A PORTFOLIO OF STUDY, PRACTICE AND RESEARCH

Prevalence of unsafe sexual behaviour, burnout and emotional distress in health care workers and volunteers working with individuals affected by HIV/AIDS.

John Anthony Church

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Conversion Programme

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CONTENTS

Acknowledgements 3
Personal Study Plan: 4
Curriculum Vitae & log of Continuing Professional Development 9

Part 1: Academic Dossier:

(1) The relationship between HIV disease and suicide: A review of the literature 19

(2) The application of cognitive behaviour therapy for depression to people with the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) 51

Part 2: Clinical Dossier:

Surrogate breast-feeding (wet-nursing) as a potential route of transmission of HIV in London, UK? 83

Part 3: Research Dossier

Prevalence of unsafe sexual behaviour, burnout and emotional distress in health care workers and volunteers working with individuals affected by HIV/AIDS. 113

Introduction 114
Method 144
Results 154
Discussion 202
Conclusion 211
References 213
Appendices 240

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My special thanks go to Susan Thornton and Chris Gillead for their supervision and support. Thanks also go to Lorraine Nanke, Christine Ryan and Sandra Roach for their help at the eleventh hour.

My thanks go to St. George's Healthcare NHS Trust and South West London and St. George's Mental Health NHS Trust for enabling me to complete this PsychD.

Finally I would like to thank Linda Clarke and Antônio Lopes for their encouragement and patience.

I dedicate this portfolio to José Varêla who has helped to keep me motivated over the past decade.
PERSONAL STUDY PLAN

This section contains my proposed outline for the PsychD conversion programme. At the time of commencing this programme of continuing professional development I was employed within the field adult of mental health, within the specialisms of HIV/AIDS within a department of Genito-urinary medicine and in a multi-partner GP surgery. The three components of this portfolio were selected with the intention of developing knowledge and skills relating to the psychology of HIV/AIDS and Genito-urinary medicine.

CURRICULUM VITAE & LOG OF CONTINUING PROFESSIONAL DEVELOPMENT

This section will demonstrate my ongoing academic and clinical commitment to the field of clinical psychology since qualifying in 1993.

PART 1: ACADEMIC DOSSIER

Title: The relationship between HIV disease and suicide: A review of the literature

Aims: To develop a greater understanding of issues relating to suicide amongst people with HIV and AIDS. To examine methodological difficulties associated with determining the prevalence of suicide in this population.

Objectives: To review the literature examining the prevalence of suicide in HIV infected populations and to examine the relationship between psychosocial variables and high suicide risk in the HIV population.
Rationale: There is increasing evidence to suggest a heightened risk of suicide in people with HIV infection. As part of my clinical duties in working with people infected with and affected by HIV/AIDS it is not uncommon to be presented with individuals who during their consultation express, or are explicitly referred because of, suicidal ideation or a history of suicide attempts. Consequently it is important to be aware of existing knowledge about the prevalence of and factors associated with suicide risk in these patients. By establishing factors which may contribute to increased risk of suicide in these patients, it is hoped that clinical practice will be enhanced both in terms of individual therapy with such patients and in terms of better detection of suicidality by members of the multidisciplinary team.

Title: The application of cognitive behaviour therapy for depression to people with the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS)

Aims: To examine the literature on cognitive behaviour therapy (CBT) and to develop a greater understanding of how CBT has been applied to depression in people with HIV/AIDS.

Objectives: To review the literature on Beck’s cognitive behaviour therapy as applied to depression in order to understand whether it is a suitable therapeutic intervention for individuals affected by HIV/AIDS.
Rationale:

There is now significant evidence, that many individuals with HIV / AIDS become depressed and present to mental health services for psychological intervention. They may be offered a variety of clinical interventions, including cognitive behavioural treatment. Given that this author treats a number of people with HIV who are depressed it is hoped that a review of literature on cognitive behaviour therapy and its use for depression in HIV/AIDS will further inform my clinical practice. Where necessary, due to gaps in the empirical literature, evidence from clinical experience will be incorporated.

PART 2: CLINICAL DOSSIER

Title: Surrogate breast-feeding (wet-nursing) as a potential route of transmission of HIV in London, UK?

Aims: To inform the Department of genito-urinary medicine of the prevalence and acceptance of wet-nursing practices by women in London.

Objectives: To carry out a questionnaire study to determine the prevalence of wet-nursing practices; investigate women's acceptance of wet-nursing practices; examine cultural differences in relation to wet-nursing and evaluate level of knowledge in relation to HIV transmission through breast-feeding.

Rationale: Anecdotal reports from women attending the Courtyard Clinic suggest, that in addition to women breast-feeding their own babies, wet-nursing
practices may also exist, in particular among women from some African countries. This is partly born out by two recent anecdotal reports, from (a) South Africa, where breast-feeding by hospital staff of patients’ babies has been reported, and (b) London, where the death, from AIDS, of a baby born to an HIV negative couple has been reported, where it subsequently transpired the couple’s nanny was HIV positive and had been breast-feeding the baby. To date it is not clear whether these reports represent isolated cases of wet-nursing (especially in London) or whether this form of risk behaviour is more widespread. What is clear however is that these reports have highlighted wet-nursing as a possible route of HIV transmission. This project was devised for two reasons: (a) concerns raised by medical colleagues that women attending our clinic may be wet-nursing and (b) the general dearth of published data on the prevalence of wet-nursing practices.

PART 3: RESEARCH DOSSIER

Title: An investigation of HIV sexual risk taking behaviours in health care workers (Staff) and volunteers working with people affected by HIV/AIDS.

Aims: To increase personal research experience and competence and to contribute to the literature on the prevention of HIV. To investigate the level of unprotected sexual intercourse in this population and factors associated with sexual risk behaviour. To determine the level of burnout and psychiatric morbidity in this population and to assess whether there is a relationship between burnout or psychiatric morbidity and attitudes to, or the practice of, risky sexual behaviour.
**Objectives:** To undertake a postal self-report questionnaire study of health care workers and volunteers, to ascertain their level of sexual risk taking and its relationship to burnout and psychiatric morbidity.

**Rationale:** Recent studies have highlighted upward trends in London in the number of new cases of sexually transmitted infections, including HIV. It is widely agreed that in the absence of a vaccine, the only clear way of preventing and containing the spread of HIV infection is by effective and sustained changes in sexual behaviour practices. A growing number of anecdotal reports have highlighted that workers on the front line of the HIV epidemic are continuing to place themselves at personal risk for HIV infection. Given that no attention has been paid to the nature or extent of sexual risk behaviour among staff or volunteers this study was set up with the primary purpose of determining the prevalence of HIV sexual risk behaviour among this population of HIV workers and to examine the relationship between sexual risk taking, burnout and psychiatric morbidity.
Since initially qualifying in 1993 and throughout the period of my registration for the PsychD I have undertaken a number of academic, clinical and research activities which represent continuing professional development in addition to the work presented in this portfolio.

In terms of academic developments I have attended a variety of workshops and training events on numerous subject areas related to my field of clinical practice (as detailed below). In addition I have completed a Diploma in Cognitive Behaviour Therapy awarded by the Institute of Psychiatry, London and have been awarded the British Psychological Societies Statement of Equivalence in Counselling Psychology. I am an Associate Fellow of the British Psychological Society, an accredited cognitive behavioural therapist registered with the British Association for Behavioural and Cognitive Psychotherapies and I am registered with the UKCP. I am currently enrolled on a clinical hypnosis diploma.

**Educational Attainments**

BSc (Hons) Psychology/Sociology University of Bath (1st Class) June '90

MSc Clinical Psychology University College London September '93

(Three year course)

Postgraduate Diploma in Cognitive Therapy Institute of Psychiatry June '95
**Professional Qualifications**

- **Statement of Equivalence in Counselling Psychology**: British Psychological Society, May '97
- **Associate Fellow**: British Psychological Society
- **Chartered Clinical and Counselling Psychologist**: British Psychological Society
- **UKCP (United Kingdom Council for Psychotherapies)**: Accredited Cognitive Behavioural Therapist
- **BABCP (British Association for Behavioural and Cognitive Psychotherapies)**: Accredited Cognitive Behavioural Therapist

**Post Qualification Continuing Professional Development**

**1999**

- **Ongoing**: Brief Strategic Diploma in Clinical Hypnosis (BST Foundation, London)
- **29th October**: Sexually transmitted infection and HIV prevention for the Millennium: What works? BPS DCP HIV/sexual health SIG
- **14-17th July**: BABCP annual conference - Bristol
- **05th July**: Workshop by Paul Salkovskis: Obsessive compulsive disorder - brief therapy
- **15th - 16th June**: Schema focussed cognitive therapy for personality disorders
- **14th May**: Gay and lesbian issues in Medicine - Dr Jim Bolton
- **22nd April**: Brief Therapy Workshop (London)
- **20th April**: Neurolinguistic Programming (First Assist) Euston
- **25th February**: BPS DCP HIV and Sexual health SIG Adherence and Compliance issues in HIV
- **02 February**: South Thames Cognitive Behavioural Therapy Special Interest Group - Garfield Harmon
1998

13 January
Issues in formulation
South Thames Cognitive Behavioural Therapy Special Interest Group

25 September
How to deal with dependency, substance abuse and compulsions. Mindfield Seminars. Joe Griffin

7-8 October

1997

29 October
Psychological impact of changing patterns of survival and of the new treatments. London Lighthouse. BPS DCP HIVSIG

4 August
Axis 11 Cluster A Personality Disorders A psychodynamic understanding Hessel Williamson

18 July
Sleep Disorders and the Dream Response Joseph Griffin

16 July
Group Approaches in Cognitive Therapy South Thames CBT SIG

9-12 July
Variety of lectures and workshops on CBT BABCP Annual Conference, Canterbury

9 July
Sexual Health and HIV BPSDCP HIVSIG

8 July
Cognitive Behaviour Therapy - A Masterclass Aaron Beck - BABCP

30 June
Working with Complex Cases Professor Glenn Waller

22 April
Stress & well-being Mind Matters Seminars

April
Working with Health Issues South Thames CBT Special Interest Group (SIG)

March
Hypnosis: A skills-based workshop SouthThames CPD Committee

March
Personality Disorders South Thames CPD Committee

March
Managing Anxiety Mind Matters Seminars
February   Glad to be Gay BPS DCP HIVSIG
February   Solution Focused Brief Therapy South Thames CPD Committee
February   Working with different sexual orientations BPS DCP HIV/AIDS SIG

1996

October   Personality Disorders South Thames Cognitive Therapy SIG
August    Self esteem Mind Matters Seminars
August    Psychodynamic approaches to HIV/AIDS BPS DCP SIG HIV / AIDS
July      Terminal illness South Thames CBTSIG
May       Schizophrenia South Thames CBTSIG
May       HIV / AIDS grief workshop BPS DCP HIV/AIDS SIG
March     Death and dying The Conference Unit - St. George’s Hospital

1995

1 year day release   Diploma in Cognitive Behaviour Therapy Institute of Psychiatry, London.
October   Psycho-Sexual Counselling Association for Psychological Therapies
May       Counselling for PTSD Centre for Stress Counselling
April     Issues in working with ethnic minorities The Conference Unit - St. George’s Hospital
February  Social anxiety Camden and Islington Department of Clinical Psychology
January   PTSD Camden and Islington Clinical Psychology Department.
In addition to the training events listed above I have also been involved with a variety in house training programmes both at St. George's Healthcare NHS Trust (Department of GU Medicine) and St. George's and Southwest London Mental Health NHS Trust (Psychology Department).

Employment History
Since qualifying I have enjoyed a range of direct clinical experience working with individuals couples and groups within the areas of community mental health, HIV/AIDS and primary care. I currently hold two part time posts as detailed below.

June '96 - Present day
Pathfinder Mental Health Service.
Springfield University Hospital
61-63 Glenburnie Road, Tooting. SW17

Title: Principal Clinical Psychologist (0.4wte)

Duties: Independently responsible for providing and co-ordinating a comprehensive clinical and counselling psychology service to a multi-partner GP practice.

Sept. '93 - Present day
St. George's Healthcare NHS Trust
The Courtyard Clinic, Blackshaw Road
Tooting. SW17 0QT
Title: **Principal Clinical Psychologist (0.6wte)**

Duties: Responsible for setting up, implementing and delivering a specialist clinical psychology service to people with HIV/AIDS for the Department of Genito-Urinary Medicine.

Guest lecturer at St. George's Hospital Medical School on the topics of Coping with Chronic Illness and Counselling in HIV/AIDS.

Sept. '95 - June '96

Pathfinder Mental Health Service
Springfield University Hospital
61-63 Glenburnie Road, Tooting. SW17

Title: **Senior Clinical Psychologist (0.5wte)**

Duties: Provision of clinical psychology services to a community mental health care team. Assessing and treating a wide range of in & outpatients with severe and enduring mental health problems.

Sept. '93 - June '94.

North West Thames Regional Health Authority
Department of Public Health
Title: Clinical / Research Psychologist

Duties: Responsible for conducting research examining long-term psychological consequences of medical negligence.

Private Practice
In tandem with my NHS appointments over the past few years I have developed a busy private practice "The Counselling Concern", which incorporates the provision of psychological treatment to adults presenting with a wide range of psychological problems and personal injury / medical negligence medico-legal reports to solicitors. In addition I am also employed by a variety of employee assistance programme providers as an approved assessor and therapist.

Publications

Journal articles


**Book Chapters**


**Conference Presentations**

Church, J., Kocsis, A. & Green, J. (1988). Effects on lovers of caring for HIV infected individuals related to the perception of cognitive, behavioural and personality changes.

**IVth International Conference on AIDS**, Stockholm.
The relationship between HIV disease and suicide: A review of the literature

Introduction

Attempts to determine the prevalence of suicide and its relationship to a diagnosis of AIDS or HIV are hampered by a range of methodological difficulties. It is the aim of this paper to review the literature on the prevalence of suicide in HIV and the psychosocial factors associated with it, as well as to highlight the methodological problems associated with this subject area. While any discussion of suicide and HIV / AIDS inevitably raises complex ethical and legal questions about euthanasia and physician assisted suicide, as these are not the primary focus of this paper they are not addressed here.

It is well known that the experience of physical or psychiatric illness can increase an individual's vulnerability to suicidal ideation and suicide attempts. Studies of cancer patients for example, have highlighted an increased risk of suicide in comparison with matched populations (Allebeck and Bolund, 1992) and a history of significant physical illness is present in a substantial number of individuals who commit suicide (Whitlock, 1986, Barraclough and Hughes, 1987). Clinicians, working with people who are infected with HIV or who have AIDS, are acutely aware of the biological, psychological and social vulnerabilities frequently present in these patients. As well as having to adjust to living with a potentially fatal infection, dramatic physical changes, whether through HIV wasting syndrome, Kaposi sarcoma or lipodystrophy syndrome and psychological distress such as depression, adjustment disorders, AIDS related dementia, psychosis or anxiety, are common. In addition to physical and psychological distress, individuals will also commonly experience a range of negative social consequences.
A number of studies have investigated the prevalence and psychosocial correlates of suicide in gay, heterosexual, haemophiliac and drug using HIV populations. Despite growing interest in this field there remains a lack of clarity as to the actual prevalence of suicide directly attributable to HIV and of the risk factors associated with it. It is unclear, for example whether suicide is directly attributable to HIV or whether it may be due to pre-existing risk factors such as drug use, pre-morbid psychiatric conditions or homosexuality, all commonly seen in people who have acquired HIV.

Studies of suicide related to HIV have used many different approaches: single case examples, (Flavin et al. 1986; Frances et al. 1985), reviews of clinical case notes (Pugh et al. 1993), epidemiological studies using official register studies (Marzuk et al. 1988, Kizer et al. 1988, Plott et al. 1989) or post-mortem examinations (Barbieri et al. 1989; Rajs & Fugelstad, 1990; Puschel & Heineman, 1995). Retrospective studies have been most commonly used although some data is available from prospective investigations (Danneberg et al. 1996; Riccio et al. 1993).

Differences found between studies often relate to the particular groups investigated, for example examination restricted to persons with end stage AIDS or people with asymptomatic infections, although some studies have now examined the incidence and correlates of suicide across the spectrum of HIV disease. Many studies have focussed on specific sub-groups affected such as gay men or intravenous drug users.

The relationship between completed suicide and AIDS
The studies which have examined completed suicides have revealed contradictory results with regard to whether there is an increased risk in the prevalence of suicide or not. Register based studies, where population statistics on causes of death are matched
with AIDS register data, are generally considered to be the most reliable approach to the quantification of suicide in this population. However, despite a number of these studies now having been conducted, the magnitude of suicide remains far from clear, given that reports for age-corrected relative risk, (that is the ratio of the suicide rate of the AIDS subjects to that of the general population in a defined age group) can differ markedly (Marzuk et al. 1988; Cote et al. 1992; Copeland et al. 1993; Kizer et al. 1988; Plott et al. 1989; Marzuk et al. 1997).

Register studies

The first epidemiological evidence suggesting an increased risk of suicide was presented by Marzuk et al. (1988). All cases of suicide certified by the Chief Medical Examiner among New York City residents between 1 January to 31 December 1985 were examined. Of the 668 suicides reported during that period 12 were found to have AIDS, representing a 36 fold increased risk compared to men of the same age group in New York City, and a 66 fold increase when compared with the general population. The clinical records of these patients revealed that all had died within eight months of their AIDS diagnosis and a third had made previous attempts to take their own lives. A follow on investigation of 30 additional cases for the period 1986-7 has also been reported (Marzuk et al. 1991), with a similar risk increase found.

Since Marzuk et al's, (1988) original study, others have also reported high levels of risk, although with variable rates of increase in risk found. Kizer et al. (1988), in California, found men with AIDS to have a 17.02 times higher relative risk of suicide than a comparable group of men without AIDS. Plott et al. (1989) provided further data in their review of the register of the Texas Department of Health, Bureau of AIDS and Sexually Transmitted Disease Control, over an 8 month period during 1987. In this study 5
individuals with AIDS out of a total of 2,255 suicides had committed suicide, which represented a 16.3 fold increase in risk over the estimated risk for the general population. Although the results were very similar in these two studies these are difficult to interpret due to a lack of data presented on possible confounding variables in the samples. In particular, the authors omitted data on the prevalence of psychiatric disorders, a known risk factor for suicide. A further weakness in Plott et al’s, (1989) study, was a failure to compare their sample with a matched age-corrected general population sample, which confounded their results. Neglect of these variables can artificially heighten estimates of suicide risk. Supporting evidence for an increase in the rate of suicide has also been reported by Engelman et al. (1988). Suicides reported to the County Medical examiner between 1982 and 1986 were cross matched with AIDS deaths reported to the Department of Public Health with 13 of the suicides found to have AIDS, which represented 4.0% of all suicides. The relative suicide risk, however, could not be compared with other studies due to a lack of data presented on the prevalence of AIDS in this State.

