection

provided an obvious example of the potential for the overlapping of the ethics of individual and community welfare.

(e) Intervening to prevent a third party from being unknowingly infected by a client acting recklessly or deceptively perhaps by breaching confidentiality could conceivably be construed as acting in the client's best interests by preventing future recrimination and blame. However, there were no examples of this point of view in this study which did not also make more committed references to stressing ethical obligations to people other than the client in order to minimise the risk of HIV infection. Any gains to the client were secondary to this obligation and indicated by statements like 'And this is probably also in the best long-term interests of the client'. The primary ethical framework has therefore been labelled as 'community welfare' (see page 208).

The ethic of individual welfare created a professional duty to prioritise the welfare of the client over all other ethical considerations. As with the ethic of autonomy, the ethic could be applied to many different situations. However in contrast with the ethic of autonomy, there were no interviewees who adopted this as their sole ethical system (see table 8.1). This was an ethic employed alongside other ethical frameworks which suggests that there may be criteria for its application. Some of these criteria have been referred to but they warrant closer consideration later when I explore the relationship between the various ethical frameworks. However, it is worth noting the variations in practice within this ethic over communications within teams. These differences in practice are not necessarily incompatible with conforming to some subsidiary principles, namely a professional responsibility to act in the 'best interests' of the client and to communicate only to those professionals who 'need to know'. Variations in the assumption of a responsibility to communicate, or limitations on the expectation of communications within teams,

do not necessarily indicate disagreement about the ethical framework, although it could be this, but may be due to differences in context and professional assessments of what constitutes 'need to know' and 'best interests'. Within an ethic of individual welfare, the application of these criteria is a matter of professional assessment (in which the client's views may be an important factor) in contrast to the ethic of autonomy where the client's own assessment of these terms is paramount.

Community welfare

An ethic of community welfare is characterised by prioritising enhancement of the welfare of others outside the immediate counsellor-client relationship. These 'others' may be an individual third-party, for example the client's sexual partner, a social group, family, community or society as a whole. This framework is distinguishable from individual welfare by the point of ethical reference. In individual welfare, it is the promotion of the welfare of the individual client which is prioritised over those outside the immediate counsellor-client relationship. In contrast, a prioritising of the wider social context over the counsellor-client relationship is characteristic of the ethical framework of community welfare. Again this was a framework which was applied to many different circumstances.

(a) An ethic of community welfare acted as widely recognised justification of the significance of confidentiality within sexually transmitted diseases in general and HIV in particular because of the deterrent effect on people seeking services related to these unless confidentiality was assured.

> I think that people go to the STD [sexually transmitted disease] clinic convinced that its going to be confidential and, if that's threatened, people will stop going.

The benefit of minimising barriers to the take up of the treatment of sexually transmitted diseases is a reduced pool of infection within the community resulting in a collective benefit of reduced illness and risk of infection.

(b) It seems probable that it was a corollary of the desirability of maximising the take up of these services that at least one interviewee considered that an ethical duty existed to promote public confidence in colleagues although this did not extend to predicting or seeking to influence how they would manage confidentiality.

> I would say that I'm referring you to someone, who professionally I have great respect for, who is going to give you the best of attention, and that is my sole parameter really [i.e. not responsible for communicating patient's desire that GP should not be informed].

(c) During an earlier phase in the responses to HIV, community welfare provided a justification for group testing in order to increase knowledge about the transmission of HIV at a stage when its infectivity was little understood.

> The diagnosis of HIV was a sudden thing because the test became available and we tested everybody, and in those days you didn't have counselling, you just tested everybody. We didn't know whether we were infected or not, as well as the patient. So we tested a whole cohort of people, including all members of staff, and if it had been the particular week that we did it, you would have been tested as well. We would have asked you for a specimen of blood because we just didn't know the parameters we were dealing with. Now it is very different because of all the needs for counselling and confidentiality, but in those days we were inspecting our ground, and it was only by making the framework and a base, if you like, on which to build, that we could cope ... We thought that only one in a thousand people would get AIDS and secondly that they would get AIDS quickly, and neither of those two have been borne out by fact.

(d) So far as I can tell the underpinning ethic behind suicide prevention strategies was primarily based on the protection of the interests of the individual client rather than a general duty to preserve life. Equivocation about people who are suicidal in the terminal stages of AIDS seems to point in this direction but it is possible that some interviewees considered that both the client's interests and a general duty to preserve life coincided and thus provided a joint justification of the implementation

of a suicide prevention strategy rather than following a client's autonomous wishes. If this were the case, it is arguable that the general duty to preserve life falls within an ethic of community welfare as the duty is attributed to a collective value.

(e) The ethical priority of protecting children also appeared to be rooted in a wider moral duty which related to a whole class of individuals.

> ... one of the things that we are very clear on is that child protection issues will frequently take precedent over other concerns about confidentiality ... we work on the principle that if there is any reason to believe that a child is at risk or may be at risk then we will inform the appropriate social services team of the information which has led us to that view.

(f) The classical moral dilemma about intervening to prevent a third party being placed at risk of infection by a client was one of the most frequent occasions when reference was made to an ethic of community welfare. Some were equivocal and considered it a matter of balance between individual and community interests.

> ... in fact I think one's got to balance up the needs ... what are required for the individual with the greater needs of society; and, also, in particular for other individuals.

Others were more adamant about the priority of community over individual interests.

> ... when it comes to a particular individual who is extremely promiscuous and in this knowledge that he is not taking any precautions towards transmitting his infection, then there would come a point that I would have to say to him, that if he is not adhering to advice, then confidentiality of his status may be breached. I think that's in the interests of public health.

Another participant specifically rejected the concept of basing HIV prevention exclusively on the concept of adults' responsibility for protecting themselves from infection.

> One could argue that everybody in this day and age should be aware of the danger of HIV and therefore should be taking appropriate measures, and therefore there isn't any need to provide a referral [for contact tracing partners of HIV positive people], but I think we're a long way from that situation.

(g) One dilemma was only raised in the context of an ethic of community welfare. It was the issue of people falsely claiming to be HIV positive in order to claim priority access to services or enhanced services.

> It's something that should actually crop up in this study, because what happens is we get contacted by some of the voluntary groups, [named examples provided], who say, we suspect we have got a chancer who is trying to tap in for resources and they perhaps put a bit of background in, and they say, he say's he's been up for testing in ... [an identified sexually transmitted disease clinic] ... can you confirm this or not? Is he positive or not? And in that situation, obviously, we're very happy ... they provide us with names and details and .... All we can say is yes, he is known positive or he's not as far as we're concerned, and I don't see any problem as far as confidentiality is concerned with that. We have had equally, people who want a letter or some document to state they are positive so they can actually pick up on resources when there has perhaps been some queries made about it, and again, you can provide that.

Another interviewee explored why he would break confidentiality over people who falsely claim to be HIV positive.

> I mean there is a circumstance under which ... I've broken confidentiality on and would again, and that is where people represent themselves as being HIV positive when they're not, and that could be anything from worried people through to psychotic changes ... We get people walking about occasionally, and they are absolutely off their heads and saying they've got HIV, and its just part of the circuit. 'I've got HIV can I have the script?' ... I think if people really screw with us, then what we do is we share information about them and in that way we defend ourselves against them. So fictitious HIV seems to me to be something where ... they're kind of stepping away from being treated confidentially. I phone people up and say 'Watch out for such and such ...'

The ethic of community welfare requires that the best interests of the community are the paramount ethical concern. In common with the preceding ethical frameworks it is applied to several different issues. Like the ethic of individual welfare, there are no interviewees who work exclusively from within this ethical framework which suggests that there may be criteria which mark the boundary between the application of this framework and others. The obvious criteria are ones of risk to public health and abuse of public services. The relationship between the ethical frameworks will be considered later.

Fidelity

There were some examples of moral reasoning which suggested the possibility of another ethical framework in which the paramount priority was honouring the trust that a client had placed in the counsellor. An ethic of fidelity could be defined as acting in good faith with clients in ways consistent with the relationship between counsellor and client that honour the trust shown by a client's disclosures of confidential information. In comparison to the other ethical frameworks, there were relatively few examples of references to this approach. Some references were ambiguous between an ethic of fidelity and autonomy.

(a) One voluntary organisation adopted the principle of defining confidentiality in terms of honouring the trust of their clients.

> We say that confidentiality is not about maintaining secrecy but its about being given information by someone else who chooses to do so, and therefore there is a trust, a relating trust, a privilege. That is about not abusing the trust having been given that piece of information, but by using the knowledge of it wisely and cautiously, but still always maintaining that the individual, as far as one can do, has control.

However, this quotation may indicate how closely an ethic of fidelity and autonomy relate to each other in practice. The emphasis on respecting individual control of information, presumably by seeking their consent for disclosures makes it practically indistinguishable from an ethic of autonomy. Therefore the occurrence of this ethic may be under reported in this study.

Another participant spoke of the importance of the sense of trust between counsellor and client influencing decisions about how to respond to someone who is dying. The thinking evidenced in the quotation is diffuse but seems to suggest that trust requires positive commitment by the counsellor to work actively towards enhancing relationships within a family during the crisis of someone dying.

> Yes. And actually saying, this is frightening, but let's see how we could actually do this jointly .... Where do you want to be? Do you want to be here in the hospital lying

on the bed holding [people close to you]? What are your fears? What could we provide? How do you want to do it? And actually trying to play it through ahead with them, so that you can then totally pace it, and I think those kind of situations are very privileged positions to be in, if you can get it right ... I think a way of using an analogy with families, is the escalator. We're all going up in the escalator, but one person will go over the top, and I would like you to be beside them on the escalator, and keep the distance as narrow as possible, so that the warmth comes out, because people will often ... find a depth of feeling and strength that they never knew they could find or handle which eventually helps them through the pain. Our job is not to control. Our job is to try and almost provide the stage for it to be played out on. I think confidentiality shouldn't be holding things at that stage ... Unless somebody wants to deny, and then you play it other ways don't you? You don't actually deny, but you don't bully them to say anything.

The closing reference to someone who is actively denying that they are dying indicates that both the commitment to enhancing relationships or respecting someone's denial are rooted in the counsellor's felt sense of the relationship as the basis for ethical decision-making. This felt-sense of the relationship was considered by another interviewee to permit some disclosures on behalf of the client on the basis of working within the dynamic of trust but did not permit other disclosures. He doubted that the distinction could be sufficiently clearly analysed and articulated to withstand rigorous scrutiny.

> ... What isn't so clear is which bit of the information we negotiate needs specific consent to pass on, and which is just implied consent, and I think that forever is the art of managing confidentiality. I don't think it will ever become a science, there is an art involved in it.

One interviewee made specific reference to the experience of maintaining trust with one client at the expense of trust with another client in the context in the context of not warning the second client of a significant health risk.

> Iee: ... There are very exceptional dilemmas, I have had a couple of these. A while ago I had somebody who was antibody positive, a drug user, partner antibody negative recently, having sex, no condoms, no protection, no pill, no nothing, and ... it's ...
>
> Ier: Both patients of your own ...
>
> Iee: Both patients of mine ... and the dilemma is do you tell the person, the partner, in order to prevent them acquiring HIV? Do you break the confidential information? What I did, which I think is the right thing to do, is I twisted the person who was antibody positive very hard, I counselled them if you can call it that ...

Ier: Counselled in the medical sense ...

Iee: You get them to wake up to what their responsibilities were, and I think at the end I actually said, I will tell her if you don't ... and you've got two weeks at the most, and you're going to use condoms from here on. You know, wake up, it's not a small thing. And he did. And in fact, I saw them both, and I think it's always preferable to persuade them or to counsel them rather than to break confidentiality. Would I have broken confidentiality? ... I've never actually done that, but I think I would have done. I said I would and I would have done that and I would have taken a ... moral standpoint that was justifiable. And that's probably the biggest issue about confidentiality.

Ier: It's the one which I think taxes most people involved in this area.

Iee: Yeah. I don't think it's easy, but ... I've thought about it quite a lot, and I've been involved in that situation and another related situation. It's very like seeing people with other sexually transmitted diseases and you know both of the partners. I've also handled it badly in the past, by not telling one partner, and regretted it forever, and they had gonorrhoea, and ... I would never do that again. I just was quite destructive, even though the partner actually forgave me, really, and I get on quite well with her now. So it's a lesson I've learned really.

I have considered whether this example falls within an ethic of fidelity or elsewhere. It is highly ambiguous with regard to the client who is placing others at risk but the emphasis on him (or her) taking the initiative for himself suggests an ethic of community welfare subsumed with an ethic of autonomy by the strategy of seeking client consent. However, the terminology for describing the consequences for a second client who was not warned of the consequences of the risk of infection suggests that this relationship was viewed in terms of trust. The language of destruction and forgiveness suggests that the primary point of reference is the relationship, and that this was viewed as damaged by a failure of fidelity or trustworthiness by the interviewee.

The existence of an ethic of fidelity which emphasises honouring the relationship of trust between counsellor and client is much less frequently referred to by interviewees than other ethical frameworks but nonetheless it is present. The tendency for it to blur into practice associated with an ethic of autonomy may mean that I have understated its presence. Certainly, it was present in varying degrees within the voluntary sector and self-help organisations. It is a characteristic of this ethic that it is applied in circumstances where there is minimal social distance between counsellor and client and in its pure form

the emphasis would be on negotiation and collaboration rather than informed consent to a professional service.

Relationship between ethical frameworks

The purpose of this chapter has been to identify some of the key features of each of the respective ethical frameworks which were evident within the consultative process. The achievement of this purpose is substantially dependent on a procedure of differentiation and establishing conceptual distance between the different ethical frameworks and the elements within those frameworks. A major feature of the differentiation process was the identification of different responses to critical situations which acted like metaphorical 'watersheds' between ethical frameworks. Comparison between the different explications of ethical frameworks (Table 9.1) enables the relationship between issues and ethical framework to be demonstrated by the ethical reasons offered by participants concerning critical and hence differentiating incidents.

Table 9.1: Differentiation of ethical frameworks

	Autonomy	Individual welfare	Community welfare	Fidelity
Disclosing important information within the expertise of another team member	client's informed consent required	protection of client's welfare	protection of colleagues'/others' welfare	consistency of disclosure with purpose for which information was given
Suicidal intent	client's choice over life or death respected	protection from (temporary) disturbance	preservation of life/protecting others from difficult bereavement	consistency of disclosure with purpose for which information was given
Preventing harm to others	client's right to autonomous action respected (may be qualified)	protection of client from recrimination and blame	protection of those at risk from client	client's lack of good faith releases counsellor from fidelity
Child protection	client's right to autonomous action respected (may be qualified)	protection of the welfare of child client	protection of other children	?

One of the effects of this diagrammatic representation is to cast the divergence between ethical frameworks into sharp relief.

If this distancing effect were to be replicated in the actual experience of participants it would be reasonable to expect that the teams would be riven with ethical conflict and perhaps dysfunctional as a consequence. This was not the case. A degree of conflict and debate was evident but not at the level which impeded most team functioning. On the contrary, the existence of different ethical frameworks appeared to assist the functioning of teams which raises the question about how these potentially competing ethical systems are perceived as relating to each other. This is the topic in the next chapter.

Chapter 10

Transitions between ethical frameworks

The use of four different ethical frameworks within the same area of HIV-related work held the potential for considerable divisiveness within the teams. Instead the teams appeared relatively cohesive and were certainly functioning at a level which permitted the co-ordination of interdisciplinary service delivery. This raised the obvious question about how seemingly competing and mutually inconsistent ethical frameworks could be in use alongside each other. Indeed the contrast between the differentiation of the ethical systems and the apparent coherence within the teams was so strong that I seriously considered that unless further explanation of these contradictions were possible that one or other of the observations must be wrong.

With hindsight, I am surprised that my instinct was to distrust the apparent cohesion within teams in preference to deconstructing the differentiated ethical frameworks. When I reflected on this I realised that I was importing assumptions based on my experience of normative ethical inquiry. Within moral philosophy, which is predominantly written in normative mode, there is a tendency to amplify differences between individual moral narratives as the basis for establishing distinctions which become the building blocks of further philosophical reasoning. In contrast I appeared to be researching a situation in which differences were understated and possibly deliberately or unconsciously minimised by an ambiguity in the usuage of terminology. The pressures of providing services to people in potentially existentially and socially extreme situations appeared to have created an opposite dynamic to that which I had imported from normative ethical discourse. The general commitment to providing a service to people affected by HIV united participants more strongly than the potentially divisive effect of the co-existence of different ethical frameworks.

When I reviewed the material gathered in the consultations reframed by this realisation, a number of other observations took on greater significance and held out the possibility that the interpersonal dynamic, with its tendency towards cohesion, was complemented by conceptual strategies to reconcile the relationship between competing ethical frameworks. The pertinent observations were:

(a) some participants moved easily between different ethical frameworks according to the circumstances they were considering. This suggested that differences were not so great to constitute a sharply defined personal dichotomy.

(b) the ethic of autonomy was a common factor between all participants (see table 8.1).

The emphasis on practical thinking within the transcribed interviews meant that the ethical reasoning was often implicit rather than explicit. Nonetheless, using a combination of the examples of explicit reasoning and inferring implied reasons, it was possible to explore the relationship between an avowed ethic of autonomy and other frameworks where these had been adopted by the same person.

The relationship between autonomy and other ethical frameworks

Although an ethic of autonomy was a common ethic shared by all participants, it was not necessarily the 'home position' from which all participants started. For example, someone mostly working within infectious diseases may be more predisposed to starting their ethical considerations from a framework of community welfare but might move to an ethic of autonomy where a person affected with HIV shares a commitment to minimise the risk of HIV transmission. Similarly someone with children or seriously ill people may be predisposed to applying an ethic of individual of individual welfare unless there is evidence of a capacity for individual autonomy. Disease progression might indicate the benefits of collective team expertise and as a consequence predispose an initial ethical analysis within a framework of individual welfare, unless contrary views were expressed

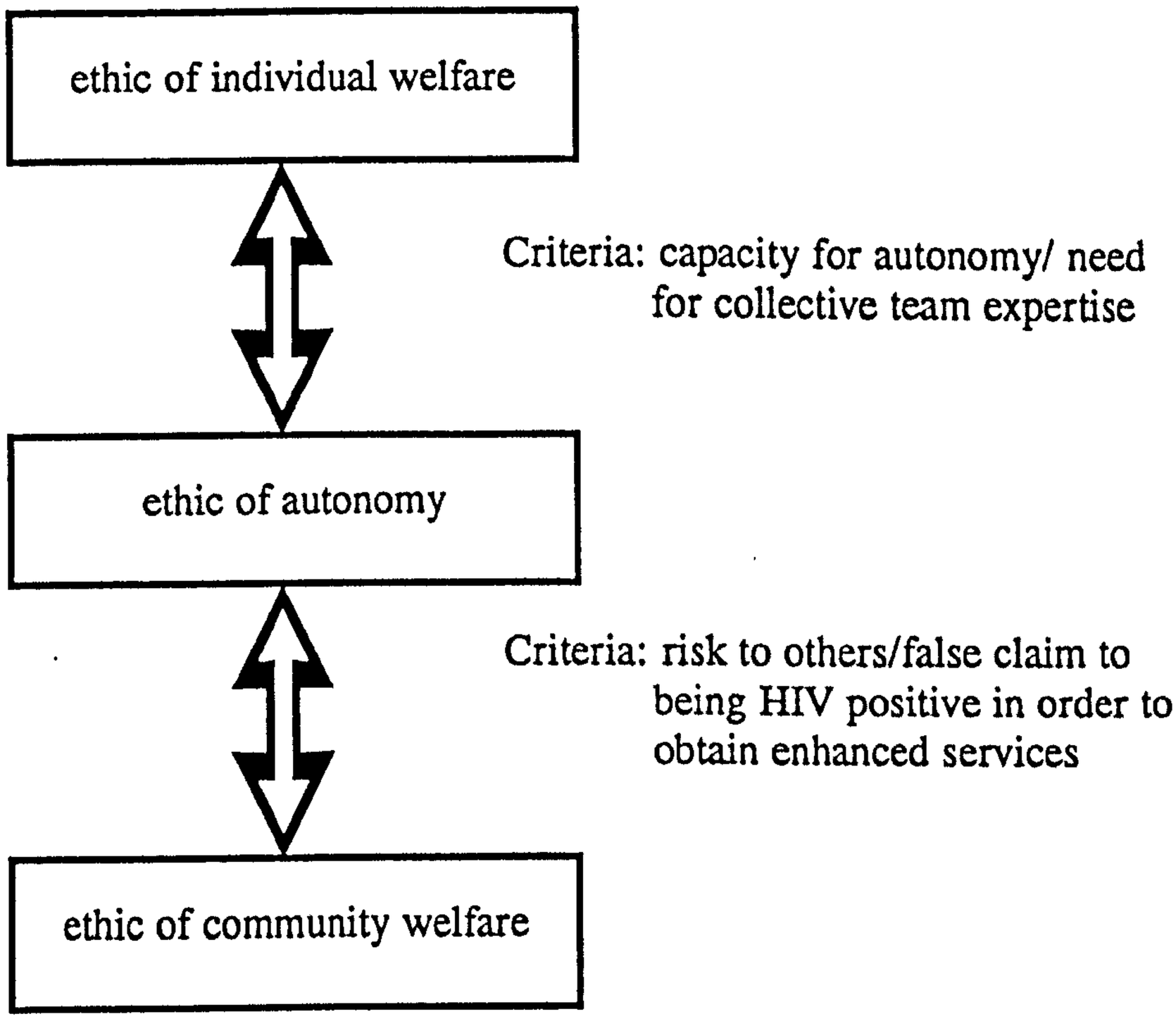
by the person concerned so that the choice between an ethic of autonomy or individual welfare became an issue. All these were examples of potential transitions towards an ethic of autonomy.

Conversely, there are examples of transitions away from an ethic of autonomy towards other frameworks. For example, posing a risk to the health of others or making false claims to being HIV positive might raise the applicability of a framework of community welfare. Someone's progressive loss of capacity for autonomous decision making due to mental or physical deterioration might similarly raise the possibility of an ethic of individual welfare.

There were examples offered during follow-up consultations where participants could recall situations in which they had made the transition from one framework to another and reversed the transition as the circumstances changed. The most common example was a transfer from an ethic of autonomy to individual welfare when someone became sufficiently ill to impair their autonomy and reversing the process as they recovered. This mobility between ethical frameworks, where it occurred, did not seem gratuitous but based on ethical considerations. This suggested that articulation of the criteria ought to be possible.

A further application of inductive analysis within a consultative process identified 'gateway' criteria which would be applied between different ethical frameworks. These can be represented diagrammatically.

Diagram 10.1: Gateway criteria between ethical frameworks



There were insufficient examples of the application of an ethic of fidelity to be included within this analysis.

Exploration of situations in which there was two-way mobility between ethical frameworks reinforced the sense of proximity between ethical frameworks and how they could almost fade into one another. The boundary between them was much less distinct than might be assumed on the basis of analysis wholly dependent on differentiating incidents. Further exploration of those examples of two way mobility between ethical frameworks held out the best possibility of explaining this conceptual proximity.

Permutation of ethical principles

A distinctive feature of accounts of how a participant moved between ethical frameworks and back again was that factors which justified the use of one ethical framework were not abandoned with the transition but were re-prioritised. For example, a counsellor

spoke about a client who had discussed what he wanted to happen to his pets and how his blood relative should be notified if he went into hospital. While the client was well these issues were considered within an ethical framework of autonomy. Following his unexpected emergency admission in a state of temporary unconsciousness, the counsellor attempted to implement these wishes as part of keeping faith with the client (fidelity) and as often happens some unanticipated complications in the implementation of planned actions arose. The counsellor attempted to make decisions for the client's good (beneficence) or at least to minimise the potential harm (non-maleficence), in this case finding alternative arrangements for a dog rather than having him put down. In other words, the ethical principles which informed the planning within an ethic of autonomy were reprioritised by the necessity of changing to an ethic of individual welfare and could be reprioritised again as the client recovered.

This specific example suggested the possibility that the ethical frameworks could be explicated in another way which is constructed in terms of permutations of ethical principles. Again it took me some time to divest myself of assumptions derived from normative debates about the application of ethical principles in biomedical ethics (Beauchamp and Childress, 1979;1994), counselling (Holmes and Lindley, 1989) and psychotherapy (Thompson, 1990) in which the focus is almost invariably on the justification or limitations of the paramount ethical principle to the exclusion of consideration of the relationship with subsidiary principles or the totality of principles within an encompassing framework. The normative ambience of differentiation rather than integration prevails in these examples of normative ethical inquiry. The lapse of time as I gradually abandoned assumptions derived from normative ethics was unfortunate and created practical limitations on further consultations. Nonetheless, some consultations have been possible which suggest that the following depiction of the relationship between ethical frameworks in terms of principles are a plausible elaboration of the concept of frameworks. The principles were derived from examples given within

the consultative process but fortuitously correspond to those adopted by Andrew Thompson (1990: 8-11) deduced by normative philosophical reasoning. The distinctive feature of this presentation based on induction within a framework of descriptive ethical inquiry is their presentation collectively in different permutations (see Table 10.2).

Table 10.2: Ethical Framework

	Autonomy	Individual welfare	Community welfare	Fidelity
Point of reference	client	client	third parties/community	counsellor-client relationship
Decision-maker (holder of authority)	client	counsellor	counsellor	joint
Key value/ethical principle	autonomy	welfare (beneficence and non-maleficence)	welfare (beneficence and non-maleficence)	fidelity
Subsidiary principles	beneficence non-maleficence fidelity justice self-interest	autonomy fidelity justice self-interest	justice fidelity autonomy self-interest	autonomy beneficence non-maleficence justice self-interest
Alternative ethical frameworks	Individual and community welfare	Autonomy and community welfare	Autonomy and individual welfare	Autonomy

The framework is defined by a combination of the point of ethical reference, the holder of ethical authority and the key or paramount principle from which the name of the ethical framework is derived. 'Welfare' is defined both positively as a responsibility to 'do good' (beneficence) and negatively as the 'avoidance of harm (non-maleficence). The meanings of autonomy and fidelity have already been defined as 'respect for an individual's right to self-government' (page 197) and 'honouring the relationship of trust between counsellor and client' (page 212). Two new principles have been included to take account of examples derived within the consultative process.

'Justice' might equally be labelled 'fairness' and directs attention to treating service users equitably in relation to each other. This principle was alluded to within the discussions about normalisation, which could form another entire research project in its own right. In summary, the debate about normalisation drew attention to the way in which practice over confidentiality had evolved through a number of stages, each of which I have illustrated with a representative quotation.

(a) Secrecy between an individual service provider and recipient of that service.

> Confidentiality can induce organisational incompetence – the left hand not knowing what the right is doing. Looking back I suspect we adopted a rather self satisfied view of the primacy of confidentiality ... it was a rather adolescent phase in this work ... we viewed it [confidentiality] as way more important than being helpful.

(b) Confidential communications restricted to members of the same profession.

> At the time we piloted multi-disciplinary non-medical involvement, [prior to] then we actually did have some pretty strict barriers to communication between the different members.

(c) Team identity is firmly established which takes precedence over professional groupings within the team.

> Our multi-disciplinary team approach has developed and it became clear that not to regard the social worker and the clinical psychologist as equal members of the team ... [i.e.] not being able to participate equally in discussion about care plans ... actually impaired the quality of the service that was being provided for individual patients.

The movement from one stage to another was viewed as progressively normalising HIV services in the sense that within the teams the kinds of working relationships which characterised good practice in teams providing non-HIV-related services were being adopted. Those who favoured 'normalisation', which had widespread but not universal support, did so because of views about fairness of treatment between clients or patients with comparable needs. One participant teased a colleague with a playful irony about an assertion that he tried to be even handed between all kinds of his clients:

> .... [name provided] doesn't understand that HIV is more important than anything else. This is it. He has the temerity to think that some of his other [i.e. non-HIV related] patients are suffering as well.

It was envisaged that 'fairness' and 'de-stigmatisation' coincided with normalisation:

> Well I feel that part and parcel of my job is to try and normalise HIV and not to make it something special and I would say ... I respect all patients' confidentiality, not just those who are HIV positive, although there are special issues surrounding that [medical condition] depending on which avenue you work in and with the patient.

Within drug-related services it was suggested that 'fairness' between clients would shift the emphasis in service provision to the benefit of the client from encouraging stigmatised dependency to greater autonomy.

> ... my own belief in drug services is that different levels of service to HIV positive and HIV negative people are divisive, patronising, a load of nonsense. What we are saying is that these poor souls have this virus which may or may not kill them and that they need to be treated differently ... I think [that] a lot of the argument presented on this is fuzzy in the extreme. I think that sometimes people argue that by giving them high levels of medication, for instance ... we are preventing them from spreading the disease. I already think that that's a kind of non-sequitur ... Individuals [drug users] need to be responsible ... and the effort needs to be put into education, needle exchange, making drug services more accessible, rather than ... stigmatising and corralling groups of HIV positive [people].

This last quotation illustrates the way in which the relative priority of these three principles has been considered in the context of one issue. The discounting of non-maleficence with regard to HIV prevention is justified in terms of the combined benefits of autonomy and justice. However, none of the principles are necessarily extinguished by the prioritisation of others.

The other principle which has been introduced is 'self-interest'. Examples of this which arose within the consultation were considerations of the consequences of one course of action over another on the participant's relationships with colleagues, and weighing up the relationship between personal and professional ethical boundaries. It is probable that this principle was understated because of the general assumption within applied ethics

that self-interest is bracketed out of ethical considerations which are essentially directed towards relationships with others. From a normative perspective, self- interest can be viewed as the counsellor's need for autonomy, beneficence, non-maleficence, fidelity and justice (Thompson, 1990: 10) which ought to be weighed in the balance alongside the needs of others. However, this full range of applications of a principle of self-interest were not evident within this particular descriptive ethical inquiry.

Issues of proximity and integration

The concept of ethical frameworks associated with different permutations of ethical principles provides a basis of resolving the opening conundrum of apparent team cohesion existing in contradiction to the avowal of different ethical frameworks. If ethical frameworks were defined solely in terms of a dominant value then the absence of shared values would constitute a major threat to team cohesion. Instead the perceived and experienced sense of shared purpose with more subtle differences in ethical emphasis according to context, role, personal disposition and perhaps other undiscovered variables is a much more credible explanation both to those participants that I have been able to consult and to my sense of the research process. It makes much better sense of teams who combine around a shared purpose and who can accommodate degrees of difference between individuals in their ethical predispositions.

It is probably more evident within this chapter than the earlier ones, the extent to which adopting a research orientation of descriptive ethical inquiry challenged my own normative assumptions and what I have understood to be existing views within normative accounts of ethics appropriate to health care and counselling. The value of descriptive ethical inquiry in combination with inductive analysis (or other inductive methods) is that it demands a different way of attending to ethical issues and as a consequence can develop new insights which themselves raise issues for normative debate. Throughout the previous two sections I have attempted to bracket out any personal predisposition to

debate what *ought* to be considered right. Instead I have concentrated on explicating the conceptual maps used explicitly and implicitly by HIV counsellors and other HIV-related service providers. The consultative process has helped me to retain a dual focus on ethics and people as the one is the creation of the other.

In the next section I shall consider some of the implications of this research in relation to research methodology, professional codification and the wider social dynamics which have influenced the development of ethics within HIV counselling.

Section 4

On learning from descriptive ethical inquiry into HIV counselling

The previous sections provide a progressive account of how the research process has unfolded over time. The benefits of this sequential narrative are that it emphasises the context of specific phenomenon and the associated ethic. The weakness is a loss of perspective on the overall implications of the research. This section attempts to redress the balance by taking an overview of what has been learnt from this application of descriptive ethical inquiry. Chapter 11 considers the relationship between this kind of research and seemingly similar procedures used in the generation of professional codes. The final chapter draws together different elements of the research to map the conceptually structural components of the ethical domain of HIV counsellors.

Chapter 11

Ethical impoverishment by professional codification?

When I started this research I rather naively failed to appreciate the extent of the difference between a consultative process used for professional codification and academic research. My motivation for the research grew out of my experience of professional consultative processes for the British Association for Counselling (BAC) codes 1985-1993. As the parallels extend beyond personal motivation to similarities in data collection and interpretation using consultative methodologies, the extent of the differences are still surprising to me as well as informative. In this chapter I intend to explore the distinction, not only because I am interested in articulating my own learning but also to construct a better map of the range of sources which can feed into the ethics associated with a professional role. The deliberately provocative question which is the title of this chapter invites consideration of the different consequences of the academically and professionally orientated constructions of ethics. I shall take the exploration of these consequences as a starting point whilst holding in abeyance the pejorative evaluation suggested by the chapter title.

Comparison of output from professional and research consultations

I shall consider some of the distinguishing characteristics separately before drawing them together diagrammatically.

Length: The most readily apparent distinction between the output of professional consultations resulting in codes/guidelines or research processes leading to detailed descriptions of professional ethics is a matter of length. The whole of the subject matter

of the previous section is compressed into thirteen sections, a total of under 500 words, in the code for counsellors (BAC, 1993: s. B.4.1-13). Of these the key requirements are:

> B.4.3 Counsellors should work within the current agreement with the client about confidentiality.