More modest increases in risk have also been reported. Cote et al. (1992), in a retrospective study conducted between 1987-1989 in 45 US states and the District of Columbia found a total of 165 AIDS suicides, with a considerably lower age-corrected relative risk of 7.4 estimated, (which was seen to decrease from 10.5 to 6.0 times during the three years of this study), compared with earlier studies. A weakness in this study, however, was the failure to compare the AIDS group with subjects from the same risk group. A lower rate has also been reported by Pugh et al. (1993). In this London based study 6 AIDS suicides were identified over a two-year period, which, compared to a sex and age matched population living in the same geographical area, represented a 10 fold risk. Case records of these subjects showed that 2 had died within six months of their
HIV diagnosis, (although it is unclear whether these subjects were asymptomatic when they presented for testing as immunological parameters were not presented), and the other four died between 13 and 25 months of receiving their diagnosis. Two thirds of these subjects had a psychiatric history predating their HIV infection. In Germany and Florida (Wedler et al. 1991; Copeland et al. 1993) similarly low risk ratios compared to age and sex matched controls have also been reported (11 time and 8.9 times respectively). An exception to the above trend has been reported by Mancoske, (1995), who described a 134.6 non-age corrected relative risk! These divergent results can be explained by the studies' inclusion criteria, which included subjects with an AIDS diagnosis and those who had an opportunistic infection commonly seen in AIDS such as CMV, KS and PCP.

A possible explanation for more modest suicide risks reported in recent studies could be related to general changes occurring in HIV in industrialised nations, where studies have predominantly been conducted. Possible variables might include improvements over time in psychological services, a reduction in social stigma and advances in anti-retroviral treatment of HIV infection and opportunistic infections over the past decade, leading to longer life spans and increased patient optimism. However, caution in interpreting and generalising these results to the rest of the AIDS population is required due to significant methodological problems associated with many of the above studies. Problems are particularly significant in those studies which fail to examine co-morbid risk factors or which use inappropriate comparison groups.
Post-mortem studies

Post-mortem studies have also been used to explore the relationship between suicide and AIDS. In these studies the records of autopsies performed on violent or suspicious deaths reported by the coroner are examined as a way of establishing the prevalence of HIV / AIDS related suicides. One of the earliest examples of post-mortem studies was carried out by Barbieri et al. (1989) in Sao Paula, Brazil. All autopsies on violent or suspect deaths between May 1985 to October 1988 were examined, with 0.3% (n=97) revealed to have HIV. 23.7% of these subjects had died through suicide. A similar rate of 25%, was found by Rajs and Fugelstad, (1990), in Stockholm. Of the 21 (of 85) autopsies in this study which had an HIV positive result, 2 had previously tried to take their lives and 8 were drug users. Only 6 had received a diagnosis of AIDS. The utility of these results is limited however, due to a lack of information on the suicide rate in HIV negative subjects.

Not all studies have found a marked increase in suicide levels. HIV prevalence among suicide victims in New York City between 1991 and 1993 was reported in a recent study to be 9%, (Marzuk et al. 1997), only moderately higher than sero-prevalence estimates in the general population. These results led the authors to conclude that HIV probably represents at most a two fold higher risk for suicide. A similar finding was reported by Paterson et al. (1996) in their London based study who found no increase in the incidence of suicide among drug users aware of their HIV status and in a prospective study of 4,147 military service applicants, HIV positive applicants had no higher risk of suicide in the months following their HIV screening than those who received a negative test result (Danneberg et al. 1996). Despite this large sample the selective nature of the sample prevents generalisation of the results to other populations.
Haemophiliacs have also been found to exhibit a low incidence of suicidal morbidity (Jones, 1995). This may be related to the extent of psychological support offered to this group, potentially ameliorating risk factors. Studies of intravenous drug users have also found no evidence for higher incidences of suicide in this population compared to non-users (Puschel & Heineman, 1995), and HIV sero-positive drug addicts had no higher incidence of suicide than those who were HIV negative (Paterson et al. 1996).

Case study reports

In contrast to large-scale epidemiological studies, single case reports of suicide completers and those who have attempted suicide have also been reported (O'Donnell et al. 1992; Morgan and Jones, 1993). A review of these case studies demonstrates the different methods of suicide used and highlights potential suicide risk factors. A wide variety of methods have been reported, for example jumping (Pugh et al. 1993; Marzuk et al. 1988) or other violent means (Haastrecht et al. 1994), but death by overdose appears to be most frequently cited (Terragna, 1990; Spear, 1988; Routy, 1989; Puschel & Heineman, 1995; Cote et al. 1992; Sherr, 1995). Cases of suicide by deliberately contracting HIV through seeking out HIV positive sexual partners, have also been reported (Durand et al. 1991; Flavin et al. 1986; Frances et al. 1985; Papathomopoulos, 1989), as have attempts by patients suffering from delusions that they had AIDS (Seymour, 1989).

Psychosocial correlates of suicidal behaviour

It is too simplistic to assume that infection with HIV is the sole cause of suicidality in these patients. Fuelled by early epidemiological studies and case reports, attempts have been made to isolate psychosocial correlates of suicidal behaviour (Perry et al. 1990;
O'Dowd et al. 1993; Rabkin et al. 1993; Rundell et al. 1988). The majority of studies have adopted a retrospective approach, examining clinical records of suicide completers to identify demographic, psychiatric and psychosocial variables associated with their deaths. Few prospective studies have been conducted (e.g. Riccio et al. 1993).

The non-HIV literature has identified a number of factors as important correlates. Depression, alcoholism, increasing age, social isolation, physical illness, drug use, hopelessness and significant loss are consistently reported (Morgan and Priest, 1984; Beck et al. 1975, 1985; Walsh and McHoldrick, 1991). Variables that have been reported to be related to suicide in HIV are not dissimilar: psychiatric illness and past suicidal attempts (Pugh et al. 1993), excessive alcohol use (Frances et al. 1985; Flavin et al. 1986); recent onset of symptomatic infection (Durand et al 1991); hopelessness (Catalan et al. 1995a), unemployment and financial losses, stigmatisation and an increased recognition of the burden caused to significant others (Starace, 1993). In one study of 107 HIV infected United States Air Force personnel additional correlates found were: multiple psychosocial stressors; perceived social isolation; perception of self as a victim; reliance on denial as central or only defense; drug abuse and perceived unavailability of social support (Rundell et al. 1988). Avoidant coping strategies and having less social support have also been related to lifetime suicidality in HIV sero-positive gay men (Gutierrez et al. 1990), and in a preliminary investigation women with HIV were found to be less susceptible to suicidal tendencies by a ratio of 1:3 (Brown and Rundell, 1989). While many of these variables are frequently reported they are not always present (Kirchner et al. 1995). For example, hopelessness, which has been associated with suicidality in several studies (Rabkin et al. 1990; Schneider et al. 1991a; Catalan et al. 1992a) has not been associated with it in others (Catalan et al. 1992b).
In the only study identified of suicidal ideation in carers, Rosengard and Folkman, (1997), reported that over half of the partners of gay and bisexual men with AIDS in their study admitted to suicidal ideation. Suicidal ideation among carers was found to be related to carers feeling burdened as a caregiver, perceived lack of social support and the use of escape-avoidance coping strategies.

Pre-existing vulnerabilities

Despite the above factors having been found to be related to increased suicide risk, the relationship between HIV and suicide remains complicated by the presence of pre-existing risk factors in groups predominantly affected by HIV in industrialised nations. Suicide risk has been found to increase, independently of HIV, in those with previous psychiatric histories, who misuse drugs or who are gay (Atkinson et al. 1988; Miller & Riccio, 1990), all commonly present in groups affected by HIV (Gala et al. 1992). For example, in a study of 213 HIV asymptomatic gay men, IV drug users and heterosexuals in Milan, 19% of the HIV positive cases had a past psychiatric history and 13% had a history of suicide attempts predating their HIV diagnosis (Gala et al. 1992). These findings led this group to conclude pre-morbid factors may be more significant predictors of suicidal behaviour than infection with HIV. In an earlier study by the same group (Gala et al. 1989), of 218 HIV infected gay men and intravenous drug users and 60 HIV negative individuals belonging to the same at-risk groups, 22% of the HIV group had attempted suicide, compared with 17% of the HIV negative group and 0.2% of a control group drawn from the general population. Both gay men and injecting drug users have also been shown to have elevated rates of attempted and successful suicides, irrespective of HIV status (Johnsson et al. 1997; Marzuk et al. 1988; Saunders and Valente, 1987), with no differences in previous or concurrent psychiatric morbidity.
between psychiatric outpatients attending a clinic for HIV related problems and a matched sample of patients attending a general psychiatry outpatient clinic having been reported (O’Dowd et al. 1989).

Lifetime prevalence of psychiatric disorders has also been addressed (Atkinson et al. 1990). In this study of 105 gay men and a control group comprising a socio-demographically matched group of heterosexual men, lifetime prevalence of major psychiatric disorders was significantly higher in the gay group. Prevalence of psychiatric disorders between gay men was independent of HIV status. These findings are important as they suggest increases in the rate of suicide might be better accounted for by the higher prevalence of psychiatric syndromes rather than HIV. Current and lifetime psychopathology in gay men with and without HIV has been investigated by Williams et al. (1991) who found the HIV sero-positive group to have a higher lifetime incidence of syndromal depression than reported for the general population. However, contradictory results have also been reported (Rabkin et al. 1993), finding no difference in current depressive syndromes found in gay men with AIDS (6%) compared with the general population (5%).

**Suicidal ideation**

Given the increased prevalence of pre-existing risk factors in this population, together with the fact that many will also experience physical and psychological distress, it is hardly surprising that suicidal ideation has been reported to be relatively common in this group (Catalan et al. 1992a; Perry et al. 1990; Rabkin et al. 1993; Sherr, 1995). Rather than specifically focussing on groups at one end of the spectrum of HIV disease, such as people with AIDS or who are asymptomatic, the relationship between suicidal
behaviours throughout the course of HIV infection is being increasingly investigated (Perry et al. 1990; Sherr, 1995),

HIV related psychological distress may occur at any stage during the process of seeking out an HIV test, testing and gaining an HIV test result (Miller, 1995). Amongst the initial reactions associated with deciding to have a test may be fear, anxiety and depression. For those people seeking to be tested, the period between having decided to have a test and the time lag between receiving their diagnosis, represents a time of intense psychological distress (Miller, 1995) with suicidal reactions around this period reported by a number of investigators (Pierce, 1987; Miller et al. 1989). The extent of this problem was highlighted over a decade ago when 7 people committed suicide during a 6-week period shortly after receiving their positive HIV result (Pierce, 1987). The risk of suicide during this stage has been emphasised by Miller et al. (1989) who reiterated the importance of pre and post HIV test counselling, suggesting that the way in which an HIV diagnosis is revealed and the availability of social, emotional and practical support at the time of diagnosis could affect the likelihood of impulsive suicidal acts occurring in this group. Other evidence for a high level of suicidal ideation in the newly diagnosed has also been reported by Perry et al. (1990), who found 16.3% of their sample having persistent suicidal ideation after receiving their diagnosis, which remained at 8 weeks post diagnosis.

Upon being informed of test results and throughout the course of infection, a variety of diverse psychological responses may occur (Catalan et al. 1995a). The impact of receiving an HIV positive result has also been examined by Hong et al. (1989). In this study a fifth of 46 randomly selected people with HIV exhibited suicidal ideation
between the time of their HIV test and the time of their assessment, (approximately 15 months later). Two (4%) had attempted suicide. Results in this area are not unequivocal. Elevated suicidal ideation has not always been found in gay men with HIV (Rabkin et al. 1993). The burden of suicidal ideation is not restricted to persons receiving a positive result. In Percy et al's, (1990) study 12.9% of those testing negative also expressed suicidal ideation.

A variable pattern of ideation throughout the course of HIV has now been reported. McKegney and O'Dowd (1992) in their assessment of risk in people with HIV referred for psychiatric assessment in New York City throughout a three-year period, found a large proportion of patients reported "suicidality" at various stages of their disease, compared with a group of non-HIV patients over the same period. 9% of the 322 patients with AIDS were considered by psychiatrists to be suicidal compared with 18% (n=82) of the group without AIDS and 9% (n=1086) of an HIV negative or never tested group. Suicidality therefore was more likely in patients with less advanced disease. Similar findings have been reported by O'Dowd et al. (1989) in a study of IV drug users and their sexual partners. It could be postulated that a reduction in suicidality in people with AIDS may occur due to the diagnosis providing a sense of certainty about ones condition, leading to the development of an attitude of acceptance, as previously described by Kubler-Ross, (1969).

**Pattern of suicidality in HIV**

Evidence for a differential risk for suicide at varying periods throughout HIV disease course has been reported (Lyketsos et al. 1994; Sherr, 1996; Perry et al. 1990). Results from the European Initiative on Suicide and AIDS, a collaborative study set up to review
suicidal behaviours in people with HIV, were presented at the XIth International Conference on AIDS (Sherr, 1996). A bi-modal pattern of suicidal acts was described, with elevated risk being associated with time of HIV diagnosis and upon confirmation of an AIDS diagnosis. Support for this bi-modal distribution has been provided by Rundell et al. (1992), who found that four out of seven attempted suicides in their sample had occurred within the first week of HIV notification. In Perry et al's, (1990) study, 30% of persons seeking HIV testing at a New York Hospital (comprising gay men, injecting drug users and non drug using heterosexuals of both sexes), also had suicidal ideation at the time of pre-test counselling. High levels of distress during this period have also been reported from a study of US Air Force recruits, in which 8 out of 147 HIV positive recruits had engaged in deliberate self harm within the first 11 months of their HIV diagnosis (Rundell, et al. 1988), and 15% of those who were HIV positive continued to have suicidal ideation 2 months after being given their result. The increased likelihood of suicidality during this period makes a strong case for the provision of pre and post test counselling.

UK studies have reported lower proportions of HIV positive patients reporting suicidal ideas than those originating from the United States. In a prospective study of gay men seeking HIV testing at a London genito-urinary clinic, Riccio et al. (1993) found similarities in the proportions of men reporting suicidal thoughts in the preceding month between those who were HIV negative and those who were found to be HIV positive. At twelve months follow up no suicidal ideation was present (Pugh et al. 1994). Studies of HIV sero-positive men with haemophilia reveal similar results. A cross sectional study of haemophiliac men who had known their sero-status for approximately two
years showed 3% as having suicidal ideas and none of the sero-negative controls (Catalan et al. 1991a).

The second peak is reported to occur around the time of an AIDS diagnosis (Sherr, 1995). Evidence for this is provided by Rabkin et al's, (1993) study. In this study one third of gay men with AIDS for at least three years in their sample admitted to having had suicidal thoughts at some point after their AIDS diagnosis. A combination of factors are likely to be responsible for this second peak which may include: HIV exerting an effect on the central nervous system with a subsequent risk of major mental disorders developing (which in themselves can be related to a higher rate of suicide); a loss of autonomy; decreasing physical health or increases in experience of AIDS related bereavements (Schneider et al. 1991b). It could also be that during this period it might be harder for those affected to use denial as a coping mechanism as a result of increased hospital visits, intrusive medical procedures, role changes and physical decline.

Methodological issues

Suicide in this population is complex and multi-factorial in its aetiology. The contradictory results reported above highlight the problematic nature of trying to determine prevalence due to AIDS and ensuring the reliability and validity of results. Any evaluation of prevalence and psychosocial correlates must therefore take into consideration methodological difficulties associated with this field of enquiry.

Over the past decade many studies have sought to identify predictors and correlates of suicide in HIV. Findings, however, have often proven contradictory, primarily due to methodological difficulties in data collection, sample diversity and the fact that suicide is a complex behaviour subject to individual and social influences. Investigating the true
extent of suicide remains a complicated endeavour due to issues associated with determining figures for this population (the numerator), and gaining an accurate indication of the extent of HIV infection within a denoted geographical area (the denominator). This is particularly difficult in terminal illness where it may not always be possible to determine, with absolute certainty, the true cause of death. Ambiguity around cause of death in terminal illness may be associated with reporting biases, for example medical staff considering death to be a normal occurrence in the natural history of the disease whatever the final cause, or death presumed to be the result of opportunistic infections, rather than from a deliberate act.

A more general problem concerns the lack of adequate registration of causes of deaths in mortality statistics which in itself lessens the validity and reliability of suicide statistics (WHO, 1982). It has been suggested that the extent of potential errors in identifying suicides may vary to such an extent as to hamper the validity of studies (Starace & Sherr, 1998). Even in cases where suicide is firmly established, it is often hard to acquire reliable data about HIV status and details relevant to suicidal risk.

Determination of prevalence is further compounded by the fact that many individuals who test for HIV undergo anonymous testing. This makes it impossible to directly relate a suicide to HIV sero-positivity. The only way to overcome this particular issue would be to conduct, as a matter of routine, post-mortem HIV testing on all violent or suspicious deaths (Starace and Sherr, 1998). Even in post-mortem studies, without clarification from clinical records there is always the possibility that some people identified as HIV positive at autopsy may not have known their HIV positive status. In those individuals knowing their sero-status, the co-existence of other risk factors complicates the extent to which the suicide can be directly attributed to HIV. A
particular problem with official register studies is that they have predominantly focussed on people with AIDS. This limited focus prevents generalisations being made to the wider, much larger group of people affected by HIV.

Doubts have therefore been raised regarding the over estimation of suicidal phenomena in this population in epidemiological studies (Starace, 1995), due to the differential competing risk of non-suicidal deaths in AIDS subjects and in the general population and the role of confounding factors such as "at risk" lifestyles, which are known to be associated with an increased prevalence of psychiatric problems and suicidal behaviours (Starace and Sherr, 1998).

Another difficulty in the study of suicide and HIV is related to the fact that the predominant groups affected (i.e. intravenous drug users and gay men) exhibit pre-existing risk factors which predispose them to being vulnerable to suicide irrespective of HIV. Additionally, trying to establish cause of death in intravenous drug users brings its own difficulties. In particular it is notoriously difficult to determine death by "unnatural" causes in this group (Pugh et al. 1993; Ayuso Mateos et al. 1996). Some suicide equivalent deaths in this group, such as those by accidents or drug overdoses, may have recorded verdicts of "misadventure", "undetermined" or "accidental overdoses", rather than one of suicide (Raj and Fugelstad, 1992). Inevitably, this would result in an under-estimation of morbidity and invalidate studies reliant on this data as a comparison. Assessing suicide in intravenous drug users and gay men, is further hampered by the findings that these groups have a number of independent risk factors (Gala et al. 1993). This point has been supported by researchers who have failed to find any significant differences between HIV negative and HIV positive subjects belonging to the same "at
risk" groups in terms of life prevalence of attempted suicide (Atkinson et al. 1990; Gala et al. 1989) but that differences did become significant when comparisons with control groups drawn from the general population were performed. The existence of these risk factors underscores the importance of using matched control groups.

A further problem is that studies frequently classify participants in a dichotomous fashion, on the basis of whether they have AIDS or are asymptomatic. There are weaknesses to this type of categorisation, particularly when information on stage of infection is omitted as asymptomatic individuals may be immunologically compromised. Omissions of medical details limit the epidemiological significance of studies and inhibits the formulation of more specific aetiological involvement in HIV suicide. This problem is particularly acute in those studies which are performed on people with asymptomatic HIV infection, given the neuro-psychological and immunological heterogeneity of this group.

The interaction between HIV and suicide remains ill understood. To increase our understanding a prospective cohort study is required to permit an examination of the association between suicide risk and other psychosocial and neuropsychiatric variables. This would hopefully result in better profiles of patients at greatest risk as well as identify trends in suicides (possibly related to epidemiological or biopsychosocial improvements). Such studies, as a minimum need to ensure the appropriate matching of suicides with comparison groups to allow "like with like" comparisons, thereby avoiding an underestimation of suicide risk in controlled populations (Hull et al. 1988). The only way to rule out confounding psychiatric illness would be to take pre HIV infection
baseline psychiatric functioning to partial out this variable in measuring the absolute impact of HIV on suicidality (Pugh et al. 1993).

Conclusion and recommendations

This review has shown that despite early reports of significantly higher rates of suicide in this population, more recent studies have reported the difference in risk to be much more modest. Studies of suicidal ideation also report diverse results. These diverse findings in terms of the prevalence of and factors associated with HIV related suicide, makes drawing any firm conclusions difficult. Many of the conflicting results have been shown to be related to methodological weaknesses of studies. There are general problems in studying the phenomenon of AIDS related suicides, some associated with the ever changing face of the epidemic in industrialised nations, where most of these studies have been conducted, whereas others are more related to peculiarities of particular groups affected. These factors may contribute to the conflicting results and highlights the problematic nature in trying to understand the extent to which completed suicides and suicidal ideation is directly attributable to HIV.

Suicide is a complex phenomenon. A potential explanation for our limited understanding of it been summed up as: "every suicidal act grows from an array of societal, psychological and biological variables; and although there are well-defined sub-groups of suicidal persons, the larger part of the "landscape" has not yet been satisfactorily mapped" (Diekstra, 1992, p84). Furthermore, prediction of suicide is difficult, 'as there is no absolute quantity of suicidality in any one patient, an individual may be suicidal one minute and not the next', (Birtchnell, 1983), As a result, the act of suicide has been
described as a kind of artefact, having immense practical consequences, but whose occurrence at any given point is largely fortuitous (Shaffer et al 1974).

Increased medical options have brought with them the possibility of renewed hope that HIV/AIDS can be managed as a chronic illness on an outpatient basis. This could have two opposite effects. On the one hand it could bring with it new hope and optimism for the future, but on the other hand could provide a longer time frame in which people are faced with living with a potentially terminal illness. Ultimately, therefore, there may be more time to confront the issue of dying and contemplate suicide. As with all other terminal illnesses suicide will continue to be considered an option by a proportion of patients with HIV. It is incumbent upon us as clinicians to help train colleagues in the identification of suicidal intent and to attempt to prevent this course of action. Suicide is not a static phenomenon but constantly changing which perhaps helps explain some of the conflicting results reported over the past decade. For the time being whether suicide is significantly increased in this population will continue to be a matter for debate and further research.
References


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The application of cognitive-behavioural therapy for depression to people with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS)

Overview

This paper considers the application of cognitive behavioural therapy to a population with terminal illness: people with HIV infection. Initially, an overview of the theory of cognitive therapy will be presented, followed by specific details related to the approaches to intervention used in this therapy. I will then examine the mechanism of change in cognitive therapy before going on to address the psychological problems faced by many people affected by HIV and AIDS. The specific application of cognitive therapy to an HIV/AIDS setting is then examined, with emphasis on differentiating between depression and normal adjustment processes to a diagnosis of HIV. An examination of the technique of 'reality testing' in this population is presented along with recommendations for applying this to this population. Due to a lack of empirical research in this area some information in this paper has necessarily derived from direct clinical experience. This is particularly the case in sections addressing the peculiar factors associated with the application of cognitive behavioural therapy to this field. Finally, suggestions for recommendations for future research in this area are highlighted.

Introduction

Cognitive behavioural therapy is one of a number of interventions under the umbrella of 'cognitive therapies'. Over recent years it has become one of the most well known approaches to the psychological treatment of depression. Beck’s cognitive distortions model has gained increasing prominence to the extent that it has probably gained the reputation as one of the most influential psychological theories of depression. It was
founded out of Beck’s belief that depression results from a disorder of thinking rather than primarily of affect. The main assumption is that there is a reciprocal relationship between cognitions (thoughts, beliefs, images and expectations), and emotions (Beck, 1979). Beck has moved from his earlier position in which he described a causal relationship between cognitions and affect to his primacy hypothesis, where he suggests that deviant cognitive processes, although intrinsic to depression, are not a necessary cause or consequence. It is argued that depressives characteristically exaggerate the significance of their misfortunes while concurrently minimising their positive capabilities for resolving problems or finding satisfaction. According to the theory, depressed cognitive interpretations distort reality, they are illogical inferences based upon an arbitrary selection of negative information, with no regard to positive information. Cognitive behavioural therapy is directed towards challenging these maladaptive distorted cognitions and substituting them with more realistic, adaptive patterns of thinking (Goddard, 1982). Although all depressed patients once depressed show similar negative cognitions the causal pathway, involving personality models and dysfunctional beliefs applies only to some. Haaga et al. (1991) note that depression results from an interaction of dysfunctional beliefs, high subjective valuation and the occurrence of an apt stressor.

Errors in thinking which habitually occur in depressed clients are the principal elements focused on in cognitive therapy. Cognitive therapy assumes a predisposition period, in which individuals gain various negative beliefs about themselves, their current experience and expectations for the future. It is suggested that these systematic illogical thinking errors (‘silent assumptions’) occur in a number of ways including: selective abstraction, dichotomous thinking, over-generalisations and catastrophising. Overall,
Beck (1979) points to the existence of a tripartite system which results in a depressed mood: the cognitive triad, cognitive distortions and depressogenic schema. The cognitive triad consists of negative beliefs regarding the self, the world and the future. Hollon et al. (1976) report on the way in which depressed individuals ‘see themselves as deprived, defeated or diseased, their world full of road blocks to their attaining even minimal satisfaction and their futures as devoid of any hope or gratification and promising only pain and frustration’. The role of distorted cognitions is to maintain the individual’s belief in the validity of their pessimistic views regardless of environmental stimuli to the contrary. Eventually this results in the characteristic personality, behavioural and cognitive symptomatology associated with depression: sadness, passivity, psychomotor slowing, negative affect, loss of self worth, self esteem, hopelessness and withdrawal.

Cognitive therapy then, views depression as the result of a negative cognitive set. Research suggests that ‘depressives’ differ from the non depressed both in terms of the content of what they think and the way in which they process information. This has led to an examination of cognitive vulnerability to depression (Teasdale and Dent, 1987). Abramson et al. (1978) in a major reformulation of Seligman’s learned helplessness model argued for a tendency in depressives' thinking to attribute negative outcomes to global, stable and internal factors. Additionally Seligman (1979) found that depressed clients were particularly likely to attribute negative outcomes, like failure, to internal factors such as personal incompetence.

To examine the effectiveness of Beck’s Cognitive Behavioural Therapy in ameliorating depression, it is necessary to examine its efficacy in relation to treatment outcome
studies. Until relatively recently, there has been a scarcity of conclusive empirical support of the clinical efficacy of Beck's cognitive therapy. Rush et al. (1977) provided the first empirical evidence which had important ramifications for both clinical practice and the theory of depression. In their controlled treatment trial, 41 depressed outpatients were randomly assigned to 12 weeks of either cognitive behavioural therapy or imipramine treatment combined with twenty minute weekly supportive visits. Results showed that while both groups improved the CBT group produced significantly greater improvements. Taylor and Marshall (1977) in a comparison study of CBT with strictly cognitive and strictly behavioural modification and waiting list controls found clear superiority of CBT. One remains cautious, however, as outcome data from more recent empirical studies show less supremacy of cognitive therapy in recovery from depression compared to pharmacological interventions. Considerable variation in efficacy is reported with the large National Institute for Mental Health collaborative multi centre trial (Elkin et al., 1989) reporting a 51% recovery rate.

The effectiveness of cognitive therapy for depression has now been supported empirically by a number of studies, however, the evidence that it is more effective than other active treatments during the acute treatment phase is not conclusive. There is promising evidence. However, that it is superior to pharmacological interventions and non behavioural psychotherapies in preventing relapse (Teasdale et al., 1984; Beck et al., 1985; Kovacs et al., 1981; Blackburn et al., 1986; Evans et al., 1992; Dobson, 1989).
Method of cognitive behavioural intervention

Given the efficacy of CBT how then does it work? From the above outline we see that the aim of therapy is to identify, evaluate and change maladaptive distorted belief systems and dysfunctional styles of information processing (Beck et al., 1979). In achieving this a structured active, therapeutic strategy of problem solving ('collaborative empiricism') is operationalised between clinician and client.

Beck identifies several methods, which can be used to create alternate, reality oriented cognitions. Using collaborative empiricism the depressed client is helped to elicit and describe their 'automatic thoughts', to appraise them and their underlying assumptions and to generate more realistic, positive alternatives. This process depends upon individuals learning that beliefs are hypotheses which have to be proven or disproved. During this process, if 'automatic thoughts' are seen as false hypotheses, they are discarded and a process of adjustment results through cognitive restructuring.

Cognitive restructuring relies on many principles among them reality testing. Such principles generate a variety of cognitive and behavioural techniques which include decatastrophising, alternative searching and costs benefit analysis. Homework assignments to encourage between, in addition to within session, confrontation of negative cognitive styles are seen as an integral and important part of therapy.

Mechanism in cognitive behaviour therapy

Although formally untested, it seems that two themes run through the application of Beck’s therapy of depression: (1) person’s self control and (2) positive reinforcement.
Self control is emphasised as Beck stresses individual’s beliefs in the uncontrollability of external events as a major factor leading to their felt helplessness. The value of positive reinforcement is self evident as it allows clients to gain confidence in their capabilities, self esteem and self worth. In combination these themes interact to increase clients' motivation to change. The relative importance of these factors in determining clinical change is yet to be the subject of systematic enquiry. Future examination of the contribution of these themes in therapy would serve to further our understanding of process variables in effecting lasting clinical improvement.

This paper has provided an outline of Beck’s cognitive theory and therapy of depression. It has portrayed CBT as an empirically efficacious treatment for depressed (psychiatric) populations. The question which needs to be addressed now is whether there is a role for the application of cognitive behaviour therapy in an HIV/AIDS setting where individuals’ emotional distress can be described as best characterised by a continuous process of adjustment and readjustment in line with illness progression and physical decline rather then having stable emotional states which cognitive theory has traditionally addressed.

Psychological problems associated with HIV
Kalichman and Sikkema (1994) reviewed empirical studies that describe and explain the psychological sequelae of HIV infection and reported that a wide range of psychological distress reactions are associated with HIV infection. They comment, in line with the belief that people with HIV infection go through a continuous process of adjustment, that depression appears to be more prevalent during the early phases of HIV disease, subsides during asymptomatic periods and recurs with the onset of HIV related
symptomatology. They further report that depression in HIV is complicated by the frequency of bereavement from AIDS related deaths. Suicide risk is high and follows a pattern similar to that for depression during the course of the illness.

At all stages from an HIV seropositive result through asymptomatic and symptomatic infection to full blown AIDS and finally death, a patient may experience a range of psychological reactions which may require intervention. Some responses will be understandable, healthy responses to life threatening situations. At other times, patients may develop more severe psychological problems requiring specific referral to mental health professionals.

Although it is not inevitable that depression and anxiety will occur in people diagnosed with HIV/AIDS, there is an increasing body of evidence highlighting the large numbers of people with AIDS (PWAs) who present for counselling in relation to depressive psychiatric symptomatology. Depression in PWAs has even been suggested (Cast et al., 1989, Jacob et al., 1989; Havens et al., 1989; Rundell et al., 1989), as measured by a variety of inventories, including the Beck Depression Inventory, to be one of the most common psychiatric reactions of PWAs to their diagnosis. Dilley et al (1985), Miller et al., (1986), Viney et al., (1989), Catalan et al (1992), Fell et al (1993) and Holland and Tross (1985) all report encountering depression in AIDS. Joseph et al (1990) in a 3 year follow up study found that all of their participants had higher levels of psychological morbidity than the general population.

Furthermore, it has been reported that the incidence of depression increases with HIV disease duration and progression (Becker and Zeger, 1989; Castro et al. 1989). Joseph
and Kessler (1989) in their 3 year examination of people with HIV found higher levels of depression, anxiety and global psychological distress associated with symptom progression. In contrast, however, Jadresic et al. (1989) report that although they found a depressed emotional response in the post diagnosis period, there were no significant increases after a 6 month ‘adjustment to diagnosis’ period. Brief transitory spells of anxiety and depression are probably universal in people with HIV related illnesses but these often resolve without formal psychological intervention. When depression becomes a problem for an individual to the extent that it interferes with their daily living, their quality of life and it becomes intense or intractable a referral for psychological therapy is often warranted.

There is much evidence in the field of terminal illness, (Greer, 1983; Greer et al., 1989; Mann, 1988; Kessler, 1989) and in the psychology of health generally, to support the importance of the role of stressful life events, especially those which involve loss, as determinants of depressive reactions. The influential work of Brown and Harris (1978) and Dohrenwend and Dohrenwend (1974) have shown the mediating influence of life events in decreasing self esteem and increasing the risk for depression. Additionally negative self-evaluation preceding the onset of depression in those exposed to a severe life threat has been reported (Beck et al. 1979).

There is an increasing body of evidence documenting the multiple severe life events which HIV and AIDS patients often experience (Viney et al 1992, Biller and Rice, 1990, Martin and Dean, 1993). These significant life events often involve some form of loss. These include: loss of relationships; partners, friends, family, job security, lengthy future and good health. The experience of multiple losses may well result in an individual's
decreased self esteem and self worth and prolonging recovery from depression or the adjustment process. The cumulative effect impact of multiple deaths from AIDS has been reported by Viney et al (1992), who found higher levels of anxiety in multiply bereaved individuals, and Biller and Rice (1990), who conclude multiple loss is different from “normal” bereavement because each grieving process is compounded by the one before it.

**Use of cognitive behavioural therapy in HIV/AIDS**

From the start of the HIV epidemic in the UK, clinical psychologists and other mental health professionals have adopted cognitive behavioural strategies to help their patients deal with the uncertainty, unpredictability and perceived uncontrollability of their adverse life circumstances. While there are a number of anecdotal reports of the efficacy of cognitive behavioural applications in this field in promoting a healthier adjustment to HIV infection and decreased psychological distress, there have been remarkably few published clinical case studies or empirical reports of the actual practice of cognitive therapy. Miller (1987), Hedge (1989), Ussher (1989), and George and Ussher (1988), refer to the use of cognitive therapy but few give specific details of its use. Auerbach et al (1992) have reported on the value of a group based behavioural intervention compared with a waiting list control condition and in a randomised controlled trial group cognitive behaviour therapy was found to be superior to non-treatment controls in improving psychological functioning by Kelly et al (1993). Small sample sizes in these studies however, prevent generalisation to the rest of the HIV population. A third controlled study comparing individual cognitive behaviour therapy with a waiting list control condition reinforced the value of this form of therapy in
reducing stress and improving quality of life in people with HIV infection (Lamping et al. 1993).

As cognitive behavioural therapy has been increasingly utilised by clinical psychologists working with people affected by HIV and AIDS, this paper now addresses whether the application of cognitive behavioural therapy to persons affected by HIV or AIDS represents an appropriate application of this therapy, particularly given that the negative internal reality of these individuals may often be consistent with the objective reality of their stressful life situation?

Differentiation in HIV/AIDS: Depression or a normal adjustment process?
Cognitive therapy views individuals' responses to stressful life circumstances as multi-factorial, including behaviours, emotions, cognitions and physical symptoms. Negative reactions in all of these spheres may be experienced by PWAs, which may predispose them to developing depression. The emotional reactions frequently expressed by terminally ill patients were first described by authors such as Kubler-Ross (1970). Miller (1989) and Green (1989) have documented similar reactions experienced by people with AIDS; shock, despair, fear, anger, depression, anxiety and self denigration. These emotions may also be manifested in behavioural terms for example by crying, or general psychomotor slowing, as well as somatically by for example experiencing pain or increased heart rate. These reactions may be interpreted as normal responses to learning of an HIV sero-positive or AIDS diagnosis and therefore can represent part of a healthy process of adjustment to trauma. Patients are often referred to clinical psychologists however, if their emotional expression becomes entrenched for example if there is an interruption in the adjustment process or if the cognitions, associated with
emotional expression, are in some way maladaptive, distorted or based on illogical thinking styles.

Any attempt to restructure patients’ negative automatic thoughts and illogical thinking errors must take into account the context and reality within which they operate. This is particularly important when dealing with people with HIV/AIDS as many of the cognitions reported to therapists may be an accurate reflection of the individuals' social reality ('depressive realism') and therefore may not be immediately appropriate to target in therapy.

Specific factors associated with HIV/AIDS

A form of CBT, Adjuvant Psychological Therapy (APT), has been used for women with breast cancer in which the aims are to promote a cognitive understanding of problems faced and a fighting spirit to enable the patient to lead as normal a life as possible (Moorey & Greer, 1989). When considering a CBT approach to people with HIV infection this author suggests some specific factors need to be taken into account which may make therapy more difficult.

1. People with HIV may have elevated levels of anxiety associated with the uncertainty of their disease progression several years prior to becoming symptomatic. Unlike in other serious illness where longer duration without relapse may indicate a decreased likelihood of disease recurrence this is not the case in HIV infection. There may be a lengthy period during which the HIV seropositive remains asymptomatic but the morbidity and mortality statistics to date indicate that the majority will develop AIDS (CDR, February 1999). This
hangs like a time bomb over their heads, generating high levels of fear and anxiety associated with inevitability together with the uncontrollability and unpredictability of when this will happen.

2. Most people with HIV/AIDS know many others who have the same virus as themselves. Additionally, many seropositive patients are likely to have seen their peers die, often having cared for them throughout their terminal stages of illness. This predisposes them to increased knowledge about what it is like to die from an AIDS related death.