Provision is made to break this requirement in 'exceptional circumstances' which

> may arise which give the counsellor good grounds for believing that the client will cause serious physical harm to others or themselves, or have harm caused to him/her.
>
> (B.4.4)

Confidentiality is treated more succinctly in the guidelines for counselling psychologists (BPS, 1995: s.1.5.1-3). The corresponding operational requirements are:

> The practitioner will clarify and explain the nature and extent of confidentiality from the start. Circumstances in which confidentiality may be breached will be identified.
>
> (1.5.1)

The brevity of the treatment is not unusual and is characteristic of the prototype of professional codes, the Hippocratic Oath, to which most doctors bound themselves until recent times.

> What I may see or hear in the course of treatment or even outside the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about.

Even the more extended requirement in the *Advice on Standards of Professional Conduct and on Medical Ethics* issued by the General Medical Council (GMC, 1993 – under 450 words) are considerably shorter than the 23,000 generated to capture the output of descriptive ethical inquiry.

Style and content: There are considerable divergences in style and content between the output of professional and research-based ethical inquiry. Stylistically professional codification is condensed into abstract and general statements in comparison to the latter where the style is discursive and the content expressed more concretely or with attention to particularities and in ways which are more contextually specific. These characteristics

of research-led ethical inquiry are not idiosyncratic to me but also characterise the writing of Gilligan (1982) and Cameron (1993).

Voice: One of the more significant ethical differences are what might be considered matter of 'voice'. If the output of professional consultations constitutes a code or guidelines it will be written normatively with injunctions like 'should', 'must', 'shall' as well as more permissive language like 'may'. The voice is authoritative and written univocally, that is from the viewpoint of the profession. In contrast, the output from research led consultations is descriptive rather than normative. A variety of viewpoints can be heard including those of the researcher and participants so that the communication is multivocal and pluralistic in describing several alternative ethical perceptions.

These differences are summarised in diagram 11.1

Diagram 11.1: Comparison of output from professional and research focused consultations

Theme	Professional	Research
Length	Short	Long
Style	Condensed	Discursive
Content	Abstract General	Concrete Contextually specific
Voice	Normative Univocal (profession) Authoritative	Descriptive Multivocal (researcher and participants) Pluralistic
Form	Code	Document to generate discussion

Of all the differences, the divergence in voice is probably most significant.

Comparison of processes involved in professional and research oriented ethical constructions

The anticipation of the outcome of the two processes has an effect throughout the consultation process. The divergences in voice correspond to differences in status, type of moral 'authority' and whether or not the content is likely to be enforced. A code or guideline is anticipated as being binding on members within a profession and gains its authority by the democratic process of formal voting within official meetings exercising constitutional powers on behalf of the membership such as annual general meetings. The process of voting affirms or denies ethical preferences held by individuals and sections of the membership. One of the consequences of producing a document for this sort of process is that participants in the consultation have a distinct tendency to be defensive about their existing practices in order to substantiate a claim of moral rectitude, avoid ethical opprobrium or maintain the status quo without the inconveniences of making changes.

My direct experience suggests that an awareness of the impending democratic filtration also influences the response to the emergence of differences of view by the facilitators of that process, usually a committee or working party. There are a range of possible assessments and strategies. A minority view which is incompatible with a majority view may be:

- ignored with/without debate and due consideration
- rejected with clearly articulated reasons to elicit further discussion or to encourage negotiation within the consultative process
- accommodated by 'finessing' i.e. artfully accommodating the minority view by creating a more inclusive and consequently more ambiguous and generalised phraseology
- special provision is made for exceptions.

The end of this process is the collation of a plurality of contributions into a codification which is expressed univocally and authoritatively. The ethical plurality of the participants is rendered invisible in the process of construction by being incorporated within a phraseology of 'boundaried ambiguity'. The ambiguity permits seemingly divergent groups to coalesce into a majority vote. The boundary marks the outer limits of accommodating a diversity of view within the 'acceptable' range of ethical opinion and practice. For example, the requirements about confidentiality developed by the British Association for Counselling accommodates several but not all the ethical frameworks identified in the previous section. Such flexibility may be appropriate but it stands in contrast with the voice with which such requirements are expressed which is authoritative and implying a single standard.

The authoritative voice which characterises codes raises the question of where is that authority derived from? This could be the subject of substantial research but it is fairly evident that validation of authority by the democratic process is the culmination of a process which has the effect of incorporating or excluding other claims to authority. This is reflected in the significance of deductive reasoning which influences the construction of the codes. Deductive reasoning is deferential in orientation towards some greater authority. These greater authorities to which the codes defer include the law as it applies to the members as citizens within a legally constituted State and collectively to the status and powers of the professional organisation. Adherence to ethical and moral norms, regardless of whether these are conceived within a socio-political or moral philosophical discourse, adds to the authority. A further source of authority is based on appeals to the dominant forms of knowledge which characterise the profession. This might be a direct appeal to some empirical knowledge about the consequences of particular kinds of intervention, e.g. arguments about effectiveness, empirical knowledge about the impact of abuse of ethical norms, etc.. More subtle deductions from the way of knowing and its assumptions which characterise sections of the professional may also be evident.

Within counselling, different therapeutic models convey different moral valences. For example, a psychodynamic orientation with its predisposition towards psychic determinism rather than free will and responsibility (Karasu, 1991: 137; Banks, 1995: 55), would tend to favour an ethic characterised in this research as individual welfare. In contrast, the core conditions of congruence, unconditional positive regard and empathy which characterise person-centred counselling founded by Rogers, would tend to favour an ethic of autonomy (Cohen, 1994: 158). Any one of these sources of ethical authority might be the source of deductive ethical reasoning in the production of a code.

One of the implications of the deductive thinking and the democratic filtering in the construction of codes is that the participants' voices cannot be heard fully in their own right. There are disincentives to exploration of views which might contradict any deductions from concepts like those outlined above.

In comparison, the research process is much less constrained both in the form in which the outcome is reported and in the process of conducting the research. Qualitative research methodologies vary in the degree to which they construct limitations on the way researchers work but they all emphasise the importance of listening to the participants and encourage exploration in depth in order to discover the world from the interviewees' point of view (Kvale, 1996: 1). The ostensible ethos is dialogical both between research participants and researcher, and the researcher and other academics, so that even if a researcher varied established methodologies or reached a minority view, it is unlikely to be invalidated merely because it is a minority view. (Other difficulties and barriers may be created in terms of future research funding or academic status but these outcomes are distinguishable from an ostensible evaluation based on systematic reasoning.) Qualitative research methodology stands in a different relationship to the process of construction. It creates a persuasive authority which it is prudent to take into account but it is not authoritative and can be varied by reasoned argument and as such is more readily

deconstructed or reconstructed than the authorities and expectations which constrain codification. The kind of justifications which have produced such a variety of approaches within qualitative research are informative because they are essentially the product of divergences of opinion about what is valid and reliable (or the post modern equivalent criteria of trustworthiness) and although being constructed and argued in different ways, they direct the researcher's attention to the integrity of the research process rather than consideration of authorities which impact on the research process.

I imagine that these observations about the differences which are summarised in table 11.2 may seem obvious to someone rooted in an academic-research based tradition but for me, not only are they intellectually intriguing but represent an experiential shift, a moment of personal realisation which marks a watershed in my personal involvement in research about professional ethics. Two ethical discourses which I started out assuming were 'one and the same' have become quite distinct. This differentiation of codification from academic descriptive ethical inquiry raises the issue of how each relate to normative ethical inquiry.

Table 11.2: Comparison of ethical consultations for professional and research purposes

Theme	Professional	Research
Conceptual method of construction	Induction from participants' experience and deductive from role of professional organisation	Induction from participants' experience. Deductions from professional organisations or moral philosophy minimised or avoided altogether.
Ethos of consultations	Assertive/defensive of existing practices.	More open to exchange of information and opinion.
Status	Binding	Informative/developmental
Type of moral authority	Democratic: individual preferences affirmed/denied by formal voting.	Persuasive: extent to which the output reflects intersubjective experience for participants and satisfies non- participants' criteria for transferability to other contexts.
Enforcement	Formal procedures adopted by profession and informal peer pressure.	No formal requirements. A persuasive document may create informal peer pressure.

The relationship between descriptive and normative ethics

Opinions vary about the relationship between these three forms of ethical expression. The way the relationship is defined is usually indicative of whether a 'strong' or 'weak' view of ethics has been adopted. When James Nickel (1988: 139-48) proposed this distinction he was not implying that 'strong' is qualitatively better than 'weak', and he concludes by expressing a personal preference for the latter (p. 148). 'Strong' or 'weak' refers to the degree of definitive authority attributed to one ethical theory relative to others. Thus a strong version of applied ethics would be associated with the claim that one particular ethical theory is true, well-founded or authoritative and it is possible, in principle, to resolve policy issues by deriving a prescription from that theory. From this

perspective the moral judgment of what is ethical would lie solely within the normative discourse of moral philosophy. The moral worth of descriptive or codified ethics would be deduced according to their conformity with the preferred ethical approach. Those who debate between Kantians and utilitarians, as though one or the other is ethically superior to the other, are clearly operating within an assumption that a strong view of ethics is achievable. From this perspective, the principle of 'respect for persons' characteristic of Kantian deontology is incompatible with the principle of beneficence derived from a utilitarian philosophy. Advocates of these different philosophical orientations would probably reach different conclusions about which ethic ought to be favoured in the socio-political analysis at the end of Section 2 of this research. Kantians would be more favourably predisposed to frameworks of autonomy. Utilitarians would favour positions characterised as welfare. However, advocates of both philosophical schools might reasonably be expected to unite in a thoroughgoing criticism of any view that suggested professional ethics might be advanced by the concept of choosing between different permutations of what from their point of view are incompatible ethical principles. The concept of 'permutation' suggested at the end of the previous section would be likely to intensify rather than defuse the kinds of criticism levelled against others who have discussed professional ethics in terms of non-hierarchical principles. Any suggestion that it might be desirable to move between different paramount principles is inimicable to the 'strong' view of ethics. As the debate between Kantian and utilitarian ethics is often considered characteristic of the current Western socio-political culture, there must be many who would not value positively the kind of description of professional ethics to emerge from this research. They would probably be equally critical of codified ethics to the extent that they cultivated ambiguity between different ethical systems.

It is possible that the concept of permutations of principles within a diversity of ethical frameworks would be less problematic for someone preferring a 'middle' view of ethics in which the use of widely accepted middle-level principles are used as guides to policy.

Beauchamp and Childress (1994) who are widely cited biomedical ethicists have adopted this middle position. They are equally critical of Kantian and utilitarian ethicists who are perceived as having forced an 'architectonic' of 'hastily reached simplicity' on ethics. In their view, 'Untidiness, complexity, and conflict are unfortunate features of communal living, but a theory of morality cannot be faulted for a realistic appraisal of them' (p.107). From this perspective descriptive, codified and normative ethics are distinguished by their functions which are respectively 'to study how people reason and act', to declare a policy on professional ethics, and to determine 'what ethically ought to be the case'(p.5). They express some sympathy with the view that 'an unconnected heap of obligations and values is an ineradicable feature of morality' (p. 107). From this perspective, creating distinct permutations of principles into frameworks partially defined by the paramount principle might seem analogous to sorting pieces simultaneously from several copies of the same jigsaw according to a number of different paramount criteria, e.g. by colour, shape, size, texture rather than concentrating on the application of a single system for completing one jigsaw. They would probably not reject such a way of proceeding if it was seen to have value in enabling professionals to work together more effectively and to talk more meaningfully about ethical differences. However, I suspect that they would be frustrated by the lack of definition and conceptual distinctions within and between the principles. There is a distinction between the level of detail that I have been able to achieve working inductively and descriptively in contrast to the level of detail and distinctions that they achieve working mostly deductively and normatively. In comparison, an exploratory piece of inductive descriptive ethical inquiry must of necessity lack that kind of precision unless it is already evident in the field. This study suggests that at least some busy and well-respected practitioners may take a fairly general and thematic view of ethics which is applied to a detailed knowledge of the therapeutic situation in contrast to the moral philosopher who reverses the attention to generality and specifics.

A third view is possibly closer to the overall paradigm of critical theory within which the research methodology for this piece of work was formulated. From this perspective, issues of ontology and epistemology merge in the assumption that all meaning is a human creation influenced by social and cultural factors which permeate all means of communication. From this perspective, it is meaningful to question what is being communicated by distinctions between descriptive, codified and normative ethics or a comparison between generalised and detailed distinctions. The answers would extend to considerations beyond the text to the socio-political implications in terms of power, status and culture. Knowledge is not accumulative but transformative within specific historical and social contexts. It is a 'dialectical process of historical revision that continuously erodes ignorance and misapprehensions and enlarge more informed insights' (Guba and Lincoln, 1994: 114). From this viewpoint, the value of what has been achieved in the research is the extent to which there has been new learning and insight primarily for all those who took part in the interaction within the research. The extent to which the research participants moved from a less complete to more complete knowledge about their collective ethical stances would be a positive outcome and ethically meritorious especially if it enhanced true communication between people (akin to the ideal speech situation envisaged by Jurgen Habermas) (Bernstein, 1995: 47-51). To the extent that the different explications of ethics about HIV counselling have succeeded in achieving this would be the focus of interest. A secondary gain would be the degree to which any gains developed within the research can be transferred by external readers to other settings using a process of 'anticipatory accommodation'.

The potential contribution of descriptive ethical inquiry within an interactive research methodology

These two phases of research have sought to find a coherence between the interaction of the researcher with participants in combination with the descriptive and developmental

task of the research. The consultative methodology was developed as a pragmatic response to the desire to maximise the range of people involved without excluding some merely because of other demands on their time and a high level of busyness. Limitations of resources were also a factor. The outcome in each case has represented a significant collective advance in the articulation of ethics applicable to the participants' work. This is not to say that the consultative methodology cannot be further improved. As with other forms of participative research, a great deal depends on finding an appropriate structure within which the interaction takes place and on the quality of the interaction that takes place. This is a process which can continue to be refined by experience and critical reflection. I would certainly like to strengthen the collective experience relative to one to one and sub-group experiences in future uses of this methodology. The interactive quality of the research has been a constant challenge to my initial tendency to view ethics normatively. As a result of observing the impact of these two research processes on participants and myself I am increasingly convinced of the value of descriptive ethics to the contemporary construction and understanding of applied ethics. For those who favour a middle- level view of ethics, descriptive ethics developed interactively represent a potential source of enrichment to their discourse. For those who take a 'weak' view of ethics and especially those who favour a post-modern paradigm, descriptive ethics are all there are. More 'authoritative' ethics are decoded into descriptive ethics within a particular socio-historical context. The combination of descriptive ethics with a participative methodology is highly compatible with this paradigm.

Finding methods of teaching professional ethics has been a longstanding problem complicated by differences in view about whether the process should be deductive from specific ethical systems, comparative between deductions from different systems or inductive as represented by casuistry (Elliot, 1992: 42). A reapplication of these research methods to the classroom would provide an additional teaching method. Maximising the interactive opportunities within the learning environment in combination with building

on the ethical experience of participants to construct ethically rich descriptions would represent an addition to the inductive ways of learning and foster an approach to ethics which extends the consideration from what is 'right' or 'wrong' to decyphering assertions of ethical correctness as socio-cultural communications. Within counselling and psychotherapy this aspect of ethics is particularly relevant and avoids the inherent ethical inhibition in claims to be 'non-moralising' by substituting a capacity to deconstruct moral claims in personal and socio-political terms. Perhaps most importantly, the experience of this research would suggest that practitioners across a wide range of professional disciplines could enter into ethical dialogue more easily when the discussion is started from a sharing of the circumstances in which the issue arose than from a moral theory. This is a sound reason for incorporating a higher level of inductive reasoning based on descriptive ethical inquiry within the teaching of professional ethics.

I started the chapter by stating that I would hold in abeyance consideration of the pejorative implications of the title to this chapter. It is not codification in itself which leads to ethical impoverishment. The analysis in this chapter suggests that the advantages and limitations of codification are more apparent when held in comparison with normative and descriptive ethics. The authoritative and univocal voice of the code which is a feature of that form of ethical expression is more readily deconstructed when it is set in a wider ethical context. The overall impact of conducting descriptive ethical inquiry within a consultative methodology has been to direct attention towards the function of ethics in terms of their aims and relationship to other possible ethical positions, rather than a structural approach in which an ethic is bureaucratised and fixed within relatively unchanging guidelines.