3. A diagnosis of HIV/AIDS often presents as a double blow for the person infected as they may find out that their lover or spouse is also infected and in some cases they may be responsible for infecting their partner. There may also be the possibility of them having infected their children.

4. AIDS is a particularly stigmatising illness because of the high incidence in the groups it has predominantly affected and because it is primarily a sexually transmitted disease. The person with AIDS may find it impossible to be open about their illness for fear that they will be rejected by friends and family alike. The lack of adequate support networks or a confidant is well known to be one factor associated with a greater vulnerability to depression (Brown and Harris, 1978). While psychological reactions may be similar across infected populations there will be many issues specifically related to the population affected for example gay men, people from ethnic minorities, women, heterosexuals, haemophiliacs, or children. Gay men, people from ethnic minorities and
intravenous drug users are more likely to seek help through mental health services and therapists need to be aware that many of these individuals may have psychiatric histories prior to their HIV infection (Catalan et al., 1995).

5. The population with HIV infection is predominantly young in an age group where illness is rare.

6. New drug treatments are being developed and drug trials implemented within the field of HIV/AIDS. Even within the past few months the availability of new groups of anti-retroviral drugs (protease inhibitors) and new markers of the potency of HIV activity (viral load tests) have stimulated an increased sense of hope among patients and health care staff. With this hope, new anxieties emerge related to the most opportune time to commence new treatments with the knowledge that taking these drugs may result in viral resistance developing to other similar drugs or preventing a patient from benefiting from future medical innovations. The issue of drug resistance also has potentially grave implications for newly diagnosed individuals who may have become infected by a strain of virus already ‘resistant’ to ‘anti-retroviral treatments’.

7. There is increasing speculation that the advances in the medical treatment of patients will continue to slow disease progression from HIV to AIDS and that management of HIV will become an increasingly outpatient based service with HIV viewed as a chronic rather than terminal illness. This potentially could result in elevated levels of psychological distress as patients living longer with
manageable HIV infection may develop more frequent severe disabling opportunistic infections leading to illnesses such as dementia or blindness.

8. Unlike in other life threatening conditions, in HIV/AIDS, there are specific issues associated with reproduction. We often see couples who are HIV discordant but who still wish to have a child.

9. An HIV positive individual needs to remain vigilant about safer sex practices even if their partner is concordant for HIV. There are many strains of HIV. Unprotected sexual intercourse brings the risk of cross-infection with different strains of HIV virus or re-infection with the same strain, thereby increasing viral load.

The patient may have known the majority of his/her friends die from the same illness, may have been rejected by their family and friends, may have infected their spouse and children, may be losing their looks and becoming physically unwell. Upon a referral to a cognitive therapist it is clear that some irreversible negative events have already occurred and this cannot be changed. These experiences may have led to cognitions related to loss, which may have resulted in the depressed mood-state. It is also clear that future negative events are also going to occur, which may produce cognitions associated with uncertainty and terror, which generate anxiety. In the author’s clinical experience a mixed emotional picture is most frequently seen in people with HIV. Cognitions, which are most commonly cited by people affected by HIV/AIDS have not been empirically studied but on the basis of clinical experience the author believes these can be divided into five main themes: (quotes taken from therapy sessions)
1. Loss - which is most often related to depression:

   'so many of my friends have died.'
   'I’ve lost my health.'
   'I have nothing to look forward to.'
   'My life is out of control.'

2. Future developments/uncertainty - which are associated with fear and anxiety:

   'I’m next to die.'
   'I’ll be so unattractive I won’t be able to go out.'
   'I’ll never find a partner now.'
   'No one will look after me when I’m dying.'

3. Being ‘caught out’ and inability to overcome the virus - which are associated with frustration:

   'Why me?'
   'The virus has taken over my life.'
   'I shouldn’t have led such a double life.'

4. Cognitions regarding self-judgement of sexuality and sexual behaviour - which are often associated with guilt:

   'Sex is off.'
   'I shouldn’t have been so promiscuous.'
‘If only I had used condoms.’

‘No one will sleep with me now.’

‘It’s God’s punishment for being gay.’

5. Anger, either directed onto those who infected them or inwards on to themselves:

‘I shouldn’t have trusted my partner.’

‘How could I have been so stupid.’

‘If only I had been more careful.’

**Reality testing**

Although patients’ thoughts are extremely negative they may also be very real, being confirmed in the patients’ medical and social reality. If people with AIDS are living in a negative medical and social reality what can cognitive therapy, which has as one of its central components ‘reality testing’, offer this group of patients? Is Beck’s cognitive therapy able to provide PWAs relief from their psychological distress when the source of that distress is firmly entrenched in negative reality?

Beck (1989) argues, even though people in adverse life situations may hold negative cognitions which are reality based, but they still tend to associate surplus meanings to their condition or situation by neglecting the possible options open to them. Consequently CBT is still able to address distorted meanings as these may be founded on maladaptive thoughts which may be challenged. It is important to remember Ellis’s (1973) point that maladjusted thoughts which are associated with negative reality must be interpreted in relation to reality, whether this reality is positive or negative. It is
equally important to remember that although many people with AIDS or HIV will experience the negative reality outlined above, others may present with a reactive depression which is primarily unrelated to AIDS or HIV issues.

The presence of cognitive distortions, misinterpretation of bodily symptoms and a sense of fatality and uncontrollability can combine with the physical symptoms of HIV/AIDS, anxiety and depression to produce a chronic escalation. Being educated about the behavioural, somatic, cognitive and physiological manifestations of depression can be a relief to patients in itself as many of the symptoms associated with depression mimic those which occur with HIV disease progression.

If negative cognitions are negative in reality it would seem an inappropriate exercise to ‘reality test’, in a non discriminatory way, as these cognitions would remain negative. Nevertheless Beck’s theory has been applied successfully in this setting (George and Ussher, 1988; Hedge, 1989), by focusing more attention on specific techniques within reality testing such as decatastrophising and depersonalising.

Decatastrophising as a cognitive technique is founded on the belief that disasters or ‘catastrophes’ are probably going to occur in an individual's future experience and for AIDS patients it is unlikely that they are going to be able to prevent negative events from occurring. By ‘decatastrophising’ these situations patients can be helped to develop coping strategies for if and when the events occur. This may help to remove the negative cognitions surrounding the anticipation of the events (Miller and Bor, 1988; Hedge, 1989) by substituting anxious and depressive cognitions with more positive ones.
(a sort of 'relapse management' approach in addiction terms). Examples of more adaptive cognitions could be:

I will get through this.

I will cope.

I may be ill now, but this will not pull me down.

Being unwell now does not mean I only have days left to live.

I want to be able to live with HIV/AIDS.

Decatastrophising, can be used to improve clients' current depressed state, by breaking the chain of thought from negative thoughts to low mood to attempt to restructure them by collaboratively considering alternatives. Therapy is not about convincing patients that they will have nothing to worry about but instilling a belief that they will be able to cope with the negative reality and thereby reducing some of the anxiety attached to events. For example where reality testing might be appropriately used to help anxious patients correctly identify their symptoms of autonomic arousal as symptoms of their psychological distress and to decatastrophise their belief that such physical symptomatology is a sign of the activation of HIV on their immune functioning. Similarly with the depressed person with AIDS, loss of weight and appetite and sleep disruption may be misinterpreted as a sign of further opportunistic infections or constitutional illness rather than a direct symptom of their depression thereby increasing their depression and generating a belief that they are physically deteriorating faster than they actually are.
Clinical experience has shown that many patients with HIV spend considerable amounts of time ruminating about their past, current and future life. They may spend much of their waking hours pondering the reasons why they had not responded to government campaigns to adopt safer sex practices or they may spend an inordinate amount of time ruminating about an inevitable process of decline or death and dying. This highlights the dysfunctional nature of some of their cognitions. Although empirical work has not been conducted to formally document and validate these processes, close parallels can be made with the elderly population where reports of death related rumination have been reported (Butler et al. 1963). If cognitive techniques are utilised in conjunction with behavioural techniques (such as structured homework, activity scheduling, distraction, setting short and long term goals, setting aside ‘worry time’, relaxation training, problem solving and thought stopping), increased coping abilities, feelings of increased enjoyment, as well as generally less depressive cognitions may result (George and Ussher, 1988; Ussher, 1989; Hedge 1989).

This author agrees with Moorey and Greer, (1989) in their study of cancer sufferers, that although these patients live within a negative reality those who seem to find the adjustment to their diagnosis most difficult are those who appraise their situation in ways which serve to elevate them from an understandable reaction of sadness to that of depression. By examining the idiosyncratic meaning of events for each individual, focusing on decatastrophising their negative appraisals, their reactions can be reality tested and their psychological distress tempered (Moorey and Greer, 1989).

In addition to the need for a change of emphasis in cognitive therapy with the terminally ill, modification to the practice and logistics of therapy may also be required. Patients
often (but by no means always) present with emotional difficulties when they are symptomatic or their HIV disease is progressing. Consequently it is argued patients need to be offered sessions which are likely to be within their life-span, the duration of sessions needs to be tailored to suit individual patients' strengths and therapy needs to accommodate medical regimes. This is particularly the case for inpatients, where the therapist will need to ensure that therapy sessions do not coincide with recent administration of strong anti-retroviral medications, which have a variety of negative side effects, or other medical procedures. Patients should be encouraged to take responsibility for the therapy sessions by giving them permission to start the session. Again this is crucial for in-patients who may not feel up to therapy but be unable to escape as therapy is taking place on the ward. It is important to maintain structure in therapy with this group but with a degree of flexibility.

It is crucial to determine at the assessment of the patient whether they are displaying a depression or an ongoing adjustment reaction. In the latter case, the role of therapy would be to facilitate the expression of emotion rather than to restructure cognitions. In cases where an adjustment process has halted or become blocked, cognitive therapy may be able to facilitate the process by examining the personal meaning of the illness to the patients, e.g. ‘If I don’t cope with this illness I am a failure’.

If patients with HIV/AIDS are depressed it is suggested that they can be helped in a number of ways, examples of these include:

1. The setting of clear aims and objectives. Fuzzy or unrealistic goals such as: ‘to help me completely accept an HIV diagnosis and my eventual physical decline
and death' are inappropriate and should be avoided in favour of e.g. ‘To help me manage my distress more effectively’ or ‘To reduce the amount of time I spend ruminating about death’.

2. Identify and challenge underlying cognitive distortions.

3. Examine personal meanings of illness for each patient.

4. Validate experiences and facilitate appropriate ventilation of feelings.

5. Teach behavioural and cognitive strategies to help manage negative cognitions, (distraction, scheduling worry time, activity scheduling etc) and achieve a sense of controllability.

6. Encourage uptake of social support by joining voluntary organisations, support groups, buddies etc. This is particularly important in HIV/AIDS where patients often are unable to tell anyone of their diagnosis in their immediate social network for fear of discrimination.

7. Prepare them for further physical decline to help them anticipate this. This can be facilitated by questioning around how they would cope with further symptoms.

8. Help implement practical solutions to problems such as: for the gay man who is worried about his male partner being financially secure in the event of his death
suggesting legal advice and the drawing up of a careful will; for the mother who is worried that her children would forget her, initiate a memory scrapbook.

The efficacy of the above recommendations and adjustments for cognitive therapy in this population to date have not been empirically studied or proven to date. Before conclusions can be drawn as the effectiveness of the approach outlined above further evaluation is required.

Conclusion and recommendations

Through the presentation of empirical and clinical data this paper has argued that cognitive behavioural therapy is an appropriate and useful therapy for people affected by HIV and AIDS, even in the context of a largely negative reality. In particular it appears to offer patients specific strategies for psychological change within a relatively short time span which is useful for individuals whether they are recently diagnosed as HIV sero-positive or in the end stages of their illness. Many people affected by HIV/AIDS express the views that their illness has taken away any sense of personal control for their lives. Cognitive therapy may act as an antidote to this, enabling PWAs to reduce feelings of fatalism and helplessness by collaborating with the therapist in learning how to take an active role in regaining control over themselves, their situation and their future, through challenging the view that illness necessarily leads to helplessness and hopelessness.

Clinical case material has been incorporated throughout this paper due to the lack of empirical research in this field, which may be because this is a difficult and challenging area for cognitive therapists to explore. There is a great deal of anecdotal evidence and
some preliminary empirical evidence, that cognitive therapy can be usefully applied to this population. The dearth of empirical work highlights the clear need for further research in this area. To date cognitions have not been the subject of systematic enquiry or assessment. The types of negative cognitions generally and more specifically those found in different terminal illnesses have yet to be examined and compared. It is argued that future research should address this omission in the literature, through examining potential groupings of cognitions (for example around issues of guilt, sexual identity, uncertainty over physical decline, being ‘found out’ or dying), to enable the similarities and differences in cognitions between different illness populations to be clarified and thereby furthering our understanding of the experiences of terminally ill patients and any specific worries associated with different illnesses. It is also argued that an increased awareness of the social and situational aspects involved in the onset and maintenance of depression should be focussed on in future work, as these remain somewhat lacking in Beck’s theory of depression.

From a clinical perspective if the goal of therapy is to help people with HIV or AIDS develop coping strategies to help them adjust to living with AIDS, then at least anecdotally CBT appears to be a viable treatment option for this.
References


PART 2: CLINICAL DOSSIER

Surrogate breast-feeding (wet-nursing) as a potential route of transmission of HIV in London, UK?

Abstract

It is estimated that up to 50% of pediatric HIV cases result from transmission of HIV from an infected mother to child through breastfeeding. Recent anecdotal reports have highlighted wet-nursing as a possible route of HIV transmission. This study was set up to determine the prevalence of wet-nursing and assess women's knowledge about the risk of HIV transmission through breast-feeding. 781 women of childbearing age (15-44) attending Genito-urinary, Antenatal and Primary care baby clinics completed an anonymous, voluntary self-report questionnaire. Mean age was 29 years. The majority of women (73%) were unaware of their HIV status, 1% knew they were HIV positive and 26% had been told they were HIV negative. 4%(n=32) of the sample knew women who had wet-nursed. 0.5% of the sample had engaged in wet-nursing practices themselves or had permitted their own child to be wet-nursed but a fifth of women would consider becoming a wet-nurse themselves or consider another woman acting as wet-nurse to their children. Only 27% knew that HIV transmission could occur through breastfeeding with 17% reporting HIV could definitely not be transmitted in this way and a further 32% professed not to know. No associations between age, ethnicity or level of education and knowledge of HIV transmission were found but older women educated to graduate level were significantly more accepting of wet-nursing practices. Prevalence of direct and indirect experience of wet-nursing is rare but willingness to wet-nurse and general acceptance is more common. Increased awareness is required when counselling women about their knowledge of HIV transmission through breast-feeding. All women need to be educated about the risk of HIV transmission through wet-nursing and breastfeeding generally. Healthcare workers, especially midwives, psychologists, health visitors and obstetricians need to be aware that wet-nursing may occur and to counsel all women about the risks associated with this practice. Clinical psychologists' knowledge of risk taking behaviours and communication skills means they are expertly placed to teach fellow health care professions about potential risk reduction strategies with this population.
Clinical Project

Surrogate breast-feeding (wet-nursing) as a potential route of transmission of HIV in London, UK?

Introduction

The Department of Genito-Urinary Medicine at St. George's Hospital (the Courtyard Clinic), plays a role of paramount importance in the treatment and prevention of HIV in South West London, for all groups of the population at risk for HIV infection. Within the Courtyard Clinic, a specialist clinic for families and children infected with or affected by HIV/AIDS (the PENTA Clinic), provides an integrated biopsychosocial service for families and children. As part of this service, advice on the prevention of HIV between sexual partners and from mother to child is provided by clinical psychologists and other members of the multi-disciplinary team. One of the recommendations in relation to the avoidance of the vertical transmission of HIV is to advise women who are pregnant or considering pregnancy not to breast-feed. To date, however, although the role of breast-feeding and HIV transmission is discussed, the issue of surrogate breast-feeding / wet-nursing is not addressed, largely due to inadequate knowledge of the prevalence of this behaviour.

Global Statistics on the prevalence of HIV and AIDS

In July 1996 World Health Organisation figures quoted at the XI International Conference on HIV/AIDS, indicated that there had been approximately 5.8 million deaths from AIDS related illnesses world wide, of which nearly 1.3 million (approximately one fifth) died in the preceding year. Current approximate figures for people living with HIV are 22 million. Of these, 8.8 million are women and 1 million are children. It is estimated that given the continuation of current trends, by the year
2000 there will be 40 million cases of people living with HIV. Currently 1.2 million of all infected cases are to be found resident within North America and Western Europe (WHO, 1999).

The incidence of HIV in the United Kingdom

The Communicable Disease Surveillance Centre weekly report of U.K. epidemiological data for the number of HIV infections and cases of AIDS, reveals that for the period up to December 1998 (CDR, February 1999) there have been a total of 37,466 cases of HIV infection in the UK. Of these infections, 13,008 are reported to have died from an AIDS related illness. 2941 new cases of HIV infection were reported for the first time in 1998 and of these 2316 were diagnosed for the first time during 1998. 35% (853) of these new infections were acquired through heterosexual sex, 4% (91) through injecting drug use with the remaining 48% (1112) acquired through homosexual sexual contact. The number of individuals newly diagnosed with HIV has failed to decrease, with the number of new infections remaining roughly the same, at approximately 3000, from year to year. London remains the area with the highest prevalence of HIV infection in the UK with 67% (25,054) of individuals infected, within the North and South Thames regions.

Incidence of HIV in Merton Sutton and Wandsworth Health Authority 1996/7 (MSW)

St. George's Healthcare NHS Trust is the largest hospital provider for HIV/AIDS in MSW. Open access services are provided at the Courtyard Clinic for people infected with or affected by HIV/AIDS. Figures for the overall number of cases of HIV/AIDS within MSW are presented below.

The AIDS (Control) Act Report is compiled each year by the Public Health Department of the Health Authority, with assistance from each of the Trusts within each authority. It
provides an opportunity to assess the current situation within each district in relation to both the spread of HIV infection and the provision of services for those who are infected and affected.

During 1996/7, 61 residents of MSW were notified to the Communicable Disease Surveillance Centre with the first report of an AIDS defining illness. As at the end of March 1997, there were thought to be approximately 169 MSW residents with AIDS. 62 new cases of HIV infection were reported. It is interesting to note that information supplied about the probable route of transmission, illustrates that the local pattern in MSW, differs from the national picture, in that new infections reported by local laboratories identify a smaller number of infections through sex between men compared to the national figure (33% and 63% respectively). Conversely 44% of new HIV infections reported locally were acquired through sex between men and women compared with 30% nationally.

During 1997, 664 MSW residents with known HIV infection were seen by NHS service providers. Of these infections 57(9%) were transmitted vertically from mother to child and 242(36%) were acquired heterosexually.

Prevalence of individuals with HIV registered at the Courtyard Clinic, St. George's Healthcare NHS Trust

As of July 1999, 387 individuals with HIV were registered at the Courtyard Clinic. 258(66.6 %) of these were male and 129 (33.3%) were female. The HIV epidemic seen in Africa is reflected in the UK among communities from high prevalence countries. As a consequence HIV services in the UK, including the one at St. George's Hospital, are seeing increasing numbers of African attenders. The ethnic origin of individuals infected
with HIV, within the Courtyard Clinic are presented in Table 2. These figures show that the majority of females registered as infected with HIV are Black Africans (67%) with Black Caribbeans comprising a further 9%. This could reflect the large refugee population from African countries in South West London which have a high prevalence of HIV infection. GUM clinics should therefore consider the specific needs of African communities in relation to HIV infection and attempt to provide an appropriate service.

Table 2  
HIV statistics by gender and ethnic group within the Courtyard Clinic (n, %)

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>142(55)</td>
<td>28(21.7)</td>
<td>170(43.9)</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>19(7.4)</td>
<td>12(9.3)</td>
<td>31(8.0)</td>
</tr>
<tr>
<td>Black African</td>
<td>79(31)</td>
<td>87(67.4)</td>
<td>166(42.9)</td>
</tr>
<tr>
<td>Black Other</td>
<td>2(0.8)</td>
<td>1(0.8)</td>
<td>3(0.8)</td>
</tr>
<tr>
<td>Indian / Pakistani / Bangladeshi</td>
<td>0</td>
<td>1(0.8)</td>
<td>1(0.25)</td>
</tr>
<tr>
<td>Other/Mixed</td>
<td>3(0.8)</td>
<td>0</td>
<td>3(0.8)</td>
</tr>
<tr>
<td>Not Known</td>
<td>3(0.8)</td>
<td>1(0.8)</td>
<td>4(1.0)</td>
</tr>
<tr>
<td>Total</td>
<td>258(66.6)</td>
<td>129(33.3)</td>
<td>387</td>
</tr>
</tbody>
</table>

Source: MSW Health.

One third of the Courtyard Clinic patients are female. 77.5% of all women are of Black African, Black Caribbean or Black other status. While the ethnic profile of the known HIV infected population resident in MSW is similar to that in 1996, the proportion of Black African individuals is increasing slightly, the majority of whom have contracted their infection heterosexually.

To place the above data in perspective, table 3 shows overall figures for ethnic composition of MSW.
Residents in Merton Sutton and Wandsworth Health Authority are from diverse ethnic and cultural backgrounds. There are larger numbers of people from black and minority ethnic communities in Wandsworth (20% of the population) and smaller, but significant proportions in Merton and Sutton (16.3% and 5.9% respectively). A larger percentage of MSW residents are Black Caribbean (9.7%), Black African (5.3%) and Indian (8.1%). The ethnic profile is broadly similar to that of Inner London.

Vertical Transmission of HIV

In incidence of HIV in Children: Global and UK statistics

The first children born with HIV-1 infection were described in 1983. As of 1999, the global HIV epidemic is continuing to have a profound impact on the health and survival of children (Bultery & Lepage, 1998). Almost all HIV infections among young children are due to vertical transmission.

Over the last decade the number of HIV infected children globally has risen significantly, due to the world-wide increase in HIV prevalence among women of childbearing age. According to the Centers for Disease Control and Prevention (CDC,
the percentage of women diagnosed with AIDS in the USA doubled from 7% in 1984 to nearly 15% in 1995, and continues to climb. 

HIV sero-prevalence rates in pregnant women world-wide have been found to range from 0-0.3% in North America, 1-5% in South America, and 35-45% in sub-Saharan Africa, where approximately 1,000 infants are born daily with HIV infection (Davison and Nicoll, 1997). Rates of perinatal transmission of HIV also differ by population and geographic area. Prior to the recommendation of Zidovudine (AZT) treatment of HIV infected pregnant women in 1994 (Connor et al. 1994), perinatal transmission rates ranged from 25% in the United States to 13% in Europe and 40% in Africa (Connor et al. 1994).

In the United States there are approximately 1,400 to 2,200 HIV infected infants born each year (Davis et al. 1995). In the UK the figures are significantly lower. Table 4 shows the incidence of paediatric HIV, among children born to HIV positive mothers by year of birth in the UK.

Table 4 Incidence of HIV infection in children born to HIV infected mothers: United Kingdom figures to end of January 1999.

<table>
<thead>
<tr>
<th>Year of Birth</th>
<th>Infected</th>
<th>Indeterminate</th>
<th>Not Infected</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1983</td>
<td>15</td>
<td>-</td>
<td>-</td>
<td>15</td>
</tr>
<tr>
<td>1984-85</td>
<td>36</td>
<td>4</td>
<td>15</td>
<td>55</td>
</tr>
<tr>
<td>1986-87</td>
<td>47</td>
<td>14</td>
<td>50</td>
<td>111</td>
</tr>
<tr>
<td>1988-89</td>
<td>70</td>
<td>14</td>
<td>53</td>
<td>137</td>
</tr>
<tr>
<td>1990-91</td>
<td>108</td>
<td>31</td>
<td>75</td>
<td>214</td>
</tr>
<tr>
<td>1992-93</td>
<td>116</td>
<td>43</td>
<td>86</td>
<td>245</td>
</tr>
<tr>
<td>1994-95</td>
<td>88</td>
<td>43</td>
<td>104</td>
<td>235</td>
</tr>
<tr>
<td>1996-97</td>
<td>80</td>
<td>60</td>
<td>147</td>
<td>287</td>
</tr>
<tr>
<td>1998-99</td>
<td>18</td>
<td>88</td>
<td>65</td>
<td>171</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>578</td>
<td>297</td>
<td>595</td>
<td>1470</td>
</tr>
</tbody>
</table>

Table 4 shows that the number of cases of children with HIV born to mothers infected with HIV in the United Kingdom rose steadily from 1983 to 1996/7 (with the exception
of a slight decrease in 1994/5) but since then has significantly decreased. Of those children born to HIV positive mothers in 1998-1999, 18 acquired HIV (thirteen of which have AIDS), 88 remain of indeterminate status and 65 are uninfected.

Statistics for the PENTA clinic reveal that during 1997/98 there were 79 paediatric HIV cases registered. Of these, 16 were new patients. It is unclear how many of these new patients were newborn, as opposed to existing children who sero-converted or who transferred from other HIV providers.

**Modes of transmission in paediatric HIV infection**

The vast majority of new paediatric HIV cases are due to perinatal transmission of the virus. (Nielsen, 1998; CDC, 1996) Transmission of HIV infection may occur in utero, intrapartum or through breast-feeding. Although perinatal HIV infection rates have declined substantially in the developed world since 1994, approximately 30-50% of infants who contract infection will acquire it in utero and 50-70% will acquire the infection during the intrapartum period (Dickover et al. 1996; Nielsen et al. 1997; Mayaux et al. 1997).

**Reduction in perinatally acquired HIV infection**

In 1994 the results of the landmark AIDS Clinical Trials Group (ACTG) 076 study, a multi-centre trial conducted in the United States and Europe, were published, (Connor et al. 1994). This was the first study to demonstrate the unquestionable efficacy of Zidovudine (AZT) in reducing vertical transmission rates (25% in the placebo arm vs. 8% in the treatment group) when given throughout pregnancy, labour and delivery and to the new-born. Since these findings were first published, increased surveillance and
anti-retroviral treatment of HIV infected pregnant women have contributed to a declining perinatal HIV transmission rate in North America and Western Europe (Cooper et al. 1996).

One of the largest studies to date, examining the prevention of mother-infant HIV transmission, was conducted by Read (1998). In this meta-analysis study, individual patient data were combined from fifteen prospective cohorts of patients, five European and ten North American. In all fifteen studies women were instructed not to breast-feed. A total of 8533 mother-infant pairs were included. HIV vertical transmission rates were reported to have decreased by 50% when elective caesarean sections were performed compared with other modes of delivery. In addition, when elective caesarean sections were performed in conjunction with receipt of anti-retroviral therapy during the antepartum, intrapartum and neonatal periods, the likelihood of transmission was reduced by 85% compared to other modes of delivery and no receipt of therapy. Other, even more encouraging results were reported by Kind, (1998). In this study no perinatal HIV transmission occurred among mother-infant pairs who received a complete Zidovudine regimen and who underwent elective caesarean sections. However, the small number of mother-infant pairs in this study (n=45), means caution is required in interpreting the results. In another recently published French study (Mandelbrot, 1998), elective caesarean section was found to be associated with a lower HIV vertical transmission rate when used in conjunction with maternal anti-retroviral therapy. However a beneficial effect of elective caesarean section in decreasing HIV vertical transmission was not present in women who did not receive anti-retroviral therapy.
Breast-feeding and postnatal HIV transmission

HIV-1 has been isolated from breast milk culture, viewed by electron microscopy and measured by HIV p24 antigen, DNA Polymerase Chain Reaction (PCR) and RNA PCR (Nielsen, 1999). It is unclear if the rate of transmission through breast-feeding is constant. An estimated one third to one half of vertical transmission of HIV-1 worldwide has been reported to be due to breast-feeding, (Kreiss, 1997). The timing of breast milk transmission during the course of lactation remains unclear, but several studies have now found an association between duration of breast-feeding and risk of infant infection (Leroy et al 1998, Ekpini et al 1997). Ekpini et al. (1997) have reported prolonged breast-feeding for 15 months or longer to be associated with a two-fold increase in transmission risk. Other, ongoing studies of late postnatal transmission have also indicated a near linear increase in post-natal HIV infection rates associated with breast-feeding in the first 15 months of life (Taha et al. 1998).

Bobat et al. (1997) in another study of infants (n=43 HIV infected and 90 non-infected) of mothers with HIV-1 in Durban, South Africa, found that 36 infants (27%) were exclusively breast-fed, 76 (57%) received a mix of breast-milk and formula and 21(16%) received only formula. HIV transmission rates for these groups were reported to be 39% of those exclusively breast-fed, 24% in those only fed on formula and 32% who received mixed feeding. With regard to exclusive breast-feeding a stepwise increase in the HIV transmission rate was found with duration of exclusive breast-feeding of 1, 2 and 3 months (45%, 64% and 75% respectively).

Although successful screening of pregnant women has reduced the incidence of breast-feeding of infants by HIV infected mothers in recent years, acquisition of infection via breast-milk remains a considerable problem in the developing world. Recent data has
reported breast-feeding transmission rates of between 5 to 12% in Africa, (Bertolli et al. 1996; Ekpini et al. 1997). Although in the UK and other industrialised countries HIV infected women are instructed not to breast-feed, in developing world countries women often have the difficult choice of balancing the risk of transmitting HIV through breast milk against the substantial benefits of breast-feeding. Recommendations against breast-feeding in developing countries have therefore been relative rather than absolute.

Wet-nursing

Anecdotal reports from women attending the Courtyard Clinic suggest, that in addition to women breast-feeding their own babies, wet-nursing practices may also exist, in particular among women from some African countries. This is partly borne out by two recent anecdotal reports, from (a) South Africa, where breast-feeding by hospital staff of patients’ babies has been reported, and (b) London, where the death, from AIDS, of a baby born to an HIV negative couple has been reported, where it subsequently transpired the couple’s nanny was HIV positive and had been breast-feeding the baby. To date it is not clear whether these reports represent isolated cases of wet-nursing (especially in London) or whether this form of risk behaviour is more widespread. What is clear however is that these reports have highlighted wet-nursing as a possible route of HIV transmission.

Despite this author conducting a number of literature searches, no references to surrogate breast-feeding / wet-nursing could be found. While articles on breast-feeding regularly discuss the potential for HIV transmission, wet-nursing practices are rarely mentioned despite the potential of this behaviour as a mode for HIV transmission. The lack of attention to wet-nursing as an HIV risk behaviour and its relationship to HIV
transmission is surprising, particularly given the focus over the last few years on trying to prevent post-natal paediatric HIV transmission through breast-feeding.

**Interventions to reduce mother-child transmission of HIV in the UK**

In support of testing pregnant women for HIV prior to delivery, Gibb et al (1997), have reported that between 1990 and 1995, 14(4%) of 314 women diagnosed with HIV infection before delivery, breast-fed their baby, compared to 109 (77%) of 142 who were diagnosed after their delivery. They conclude that knowledge of HIV status by pregnant women prior to delivery results in women becoming increasingly active in taking up interventions to reduce transmission to their infants. They suggest all HIV infected women attending for antenatal care consent to being tested for HIV, to enable adequate perinatal and postnatal prevention strategies to be employed and to ultimately reduce new paediatric infections.

**Project rationale**

UK HIV statistics show an increasing incidence of new cases of heterosexually transmitted HIV infection, particularly in women. The only clear way of preventing and containing the spread of HIV is by effective and sustained behavioural changes. Breast-feeding has been reported to account for up to 50% of the cases of HIV infected children world-wide. In recognition of the potential role of breast-feeding in transmitting HIV, the World Health Organisation has recommended that in areas where infectious diseases and malnutrition are not major causes of infant mortality, and where safe alternatives to breast-feeding are available, women known to be HIV seropositive should not breast-feed or supply their milk for the nutrition of their own or other infants.

For health education to effectively reduce the number of newly acquired paediatric HIV cases, it is essential to know as much as possible about the risk behaviours, which place
infants at risk of acquiring infection. Physicians involved in the care of infants born to women either infected with HIV or at risk of contracting the virus, will often discuss issues of breast-feeding and whether expressed milk should be provided, given that maternal milk can be an efficient route of postnatal HIV transmission. Our lack of knowledge about the prevalence of surrogate breast-feeding (wet-nursing) practices and its association with infant HIV infection to date, means this behaviour is rarely formally discussed with women. This lack of knowledge is a particular cause of concern at St. George's where a large percentage of women with HIV originate from countries where wet-nursing practices may, at least anecdotally, be more widely accepted and practised.

Based on concerns raised by staff of the possibility that Courtyard Clinic attenders may be engaging in or at least considering this method of feeding their infants and in view of the lack of data on the prevalence of wet-nursing practices, this project was set up to:

AIMS OF STUDY

(1) Determine the prevalence of wet-nursing practices in London in the population under investigation
(2) Investigate women’s acceptance of wet-nursing practices
(3) Examine any cultural differences in relation to wet-nursing practices
(4) Evaluate level of knowledge in relation to HIV transmission through breast-feeding.

Method

Participants and sample recruitment

880 questionnaires were distributed to women attending three hospital clinics and one community clinic in London: the Departments of Genito-Urinary Medicine at
St. George's Healthcare NHS Trust (the Courtyard Clinic) and St. Thomas's Hospital; the Ante-natal Department at St. George's hospital and a local primary care baby clinic.

The majority of questionnaires were distributed to participants by clinic receptionists when they registered for their clinic appointment. To aid questionnaire completion, pens were supplied. Completed questionnaires were returned to a survey box strategically placed within the clinic reception area. Approximately two hundred questionnaires were handed to participants by a medical student, again while women awaited for their clinic appointments.

Study Design and Measures

A self-report questionnaire study design was employed. An anonymous, voluntary two page self-report questionnaire was devised specifically for this study (see appendix 1). The questionnaire included sections on demographic characteristics and HIV status, attitudes towards breast-feeding and wet-nursing practices and knowledge of the risk of HIV transmission through breast-feeding. The questionnaire was initially piloted on HIV health care workers and Courtyard Clinic attenders, to ensure terminology used was understood, to reduce other potential sources of ambiguity and ensure logical question sequencing. Data collection took place between December 1998 and March 1999.

Ethical Committee Approval

The study sought and was given local ethical committee approval at both St. George's and St. Thomas' Hospitals.
Data Analysis

All data were analysed using the Statistical Package for the Social Sciences (SPSSWIN).

Results

Sample and demographic characteristics

Mode of distribution and response rate

834 questionnaires were returned representing a 95% response rate. 418 (50%) participants were recruited from the Antenatal Clinic, 333 (40%) from Genito-urinary Medicine and 70 (8%) from the Primary Care Baby Clinic. The recruitment site for 13 questionnaires could not be determined so these were excluded from further analyses.

This project is primarily concerned with the prevalence and experience of wet-nursing. Analyses were therefore restricted to women aged 15 - 44 years, those deemed to be of childbearing age (Department of Public Health, 1999). Participants not fulfilling these age criteria were removed, leaving a total of 781 participants.

Demographic characteristics

The mean age of participants was 29 years (range 15-44). In terms of educational attainment 55% had no formal qualifications, 33% had reached CSE / O’Level standard, 21% had A’Level’s and 38% were educated to degree level. Two thirds of women were in paid work. Over half (56%) described their ethnicity as White (UK), 16.4% as Black Caribbean, 9.7% Black African, 9% Asian and 9.8% as other. 74% were born in the UK and 2.6% in Jamaica. The remainder cited one of a further 62 countries as their country of birth. Almost three-quarters (73%) of women were unaware of their HIV status, a further 26% had been told they were HIV negative and only 1.6% (n=12) were HIV positive.
Only a quarter of participants (27%) knew that HIV could definitely be transmitted through breast-feeding, 17% reported it definitely could not be transmitted in this way and a further 32% did not know. There were no associations between knowledge of HIV transmission and age, ethnicity or level of education. Results suggest that women remain generally uninformed about the risks of HIV transmission through breast-feeding.

**Prevalence of wet-nursing**

Less than 1% had engaged in wet-nursing practices themselves, or had permitted their own child to be wet-nursed (see table 1).

**Table 1** Proportion of women having experience of wet-nursing (n, %).

<table>
<thead>
<tr>
<th>Have you wet-nursed?</th>
<th>Has another woman wet-nursed your child?</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>4(0.5)</td>
</tr>
</tbody>
</table>

**Ethnic Origin**

<table>
<thead>
<tr>
<th>Ethnic Origin</th>
<th>YES</th>
<th>Has another woman wet-nursed your child?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black-African</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Black-Caribbean</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>White (UK)</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Other (Columbia)</td>
<td>1</td>
<td>-</td>
</tr>
</tbody>
</table>

Table 1 shows the wide ethnic composition of women in the two categories. Of the women who had wet-nursed, 2 cited their country of birth as the UK, 1 as Bangladesh and 1 as Columbia. All four women reported feeding infants belonging to friends or relatives. Three women did not know their HIV status and one was HIV positive. It is unclear whether the woman with HIV wet-nursed before or since her diagnosis.
Within the group whose children had been wet-nursed, ethnicity and country of origin was also diverse. Of these, 1 woman was born in the UK, 1 in India, 1 in Uganda and 1 in South Africa. All four women reported their child had been wet-nursed by a close friend or relative. Three women did not know their HIV status and one reported knowing she was HIV negative.