Chapter 12

Mapping the ethical domain of HIV counsellors

> There is not just the problem of the ambiguity of ethics. More important is the question of the *ethics of ambiguity*. The incumbent of an emergent role is constantly forced to take ethical positions in the face of ambiguity.
>
> (Goldner, 1967: 264)

This research started as an exploratory study within the parameters of descriptive ethical inquiry. Three distinct aspects in the development of ethics of HIV counselling have been considered. First, the outline of stereotypical views within the wider ethical arena formed the context within which the ethics for HIV counselling were being developed. The fieldwork undertaken in 1990 constituted the second aspect and represented the state of affairs within a newly emergent professional role aspiring to its own professional identity with correspondingly distinct requirements for supervisory support and training. The third aspect captured the developmental process in 1994 when the role of counselling within HIV-related services in the area studied had become interprofessional in character rather than a distinct role in its own right. The major feature of the detailed studies of ethical views within all three aspects of this research is the persistence of some distinct perspectives throughout the research regardless of the wider or narrower focus on aspects of HIV-related services and the transformation in the aspirations for HIV counselling from a profession in its own right to a role which ran across and between different professions.

In this final chapter I intend to present an overview of the socio-historical context of this study to provide a basis for theorising about the dynamic influences on the construction of professional ethics and the persistence of recurrent positions. Consideration of three major research reports on HIV-related issues which have appeared towards the end of this research process provides an opportunity to define the relationship between the outcome of this descriptive ethical inquiry with other methodologies and to consider the

relationship between these different kinds of metaphorical maps. The chapter concludes with an exploration of the implications of this research for counselling practice and further research.

A socio-political context for ethical development

One of the features of this research is the reciprocal dynamic between social and political valences and the construction of professional ethics. Unlike in some accounts of normative ethics which are presented as longstanding, if not perpetual verities within the strong view of moral philosophy, this study, within the parameters of descriptive ethical inquiry, is firmly located within a specific historical context covering the short period between the origin of AIDS and 1995 with a specific focus on the key years for the development of HIV counselling from 1990 to 1995. Succinctly encompassing the key events during this period is a considerable challenge and one which can be best accomplished in a chronological table which sets out each of the major areas of influence contributing to the overall dynamic. The chronological time bands are somewhat arbitrary and have been chosen to facilitate the compression of the material into a more informative presentation than would be possible in a spread sheet format based on annual events. With some minor variations, these time bands are broadly compatible with those suggested by Virginia Berridge (1996: 6-8) in her social-historical account the development of AIDS policy. She identified four major phases. The first phase from 1981-5 was characterised by a movement away from government indifference which had left 'AIDS missionaries' to pioneer self help and the initial response. By the end of this phase public policy was actively taking AIDS into account within a liberal ethos. An emergency response on a scale not usually seen outside wartime placed AIDS high on the public policy agenda for 1986-7. This phase was followed by a gradual downgrading of the epidemiological threat posed by HIV and AIDS in Britain with advances in clinical treatments which Berridge characterises as a phase of normalisation and

professionalisation for the newly developed services, especially counselling (1996: 286) from 1987-89. From the viewpoint of this study, the implementation of this phase extended to 1991. The final phase from 1990-94 in her study (1991-95 in this research) represents the combined consequences of a downgrading of the threat of HIV and corresponding reduction in resource allocation with an increasing challenge to the prevailing liberal ethos of the medical approach to HIV and AIDS from a Conservative government intent on re-moralising this area of work and a radical gay agenda determined to repoliticise AIDS. Neither the remoralisation nor the repoliticisation are particularly evident in the 1994 phase of this research, although both these trends were evident in other work that I was undertaking for the inner London health authorities over this period. Within a regional study distanced from London geographically by 250 miles and experientially by a much lower incidence of HIV, the prevailing changes were normalisation and adapting to the transfer of services from hospitals to the community at a time of increasing financial constraint for this area of work. The other major difference between the account presented in table 12.1 and Berridge is the inclusion of evidence during this last phase of the downgrading of HIV counselling as a distinctive and specialised activity.

The key events are classified into bands which represent key categories of social activity which interact with each other. These thematic categories include public attitudes, public policy ethos, epidemiology, clinical developments, HIV counselling and counselling.

Table 12.1: The socio-historical events associated with HIV counselling

	1981-2	1983-4	1985	1986-7	1988-91	1991-95
Public Attitudes	Mostly indifferent.	First popular media reports. Conflicted responses divided between 'them' and 'us'.	Highly conflicted 'moral panic' in opposition to public policy.	Conflicted responses to public education campaign.	Periodic expressions of divided attitudes. Media campaign on behalf of haemophiliacs (1990).	Ray Cornes (haemophiliac) reported to have infected girlfriends (1992). Apparent legitimation of remoralising public policy matches government mood.
Public policy ethos	Mostly indifferent.	Mobilised by concern to protect blood transfusions.	Liberal ethos of public policy established.	National emergency response mobilised. Public education 'Don't die of ignorance' campaign. Dedicated allocations of ring-fenced funding set at high levels.	Routinisation of responses in line with declining epidemiological predictions. Haemophiliacs viewed as 'innocent victims' and compensated (1989, 1990). New services funded. Existing services upgraded.	Moralisation of public policy – contact tracing required nationally (1992). Pre-test 'discussions' introduced in expanded ante-natal testing (1993) Repoliticisation of AIDS activists. Targeting and mainstreaming adopted and funding 'capped' (1993). Ring-fencing abolished (1995). Funding substantially reduced.
Epidemiology		Potential for epidemic becoming apparent.	Apprehension about the scale of an invisible 'clinical iceberg' of infection. Highest predictions of impact made.	Existence of asymptomatic infected people established by named tests but on unknown scale.	Anonymous testing authorised (1988). Predictions of epidemic downgraded in Cox Report (1988). Day Report (1989).	Absence of heterosexual spread on scale of Central Africa confirmed. Knowledge about scale of epidemic considered reliable.

	1981-2	1983-4	1985	1986-7	1988-91	1991-95
Clinical development	Little known. Clinicians defensive of own health. Clinical presentation: small numbers of terminally ill people with rare diseases. Acute terminal.	Putative discovery of virus (1983).	Antibody blood tests developed of sufficient reliability for general testing.	Availability of confidential testing established. Clinical trials initiated on large scale. Clinical presentation changes to include asymptomatic infected people.	Disease progression from infection through symptomatic phases increasingly understood. Treatments of opportunistic infection improve. Prophylactic treatments begin. Growth in clinical trials. Clinical model gradually changes from acute to chronic health conditions.	Prophylactic and therapeutic treatments continue to advance.
HIV counselling	Peer/co-counselling and mutual support groups are an existing feature of the gay movement.		Terrence Higgins Trust employs first counselling administrator. National AIDS Counselling and Training Unit (NACTU) established.	Statutory pre- and post-test HIV counselling expands rapidly with increased take-up of tests – provided by health advisors and newly appointed counsellors. National AIDS Helpline using 200 trained telephone counsellors established early 1987.	Demand for longer term psycho-social counselling increases for all client groups with HIV where peer support proved inadequate. Body Positive locates itself in new premises next to Red Admiral Trust – a counselling service. Provision of HIV counselling in voluntary sector expands considerably. Official reports – Chester (1988), Monks (1988), Bond (1990) recommend role clarification and adequate resourcing of HIV counselling.	Reductions in AIDS funding gradually reduce availability of dedicated HIV counselling. Separation of pre- and post-test functions and psycho-social support between health advisors and psychology/counselling services in NHS. National AIDS Helpline abolishes independent supervision of counsellors. Policy Studies Institute (Allen and Hogg, 1993) recommends downgrading of HIV counselling.

	1981-2	1983-4	1985	1986-7	1988-91	1991-95
Counselling	Proposed legislation by Bright MP, to regulate talking therapies fell at Second Reading (1981). Early stages of national organisation (British Association for Counselling founded 1977) Most counselling provided in voluntary sector. Marriage Guidance Council is a major provider. Counselling Psychology Section of British Psychological Society founded 1982.	First code of ethics for counsellors published (BAC, 1984). Private practice in counselling gathering momentum.	Counselling in higher education and schools becomes increasingly common and continues to expand erratically.	Counselling increasingly available from wide range of sources.	Role definition of counselling becomes important. Distinction between counselling and counselling skills established (1989). Code of ethics for counsellors revised (BAC, 1990).	Substantial growth of counselling within primary health care. Counselling Psychology Division established with BPS (1994). First guidelines for counselling psychology (BPS, 1995) United Kingdom Council for Psychotherapy established (1993).

When the studies are set against the wider social and political context, the retraction from the development of HIV counselling as a new professional role providing an integrated range of services as envisaged in diagram 4.12 becomes explicable as a combination of different factors. The downgrading of the projected level of infection, the resistance of some HIV counsellors to undertaking all aspects of preventative work reported as a result of the 1990 research (Bond, 1991: 67-8), the development of medical knowledge and

treatment making HIV infection increasingly analogous to other chronic illnesses for which there are no specific counselling services in existence, the resistance of established teams to the integration of a new profession and the competition for HIV antibody test counselling from health advisers and for working with people with HIV from clinical psychologists, were probably all contributory factors. The necessity to rationalise services in order to manage funding restrictions was thought to be a major factor by service managers with whom I have discussed the issue. There may also have been an ethical component. The professionalisation of counselling along the lines suggested by participants in the 1990 research would have secured a professional role based on a non-moralising ethic at a time when there was an opposite moral agenda beginning to be implemented at ministerial level in the Department of Health. Health ministers appear to have been determined to incorporate AIDS policy within a wider moral agenda of traditional values which characterised the rhetoric of the Conservative party in the early 1990s. Berridge (1996) provides examples of how this was achieved. The introduction of national HIV contact tracing in 1992 was a ministerial initiative (p. 258). In 1993 Brian Mawhinney instituted a review of the Health Education Authority which was seen as simultaneously downgrading of AIDS as an issue as well as a curb on an agency which was actively promoting a liberal view on sex and drugs. Mawhinney is also reported by Berridge as opening a 'Health of the Nation Conference' (1993) with a speech which included an assertion that the word 'No' was a factor in producing good sexual health and he announced a determination to introduce policies to discourage illicit drug use (p. 258). In taking this stance, he was joining with Michael Howard as Home Secretary and the Home Office's preference for a hard-line against the medico-bureaucratic traditions and associated ethical ethos of moral 'neutrality' characteristic of the Department of Health. It is in this context that a civil servant is reported as commenting that Mawhinney was called 'the Prince of Darkness by his civil servants' and that he was trying single-handedly to reverse the policies of harm minimisation towards abstinence and

moral counselling (p. 259). These circumstances would suggest the professionalisation of HIV counselling around an ethic of autonomy and a qualified support for HIV prevention was unlikely to succeed. This appears to have been the case. Counselling achieved and continues to hold much more professional status in other medical settings such as human fertilisation and embryology where, for example, the additional confidentiality espoused by counsellors is included within a code of practice authorised by statute (HFEA, 1990: s.6.2-25) or in primary health care where the employment of counsellors has expanded rapidly during the 1990s (Corney, 1997: 162; East, 1995: 23; Keithley and Marsh, 1995: xi). The involvement of people with HIV and especially gay men in the provision of counselling (see chapter 4) may have meant that the original opportunity created by the development of HIV counselling for people close to the experience of clients to influence service delivery also brought conflict within the clinical setting. A persistent resistance to the advocacy of HIV testing by the gay community in favour of education, information and counselling supported by an ethic of radical autonomy may have contributed to the conflict. This antagonism to testing conflicted with the growing scientific and clinical support for the use of testing, not simply on the grounds of protecting the community, but because of improvements in prognosis associated with regular health checks and early prophylactic treatments. The gay and medical alliances which had characterised the early phases of AIDS policy-making and were subsequently replaced by an exclusion of formal gay representation at policy making level (Berridge, 1996: 128) may well have been re-enacted less publicly in the clinical settings during the early 1990s. Some of the intense feelings evident in the discussions of HIV prevention (chapter 5) appear to be a consequence of conflict within interprofessional teams along these lines. The relative absence of this conflict in the 1994 research may have been either an indication that it had subsided or had been less of an issue in the Tyneside area. If this interpretation of events is correct, it is an indication that the selection of particular ethics may be inseparable from issues of social identity

and group allegiances. The remoralisation of AIDS towards moral traditionalism by senior politicians and repoliticisation towards radical autonomy by some gay men as an activist revision of AIDS deconstructivism represent declarations of membership of particular groups in society. Similarly the non-moralising liberal ethic with relatively directive interventions based on scientific evidence represents a commitment to a particular version of a professional class within society. Further analysis of the relationship between the five ethical positions which persist throughout this research in various guises will amplify this point.

These five ethical positions are identifiable either because they are adopted by participants or expressly rejected in the process of defining a more acceptable position. They are reformulated for this final analysis in order to integrate elements of all the previous descriptions as:

Radical community welfare:	an ethical orientation which is consequentialist in emphasis, subordinating the individual to the perceived collective good. In the context of HIV, this ethic would attract the support of pre-modern responses to plague such as a return to traditional moral values (moral panic discourse) as well as those committed to a social welfare (as opposed to liberal) style of government. Both positions would advocate the use of the coercive powers of the State to enforce segregation or testing.
Qualified community welfare:	the application of this ethical approach is qualified by the expectation that it will be applied only to those who have foregone their right to be treated within an ethic which prioritises the individual over the collective because of the threat that they pose to the wider community due to incapacity, recklessness or deliberately placing others at risk of infection. In compulsory

treatment or hospitalisation of specific individuals and situations where HIV testing is undertaken without consent either by deception (perhaps justified by the 'public good') or anonymously for national screening would be examples of applications of this ethic.

Individual welfare: The emphasis within this ethical perspective is on acting in the 'best interests' of the individual often defined in terms of 'beneficence' and conversely 'non-maleficence' in biomedical ethics. The autonomous wishes of the person concerned would usually be taken into consideration but would not be paramount in a utilitarian orientated analysis. Within these studies the use of advice or directiveness within HIV counselling, the non-negotiable prior condition of client-team confidentiality, the overriding of client's suicidal intent by the mobilisation of prevention strategies could all be construed as examples of the application of this ethic. This ethic would be limited to situations where the 'good' of the specific individual would not significantly violate the 'good' of others.

Limited autonomy: Respect for individual autonomy is paramount and would be qualified only where respect for the autonomy of the individual concerned would directly and significantly threaten the autonomy of others. In this ethical orientation, respect for people as 'ends in themselves and not means' is a guiding principle and is characteristic of the deontological ethics of Kant. Within this research, evidence of an *a priori* emphasis on informed consent for testing, treatment or counselling, respect for suicidal wishes

and a moral emphasis on prioritisation of 'psycho-social care provided on the basis of informed consent' over 'HIV prevention' have been interpreted as evidence of this ethic.

Radical autonomy: Unlimited respect for the autonomy of individuals is characteristic of this ethical perspective. In the context of HIV counselling, this ethic would preclude breaching confidentiality or the imposition of constraints on individual freedom because responsibility for HIV prevention is exclusively allocated to each individual to protect themselves. The ethical responsibility of HIV counsellors in all circumstances is to endeavour to ensure that individuals are sufficiently empowered to protect themselves by the provision of knowledge, social skills and appropriate support which includes counselling. This ethic probably motivated the peer education and support movements which characterised the gay response to AIDS and was strongly associated with a resistance to any remedicalisation of sexuality as a consequence of AIDS.

In broad terms, the liberal range operated within the accepted principles of deontological and utilitarian ethics which characterise this cultural stance would include a variety of positions within the three middle ethical positions. (From a normative line of argument it has been suggested that neither a utilitarian nor a deontological ethic could justify the level of sacrifice of individuals for the good of society permitted in radical community welfare (Bassford, 1991: 110-13; Gillett, 1990: 67; Illingworth, 1990: 133). Similarly, it has been argued that unlimited respect for autonomy is not a requisite of either of these ethics (Cohen, 1994: 172-3; Crisp, 1990: 77). Professionals who adopt any of these three ethical positions (specifically qualified community welfare, individual welfare and

limited autonomy), or combinations of them are working within a mainstream ethic in Western society which complements and endorses claims for self-regulation by devolved governmental power in many situations. In comparison, radical community welfare and radical autonomy represent sectional interests attempting to shift the broader moral agenda in their favour. It is one of the ironies of the social history of AIDS that a government committed to deregulation and laissez faire in economic matters adopted a stance with regards to AIDS which was more characteristic of state planned economies. Conversely, the radical ethical agenda of AIDS deconstructivists ran the risk of achieving the opposite of its avowed aims by placing those it represented outside the ethical mainstream and paradoxically provoking a reversal of the social acceptance of diversity in sexuality that they were fighting to achieve.

These stereotypical interpretations provide a basis for illustrating the claim that the adoption of an ethical stance was reciprocally related to allegiance to a social group. However this research also demonstrates that these observations may only apply in broad terms. The detailed picture is more complicated. There is some evidence of a subtle shift in the balance between acceptable ethical stances within HIV-related service provision including HIV counselling in its specialised and interprofessional forms.