4% (n=32) of the sample knew women who acted as wet-nurses. The ethnic composition of women knowing wet-nurses is shown in table 2.

**Table 2 Ethnic origins of women reporting knowing wet-nurses (n. %)**

<table>
<thead>
<tr>
<th>Know someone who wet-nurses</th>
<th>Black African</th>
<th>Black Caribbean</th>
<th>Asian</th>
<th>White (UK)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Know someone who wet-nurses</td>
<td>4(4.9)</td>
<td>5(3.9)</td>
<td>5(7.6)</td>
<td>14(3.2)</td>
<td>4(4.9)</td>
</tr>
</tbody>
</table>

Women who know wet-nurses belong to various ethnic groups with similar proportions of women within each ethnic category. Asian women were slightly more likely to know wet-nurses. Unfortunately the data do not allow further examination of the socio-demographic characteristics of the known wet-nurses. It would have been particularly interesting to have gained information on the ethnic origin of known wet-nurses and where (in which country) wet-nursing had occurred.

**Willingness to wet-nurse**

The proportion of participants having personal experience of wet-nursing was low. However, a larger proportion indicated, that they would consider it, through expressing at least partial approval of wet-nursing practices (see table 3).
The results in table 3 show that approximately one fifth of women would consider becoming a wet-nurse, or would permit another woman to feed their child. This suggests that potentially wet-nursing could become a possibility for a significant number of women in this sample. Significant age ($X^2 = 31.46$, d.f. = 8, $p = .000$) and education ($X^2 = 23.41$, d.f. = 6, $p = .001$) effects with overall willingness to wet-nurse were found, with older highly educated women being more willing to accept wet-nursing practices.

Wet-nursing in women with children - Prevalence

To examine whether experiences of wet-nursing for women with children differed from the whole sample of women, further analyses were conducted restricting analysis to mothers ($n=483$). As detailed in table 1, four mothers had personal experience of wet-nursing other children and four of permitting their own children to be wet-nursed. Interestingly all of the women who knew of other women who wet-nursed (5%, $n=32$), were mothers.

Knowledge of mother-to-child HIV transmission through breast-feeding was similar in the group of mothers to rates reported for the whole sample with 28% knowing HIV could definitely be transmitted in this way, 16% believing that it definitely could not and 30% stating that they did not know.
Acceptance of wet-nursing practices

Overall, the proportion of mothers having personal experience of wet-nursing was low. However, a far greater proportion expressed at least partial approval of wet-nursing practices, by indicating they would consider them (see table 4). These results are comparable to those found for the whole sample.

Table 4 Proportion of mothers who would consider wet-nursing practices (n, %).

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Maybe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you permit another woman to wet-nurse your child?</td>
<td>30(6)</td>
<td>67(14)</td>
</tr>
<tr>
<td>Would you wet-nurse another woman's child?</td>
<td>24(5)</td>
<td>90(19)</td>
</tr>
</tbody>
</table>

The results indicate that having experience of child-rearing does not appear to significantly affect women's views about wet-nursing practices as mothers were as willing to consider using a wet-nurse or to become a wet-nurse themselves.

Reasons for wet-nursing

Of the 20% of mothers who would consider using wet-nurses, 92% (n=88) provided reasons why they would allow their child to be breast-fed by another woman (see table 5).
Table 5  Reasons why mothers would consider using a wet-nurse

<table>
<thead>
<tr>
<th>Reason</th>
<th>(n, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>If unable to or unavailable</td>
<td>31(34.8)</td>
</tr>
<tr>
<td>In cases of emergency</td>
<td>36(41.6)</td>
</tr>
<tr>
<td>If by friends or relatives</td>
<td>10(11.2)</td>
</tr>
<tr>
<td>If they express milk</td>
<td>3(3.4)</td>
</tr>
<tr>
<td>Other</td>
<td>8(9)</td>
</tr>
</tbody>
</table>

Most participants cited an "emergency", for example during a bout of ill-health, a matter of life and death or if this was the only form of nutrition available for the child, as the reason why they would consider using a wet-nurse. It is unclear if the second most frequently cited reason "If I was unable to/unavailable" reflects a general acceptance by mothers of this behaviour or whether it also alludes to acceptance in exceptional (possibly emergency) circumstances only.

Of the mothers who reported that they would consider acting as a wet-nurse themselves (n=114), 102 (89.5%) provided a description of the reasons why they would wet-nurse (see table 6).

Table 6  Reasons why mothers would consider wet-nursing

<table>
<thead>
<tr>
<th>Reason</th>
<th>(n, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>If mother unable / unavailable</td>
<td>29(28.4)</td>
</tr>
<tr>
<td>In cases of emergency</td>
<td>23(22.5)</td>
</tr>
<tr>
<td>If a friend or relative asked me to</td>
<td>28(27.5)</td>
</tr>
<tr>
<td>If I expressed milk</td>
<td>3(3.4)</td>
</tr>
<tr>
<td>If I had too much milk</td>
<td>7(6.9)</td>
</tr>
<tr>
<td>Other</td>
<td>9(8.8)</td>
</tr>
</tbody>
</table>
Most women, who cited reasons for wet-nursing, reported a willingness to consider wet-nursing if a child's biological mother was unavailable or unable to breast-feed, with a similar proportion considering it if asked to by a friend or family member. The data do not permit further exploration of what women meant by this category, for example whether it refers to emergency situations or suggest a more relaxed attitude to wet-nursing generally. Over a fifth of participants cited "an emergency" as their reason for considering wet-nursing. 6% of mothers said they would express their milk if asked to wet-nurse, although this may be an under estimation as this issue was not specifically addressed. 10% (n=45) of mothers believed that the reasons they cited for considering becoming a wet-nurse definitely could occur in the UK with a further 9% (n=41) stating such circumstances might possibly occur in the U.K. These rates are similar to ones found for the unselected sample.

Factors associated with acceptance of wet-nursing

To examine differences in mothers' willingness to wet-nursing, one way ANOVA's and Kruskal Wallis tests were conducted. These revealed significant age (F (4,474)=3.18, p<.001) and education effects (X^2 =23.1, d.f. (3), p< .000) with older women educated to graduate level being more accepting of wet-nursing practices. No association was found between ethnic origin and acceptance. Comparison of women attending the antenatal and GUM clinics (the two largest groups) showed mothers attending the GUM clinic as more willing to consider the future use of wet-nurses (X^2 = 6.47, d.f. =2, p=.039).

Mothers overall acceptance of wet-nursing was highly significantly associated with other wet-nursing variables such as their own children having been wet-nursed (X^2 =
Summary of results

Prevalence of direct and indirect experience of wet-nursing is rare but willingness to wet-nurse and general acceptance of wet-nursing practices is more common. Findings were similar in the whole sample of women and the group of mothers. A greater willingness to wet-nurse was associated with being older and educated to graduate level. All other demographic variables, including ethnicity, were unrelated to experiences. Women who would consider wet-nursing were more likely to know wet-nurses and to show a greater acceptance of these practices.

Discussion

This study examined the prevalence and acceptance of wet-nursing. The finding that highly educated, older women were more likely to accept wet-nursing practices combined with the variety of women from different ethnic origins and countries of birth reporting experience of wet-nursing means assumptions that this behaviour is restricted to African women cannot be supported. While actual prevalence of wet-nursing was low (0.5%), a fifth of women of child bearing age reported that they would at least consider it.

Breast-feeding increases the risk of mother-to-child HIV transmission and as cases of HIV transmission through wet-nursing have been reported in London, information about the risks associated with breast-feeding generally and wet-nursing more specifically should be included in discussions of HIV prevention. This is particularly important
given as one half of women did not know HIV could be passed on through breast-feeding.

Women attending the GUM clinics expressed a greater willingness to use wet-nurses which suggests the Courtyard Clinic, as the main HIV service provider for families affected by HIV in MSW Health Authority, should pay particular attention to informing their patients of the potential risks associated with wet-nursing. This would best be delivered by health care workers directly involved in the care of women and children with HIV, for example clinical psychologists, health visitors, obstetricians and paediatricians. The results of this study suggest it is no longer sufficient to recommend cessation of breast-feeding, by women with HIV in the UK, without including information about surrogate breast-feeding. Continuing to inform women about the risks of HIV transmission associated with breast-feeding and wet-nursing remains a priority, if new cases of postnatal HIV infection are to be avoided.

While the best way to prevent post-natal mother-to-child HIV transmission in the UK would be to reduce the incidence of breast-feeding by HIV positive mothers and discourage wet-nursing practices by women of unknown HIV status, in developing countries the prevention of breast-feeding and possibly wet-nursing practices, is more problematic, particularly given the absence of safe alternatives to breast milk. Women in these countries are often faced with weighing up the costs and benefits of breast-feeding for themselves, their family and for their child.

In this study cultural differences were unrelated to prevalence, experience or general acceptance of wet-nursing practices. However, given that most women attending the
Courtyard Clinic with HIV infection originate from Sub-Saharan Africa, where, at least anecdotally the incidence of wet-nursing is reported to be higher, discussions of issues associated with HIV transmission via wet-nursing may require more emphasis, especially if these women plan (or are forced) to return home where the issues of discontinuation of breast-feeding may be more complicated.

Relevance of clinical project to clinical psychology practice

Clinical psychologists, by the nature of their varied training in research, clinical work and organisational issues puts them within a unique position within many organisations. Often clinical psychologists are deemed as the most suitable health care professionals to devise, implement and analyse research studies relevant to the departments in which they are employed. This clinical project is an example of the utilization of the diverse nature of clinical psychology skills used within the work place. Through devising and executing methodologically sound research a new area of study has been developed which has clinical implications within the Department of Genito-urinary Medicine at St. George's Hospital. As a result of the research findings fellow health care professionals have been trained by the clinical psychologist about the psychology of risk taking and risk reduction strategies. By conducting and reporting on this clinically relevant research, new clinic policies have evolved and as a consequence patient care has been improved.

Future research

This study has documented the prevalence of wet-nursing practices and women's acceptance of it, in South West London. Clearly further research is required to substantiate and extend this work, for example by addressing the environmental, social
and cognitive factors, which may affect the likelihood of wet-nursing occurring. A similar study is currently underway in South Africa. Results from this study will help us determine the prevalence of wet-nursing in South Africa and provide data for cross cultural comparisons.

Conclusion

It is estimated that approximately 6000 women of childbearing age, mostly living in the developing world, acquire HIV infection every day (Giaquinto et al. 1998). Taking into account, that approximately 98% of HIV infected children have acquired HIV from the mother during pregnancy, at delivery or through breast-feeding, prevention of mother to child transmission remains a major health priority.

The early identification of HIV infected women remains crucial to allow appropriate information about breast-feeding to be given and therefore increase the likelihood that new cases of paediatric post-natal HIV will be avoided. Many current intervention strategies to prevent vertical transmission of HIV-1 are aimed at in utero or perinatal transmission combined with counselling about the dangers of breast-feeding, but wet-nursing practices are rarely discussed. This study has shown that a significant proportion of women would consider engaging in wet-nursing practices and therefore highlights that information about wet-nursing as a potential mode of mother-to-child HIV transmission, needs to be incorporated into the advice given by health care professionals to women and families affected by HIV.
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PART 3: RESEARCH DOSSIER

Prevalence of unsafe sexual behaviour, burnout and emotional distress in health care workers and volunteers working with individuals affected by HIV / AIDS.

Abstract

This study examines the level of unprotected sexual intercourse (USI) in staff working or volunteering in the HIV field. Attitudes to safer sex and to HIV working, along with burnout and psychological morbidity were also examined and the relationship between these variables and unsafe sexual practices investigated. Using a cross sectional postal self report questionnaire design, a heterogenous group of 218 HIV/AIDS staff (155 health care workers and 63 volunteers) were recruited. A 40% response rate was achieved. 44% of the sample were gay men and 56% heterosexual. Results indicate 15% of the sample engaged in USI with casual partners (CP) and 58% with regular partners (RP). For gay men figures were 23% and 44% respectively and for heterosexual women, 33% and 84%, suggesting staff are engaging in at least as much USI as other unselected gay and heterosexual samples. Rates of psychological morbidity measured by the GHQ-12 were higher than reported for normative UK samples but similar to comparable groups of HIV workers. Levels of burnout were similar to comparable UK samples and was significantly associated with higher levels of direct contact with people with HIV/AIDS although this was not found for psychological morbidity. Rates of psychological morbidity were similar for both groups. USI was unrelated to burnout, psychological morbidity, attitudes to safer sex, self esteem, or immersion in HIV. The only significant association with USI was minimisation of the personal effects of HIV which was associated with USI within regular relationships. The results suggest that front line staff in the care of people with HIV are engaging in USI to a similar extent as and may, therefore, represent a specific population to whom health prevention needs to be targetted.
Prevalence of unsafe sexual behaviour, burnout and emotional distress in health care workers and volunteers working with individuals affected by HIV / AIDS.

Introduction

This research project is concerned with the prevalence of HIV risk sexual behaviours, burnout and psychological disorder among paid and voluntary staff working in the field of HIV infection. Initially epidemiological data will be presented on the unremitting spread of HIV infection in this country through sexual activity. Such data highlight that, despite a variety of health education and prevention campaigns, HIV remains one of the most serious public health problems with many new infections still occurring. In the absence of a vaccine, generalised sexual abstinence or complete fidelity within couples, the only clear way of preventing and containing HIV infection in the U.K. population is by effective and sustained changes in sexual behaviour towards safer sex practices. Recent surveillance data, however, have highlighted the increase in heterosexually acquired HIV infections and the continuing high rate of homosexually acquired infections as well as the general increase in other sexually transmitted infections (see below).

Research evidence about HIV risk sexual behaviour has accumulated over the past 17 years since HIV was first reported in the U.K. Empirical work has predominantly focussed on the so-called "at risk" groups - gay men, intravenous drug users and those involved in the commercial sex industry. More recent work has also examined the sexual behaviour of the heterosexual population in relation to HIV transmission (Gold et al. 1992; Wight, 1992). To date, however, no attention has been paid to the nature of sexual
risk taking that may have occurred among staff and volunteers who have chosen to work with people affected by HIV infection.

On the topic of occupational stress (burnout) and emotional distress, while some research has been conducted among HIV health care workers and volunteers, none has examined the implications of high levels of emotional distress and burnout on other areas of personal life and specifically on sexual practices. This study aims to remedy these gaps in the research literature.

The HIV pandemic

HIV is a potentially fatal virus. It decreases the infected individual’s life span and reduces the quality of his or her life. The virus has four predominant means of transmission between individuals: penetrative sexual intercourse (both anal and vaginal); the use of infected syringes and needles (usually by injecting drug users); via contaminated blood transfusion; and vertical transmission from infected mother to unborn child. Since the onset of the epidemic in the early 1980s the vast majority of infections have been via sexual behaviour.

At the XI International Conference on HIV and AIDS (Vancouver, July 1996) figures cited by the World Health Organisation indicated that there had been approximately 5.8 million deaths from AIDS related illnesses world wide, of which nearly one fifth (1.3 million) died in 1995. Current approximate figures for people living with HIV are 22 million, of whom 12.1 million are men, 8.8 million are women and 1 million are children. Given the continuation of current trends, it is estimated that by the year 2000
there will be 40 million cases of people living with HIV. 1.2 million of all infected cases are to be found resident within North America and Western Europe (WHO, 1999).

The extent of the HIV problem in the UK

On a monthly basis, the Communicable Disease Surveillance Centre produces a U.K. epidemiological report for the number of HIV infections and cases of Acquired Immune Deficiency Syndrome (AIDS). The February 1999 issue (Communicable Disease Report, 1999) reports that in the U.K. for the period up to the end of December 1998, there have been a total of 37,466 cases of HIV infection, of whom 17,647 were recorded as having AIDS, since reporting began in 1982. Of the 37,466 HIV infections, 13,008 are reported to have died from an AIDS related illness. In terms of mode of transmission, of the 2941 cases of new HIV infection reported for the first time in 1998, 2316 of which were diagnosed during 1998, 48% (1112) were infections acquired through sex between men, 35% (853) through sex between men and women and 4% (91) through injecting drug use. Statistics reveal that London remains the area with the highest prevalence of HIV infection with a total of 25,054 (67%) individuals having been diagnosed within the North and South Thames regions. The number of individuals newly diagnosed with HIV has failed to decrease and the CDR highlights that the number of new infections remains roughly the same from year to year at approximately 3000 while the total number of HIV and AIDS cases has continued to increase since the epidemic began. The most significant transmission route for new infections remains sexual intercourse between men. By 1998, there were more than three times as many cases in this exposure category than in the category of heterosexual sexual intercourse although this category now accounts for approximately one third of all new infections.
Nevertheless infection due to sexual intercourse between men accounts for more reports of HIV than any other category.

The above data indicates that both homosexual and heterosexual HIV risk sexual behaviour is continuing. Surveillance data on sexually transmitted diseases other than HIV serve to substantiate this finding, demonstrating that the rates of acute gonorrhoea acquired both heterosexually and homosexually have increased since 1994. (Department of Health HIV/AIDS Strategy: report of a conference on 27 October 1998. London Dept. Health, 1998. Reported in CDR 8, 48). It is now well established that having a sexually transmitted infection increases the risk of HIV transmission.

**Safer sex behaviour**

Throughout the U.K. there has been a great deal of effort aimed at preventing HIV transmission (e.g. Health Education Authority, 1990; Knox et. al, 1993). Health educators have devised and implemented a variety of innovative health education campaigns, which have sought to change behaviour. While early U.K. government campaigns predominantly focussed on educating the whole community about the nature and spread of HIV, voluntary community organisations such as The Terrence Higgins Trust (1992) targeted their safer sex message at the homosexual and bisexual communities. Throughout the 1990s the targeting of safer sex campaigns towards gay and bisexual men has continued, although there has also been an ever widening focus of HIV health education and prevention onto other groups, particularly ethnic minorities and young people (Health Education Authority, 1990).
General approaches to HIV health education aimed at the population as a whole have had only limited success in bringing about behaviour change (Sherr, 1990). This compares with health education programmes which have targeted specific sub-groups within the population sharing specific vulnerabilities or risk behaviours, which have produced more favourable behaviour change and which seem to maximise the probability of such change (Terrence Higgins Trust, 1992).

While it is clear that large proportions of the gay community have adopted and maintained sexual behaviour changes, the continued increase in newly infected cases among gay men indicates that many individuals have either failed to adopt safer sex precautions or have occasionally relapsed. Condom use among gay men is by no means a consistent phenomenon as highlighted by Project Sigma (Hunt et al. 1992).