Diagram 12.2: Relationship between ethical stances 1990-1994

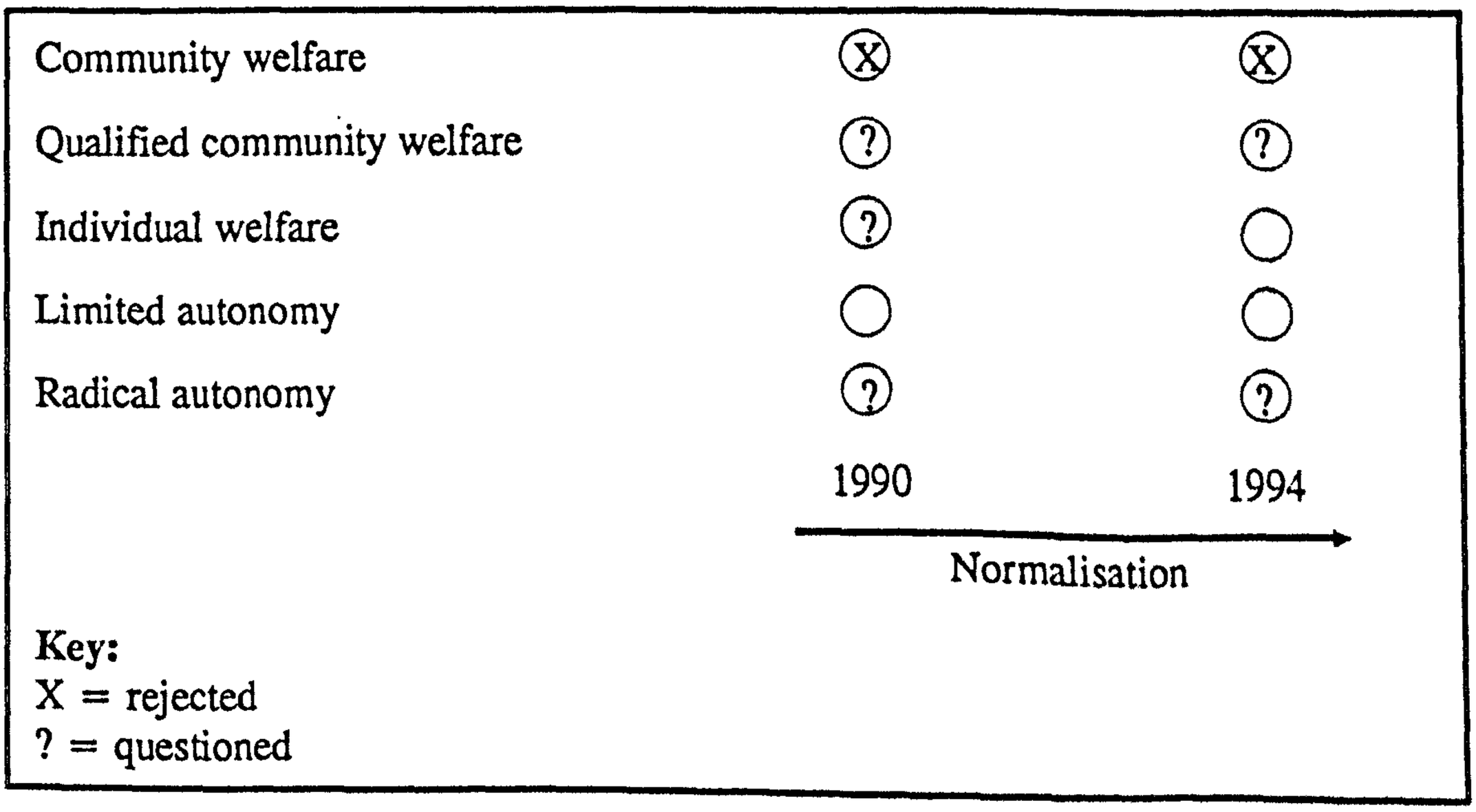


Diagram 12.2 represents the exclusion of radical community welfare from the acceptable range of ethics for the delivery of HIV-related services. So far as I am aware, there is no evidence of HIV-related services becoming more moralising as a result of government policy nor has there been any extension of coercion reported in the treatment of people with HIV, either in this research or elsewhere. The acceptance of an ethic of radical autonomy has always been questioned by some service providers but has also been advocated by those who welcomed the involvement of members of the communities most affected by HIV within the provision of services. The questioning of an ethic of limited community welfare represents the converse of the debate about radical autonomy about whether adults should be protected from the actions of other adults or be regarded as responsible for protecting their own health. A comparison between the two major periods of fieldwork conducted in this research suggests that the shift from specialised HIV counselling to interprofessional HIV counselling may also have been accompanied with less questioning of medical directiveness (which should not be confused with overt moralising) with an ethic of individual welfare. This may amount to no more than observing that the interprofessionalisation of counselling represented an incorporation of medico-clinical ethos alongside the ethos of generic counselling within the interprofessional role. This range of ethics evident at that moment in the history of HIV counselling created the circumstances for explicating the various approaches to HIV counselling identified in Section 3 of this research.

Another level of potential interpretation is partially masked by the necessity of avoiding disclosure of personally sensitive information which has been communicated by participants and the withholding of less personally sensitive information which could have led to the deductive disclosure of the identity of individuals. Within professions, there were differences of view about the appropriate ethics to be applied. This sometimes reflected considerations about the specific aims of a particular post or the circumstances of the clients. Personal experience was also a factor. However there were also divisions

of opinion between members of groups who stereotypically might be expected to share the same ethic. Some of the fiercest arguments that I witnessed were between gay counsellors debating a choice between qualified community welfare and radical autonomy or between specialised HIV counsellors debating the appropriateness of individual welfare and limited autonomy. The ferocity of these exchanges extended beyond differences based on rational reasoning and seemed to be influenced by the desire to preserve a social identity.

The relationship between this research and other research based publications

During the course of this research four other publications have appeared, none of which is directly concerned with the same subject matter of mapping the ethical domain of HIV counsellors, but each is sufficiently close to the subject of this research to be of interest. One of these has already been mentioned several times during this chapter.

In her history of the development of policy about AIDS, Virginia Berridge (1996) makes many references to counselling, but in a very wide ranging social history does not appear to give it systematic attention. As a consequence her assessment that 'the role and professionalisation of counselling reached new heights' is not supported by an analysis of the basis for this claim. Her interpretation would probably have been more accurate if she suggested that the heights were 'aspired to' rather than 'achieved'. The first phase of my research was funded by the Department of Health alongside other projects intended to standardise and regularise the new initiatives brought into being during the national emergency response to HIV infection. Professionalisation in terms of establishing a role identity, a coherent and integrated view of the services to be provided by people with adequate training and counselling-supervision was a part of the collective vision for this new service endorsed by the participants in the first phase of the research. Berridge is aware of these aspirations and cites the report of this phase of the research (pp. 303,

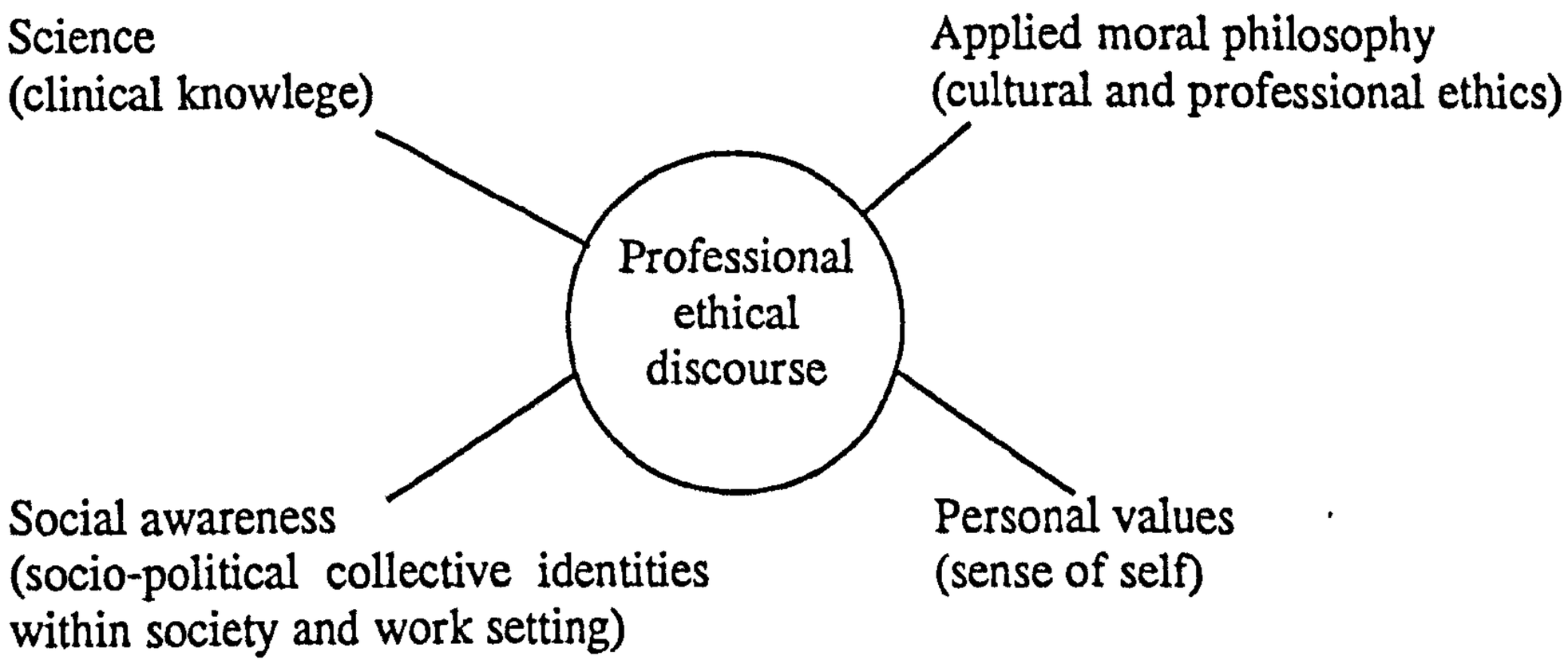
345). However, she appears to be unaware of the report of the Policy Studies Institute (Allen and Hogg, 1993) with its recommendation that HIV counselling be rationalised. Nor does she take into account the possible significance of the other reasons already mentioned earlier in this chapter for the downgrading of HIV counselling especially in the resistance of specialised counsellors to directiveness characteristic of the medico-clinical ethos in which many were working, their qualified support for HIV prevention and their opposition to moralising increasingly advocated by government ministers. This research does not claim to be social history within the usual meaning of that academic discipline but there would appear to be some grounds for revising what constitutes a minor theme in Berridge's very comprehensive and multifaceted account.

A study by Miriam Cameron (1993) of the ethics adopted by people living with an AIDS diagnosis is particularly interesting as the only other research known to me working within the parameters of descriptive ethical inquiry and specifically applied to AIDS. Using a phenomenological methodology to construct depictions of a range of ethical dilemmas, she was impressed by the correspondence between the way participants in her research approached ethical dilemmas and virtue ethics. The prototype for virtue ethics remains Aristotle (1987). The essential features are that the identification of 'the right thing to do' involves developing contemplative reasoning and moral virtue and then using calculative reasoning to resolve the problem. Contemplative reasoning is defined by Cameron as 'an intuitive grasp of first principles' resulting in philosophic wisdom. Moral virtue is an excellent character or disposition to choose the mean between excess and deficiency of a human behaviour. For example the mean between cowardice and rashness is courage. Calculative reasoning is the rational determination of how to secure the ends of human life. In exploring the relationship between virtue ethics and the kind of principled reasoning which characterises this research she suggests that the emphasis on principle is at the expense of meaning and integrity, which are central to an approach based on virtue. This comparison is interesting because it was my sense of the individual

integrity of the research participants which directed my attention to contributions which suggested a conceptual basis for this felt sense of personal coherence and to describe these concepts in terms of combinations of principles. It is difficult to know what to make of the differences between Cameron's and my own approach other than to acknowledge their existence. It is possible that our respective prior knowledge and philosophical predispositions influenced the outcome in the researcher-participant dynamic because she was also consulting with participants as the research evolved, although perhaps more in the mode of validating her account of their experience than in developing an interpretative frame but this is difficult to determine in her account. I suspect that the priority of confidentiality and preserving the anonymity of participants has limited the detail disclosed in her account of the interaction with participants, much as it has done in this account. The possibility of cultural differences between the research participants cannot be excluded as a factor. Cameron was specifically concerned to include women and people of colour who are often excluded from research and ethical discourse in the Western tradition. Both groups contributed to my research. Collectively, women accounted for 50% of participants in this research but people of colour were under 5% of participants. The cultural divide between the United States and Britain could also have been a factor. Not withstanding these differences, my intuition is that the critical factor is the difference between being a service provider and recipient, not that these were totally mutually exclusive categories in either research; but, there is a specific focus which privileges the experience of the former in my research and the latter in Cameron's. There were a number of instances when participants in this research suggested that they would have viewed their ethical situation differently had they been in the same circumstances in their personal life rather than taking on a role as a formal carer or counsellor. It seems as though the process of moving into a professional role created by many of the social dynamics identified in the previous section and Table 12.1 may create a degree of distancing from a possibility of achieving full personal ethical expression in

the role, perhaps at the expense of contemplative reasoning. There may be a degree of personal dissociation between a sense of 'self' and 'self in role' as a consequence of the role being directly subject to socio-political dynamics. This dissociation might well account for the different philosophical modes chosen by Cameron and myself for approaching professional and personal ethical issues as virtue-based and principle respectively. The dissociation and any associated ethical implications would certainly be worthy of further research. Incidental comments made during this research suggest a number of potential sources for the adoption of a role-determined ethic by individual participants. The main elements are represented in diagram 12.3.

Diagram 12.3: Sources of professional ethical discourse



One of the implications of this interpretation of the differences between Cameron's findings and this research is to highlight the dissociation between professional and personal ethics.

Another study raises more radical questions about the relationship of this research to findings based on direct observations of HIV counsellors working with clients. *Discourses in HIV Counselling* by David Silverman is an analysis of video recorded counselling sessions in this country and the United States. He makes several references to the published account of the first phase of this research (Bond, 1991) which he

compares with Robert Chester's report on *Advice, Guidance and Counselling for People with HIV and AIDS* (1988) and characterises each as 'client-centredness' and 'authoritarian' respectively. Although not a comprehensive description of either research, these descriptions seem relatively appropriate to the relationship between them. Most significantly for the client-centred position that I had reported as typifying most HIV counsellors, he argues that it would be naive to assume that 'client-centred' counselling, while less obviously authoritarian than medically orientated models, is necessarily free of the effects of power (p. 9). In particular, he demonstrates an exercise in power through what he calls an 'incitement to speech' by which counsellors elicit 'troubles talk' from clients (p. 197) in 'a discourse of enablement' within which clients were construed as free to choose (p. 205). Following Foucault (1973, 1977, 1980) he suggests institutionalised discourses, like the discourse of enablement, are sites of power and discipline through which participants act in, and shape, their social worlds. It is a collaborative process in which all the participants act within the available institutional discourses to define, contextualise and remedy clients' troubles. The power to which Foucault and Silverman refer is not necessarily hierarchical. Instead Silverman stresses the power embedded in social relations and activities and its productive aspects. The micro-political processes and social interactions, through which power operates, produce distinctive social realities and kinds of human subjects in the process. Professional knowledge is used within the power relationship in order to constitute people, individually and in groups, as appropriate objects of institutional interest and action. Silverman's research is largely a detailed account using a methodology of 'conversation analysis' of the interactional subtleties and sophistications by which even client-centred counsellors exercise this form of institutionally-validated interactional power. This is important research because he questions many counsellor based interpretations of topics such as 'empathy' and an avowal to refrain from advice-giving.

I have asked myself what are the implications of applying these insights into discourses to this descriptive ethical research. Firstly, it widens any gap between avowed ethics and what is implemented by questioning the notion that the ethics of autonomy achieve the level of 'client-centredness' that is claimed. He provides examples which demonstrate how power can work by constructing subjects who discipline themselves apparently of their own free-will and thus appear to corroborate Foucault's notion of interactive power (pp. 196, 201). Secondly, it raises the possibility that the whole exercise of developing ethical constructs of professional relationships is a self-serving and ultimately self-deceiving device to legitimise the insidious application of interactional power so that for example the rhetoric of an ethic of autonomy legitimises the opposite. For example the 'agenda-offer' to the client aligns the counsellor with the client which may be a more powerful position from which to deconstruct the sense of self than any overt or hierarchical expression of power. Silverman offers these challenges in a positive spirit and supports Peräkylä's (1995: 332) observation that the counselling that they analysed 'is most effective in shaping in a controlled and conscious fashion, the way that people interact with one another in the counselling setting'. However this positive evaluation intensifies the ethical challenge and would suggest that an avowal of an ethic of autonomy may in practice be more closely allied with the ethic of individual welfare. This is an important challenge which merits further research. It also draws attention to a potential limitation of descriptive ethical inquiry using a consultative methodology that is founded on avowed ethics. The level of corroboration possible within the consultative process is substantially less than is possible by analysis of detailed records of actual transactions. Nonetheless, it is not without its value.

The final study to be considered is Philip Burnard's *Perceptions of AIDS Counselling* (1992) which is of much less interest than the others because, in spite of its title, it largely confines itself to the perceptions of nurses in a field which was clearly multidisciplinary. However he does provide evidence of a predisposition towards directiveness with generic

nursing (Burnard and Morrison, 1991) and systematically addresses some of the issues which might be involved in assisting nurses to become more competent and confident in facilitative skills to extend their range of communication styles, if they are to take on more of a counselling role. However, the absence of either a clear contextual location of this book in relation to the research subjects or an apparent awareness of the wider ethical or cultural implications makes this study of limited interest to anyone outside the field of nursing and probably curtails its usefulness to those within nursing.

Implications for interprofessional working involving counselling

Two separate but interrelated issues run thematically throughout this research. These concern professional identity and ethical norms. During the early phases of this research it was assumed that each reinforced the other, a view which would seem to be supported by the professionally authoritative pronouncements in codes and guidelines. However, the second phase of the research goes behind this cloak of professional identity to identify a much greater diversity of ethical positions within any single profession and in use by individuals responding to circumstantial variations than is consistent with the original assumption. The relatively high acceptance of ethical differences between individual participants was a feature of team cohesiveness in which differences were not maximised or viewed pejoratively. Equally they were not ignored and there was a readiness to discuss similarities, differences and difficulties with sufficient openness to make the research meaningful. Perhaps if there had been greater divisiveness and retrenchment to stereotypical professional ethical positions, the second phase of the research would have been easier to conduct. However, the dissolution of ethical boundaries which might have defined specific professional identities raises new issues which appear to have been neglected in a rapidly growing literature about interprofessional working. The sharing of power across professional boundaries in health care teams is considered characteristic of successful interdisciplinary working (Jones, 1986; Pritchard and Pritchard, 1994).

However even in the most recent and comprehensive studies the ethical implications of sharing power between professions passes unnoticed (Otreveit, Mathias and Thompson, 1997). This may be because practitioners have already learnt to accommodate a degree of ethical diversity within their own professions and therefore a continuation of this situation in the shift towards interprofessionalism is not sufficient of a change to merit consideration. However a substantial area of ethical ambiguity has been identified in this research both within professions and between professions, even within apparently successful interdisciplinary teams. This has implications not only for team-members but also for service-users.

One of the avowed aims of codified ethics is to clarify what can be expected of service providers by their clients. It would be unrealistic to expect ethics to eradicate uncertainty in the resolution of all moral dilemmas within the professional-client relationship. Nonetheless the service-user is considerably empowered by prior knowledge of the parameters of reasonable certainty and how areas of uncertainty will be addressed. Where interprofessional working is established, there may be a need for processes which parallel this research to be used in helping the development of an interprofessional and collective ethic within that context. Knowledge of individual differences within teams not only helps to clarify collective ambiguities but may validate some by relating them to particular circumstances and contexts. The advantage of viewing different ethical positions in terms of corresponding permutations of ethical principles becomes apparent in this context. Most importantly, this approach makes the potential proximity between seemingly different positions apparent and avoids an exaggerated and decontextualised amplification of differences which can be characteristic of debates based on moral philosophy where different approaches are often 'presented as warring armies locked in combat' (Beauchamp and Childress, 1994: 110). A more comprehensive review of the advantages would include:

(a) It establishes a conceptualisation of ethical diversity which does not require others to be acting in bad faith or in an ill-considered way in order to hold a different point of view. The standing of one permutation of the same principles relative to another is conceptually closer than a representation of a conflict between basic principles.

(b) The explanation of transitions between ethical positions in terms of reprioritising the same principles in relation to each other corresponds to participants' direct observations of how colleagues could hold different but proximate positions based on consideration of slightly different moral or clinical assessments. It made the acceptance of ethical diversity within a team seem more ethically justifiable and provided a terminology for analysis.

(c) Points (a) and (b) countenance moral divergence without any corresponding requirement to amplify the differentiation.

(d) The criticism of 'principalism' in moral philosophy that principles used in this way cannot resolve issues of moral authority or ontological issues becomes a strength in a professional setting which incorporates people as practitioners with diverse cultural, religious and social allegiances. Permutations of principles have sufficient inherent flexibility to offer a degree of accommodation to diverse pre-dispositions.

(e) The application of combinations of principles to describe different ethical frameworks constitutes a development of both Beauchamp and Childress (1994: 105) and Thompson (1990: 7) as they present ethical considerations in terms of identifying the decisive principle rather than between permutations.

(f) Beauchamp and Childress (1994: 110) value the convergent effect of principles as a way of avoiding the exaggeration of differences of moral philosophical theories. This modification of their approach suggests that an ethical narrative of

permutations of principles may also have a convergent effect in accounting for moral differences discovered by descriptive ethical inquiry which is founded on direct personal experience and perception.

(g) The analysis in chapter 10 which applied the principles to the moral frameworks considered in the previous section provides an ethically sophisticated account of the range of positions possible within a liberal professional ethic which is not as homogenised or authoritatively restricted as an examination of codes might suggest. This interpretation parallels comparable findings using other methodologies and addressing other aspects of the ethical diversity within professions (Goldner, 1967; Strauss and Bucher, 1961; MacDonald, 1995).

Implications for counselling practice

The major implication for counselling is that this research provides a way of accounting for a diversity of ethical approaches permitted within the parameters of any of the major ethical codes (BAC, 1993; UKCP, 1993; BPS, 1995). A great deal more work is required to be confident that the categories generated by this research are relevant to people outside the field of HIV counselling. Early consultations with school counsellors (Dudley, UK, 1997), counsellors in primary health care (Derby, UK, 1997), internationally at workshops in conferences hosted by the International Association for Counselling (Cambridge, UK, 1997) and the European Association for Counselling (Gubbio, Italy, 1997) suggest that the categories may not be comprehensive but many are transferable to other settings. The limitations of codification means that this diversity and ethical sophistication falls outside the direct consideration of professional bodies and therefore will only become apparent by research.

An understanding of the inherent components of counselling ethics creates an understanding of the ways in which counselling ethics adapt to social circumstances.

However, questions are raised about how far some ethical positions are compatible with a radical tradition in counselling which challenges some forms of collective political action (Halmos, 1978) and yet retains a socially radical agenda of empowering social minorities in the tradition of its originators, Frank Parsons who pioneered counselling for immigrants to Boston at the beginning of this century (Zytowsaki, 1985) or as evidenced especially in the early stages of HIV counselling. Carl Rogers can be viewed as part of this radical tradition by directly challenging the medico-therapeutic power balance in the therapist-patient relationship and reconstructing the relationship on more equal terms (Rogers, 1967: 12) which is continued within the person-centred tradition (Mearns and Thorne, 1988: 19; Mearns, 1994: 77-80; Mearns, 1997: 30-1). One of the issues which is inadequately explored in this research is how more authoritative or overtly interpretative models of therapy construct their ethic in a process of working towards individual autonomy.

Most importantly, if the general ideas generated by this research prove to be sustainable in other contexts, a new approach to ethical training and problem-solving will become possible which brings moral philosophy and social science closer together but without necessarily blurring the descriptive-normative divide. The ethical issues and dilemmas associated with counselling will not disappear. They may even increase. This research holds out the possibility of improving the terminology and concepts by which they can be considered and discussed. This possibility might not have become as apparent in a less conflicted and morally ambiguous area of work than that which has confronted HIV counsellors.

Implications for further research

Descriptive ethical inquiry deserves more systematic attention both as a distinctive area of academic and professional interest than it has received to date. The typical way of constructing ethical narrative is normative within applied or practical ethics (cf. Almond,

1995; Singer, 1994) and professional ethics (cf. Thompson, 1990; Bloch and Chodoff, 1991; Beauchamp and Childress, 1994). Identified precursors to this study suggest that the research methodology used in descriptive ethical inquiry can be diverse but that the findings can challenge the basis of conclusions reached by normative debate. Studies of the way women develop ethically (Gilligan, 1982; Gilligan, Ward and Taylor, 1988) have proved a significant challenge to justice-based social ethics, especially the dominance of philosophers like Rawls (1973) and as a consequence have stimulated a diverse range of feminist approaches to ethics (Gatens, 1995; Tong, 1997). Similarly Cameron's study of the ethical issues which confront people with AIDS and how they resolve them challenges any ideas that people with this socially stigmatised illness are lacking in morality. This study continues in this tradition of providing an additional perspective on professional ethics which challenges the normative discussions by suggesting simultaneously both a greater diversity and proximity in ethical views within a professional role as well as the fluidity of professional ethics. Certainly as someone who has frequently written within the normative tradition (Bond, 1988, 1989, 1990, 1991, 1992, 1993, 1994 a and b, 1995, 1996; Bond and Russell, 1993; Russell, Dexter and Bond, 1992), I have been personally challenged and intrigued to move into a different way of thinking and writing involved in generating descriptive ethics. The range of methodological and ethical learning that I have gained has far outstripped my expectations at the beginning of this study. I suspect that the potential is considerably greater than any achievements to date as my understanding of descriptive ethical inquiry was evolving with the research process. Now that it is better established I would hope to be more aware of opportunities which may have been missed in this study.

Some of the most productive follow-up to this research will be the mapping of the ethical constructs of people in other situations, e.g. child protection, drug addiction, and primary health care, focusing on specific professions and multidisciplinary working. A multiplication of studies will provide the best understanding of the relationship between

how ethics are constructed *in situ* and their relationship with the schools of thought evident in normative ethics.

The quotation with which I started this chapter was written by a researcher conducting research within a large organisation. The ethics of qualitative research could themselves be researched by descriptive ethical inquiry. Studies of academic qualitative researchers would be likely to contribute to greater ethical sophistication by exploring the implications of variations in ontological, epistemological and methodological variations. The academic background of research subjects would be likely to bring these issues to the forefront of a consultative research process in ways which are usually excluded in the application of consultative and participative methodologies to professional carers or other professions. Descriptive ethical inquiry has many potential applications. Ethical ambiguity is not unique to the caring professions.

In a small way, this research has attempted to contribute to the larger ethical challenge, that we share collectively as human beings. The challenge is finding ways of collaborating with people who hold a diversity of ethical views without undermining the significance of a commitment to being ethical. This research has described and analysed a microcosm within health-related services which may provide a template for the macrocosmic challenge for society in general. To conclude this research, I will consider the relationship between the specific findings of this research with these broader issues.

Present day society is characterised by a diversity of individual and collective differences which has many manifestations including a plurality of personal and cultural constructions of ethics. This might not matter if ethics were not inextricably linked to the search for meaning in life. Simply to accept that all possible ethical positions are relatively valid, in other words a stance of moral relativism, can be construed as admitting the absurdity of life by which all ethical endeavour becomes meaningless. Following writers like Albert Camus (1947) and Simone de Beauvoir (1948), it may be better to take an alternative

position by describing life as ambiguous and to assert that its meaning is never fixed and must be constantly won. In these circumstances, the emergence of ethical plurality is neither surprising nor contradictory with a commitment to being ethical as an expression of the search for meaning. The challenge of ethical plurality is finding a wide ethical frame within which such plurality can be advocated and defended against monopolistic or fundamentalist claims inimicable to plurality. From this viewpoint, the range of ethical positions adopted by HIV counsellors and other service providers participating in this research existed within a shared frame of resisting dehumanising and oppressive responses to the emergence of HIV-related illnesses. In doing so, they encountered within a tightly defined social sphere what is a larger ethical challenge for present day society as a whole, sometimes and probably rather inaccessibly, described as post-modern ethics. There are close parallels between the experience of participants in this research and with post-modern ethicists like Zygmunt Bauman who were deeply affected by the reality of enforced segregation and extermination of Jews and other social minorities during the 1930s and 1940s. This is the context in which he rejects full blown moral relativity. In his analysis of *Modernity and the Holocaust*, Bauman (1989: 190) argues that the oppression and extermination of so many people was made possible by a deliberately orchestrated and progressive social distancing from potential victims who become depersonalised in the eyes of other members of their community. He suggests that depersonalisation and dehumanisation need not necessarily be the result of such deliberate social planning. He points out that in present day society there are insidious dangers present, especially becoming accustomed to moral indifference with regard to actions not immediately related to one's own sphere of experience (1989: 192). The ethical basis on which he challenges both active and passive depersonalisation is a concept of 'being with others' which is not an optional extra but intrinsic to ethical being and the quest for meaning. 'Being with others' is advocated as that most primary and irremovable attribute of human experience which becomes the basis for ethical responsibility. (In making this

point, he draws upon the philosophy of Sartre, the morality of Dostoevsky and the theology of Levinas, amongst others.) The encounter with 'the other' as a person is what challenges us to act ethically and is the foundation for all ethical endeavour. Bauman's views not only offer an alternative to the potential nihilism of post-modernism but seem to accord more closely with the general sense of moral purpose within ethical diversity that I encountered in the participants in this research. From this perspective, the research itself becomes a moral endeavour in which moral and academic value cannot be disentangled. In so far as this research catalyses dialogic understanding through 'being with others' it serves both academia and morality (Bauman, 1995: 242). The foundation for post-modern morality would also set one of the paradoxes of this research in a new perspective. A research process based on human encounter with each other seeking and encouraging dialogue and responsiveness to others, contributed to the development of a professional role with all the potential for social distancing and creating collective authority that professionalisation can entail. From a post-modern ethical perspective, professionalisation is neither moral nor immoral in itself, but becomes another context in which the challenge of 'being with others' is encountered. Professionalisation ought only to be pursued in so far as it is consistent with the ethical foundation of 'being with others'. Zygmunt Bauman (1993: 245) succinctly encapsulates the post-modern ethical dilemma evident in this research. The post-modern perspective offers more wisdom: the post-modern setting makes acting on that wisdom more difficult.

Bibliography

Adams, E.M. (1992). Naturalism. In L.C. Becker and C.B. Becker (editors), *Encyclopaedia of Ethics*. Chicago: St. James Press, pp. 880-3.

Aggleton, P. and Lomas, H. (1988). Introduction. In P. Aggleton and H. Lomas (editors), *Social Aspects of AIDS*. Lewes: Falmer Press, pp. 1-9.

Allen, I. and Hogg, D. (1993). *Work Roles and Responsibilities in Genito-urinary Medicine Clinics* (Dept. of Health funded research). London: Policy Studies Institute.

Almond, B. (editor) (1995). *Introducing Applied Ethics*. Oxford: Blackwell.

Altman, D. (1986). *AIDS and the New Puritanism*. London: Pluto Press.

Aristotle (1987). *The Nicomachean Ethics* (Translator D. Ross, 1954. Revised J.L. Ackrill and J.O. Urmanson, 1973). New York: Oxford University Press.

Banks, S. (1995). *Ethics and Values in Social Work*. Basingstoke: Macmillan.

Bartholomew, K. (1987). AIDS: Guiding people home. In *Involve*, 57: 8.

Bassford, H.A. (1991). HIV testing and confidentiality. In C. Overall and W.P. Zion (editors), *Perspectives on AIDS: Ethical and Social Issues*. Toronto: Oxford University Press, 106- 21.

Bauman, Z. (1989). *Modernity and the Holocaust*. Cambridge: Polity Press.

Bauman, Z. (1993). *Postmodern Ethics*. Oxford: Blackwell.

Bauman, Z. (1995). *Life in Fragments: Essays in Postmodern Morality*. Oxford: Blackwell.

Beauchamp, T.L. and Childress, J.F. (1994, first edition 1979). *Principles of Biomedical Ethics* (Fourth Edition). New York: Oxford University Press.

Beck, E.J., Cunningham, D.G., Moss, V.W., Harris, J.R.W., Pinching, A.J., and Jeffries, D.J. (1987). HIV testing: changing trends at a clinic for sexually transmitted diseases in London. *British Medical Journal*, 245 (6591): 191-3.

Bernstein, B. (1971). On the classification and training of educational knowledge. In M.F.D. Young (editor), *Knowledge and Control*. London: Collier-Macmillan, pp. 47-69.

Bernstein, J.M. (1995). *Recovering Ethical Life: Jurgen Habermas and the Future of Critical Theory*. London: Routledge.

Berridge, V. (1996). *AIDS in the UK: The Making of Policy, 1981-1994*. Oxford: Oxford University Press.

Biestek, F.P. (1961). *The Casework Relationship*. London: Allen and Unwin.

Bloch, S. and Chodoff, P. (editors) (1991). *Psychiatric Ethics* (Second Edition). Oxford: Oxford University Press.