The situation is complicated by some uncertainty over exactly what changes are required to prevent HIV transmission during sexual activity. It is clear that the one fact which is not in doubt is that penetrative anal sex without a condom constitutes the highest risk for HIV transmission. Although anal sex is practised among heterosexuals, it is primarily associated with gay men. There is some differential risk involved in insertive versus receptive anal intercourse, but as both carry a very high risk for HIV transmission, the relative risks involved have not been differentiated in health education campaigns. It should be recognised that anal intercourse with a condom though safer, is not totally safe. It still carries a risk for HIV transmission, as condoms may fail or not be used correctly. Given the very real risks associated with penetrative sexual activity, prevention campaigns have emphasised the reduction, or better still, the avoidance of
sexual intercourse, in particular anal intercourse for gay men, whereas others have
targeted the proper use of condoms (Gold, 1995).

The U.K. health education message has also emphasised that HIV can be transmitted
during sexual activity for the heterosexual population. People have been advised to
reduce their number of sexual partners and to use condoms if they do have a number of
partners. Despite widespread campaigns specifically targeted towards the general
heterosexual community, empirical evidence indicates that this public health message
has consistently failed to change the sexual behaviour of the vast majority of

It is generally considered that sexual activities between women carry the least risk for
HIV transmission. In an Italian study the risk of female to female HIV transmission was
examined by studying 28 HIV discordant couples over a five-year period. Results
demonstrated that despite a broad repertoire of sexual practices, no HIV transmission
occurred, suggesting female to female HIV transmission is rare (Raiteri et al., 1998).
Because of the negligible risk there has been little safer sex advice directed specifically
toward women who have sex with other women.

Factors associated with unsafe sexual behaviour

Over the past fifteen years many studies have sought to identify predictors and correlates
of HIV sexual risk behaviour. Findings, however, have often proven inconclusive or
contradictory primarily due to methodological difficulties in data collection, sample
diversity and the fact that sexual behaviour is a complex behaviour subject to a variety
of individual, cultural and social influences. The difficulty in examining sexual activity
is easily highlighted by examining the variety of operational definitions prevalent in the literature of what actually constitutes "risk behaviour". In some studies the index of risky sexual behaviour could be the frequency of unprotected anal intercourse (whether receptive or insertive); the proportion of unprotected to protected episodes; the number of sexual partners; number of partners of unknown HIV sero-status or some combination of these. As well as the above difficulties other factors such as study design, timing of research, method of sample collection, time frame and even geographical location in relationship to prevalence and awareness of the infection may also affect findings. In the developed countries most of the research has focussed on gay men with only limited information about risk behaviours among heterosexuals and intravenous drug users.

The health psychology literature abounds with reports that having knowledge about a particular risk does not necessarily lead to behavioural change (Meichendaum & Turk, 1987; Hackett et al. 1986). While the early years of the HIV epidemic were characterised by a marked reduction in unsafe sexual practices (e.g. Martin 1986, Winkelstein et al. 1987; Siegel et al. 1988; Hunt et al. 1991) and a concomitant decrease in the incidence of sexually transmitted diseases among gay men (Van de Laar et al. 1990; Winkelstein et al. 1987), more recent evidence indicates a widespread pattern of inconsistent safer sex over time (Adib et al. 1991; de Wit and Grienvsen, 1994, Gold, 1994) and an increase in the prevalence of rectal gonorrhoea in this group (de Wit et al. 1993; Evans et al. 1993).

Many studies have found knowledge about sexual behaviours which place people at risk for HIV to be generally high particularly among gay men (e.g., Becker and Joseph, 1988, Gold et al. 1991; Gold et al. 1992; Weinstock et al. 1993) and HIV health care
workers (Holder et al. 1997, Degionanni et al. 1996) but this is not necessarily associated with a decrease in risky sexual practices. Whereas knowledge may be seen as a necessary factor for the practice of safer sex, many other factors appear to be involved in whether such safer sex practices are adopted or maintained.

Sexual intercourse is the norm for heterosexuals and given the very low prevalence of HIV in the indigenous population, unlike in the homosexual population, unprotected sexual intercourse is not necessarily viewed as a risky sexual practice for HIV transmission. Most concerns about unprotected intercourse among heterosexuals, are more likely to be related to fears of unwanted pregnancies than as a protection from HIV transmission which is the predominant reason for condom use among gay men (Gold et al. 1992). Even now condoms are not routinely used, especially within regular relationships, unless a potential risk factor is identified such as having intercourse with someone known to be HIV positive or who belongs to one of the so called “at risk groups”. Research conducted on the sexual behaviour of heterosexuals shows, like the homosexual population, that knowledge about the transmission of HIV is high but that this has little effect on changing unsafe sexual practices (Hillard et al. 1992).

Several investigators have examined geographical location as a factor potentially influencing sexual behaviour. Researchers have suggested that gay men living in areas of low HIV prevalence are more likely to engage in sexual risk-taking behaviour (e.g. Jones et al. 1987; Kelly et al. 1990). Weatherburn et al (1991) examining UK data found that men resident in London were significantly more likely to use condoms compared with men who lived outside London. This contrasts with Castilla et al (1998) who found, in their Spanish general population sample, that participants who lived in larger towns
and cities were more likely to engage in unprotected sexual behaviour with casual partners.

In an examination of whether cultural and political factors influence the adoption and maintenance of safer sex, Bochow et al (1994) distributed questionnaires to gay men in eight European countries. A total of 12,347 questionnaires were obtained with results showing that gay men’s pattern of safer sex varied widely across the eight countries, as does the prevalence of HIV. Bochow et al. suggest that HIV sexual risk reduction was greater in those countries where the gay community had been included in targeted prevention campaigns during the early phase of the HIV epidemic.

Social and cultural norms about safer sex have also been found to predict safer sex practices. The perception that insistence on safer sex is not acceptable within one's peer group, together with an absence of peer support for safer sex, are associated with high risk sexual behaviour (Kelly et al. 1990; Stall et al. 1990; Kelly et al. 1996) and changes to lower risk with the perception that social norms favour safer sex (CDR, 1991; Hays et al. 1992; Lemp et al. 1994). Joseph et al. (1987) found a strong positive relation between social norms supportive of behaviour change and risk-reduction behaviour. Similarly in a sample of physicians Klein et al. (1987) found that the perception that other gay men had changed their sexual practice predicted behaviour change. This relationship was not, however, found in their sample of university students.

**Relationship status**

Many studies have reported strong relationships between unsafe sexual behaviour and having a regular or significant partner (e.g. Adib et al. 1991; Hunt et al. 1992; Hunt et al.
The affective elements of sexual activity in long-term relationships can result in quite different sexual behaviours (e.g. greater likelihood of anal intercourse) than those found in casual sexual encounters. Hence gay men are more likely to have unsafe sex in longer-term relationships rather than with casual encounters (Bochow et al. 1994; Hunt et al. 1992; Gold et al. 1991). Similarly heterosexuals are even less likely than gay men to use a condom in an on-going relationship than in a “one night stand” (Clift et al. 1993). Of course any prevention of HIV transmission is ultimately determined by the accuracy of any assumption by the sexual partners that the relationship is monogamous and that HIV status is concordant. In a recent study of gay men Hoff et al. (1997), only about half of participants in primary relationships were reported to be monogamous, regardless of whether their partner was concordant or discordant for HIV.

Dublin et al. (1992), in their study of predictors of high-risk sexual behaviour in female partners of HIV infected men with haemophilia, found that in the period between 1985 to 1991 the proportion of women at low risk for HIV transmission increased from 6.7% to 69.5% with increased condom use being the most significant behaviour change accounting for the reduced risk. However almost one-third of the women in their cohort continued to have unprotected vaginal sex with their HIV positive partner at least occasionally, despite knowing they risked HIV infection. Using logistic regression analysis factors associated with unprotected vaginal intercourse were a lower educational standard, being single and women whose partners' remained "AIDS-free".

In a more recent study of heterosexuals Castilla et al. (1998) found that 38% of those that had had casual sexual partners in the preceding 12 months always used a condom
and 12% reported occasional use. Systematic condom use was more frequent in their male sample (43% versus 28%) and was less frequent among married participants (13%) and among those who reported having a regular partner during the preceding 12 months. Logistic regression analysis found that failure to use condoms systematically in casual encounters, was associated with increasing age, being married, living in larger towns/cities and a lower level of education. Participants in regular relationships were more likely to engage in unprotected intercourse.

Knowledge of HIV Sero-status
McKusker et al. (1989) & van Griensven et al. (1993) have demonstrated that knowledge of sero-positivity is associated with increases in the adoption of safer sex and yet many studies report that up to 40% of sero-positive men continue to participate in unprotected intercourse at least occasionally (Coleman and Miller, 1994; Marks et al. 1994; Robins et al. 1994), although a substantial proportion of the unsafe encounters may actually occur within regular relationships. Recent U.K. data (Catchpole et al. 1996) has shown that among seropositive gay men with a newly diagnosed sexually transmitted disease (STD), almost half knew themselves to be positive prior to contracting their STD, indicating that a substantial number of seropositive men are practising unsafe sex. It is also the case that some individuals engaging in high-risk behaviours are unaware of their HIV positive serostatus (Lemp et al. 1994; Hays et al. 1997).

Attitudes to Condom Use
To date, the use of condoms is the only widely available means of reducing sexual risk and yet most people dislike using them (e.g. Valdiserri et al. 1988) or find talking about
them difficult (Wight, 1992). Enjoyment of unprotected intercourse has been demonstrated to be associated with persistent risk behaviour and a change from low to high risk (Hays et al. 1992; Stall et al. 1990).

Many studies have demonstrated an association between illicit drugs and alcohol use both before and during unsafe sexual activity (e.g. Doll et al. 1991; McKusick et al. 1990; Stall et al. 1990). On the other hand many investigators have failed to find such an association (Gold et al. 1991; Gold and Skinner, 1992; Myers et al. 1992, Weatherburn et al. 1993).

**Communication and sexual negotiation skills**

Another factor potentially significant in predicting the occurrence of safer sex is that some men who engage in unsafe sex may have difficulty in communicating their wishes about condom use to their partners. Gold's studies (1991: 1992; 1994) show that verbal communication regarding use of condoms occurred significantly more often in safe than unsafe encounters and multiple logical regression showed that poorer assertiveness skills in negotiating safer sex predicted relapse to less safe practices in a large longitudinal study (Adib et al. 1991). Other studies have also reported an association between poor sexual communication skills and unsafe sex (Hays et al. 1990; 1992) and between improvement in the ability to talk to partners about sex and condom use and behaviour change in the direction of safer sex (Centres for Disease Control 1991).

Ingham et al. (1991), in their study of knowledge and ease of communication about sexual histories in young heterosexuals found that sexual histories were rarely discussed and when they were it was for reasons to do with the relationship rather than fear of
infection and almost never involved details of condom use. Consequently, as Wight (1992) points out, the general absence of explicit talk about sexual behaviour means that contraception is often only discussed after first intercourse (Kent et al. 1990).

Mood and Psychological Disorder

Although mood is a factor which could be expected to affect the occurrence of unsafe sex, the evidence available does little to clarify whether and how it does so. In examining the type of occasion and thoughts involved in gay men’s unsafe sexual encounters Gold et al. (1992) employed structured interviews with men aged 15-21 years. Participants were asked to recall two sexual encounters from the preceding six months; one in which they had unprotected sexual intercourse and one in which they had resisted a strong temptation to have unprotected sexual intercourse. In these young gay men a negative mood state was associated with unsafe sex. The two main self justifications for unsafe sex were a switching off from the topic of AIDS by telling themselves that the risk of infection was no worse than other risks encountered in the normal course of events (minimisation) and a tendency among the sample to infer from perceptible characteristics that their partner was unlikely to be infected. Reported mood distinguished between the safe and unsafe encounters in the sample of young gay men; but in other studies of three older groups (Gold et al. 1994) better mood was reported for the unsafe than the safe encounter. McKusick et al. (1990) have also reported a positive association between low levels of depression and high-risk sexual activity.

Two further studies looking at lapses from safer sex suggest that low mood is not a risk factor for unsafe sex. Kelly et al. (1991b) found that lower levels of depression predicted vulnerability to lapses and de Wit and Griensven (1994) reported that time from safer to unsafe sex was independent of both depression and psychological wellbeing. On the
other hand feeling depressed was one of the three barriers to condom use most frequently reported in a survey of 964 gay men (Sandfort et al. 1994). Fatalistic thinking and life satisfaction were assessed by Kalichman et al. (1997), using standardised measures together with perceived life expectancy among 430 gay men and the relationship of these variables with risk behaviour. They found that men who engaged in unprotected anal intercourse outside exclusive relationships had higher fatalism and lower life satisfaction scores and shorter perceived life expectation than men who practised only safer sex and those in exclusive relationships. Kalichman et al. (1997) therefore speculate that these variables might index other constructs such as depression or personality dispositions. Three studies of HIV positive groups provide contradictory results. Condom use for anal intercourse was negatively correlated with depression scores on two measures in a small sample of asymptomatic men (Kelly et al. 1991) but in another study which included individuals with AIDS, depression and recreational drug use were significant predictors of high risk sexual behaviour (Kelly et al. 1993). By contrast, Robins et al. (1994) report that seropositive men engaging in risky sexual practices had lower levels of psychological distress than those who were not risky. A further study by Camacho et al. (1996) found in their study of psychological dysfunction and HIV risk behaviours in 834 daily opiod users entering methadone treatment programmes in the United States, that depression and anxiety were both significantly related to sexual risk taking in terms of number of partners, unprotected sex with other injection drug users and trading sex.

The above findings do not allow any firm conclusions about the possible effects of low mood on risk behaviour. However, the presence of mental health problems may be relevant. One study of young gay men over a two year period showed that one of the
factors distinguishing the small proportion engaging in very high risk behaviours from other risk takers in the sample was the presence of mental health problems (Meyer & Dean, 1995).

Advances in anti-retroviral treatments

The past two years have seen a rapid increase in the number of anti-retroviral treatments (particularly protease inhibitors) available to people infected with HIV. Some hospital wards designated for the care of people with AIDS have closed or the number of beds has been reduced. The reduced mortality associated with HIV and the perception that HIV can be managed as a chronic illness is accepted by many as evidence of the diminishing impact of HIV. In tandem, we have seen the arrival of the increasing availability of post exposure prophylaxis. This increased optimism about the medical management of HIV, combined with the availability of post exposure prophylaxis, may have resulted in a reduction in protected sexual intercourse. It is a disheartening fact that recently reports have revealed that a small number of both HIV positive and negative men have begun to "consciously, wilfully and proudly" engage in unprotected anal sex. This new phenomenon, referred to as "raw", "skin on skin" or "bareback" sex may be linked to the perceived effectiveness of protease inhibitors and the promise of "morning after" exposure treatment (Sheon and Plant 1997; Katz et al 1997). Although the majority of evidence for this phenomenon to date is anecdotal, in August 1998 a letter to the New England Journal of Medicine (Dilley et al. 1997), suggested that protease inhibitors had "altered the perception of risk" of contracting HIV for gay men and that 26% of the men surveyed reported being "less concerned" about becoming HIV positive because of the new treatments with 15% having already engaged in unprotected anal sex because of their decreased concern.
In summary, many factors have been reported as potentially involved in reducing or facilitating HIV sexual risk behaviours. Although the mediating effect of many of these variables remains equivocal, some factors such as ability to communicate about issues related to safer sex, attitudes to condom use, HIV status and being involved in a regular relationship are more consistently associated with unprotected sexual intercourse.

Anecdotal reports from HIV sero-positive health care workers and volunteers seen clinically by this author suggest there may be an association between sexual risk taking, psychological morbidity and work related stress (burnout). To examine this potential relationship the literature on burnout in health care workers and volunteers and its relationship to non work lives is now reviewed.

**Burnout and Emotional Distress**

The effect of caring for people affected by HIV / AIDS

It has been well established that staff, in particular those dealing with people suffering from serious illness and those exposed to multiple deaths are at risk for developing work related psychological problem disorders (Maj, 1991; Silverman, 1993).

For every person infected with HIV there are a number of other people involved in their everyday care and management. These range from the partners and other intimate caregivers through to the wide range of volunteers (eg buddies, help-line workers, counsellors) and health care workers (nurses, doctors, health advisors, mental health professionals and other members of the multidisciplinary team). It is well recognised that caring for the seriously ill has both its positive side and its stresses.
Burnout

One of the effects of prolonged occupational stress that has received much attention in recent years is that of "Burnout" (Freudenberger, 1974). Burnout is the term given to a particular form of stress that is especially relevant in human service environments. Burnout may be defined as the feelings of physical, emotional and mental exhaustion that are associated with an intense involvement with the recipient of care over a prolonged period of time (Pines and Aronson, 1981). Burnout is a particularly disabling form of stress, which is usually recognised when previously committed carers lose their motivation, enthusiasm and commitment to caring (Bailey, 1988, p328). Burnout can thus also be seen as a loss of motivation for creative involvement (Marshall, Kasman and Cape, 1982). This loss of motivation or disengagement occurs as a response to the stress or strain experienced in the job and is thought to generally occur in three stages: an initial perceived imbalance between demand and resources; a variety of short term effects (which may include anxiety, exhaustion, fatigue and tension) and finally changes in attitude and behaviour with the individual becoming increasingly detached and cynical (Cherniss, 1980).

More work into the development of the construct of burnout, its measurement and subsequent investigation has been carried out by Maslach (1982) than anyone else. Maslach has conceptualised burnout as a continuous variable that ranges from low to high degrees of experienced distress in three related dimensions of a unified syndrome. She has developed an instrument, the Maslach Burnout Inventory (MBI) (Maslach, 1981; 1986) which consists of 22 statements regarding attitudes and personal feelings which assess the three aspects of the burnout syndrome: emotional exhaustion (feelings of being emotionally exhausted by one's work - 9 items), depersonalisation (an
impersonal and unfeeling response to one’s clients – 15 items) and lack of personal accomplishment (feelings of incompetence and lack of personal achievement in one’s work - 8 items). The MBI is by far the most frequently used measure of burnout.

**Working with people with HIV/AIDS**

**AIDS Volunteering**

AIDS volunteering has been described as the most “remarkable and heartening byproduct of the HIV epidemic” (Fineberg, 1989, p117 cited by Omoto and Crain, 1995) and as a testimony to human kindness and to the power of communities of “ordinary people” to unite and work together in times of crisis (Omoto and Crain, 1995). Volunteering for HIV/AIDS work involves making a deliberate decision to engage in sustained helpfulness characterised by a continuing commitment to a recipient's care at high personal cost (Snyder and Omoto, 1992b). Despite the fact that there is widespread agreement about the importance of the voluntary sector in responding to the HIV/AIDS crisis (Weeks et al. 1994) there is relatively little published literature on the personal effects of AIDS volunteerism. Peer support is often considered the most appropriate intervention for people suffering from terminal illness. As a result many voluntary organisations have set out to provide a person with HIV/AIDS with a supportive friend or “Buddy” (Guinan et al. 1991). A growing literature now documents the rewards and stresses associated with being an HIV/AIDS volunteer.