Bond, T. (1986). *Games for Social and Life Skills*. London: Hutchinson.

Bond, T. (1988). Confidentiality: the need for greater clarity in the Code of Ethics and Practice for Counsellors. *Counselling, Journal of the British Association for Counselling*, 66: 3-8.

Bond, T. (1989). Towards defining the role of counselling skills. *Counselling, Journal of the British Association for Counselling*, 69: 3-9.

Bond, T. (1990). Counselling supervision – ethical issues. *Counselling, Journal of the British Association for Counselling*, 1(2): 43-6.

Bond, T. (1991). *HIV Counselling: Report on National Survey and Consultation 1990* (British Association for Counselling/Department of Health Joint Project). Rugby: British Association for Counselling.

Bond, T. (1993). *Standards and Ethics for Counselling in Action*. London: Sage.

Bond, T. (1994a). *Counselling, Confidentiality and the Law*. Rugby: British Association for Counselling.

Bond, T. (1994b). *Ethical Standards for Counselling in Primary Health Care*. Staines: Counselling in Primary Health Care Trust.

Bond, T. (1995). *The Management of HIV Counselling about HIV in Multidisciplinary Teams*. Newcastle: Northern and Yorkshire NHS Executive.

Bond, T. (1996). Competition or collaboration within the talking therapies. In I. James and S. Palmer (editors), *Professional Therapeutic Titles: Myths and Realities*. Leicester: British Psychological Society Occasional Papers Volume 2.

Bond, T. and Russell, J. (1993). *Report on Ethical Standards and Equality of Opportunity for Advice, Guidance and Counselling*. London: Department of Employment.

Bor, R. and Miller, R. (1988a). *AIDS: A Guide to Clinical Counselling*. London: Science Press.

Bor, R. and Miller, R. (1988b). Addressing 'dreaded issues': a description of a unique counselling intervention with patients with AIDS/HIV. *Counselling Psychology Quarterly*, 1(4): 397-406.

British Association for Counselling (1984). *Code of Standards and Ethics for Counsellors*. Rugby: BAC.

British Association for Counselling (1985). *Counselling: Definition of Terms in Use with Expansion and Rationale*. Rugby: BAC.

British Association for Counselling (1988). *Code of Standards and Ethics for Counselling Skills*. Rugby: BAC.

British Association for Counselling (1989a). *Accreditation Guidelines*. Rugby: BAC.

British Association for Counselling (1989b). *Code of Standards and Ethics for Counsellors* (Consultative Document). Rugby: BAC.

British Association for Counselling (1990). *Code of Ethics and Practice for Counsellors*. Rugby: BAC.

British Association for Counselling (1993). *Code of Ethics and Practice for Counsellors*. Rugby: BAC.

British Association of Social Workers (1986). *A Code of Ethics for Social Work*. Birmingham: BASW.

British Medical Association (1993). *Medical Ethics Today - Its Practice and Philosophy*. London: BMA.

British Psychological Society (1993). *Code of Conduct, Ethical Principles and Guidelines*. Leicester: BPS.

British Psychological Society (1995). *Guidelines for the Professional Practice of Counselling Psychology*. Leicester: BPS.

Broadbent, J. (1987). Assessing the counselling of HIV positive clients. *Health Visitor*, 60(8): 262-4.

Bryman, A. (1988). *Quantity and Quality in Social Research*. London: Routledge.

Burnard, P. (1992). *Perceptions of AIDS Counselling*. Aldershot: Avebury.

Burnard, P. and Morrison, P. (1991). Client-centred counselling: a study of nurses' attitudes. *Nurse Education Today*, 11: 104-9.

Bury, J.K. (1989). Counselling with HIV infection and pregnancy. *British Journal of Family Planning*, 14(4): 116-22.

Cahoone, L. (1996). Introduction. In L. Cahoone (editor), *From Modernism to Postmodernism: An Anthology*. Cambridge, MA: Blackwell, pp. 1-28.

Cameron, M.E. (1993). *Living with AIDS – Experiencing Ethical Problems*. Newbury Park, CA: Sage.

Campbell, A.V. (1990). Education or indoctrination? The issue of autonomy in health education. In S. Doxiadis (editor), *Ethics of Health Education*. Chichester: Wiley, pp. 15-41.

Camus, A. (1947). *The Plague* (Translator: S. Gilbert). Harmondsworth: Penguin.

Carballo, M. and Miller, D. (1989). HIV counselling: problems, opportunities defining the new agenda for the 1990s. *AIDS Care*, 1(2): 117-23.

Carter, E. and Watney, S. (editors) (1989). *Taking Liberties: AIDS and Cultural policies*. London: Serpent's Tail.

Cawley, R.H. (1986). Introduction. In L. Paine (editor), *AIDS: Psychiatric and Psychosocial Perspectives*. Beckenham: Croom Helm, pp. vii-ix.

Centers for Disease Control (1981). Pneumocystis pneumonia -- Los Angeles. *Mobility and Morality Weekly Report*, 5 June 1981. Atlanta: CDC, p. 2.

Chester, Robert (1988). *Advice, Support and Counselling for the HIV Positive: A Report for the DHSS*. Hull: Institute of Health Studies, University of Hill.

Cohen, E.D. (1994). What would a virtuous counselor do? Ethical problems in counseling clients with HIV. In E.D. Cohen and M. Davis (editors), *AIDS: Crisis in Professional Ethics*. Philadelphia: Temple University Press, pp. 149-76,

Cohn, R. (1972). Style and spirit of the theme-centred interactional method. In C.J. Sager and H.S. Kaplan (editors), *Progress in Group and Family Therapy*. New York: Brunner/Mazel.

Collier, C. (1987). *The Twentieth Century plague*. Tring: Lion Paperback.

Cooper, A. and Bender, M.P. (1987). AIDS: what should psychologists be doing?. *Bulletin of the British Psychological Society*, 40: 130-3.

Corney, R. (1997). Counselling in the medical context. In S. Palmer and G. McMahon (editors), *Handbook of Counselling* (Second Edition). London: Routledge, pp. 161-75.

Crabtree, B.T. and Miller, W.L. (1992). *Doing Qualitative Research*. Newbury Park, CA: Sage.

Crisp, R. (1990). Autonomy, welfare and the treatment of AIDS. In Brenda Almond, *AIDS, A Moral Issue– The Ethical, Legal and Social Aspects*. Houndmills: Macmillan, pp. 68-81.

Curran, L., McHugh, M. and Nooney, K. (1989). HIV counselling in prisons. *Counselling Psychology Quarterly*, 2(1): 33-51.

Davies, E. (1989). Minutes of meeting about HIV counselling on 15 June 1989 at National AIDS Trust'. Rugby: British Association for Counselling – unpublished document.

Dawson, J. (1983). Data Protection and the Medical Profession' in C. Bourn and J. Benyon (editors), *Data Protection Perspectives on Information Privacy*. Leicester: University of Leicester.

de Beauvoir, S. (1948). *The Ethics of Ambiguity*. New York: Philosophical Library.

Denzin, N.K. (1997). *Interpretive Ethnography: Ethnographic Practices for the 21st Century*. Thousand Oaks, CA: Sage.

Denzin, N.K. and Lincoln, Y.S. (1994). Introduction: Entering the field of qualitative research. In N.K. Denzin and Y.S. Lincoln (editors), *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage.

Denzin, N.K., Lincoln, Y.S. (editors) (1994). *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage.

Department of Health (1988a). *Personal Social Services: Confidentiality of Personal Information* (Ref. LAC (88) 17). London: HMSO.

Department of Health (1988b). *Report of the Working Group to Examine Workloads in GU Medicine (Monks Report)*. London: DH.

Department of Health (1988c). *Short-Term Prediction of HIV Infection and AIDS in England and Wales: Report of a Working Group (Cox Report)*. London: DH.

Department of Health (1991a). *AIDS and Life Insurance*. London: HMSO.

Department of Health (1991b). *Working Together*. London: HMSO.

Department of Health (1991c). *Care Management and Assessment: Practitioners' Guide*. London: HMSO.

Department of Health (1992). *Department of Health Guidance: Additional Sites for HIV Antibody Testing; Offering Voluntary Named HIV Antibody Testing to Women Receiving Antenatal Care; Partner Notification for HIV Infection*. London: DH, PL/CO(92)5, Appendices 1-3.

Department of Health (1993). *AIDS – HIV Infected Health Care Workers: Guidance on the Management of Infected Health Care Workers*. London: DH (April).

Department of Health and Social Security (1985). *Acquired Immune Deficiency Syndrome: Information for Doctors Concerning the Introduction of the HTLV3 Antibody Test (AIDS Booklet 2)*. London: HDSS, CMO(85)12.

Dilley, J.W. (1988). Psychiatric sequelae of HIV. In L. Paine (editor), *AIDS: Psychiatric and Psychosocial Perspectives*. Beckenham: Croom Helm, pp. 25-44.

Downie, R.S., Fyfe, C., and Tannahill, A. (1990). *Health Promotion: Models and Values*. Oxford: Oxford University Press.

East, P. (1995). *Counselling in Medical Settings*. Buckingham: Open University Press.

Elliot, C. (1992). Solving the doctor's dilemma?' *New Scientist*, 11 January, pp. 42-4.

Faltz, B.G. (1988). Counselling substance abuse clients infected with human immunodeficiency virus. *Journal of Psychoactive Drugs*, 20(2): 217-21.

Family Rights Group (1987). *Confidentiality of Personal Social Services Records*. London: FRG.

Feltham, C. (1995). *What is Counselling? The Promise and Problem of Talking Therapies*. London: Sage.

Forster, G. (1986). Venereology. In D. Miller, J. Weber, and J. Green (editors), *The Management of AIDS Patients*. Basingstoke: Macmillan, pp. 65-80.

Foucault, M. (1973). *The Birth of the Clinic* (Translator A. Sheridan). New York: Pantheon.

Foucault, M. (1977). *Discipline and Punish* (Translator A. Sheridan). New York: Pantheon.

Foucault, M. (1980). *Power/Knowledge* (Editor and Translator C. Gordon). New York: Pantheon.

Freire, P. (1972). *Pedagogy of the Oppressed* (Translated by M.B. Ramos). London: Sheed and Ward.

Fulford, K.W.M. (1995). Psychiatry, compulsory treatment and the value-based model of mental illness. In B. Almond (editor), *Introducing Applied Ethics*. Oxford: Blackwell, pp. 148- 65.

Gallo, R.C., Salahuddin, J.Z., Popovic, M. *et al.* (1984). Frequent detection and isolation of cytopathic retro viruses (HTLV-III) from patients with AIDS and at risk from AIDS. *Science*, 224: 500-3

Gatens, M. (1995). Between the sexes: care or justice?. In B. Almond (editor), *Introducing Applied Ethics*. Oxford: Blackwell, pp. 41-57.

Geertz, C. (1973). *The Interpretation of Cultures: Selected Essays*. New York: Basic Books.

Geertz, C. (1983). *Local Knowledge: Further Essays in Interpretative Anthropology*. New York: Basic Books.

General Medical Council (1993a). *HIV and AIDS: The Ethical Considerations*. London: GMC.

General Medical Council (1993b). *Professional Conduct and Discipline: Fitness to Practice*. London: GMC.

Gibson, D.R., Wermuth, J.L.D., Ham, J. and Sorensen, J.L. (1989). Brief counseling to reduce AIDS risk in intravenous drug users and their sexual partners: preliminary results. *Counselling Psychology Quarterly*, 2(1): 15-20.

Gillett, G. (1990). AIDS and confidentiality: the doctor's dilemma. In B. Almond (editor), *AIDS, A Moral Issue – The Ethical, Legal and Social Aspects*. Basingstoke: Macmillan, pp. 56-67.

Gilligan, C. (1982). *In a Different Voice: Psychological Theory and Women's Development*. Cambridge, MA: Harvard University Press.

Gilligan, C., Ward, J.V., and Taylor, J.M. (editors) (1988). *Mapping the Moral Domain: A Contribution of Women's Thinking to Psychological Theory and Education*. Cambridge, MA: Harvard University Press.

Glaser, B. and Strauss, A. (1965, as cited in P.K. Manning, 1991). Discovery of substantive theory: A basic strategy underlying qualitative research. *American Behavioral Scientist*, 8 (February): 5-12.

Goffman, E. (1971). *Relations in Public: Microstudies of the Public Order*. New York: Basic Books.

Goldmer, F.H. (1967). Role emergence and the ethics of ambiguity. In G. Sjoberg (editor), *Ethics, Politics and Social Research*. Cambridge, MA: Schnenkman, pp. 245-66.

Green, J. (1986). Counselling HTLV-III Sero-positives. In D. Miller, J. Weber and J. Green (editors), *The Management of AIDS Patients*. Basingstoke: Macmillan, pp. 151-168.

Green, J. (1987). Working with AIDS: a personal perspective. *Social Work Today*, 16 February, 18(24): 8.

Green, J. (1989a). The role of voluntary groups in the community. In J. Green and A. McCreaner (editors), *Counselling in HIV Infection and AIDS*. Oxford: Blackwell, pp. 238-47.

Green, J. (1989b). Counselling for HIV infection and AIDS: the past and the future. *AIDS Care*, 1(1): 5.

Green, J. and McCreaner, A. (editors) (1989). *Counselling in HIV Infection and AIDS*. Oxford: Blackwell.

Green, J. and Miller, D. (1986). Hospital counselling: structure and training. In D. Miller, J. Weber and J. Green (editors), *The Management of AIDS Patients*. Basingstoke: Macmillan, pp. 187-93.

Guba, E.G. and Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In N.K. Denzin and Y.S. Lincoln (editors), *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage, pp. 105-17.

Habermas, J. (1992). *Knowledge and Human Interests* (Translator: J.J. Shapiro). London: Heinemann.

Hall, S. (1978). *Policing the Crisis*. London: Macmillan.

Halmos, Paul (1978). *The Faith of the Counsellors*. London: Constable.

Harre, R (1981). The positivist – empiricist approach and its alternative. In P. Reason and J. Rowan (editors), *Human Inquiry: A Sourcebook of New Paradigm Research*. Chichester: Wiley, pp. 3-17.

Heelas, P., Lash, S. and Morris, P. (editors) (1997). *Detraditionalization*. Oxford: Blackwell.

Helbert, M. (1987). AIDS and medical confidentiality. *British Medical Journal*, 295: 552-3.

Heley, A. (1987). AIDS patients made me rethink the general practice. In *Medeconomics*, 8(3): 38-42.

Her Majesty's Stationery Office (1968). *Report of the Committee on Local Authority and Allied Personal Social Services (Seebohm Report)*. London: HMSO, Cmnd. 3703.

Her Majesty's Stationery Office (1987). *Future Trends in AIDS: A Seminar to Discuss the Prediction of the AIDS Epidemic*. London: HMSO.

Heron, J. (1981). Experiential research methodology. In P. Reason and J. Rowan (editors), *Human Inquiry: A Sourcebook of New Paradigm Research*. Chichester: Wiley, pp. 153-66.

Heron, J. (1988). Validity in co-operative inquiry. In P. Reason (editor), *Human Inquiry in Action: Developments in New Paradigm Research*. London: Sage, pp. 40-59.

Heron, J. (1992). *Feeling and Personhood: Psychology in Another Key*. London: Sage.

Heron. J. (1996). *Co-operative Inquiry: Research into the Human Condition*. London: Sage.

Hill, M. (1980). *Understanding Social Policy*. Oxford: Blackwell and Robertson.

Hills, A. (1987). AIDS line coping with thousands. *Social Work Today*, 6 July, 18(44): 6.

Hockings, J. (1989). AIDS counselling in the context of the Terrence Higgins Trust. *Counselling Psychology Today*, 2(1): 83-7.

Holmes, J. and Lindley, R. (1991). *The Values of Psychotherapy*. Oxford: Oxford University Press.

House of Commons Social Services Committee (1986-97). *Problems Associated with AIDS*. Westminster: House of Commons.

Human Fertilisation and Embryology Authority (1990). *Code of Practice*. London: HFEA.

Illich, I. (1975). *Medical Nemesis*. London: Calder and Boyars.

Illingworth, P. (1990). *AIDS and the Good Society*. London: Routledge.

Johnson, A. (1989). The epidemiology of HIV in the UK: Sexual transmission. *HIV and AIDS: An Assessment of Current and Future Spread in the UK* – Proceedings of a Symposium held on 24 November 1989. London: UK Health Departments and Health Education Authority, pp. 14-8.

Jones, R.V.H. (1986). *Working Together: Learning Together*. London: Royal College of General Practitioners Occasional paper no. 33.

Karasu, B. (1991). Ethical aspects of psychotherapy. In S. Bloch and P. Chodoff (editors), *Psychiatric Ethics* (Second Edition). New York: Oxford University Press.

Keithley, J. and Marsh, G. (1995). Preface. In J. Keithley and G. Marsh (editors), *Counselling in Primary Health Care*. Oxford: Oxford University Press, pp. xi-xv.

Kennedy, I. (1981). *The Unmasking of Medicine*. London: George Allen and Unwin.

Kennedy, I. and Grubb, A. (1994). *Medical Law - Text with Materials*. London: Butterworths.

Kimmel, A.J. (1988). *Ethics and Values in Applied Social Research*. Newbury Park, CA: Sage.

Kincheloe, J.L. and McLaren, P.L. (1994). Rethinking critical theory and qualitative research. In N.K. Denzin and Y.S. Lincoln (editors), *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage, pp. 138-157.

King, M. (1988). AIDS and the general practitioner: views of patients with HIV infection and AIDS. *British Medical Journal*, 297: 182-4.

Kockelmans, J.J. (1992). Camus, Albert (1913-1960). In L.C. Becker and C.B. Becker (editors), *Encyclopaedia of Ethics*. Chicago: St. James Press, pp. 121-2.

Kohlberg, L. (1966). Moral education in the schools: a developmental view. *The School Review*, 74(1): 1-30.

Kohlberg, L. (1971). From Is to Ought: How to commit the naturalistic fallacy and get away with it in the study of moral development. In T. Mischel (editor), *Cognitive Development and Epistemology*. New York: Academic Press, pp. 151-235.

Kohlberg, L. (1985). A current statement on some theoretical issues. In Mogdil, S. and Mogdil, C. (editors), *Lawrence Kohlberg – Consensus and Controversy*. Philadelphia: Falmer Press, pp. 485-546.

Kohlberg, L. and Gilligan, C. (1971). The adolescent as philosopher: the discovery of the self in a post-conventional world. *Daedalus*, 100: 1051-86.

Kvale, S. (1996). *Inter Views: An Introduction to Qualitative Research Interviewing*. Thousand Oaks, CA: Sage.

Lather, P. (1991). *Getting Smart: Feminist Research and Pedagogy With/in the Postmodern*. New York: Routledge.

Lather, P. (1993). Fertile obsession: Validity after post-structuralism. *Sociological Quarterly*, 34(4): 673-93.

Lee, R.M. and Renzetti, C.M. (1993). The problems of researching sensitive topics. In C.M. Renzetti and R.M. Lee (editors), *Researching Sensitive Topics*. Newbury Park, CA: Sage, pp. 3-13.

Lévi Strauss, C. (1966). *The Savage Mind* (Second Edition). Chicago: University of Chicago Press.

Lincoln, Y.S. (1995). Emerging criteria for quality in qualitative and interpretive research. *Qualitative Inquiry*, 1(3): 275-288.

Lowry, S. (1988). To the Lighthouse. *British Medical Journal*, 297(6652): 812.

Luckman, T. (1978). *Phenomenology and Social Policy*. Harmondsworth: Penguin.

MacDonald, K.M. (1995). *The Sociology of the Professions*. London: Sage.

Malmos, A. (1990). *Our Response to a Deadly Virus: The Group Analytic Approach*. London: Karnac Books.

Mann, J. (1989). The international position. *HIV and AIDS: An Assessment of Current and Future Spread in the UK*. Proceedings of the Symposium held on 24 November 1989. London: UK Health Departments and Health Education Authority.

Mann, J.M., Chin, J., Piot, P. and Quinn, T. (1988). The international epidemiology of AIDS. *Scientific America*, 259(4): 60-9.

Manning, P.K. (1991). Analytic induction. In K. Plummer (editor), *Symbolic Interactionism: Volume 2. Contemporary issues*. Brookfield, VT: Edward Elgar, pp. 401-30.

Mansfield, S. and Singh, S. (1989). The general practitioner and human immunodeficiency virus infection: an insight into patient's attitudes. *Journal of the Royal College of General Practitioners*, 39: 104-5.

Margolis, J. (1992). Psychology. In L.C. Becker and C.B. Becker (editors). *Encyclopaedia of Ethics*. Chicago: St. James Press, pp. 1039-43.

Mason, J. (1996). *Qualitative Researching*. London: Sage.

Mason, J.K. and McCall Smith, R.A. (1994). *Law and Medical Ethics*. London: Butterworths.

McLeod, J. (1994). *Doing Counselling Research*. London: Sage.

McManus, T. (1989). Male homosexual sexual behaviour. In J. Green and A. McCreaner (editors), *Counselling in HIV Infection and AIDS*. Oxford: Blackwell, pp. 224-32.

Mearns, D. (1994). *Developing Person-Centred Counselling*. London: Sage.

Mearns, D. (1997). *Person-Centred Counselling Training*. London: Sage.

Mearns, D. and Thorne, B. (1988). *Person-Centred Counselling in Action*. London: Sage.

Melville, J. (1987). Help for helplines. *New Society*, 24 July, 81(1282): 24.

Miles, M.B. and Huberman, A.M. (1994). *Qualitative Data Analysis*. Thousand Oaks, CA: Sage.

Miller, D. (1986a). The worried well. In D. Miller, J. Weber and J. Green (editors), *The Management of AIDS Patients*, pp. 169-73.

Miller, D. (1986b). Psychology, AIDS, ARC and PLC. In D. Miller, J. Weber and J. Green (editors), *The Management of AIDS Patients*, pp. 131-49.

Miller, D. (1987). *Living with AIDS and HIV*. Basingstoke: Macmillan.

Miller, E. (1993). *From Dependency to Autonomy: Studies on Organisation and Change*. London: Free Association Books.

Miller, J. (1991). Acquired immanent divinity syndrome. In C. Overall and W.P. Zion (editors), *Perspectives on AIDS: Ethical and Social Issues*. Toronto: Oxford University Press, pp. 55-74.

Miller, R. (1989). Living with hope. *The Bulletin*, 4: 16-17.

Miller, R., Goldman, E., Bor, R. and Kernoff, P. (1989a). AIDS and children: some of the issues in haemophilia care and how to address them. *AIDS Care* 1(1): 59-65.

Miller, R., Goldman, E., Bor, R. and Kernoff, P. (1989b). Counselling children and adults about HIV/AIDS: the ripple effect on haemophilia care settings. *Counselling Psychology Quarterly*, 2(1): 65-72.

Mitroff, I. (1974). *The Subjective Side of Science: Philosophical Inquiry into the Psychology of the Apollo Moon Scientists*. Amsterdam: Elsevier.

Morgan, D.L. (1988). *Focus Groups as Qualitative Research*. Newbury Park, CA: Sage.

Moss, V. (1989). Mildmay Mission Hospital. *Journal of Palliative Care*, 4(4): 102-6.

Natin, D. (1989). GPs' attitudes to HIV. *The Practitioner*, 233: 1372-5.

Nickel, J.W. (1988). Philosophy and policy. In D.M. Rosenthal and F. Shehadi (editors), *Applied Ethics and Ethical Theory*. Salt Lake City: University of Utah Press, 139-48.

Nitabach, L. and Richards, J. (1988). AIDS: Be prepared. *Care Weekly*, 21 October, 53: 10.

Ovretveit, J., Mathias, P. and Thompson, T. (editors) (1997). *Interprofessional Working for Health and Social Care*. Basingstoke: Macmillan.

Patton, C. (1985). *Sex and Germs: The Politics of AIDS*. Boston, MA: South End Press.

Patton, M.Q. (1990). *Qualitative Evaluation and Research Methods* (Second Edition). Newbury Park, CA: Sage.

Payne, M. (1991). *Modern Social Work Theory: A Critical Introduction.* Basingstoke: Macmillan.

Peräkylä, A. (1995). *AIDS Counselling: Institutional Interaction and Clinical Practice.* Cambridge: Cambridge University Press.

Phillips and Dawson (1985). *Doctors' Dilemmas - Medical Ethics and Contemporary Science.* Brighton: Harvester Press.

Pinching, A.J. (1986). The spectrum of human immunodeficiency virus (HIV) infection:L Routes of infection, natural history, prevention and treatment. In A.J. Pinching (editor), *Clinics in Immunology and Allergy: AIDS and HIV Infection*, 6(3): 467-88.

Plummer, K. (1988). Organizing AIDS. In P. Aggleton and H. Lomas (editors), *Social Aspects of AIDS.* Lewes: Falmer Press, pp. 20-51.

Polanyi, M. (1958). *Personal Knowledge: Towards a Post- Critical Philosophy*. London: Routledge and Kegan Paul.

Polanyi, M. (1967). *The Tacit Dimension.* London: Routledge and Kegan Paul.

Pritchard, P. and Pritchard, J. (1994). *Teamwork for Primary and Shared Care* (Second Edition). Oxford: Oxford University Press.

Proctor, B. (1988). Supervision: a co-operative exercise in accountability. In M. Marken and M. Payne (editors), *Enabling and Ensuring Supervision in Practice*. Leicester: national Youth Bureau, pp. 21-34.

Punch, M. (1994). Power and ethics in qualitative research. In N.K. Denzin and Y.S. Lincoln (editors). *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage, pp. 83-97.

Rawls, J. (1973). *A Theory of Justice.* Oxford: Oxford University Press.

Reason, P. (1994). Three approaches to participative inquiry. In N.K. Denzin and Y.S. Lincoln (editors), *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage, pp. 324-39.

Reason, P. and Rowan, J. (editors) (1981a). *Human Inquiry: A Sourcebook of New Paradigm Research.* Chichester: Wiley.

Reason, P. and Rowan, J. (1981b). Issues of validity in new paradigm research. In P. Reason and J. Rowan (editors), *Human Inquiry: A Sourcebook of New Paradigm Research.* Chichester: Wiley, pp. 239-50.

Reinharz, S. (1979). *On Becoming a Social Scientist*. San Francisco, CA: Jossey-Bass.

Rhodes, T., Gallagher, M., Foy, C., Philips, P. and Bond, J. (1989). Prevention in practice: obstacles and opportunities. *AIDS Care* 1(3): 257-67.

Rogers, C.R. (1955). Persons or science? A philosophical question. *The American Psychologist*, 10: 267-277.

Rogers, C.R. (1961). *On Becoming a Person: A Therapist's View of Psychotherapy*. London: Constable.

Rogers, C.R. (1967). *On Becoming a Person: A Therapist's View of Psychotherapy* (Third Edition). London: Constable.

Rogers, C.R. (1977). *On Personal Power*. New York: Delacorte Press.

Rose, N. (1989). *Governing the Soul: Technologies of Human Subjectivity*. London: Routledge.

Ross, W.D. (1930). *The Right and the Good.* Oxford: Clarendon Press.

Rowan, J. (1981). 'The leaves of spring' by Aaron Esterson: An appreciation. In P. Reason and J. Rowan (editors), *Human Inquiry: A Sourcebook of New Paradigm Research*. Chichester: Wiley, pp. 167-171.

Russell, J., Dexter, G. and Bond, T. (1992). *A Report on Differentiation between Advice, Guidance, Befriending, Counselling Skills and Counselling*. Rugby: British Association for Counselling/London: Department of Employment.

Sartre, J.P. (1969). *Being and Nothingness*. London: Routledge.

Schwandt, T.A. (1994). Constructivist, interpretivist approaches to human inquiry. In N.K. Denzin and Y.S. Lincoln (editors), *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage, pp. 118-37.

Shaffer, J.B.P. and Galinsky, M.D. (1974). *Models of Group Therapy and Sensitivity Training*. Englewood Cliffs, NJ: Prentice Hall.

Sherman, J. (1985a). Situations vacant. *Nursing Times*, 4 December, 81(49): 19-20.

Sherman, J. (1985b). Advice and sympathy for AIDS sufferers. *Health and Social Service Journal*, 95(4976): 1506-7.

Sieber, J.E. (1993). The ethics and politics of sensitive research. In C.M. Renzetti and R.M. Lee (editors), *Researching Sensitive Topics*. Newbury Park, CA: Sage.

Silverman, D. (1997). *Discourses of Counselling: HIV Counselling as Social Interaction*. London: Sage.

Silverman, D. and Perakyla, A. (1991) AIDS counselling: the interactional organisation of talk about 'delicate' issues. *Sociology of Health and Illness*, 12(3): 293-317.

Singer, P. (1993). *Practical Ethics* (Second Edition). Cambridge: Cambridge University Press.

Sketchley, J. (1989). Counselling people affected by HIV and AIDS. In W. Dryden, D. Charles-Edwards and R. Woolfe (editors), *Handbook of Counselling in Britain*. London: Tavistock/Routledge, pp. 347-63.

Sketchley, J. (1990). Terminology about people with HIV/AIDS. London: Unpublished research briefing paper.

Sontag, S. (1988). *AIDS and its Metaphors*. London: Penguin.

Spence, C. (1986). *AIDS: Time to Reclaim Our Power*. London: Lifestory.

Stake, R. (1994). Case studies. In N.K. Denzin and Y.S. Lincoln (editors), *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage, pp. 236-47.

Standing Conference on Drug Abuse/Alcohol Concern (1994). *Building Confidence: Advice for Alcohol and Drug Services on Confidentiality Policies*. London: SCODA/Alcohol Concern.

Stimpson, G. (1988). Syringe exchange. *Druglink* 3(3): 10- 11.

Strauss, A. and Bucher, R. (1961). Professions in process. In A. Strauss (editor), *Creating Sociological Awareness*. New Brunswick: Transaction Publishers, pp. 245-62.

Tatchell, P. (1986). *AIDS: A Guide to Survival*. London: Gay Men's Press.

Thomas, B. (1989). A dearth of knowledge. *Nursing Times*, 11 January, 85(2): 49-51.

Thomas, T., Noone, M. and Rowbottom, T. (1993). *Confidentiality in Social Services - Living and Working with HIV*, Discussion Paper Number 7. London: Central Council for Education and Training in Social Work.

Thompson, Andrew (1990). *Guide to Ethical Practice in Psychotherapy*. New York: John Wiley and Sons.

Todorov, T. (1977, as cited in Denzin, 1997: 11). *The Poetics of Prose*. Ithaca, NY: Cornell University Press.

Tong, R. (1997). *Feminist Approaches to Bioethics: Theoretical Reflections and Practical Applications*. Boulder, CO: Westview Press.

United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1987). *Confidentiality* - A UKCC Advisory Paper. London: UKCC.

United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1992). *Code of Professional Conduct*. London: UKCC.

United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1994). *Registrar's Letter 4/1994* - 25 March 1994 and Annex 2. London: UKCC.

United Kingdom Council for Psychotherapy (1993). *National Register*. London: UKCP.

Wanigaratne, S., Wallace, W., Pullin, J., Kenney, F. and Farmer, R. (1990). *Relapse Prevention for Addictive Behaviours: A Manual for Therapists*. Oxford: Blackwell.

Watney, S. (1987). *Policing Desire: Pornography, AIDS and the Media*. London: Media.

Watney, S. (1988). AIDS, 'moral panic' theory and homophobia. In P. Aggleton and H. Lomas (editors), *Social Aspects of AIDS*. Lewes: Falmer Press, pp. 52-64.

Watney, S. (1989). AIDS, language and the Third World. In E. Carter and S. Watney (editors), *Taking Liberties: AIDS and Cultural Politics*. London: Serpents Fail, pp. 183-92.

Weber, J. (1988). The biology of HIV. In L. Paine (editor), *AIDS: Psychiatric and Psychosocial Perspectives*. London: Croom Helm.

Weeks, J. (1988). Love in a cold climate. In P. Aggleton and H. Lomas (editors), *Social Aspects of AIDS*. Lewes: Falmer Press, 10-19.

Weller, I.V.D., Hindley, D.J., Adler, M.W. and Moldrun, J.T. (1984). Gonorrhoea in homosexual men and media coverage of the acquired immune deficiency syndrome in London 1982-3. *British Medical Journal*, 289: 1041.

West, W. (1996). Using human inquiry groups in counselling research. *British Journal of Guidance and Counselling*, 24(3): 347-55.

Whitehead, T. (1989). The voluntary sector. In E. Carter and S. Watney (editors), *Taking Liberties: AIDS and Cultural Politics*. London: Serpent's Tail, pp. 107-111.

Wilson, M. (1988). A beacon of hope for black AIDS sufferers. *Health Service Journal*, 29 September, 98: 1115.

Wolf, J. (1988). Supporting HIV patients in the community. *Nursing Times*, 26 October, 84(43): 75.

Wolfe, A. (1989). *Whose Keeper? Social Science and Moral Obligation*. Berkeley, CA: University of California Press.

World Health Organisation (1989). *Global Programme on AIDS Definition of HIV Counselling*. Geneva: WHO.

World Health Organisation (1990). *Guidelines for Counselling about HIV Infection and Disease*. Geneva: WHO.

Zytowsaki, D. (1985). Frank, Frank! Where are you now that we need you? *Counselling Psychologist*, 13: 129-35.