**The rewards and stresses of volunteering**

A number of studies on HIV/AIDS volunteerism have concluded that this type of voluntary work results in positive consequences for the volunteer including an increased sense of acting on personal values and beliefs (Omoto and Crain, 1995). The major rewards of AIDS voluntary work have been found to include developing new skills, a
heightened sense of personal effectiveness, increased self esteem, increased self knowledge and new friendships (Guinan et al. 1991; Snyder and Omoto, 1992b). This literature concludes that volunteers report a high degree of satisfaction as a result of “being able to make a difference” and a resultant sense of heightened learning and personal growth (Mount, 1992).

Based on hospice volunteer responses to telephone interviews, Paradis et al. (1987) identified four types of volunteer stress; (1) role ambiguity, where volunteers experience conflicting obligations and responsibilities; (2) “Status Ambiguity” where volunteers are unsure of their status in an organisation's hierarchy, (3) stresses associated with the type of work with clients and their families in which volunteers reported feelings of inadequacy or frustration in attempts to provide support and (4) factors associated with volunteers’ own personal characteristics and own life.

HIV related disease could place unprecedented demands on both health care workers and volunteers. Maslanka (1996) has defined the breadth and intensity of problems associated with HIV/AIDS as unique. In particular HIV workers may face peculiar stresses such as the relative youth of those infected and the uncertainty of the progression of HIV (Collins, 1995). One further unusual aspect of HIV/AIDS care is that many help providers are also relatives, partners and friends of people with AIDS. The experience of losing people with HIV/AIDS from close relationships while acting as professional carers has been described as an emotionally taxing combination (Bennett, 1995). In addition, having been a buddy to more than one person with AIDS or knowing another buddy who has himself / herself been diagnosed with AIDS are both correlated with an increase in the amount of psychological distress experienced by a volunteer.
Williams, 1988). High levels of volunteer distress may therefore result from the intense interaction with clients and emotional investment associated with volunteering. Volunteers may also experience higher degrees of stress than health professionals because of their undefined roles which may lead volunteers to question their efficacy (Jimenez and Jimenez, 1990).

A persistent frustration in voluntary programmes is the high rate of attrition amongst volunteers (Snyder and Omoto, 1992b). Turnover rates amongst HIV/AIDS volunteers have been found to be high compared with voluntary organisations generally and part of the explanation given for this is the unusual nature of the workforce. That is, HIV/AIDS organisations are frequently staffed by young male, geographically mobile and often unemployed volunteers (Bebbington and Gatter, 1994).

**Burnout and emotional distress in volunteers**

Despite the importance of volunteers in the care of people with HIV infection and AIDS they have received only limited attention in the research literature. This is particularly surprising given the impact that volunteers have. Raphael et al. (1990) for example found that AIDS emotional support volunteers are responsible for a major part of the care of people with AIDS and make a significant contribution to the costs.

The prevalence of psychological distress amongst buddies has been reported in several studies. Using the GHQ28, more than a third of buddies have been reported to meet the criteria for a psychiatric case (Raphael et al. 1990, Guinan et al. 1991) and between 10-20% of buddies will also meet the more conservative probability for severe
psychological distress (defined as $\geq 7$ on the GHQ-28), (Williams et al. 1988, Raphael et al. 1990).

Burnout is less common than psychiatric caseness and Guinan et al (1991) found that approximately one fifth of buddies obtained moderate to high scores on emotional exhaustion (17%) and depersonalisation (21%) and a similar proportion obtained low scores on personal accomplishment (24%). Clearly the prevalence of burnout depends upon the criteria and measuring instruments used but the studies reported above indicate that a substantial proportion of buddies are likely to report severe psychological distress or burnout or both.

Burnout in volunteers is said to lead to the continual training of new personnel, discontinuity in relationships with clients, financial strain on the health care system and personal strain on people living with AIDS (Nesbitt et al. 1996).

Claxton et al. (1998) examined burnout through a cross sectional single cohort postal questionnaire study. Buddies at Terrence Higgins Trust were assessed for psychological morbidity on the Hospital Anxiety and Depression questionnaire (Zigmond and Snaith , 1983) and MBI. Of the 324 participants, 24% of buddies were classified as probable cases of burnout on one or more of the MBI sub-scales and this was lower than rates reported in the medical and nursing staff working with people living with AIDS.

While reports of burnout among volunteers are increasing (Claxton et al. 1998, Raphael 1990; Nesbitt et al. 1996; Bennett 1995) it is often argued that burnout in volunteers may be less prevalent than in health care professionals since volunteers choose and are
internally motivated to work in the HIV/AIDS field. In addition, it is argued that volunteers have greater control over the time they spend in voluntary work and if they do not enjoy their work, they can terminate their involvement with minimal cost (Nesbitt et al. 1996). These authors suggest that volunteers' susceptibility to burnout may be influenced by volunteers having more choice over their area of care, over the time they spent volunteering and over staying or leaving the AIDS field. Others such as Maslach and Ozer (1995) have concluded that volunteer HIV/AIDS caregivers face some of the same risk factors for burnout as paid health care professionals.

**Burnout and emotional distress in health care professionals**

Many jobs in the health service are, by their very nature, subject to high levels of stress (Spencer, 1986; Harvey, 1992). In a recent survey of 1800 nurses (Cole, 1992) 93% of nurses questioned said that they felt stressed at work, with 26% saying that they felt "very" stressed. In a similar study of occupational therapists, speech therapists and physiotherapists, Kersner and Stone (1990) found that 82% of members of the later three health professions surveyed also reported feeling stressed.

Many recent surveys of occupational stress in the health professions (e.g. Cole, 1992; Cull, 1991; Cushway; 1992, Firth; 1986, Firth-Cozens; 1987) cite a variety of potential stressors including: poor and ineffective communication, lack of managerial support, little control of work rate and uncertainty about the future. However, Jacobsen (1983) found that emotional stressors were rated the highest of ten sources of stress perceived by nurses in one of many clinically stressful areas, a special care baby unit. It is claimed (Orlans, 1986) that the sense of isolation which can result from a lack of support within
the health service leads to nurses heading the list of members of professions who go to seek psychiatric help.

A variety of studies have been carried out which have found high levels of burnout in health care professionals. Many of these have been conducted within the US and UK (e.g. Ceslowitz, 1989; Firth, McIntee and Britton, 1985; Firth et al. 1986; Lahoz and Mason, 1989; McGrath, Reid and Boore, 1989; Morrice, 1984; Raffety et al. 1986).

Two studies of medical practitioners (Morrice, 1984; Rafferty et al. 1986) both found moderate to high levels of burnout amongst GPs and similarly Rafferty et al. (1986) found that 67 American family practice physicians scored in the moderate to high range on all three of the burnout sub-scales.

The majority of studies to date have focussed on burnout in nurses. Firth et al (1985) used the MBI to assess levels of burnout in 200 qualified British nurses. Whilst they found mean burnout scores to be in the low to moderate ranges the scores they obtained for personal accomplishment were broadly in line with those obtained from other studies whereas depersonalisation scores were found to be lower than in Maslach’s original standardisation sample.

McGrath et al. (1989) in a study of 171 Northern Ireland nurses, found like Firth et al. (1985) that whereas the nurses experience less burnout on the depersonalisation and emotional exhaustion subscales than in Maslach and Jackson’s (1981) standardisation sample 94-97% fell into the high burnout category on the lack of personal accomplishment subscale. In addition, however, they found that 27% of responders
described symptoms, which could be classified as showing mild psychiatric morbidity when tested with the GHQ-28 (Goldberg 1978).

Research on burnout, overall, demonstrates some variations in levels and patterns of burnout across different personnel groups but in general they show that health professionals often have moderate to high levels of burnout and that the level of burnout showed in the personal accomplishment subscale usually exceeds that shown in the other two subscales.

Length of time working has also been related to burnout but results again are equivocal. In one study the more experience nurses had in providing direct care to patients, the less burnout these nurses experienced (Cronin-Stubbs and Brophy, 1985). In contrast Silverman, (1993) reports that those nurses who had worked longest in a particular unit were more vulnerable to burnout.
Burnout and emotional distress in Health Care Workers working in HIV/AIDS

In the HIV field conflicting results have also been reported. Horstman and McKusick (1986) found that health care workers are more likely to experience stress related to caring for people with AIDS the longer they work with such patients compared with O’Donnell et al. (1987), Brennan (1988), Sherr and George (1988), Randall and Scott (1988) who found burnout negatively correlated with years of care-giving and length of service correlated with increase in personal satisfaction and a decrease in AIDS associated stress.

Many health care workers find that working with these patients is both physically and emotionally difficult at times (Scott and Hilliard, 1992). It is argued that the chronic and terminal nature of HIV/AIDS often leads to feelings of helplessness, isolation and fear in those who support people with AIDS and these feelings can lead to the development of burnout (Guinan et al. 1991).

In a comparison study of HIV/AIDS and oncology health care workers in the UK, (comprising predominantly nurses and doctors), Catalan et al. (1996) found no difference on overall levels of emotional distress using the General Health Questionnaire (GHQ-28). Both groups experienced moderate levels of burnout on each dimension of the Maslach Burnout Inventory with few differences between the two groups. The majority (76%) exhibited some degree of occupational stress, defined as having at least one high score among the 6 subscales of the MBI, with 23% having three or more MBI subscale points above the cut off. HIV/AIDS staff reported a lower frequency and intensity of personal accomplishment than oncology staff but there were no differences between the two on emotional exhaustion or depersonalisation. Higher levels of
emotional exhaustion were associated with higher levels of emotional distress as measured by the GHQ. In contrast, Bennett et al. (1993) described burnout in HIV/AIDS staff in Australia as manifesting itself more sharply and strongly than in other fields including oncology.

Although burnout appears to be common amongst health care workers and volunteers, relatively little is known about what risk factors there may be. On the whole demographic factors are not consistently associated with burnout (Williams et al. 1988; Raphael et al. 1988; Guinan et al. 1988; Maslanka et al. 1996). Three studies have found that age is significantly correlated with burnout in that younger buddies are more likely to burn out than their older colleagues (Williams 1988, Raphael et al. 1990, Maslanka 1996), a finding that has also been reported in other occupational groups (Maslach 1982, Bennett and Kelaher 1994, Bellani et al. 1996, Catalan et al. 1996, Miller and Gillies 1996).

Psychosocial factors have also been reported to be protective against burnout. Visitini et al. (1996) for example, in their questionnaire study of 41 Italian infectious disease nurses in AIDS found empathic, involved relationships are protective against burnout and work stress is better tolerated if supportive social rewards are received. Horstman and McKusick (1986) in a study of psychosocial reactions of doctors working in HIV/AIDS reported that working within the AIDS field does not only lead to stress and burnout but also to higher levels of anxiety. In a further study Bellani et al. (1996) found burnout to be associated with shyness and ego weakness in HIV nurses and doctors.
The link between work and non-work lives remains remarkably under-researched in the occupational stress literature. There is also little literature on whether those exposed to diseases with a known risk factor (e.g., smoking and lung cancer) through their work are more or less likely to avoid the risk themselves. In one study, however, Baggaley et al. (1996) considered the impact of HIV counselling on Zambian counsellors' attitudes and non-work (especially sexual and emotional) behaviours. This descriptive study is particularly valuable because it highlights, directly, the tensions that may exist between messages that health care workers give others and those that they take home themselves – in this case about sex and condom use. They found that although counsellors were all in favour of promoting condoms as protection against HIV transmission, only 27% had ever used one themselves. Many of the counsellors felt unable to discuss the issue of safer sex with their partners. Baggaley advocates the need to increase the personal efficacy and skills in front line HIV staff for use in and out of the work setting.

Miller and Gillies, (1996) in a further study also examining the work / non-work dichotomy, particularly the impact of work on socialisation and domestic relationships, found few differences between HIV/AIDS and oncology staff. They posit that this similarity between the two populations is evidence that the stresses identified in HIV/AIDS care are an increasingly identifiable feature of health care generally.

Many health care professionals and volunteers who elect to work in the HIV field are themselves young and gay. Very often therefore, they may share many demographic and social characteristics in common with the patients in their care. Such similarities may themselves increase psychological morbidity.
Rationale for the current study

It is of some concern that recent anecdotal reports have indicated that some health care workers and volunteers, involved in the care of people with HIV for many years, are still failing to consistently adopt safer sexual practices and therefore remain sexually vulnerable to HIV infection themselves. It is unclear why this is and whether such cases are an indication of non-adherence to safer sex guidance (a failure to practice what is preached) or represent a "relapse" in previously adopted safer sex strategies. Degioanni et al (1996) in a study of hospital nurses working with people affected by HIV in Italy, found staff continued to engage in risky sexual practices in terms of having multiple partners and failing to systematically use condoms with their regular or casual partners. There has been no systematic research in the UK on this group whose very jobs place them in direct contact with individuals who have HIV. While systematic empirical evidence is lacking, clinical observations suggest some individuals with extensive and direct involvement with HIV, continue to engage in risky sexual practices. This author is aware of HIV healthcare staff having sero-converted through their sexual behaviour while employed in the HIV sector. Such anecdotal data suggests that extensive knowledge about the risks of HIV transmission and resultant illnesses, combined with personal exposure to individuals living with and dying from HIV related disease, is not sufficient to protect them from HIV. It is possible that sexual risk taking could be a function of work-related stress, psychological dysfunction or both.

To date, there has been no empirical work in the UK examining the effect of direct contact with people affected by HIV on the sexual risk taking behaviour of paid or unpaid staff in this field. Staff are very often at the front line in trying to implement
behaviour changes in the patients they work with and yet the very nature of their proximity to the HIV epidemic may have resulted in their personal sexual behaviour/risk reduction needs having been neglected. If anecdotal reports are correct and sexual risk taking is continuing in this well-informed group, this may suggest workers and volunteers form a distinct sub-group in relation to HIV health education, requiring specifically targeted health education.

This study has been designed to examine the following research questions:

1. To investigate the level of unprotected sexual intercourse (risk for HIV and other sexually transmitted diseases) in this population and factors associated with sexual risk behaviour.

2. To determine the level of burnout and psychiatric morbidity in this population and factors associated with it.

3. To assess whether there is a relationship between burnout or psychiatric morbidity and attitudes to safer sex / HIV working, and the practice of risky sexual behaviour.
Hypotheses

1. Individuals working within the HIV/AIDS field are less likely to engage in unsafe sexual behaviour for HIV/STDs than the general population.

2. Given the nature of HIV/AIDS work there will be high levels of (a) burnout and (b) psychiatric morbidity in this group, and those with most direct contact with people with HIV will exhibit higher levels of (c) burnout and (d) psychiatric morbidity, especially if they have symptomatic disease or mental health problems.

3. There will be higher levels of (a) burnout and (b) psychiatric morbidity in professional health care workers than in volunteers.

4. Workers (a) with lower self esteem, (b) less positive attitudes to safer sex, (c) who are more immersed in their HIV work (d) who minimise the personal effects of HIV and (e) who are more fatalistic about HIV, will have higher levels of burnout and psychiatric morbidity and will be more likely to engage in unsafe sex.

5. Workers with higher levels of (a) burnout and (b) psychiatric morbidity will engage in higher levels of sexual risk taking.
METHOD

Participants
A heterogeneous group of 218 HIV/AIDS workers were recruited. These comprised 155 health care workers and 63 volunteers.

Sample Recruitment
The sample of health care workers was recruited by distributing questionnaires via a variety of statutory HIV/AIDS bodies. These included NHS hospital Genito-Urinary Medicine Departments specialising in the treatment of HIV/AIDS and Local Authority Health Promotion units. In addition, the majority of health adviser respondents were obtained by mailing questionnaires directly to named individuals recorded in the membership list of the Society for Health Advisers working in Sexually Transmitted Diseases. A number of respondents were recruited by targeting attendees at two British Psychological Society Divisions of Clinical Psychology HIV/AIDS Special Interest Group meetings. Volunteers were recruited through targeting voluntary sector HIV organisations identified through the National AIDS Manual (1997). The principal voluntary organisations targeted were: the Terrence Higgins Trust, AIDS Care and Education Service, Body Positive, Aled Richards Trust, Blackliners, Care and Resources for people affected by AIDS/HIV Trust and Open Door.

All organisations were initially contacted by telephone to explain the nature of the research and gain permission to send questionnaires. Questionnaires were usually sent to a named individual within each organisation for onward distribution. A small proportion of questionnaires (N=12, 5.5%) were received following direct advertising within the
gay press. Organisations throughout the United Kingdom were targeted to achieve as wide a geographical distribution of respondents as possible.

Measures

This study incorporated both standardised measures and a questionnaire specifically devised for inclusion in this research.

Questionnaire devised for the study

Two versions of an anonymous self-report postal questionnaire were devised specifically for this study, one for health care workers and one for volunteers (see appendix 2). An anonymous postal questionnaire was decided upon to reduce issues of social desirability (Crowne and Marlowe, 1960) and the possibility of faking good in reporting sexual behaviour, in a face to face encounter. The two questionnaire versions were essentially identical except for a few word alterations, for example the substitution of words related to “work” in the health care worker version for “volunteering” in the volunteer version.

A pilot questionnaire was circulated to ten health care workers and volunteers and comments solicited. Ambiguous questions were clarified and the most user-friendly presentation and logical question sequencing determined. The final versions are shown in appendix 2.
Questionnaire Content (see appendix 2)

Socio-demographic Data

Demographic information including age, gender, ethnic origin, level of education and marital status was recorded.

Details of HIV work / volunteering

Information was gathered about voluntary and paid HIV work experiences including: occupation details, whether working/volunteering full or part time, duration in current post, time spent in face to face contact with people with HIV, total length of time within the HIV field and the extent to which respondents worked with people with symptomatic HIV infection or mental health problems.

Sexual Behaviour

Information on penetrative sexual behaviour was recorded including: frequency of protected and unprotected sexual intercourse and experience of regular and/or casual sexual relationships within the past year. Respondents were asked to record the frequency of both protected and unprotected sexual intercourse that had occurred in the past week, month and 3 months for both their regular and casual partner/s. Great care was taken in wording questions to avoid confusion and subjective considerations. For the questions pertaining to respondent’s regular partner, ‘Regular Partner’ was defined as: “someone you have been with for at least one month, whom you have had sex with on more than one occasion and to whom you have some sexual commitment”.

146
Participants were asked whether they had sexual contacts with men, women, or both rather than to identify their sexual orientation. Information on respondent's own, as well as their sexual partner's HIV status, was also recorded.

Attitudes to safer sex / HIV working scale

The final section of the questionnaire asked respondents to rate the degree to which they agreed or disagreed with 31 statements thought potentially significant in HIV risk sexual practices in this group (HIV Attitudes Scale). These statements were divided into five main categories: Attitudes to safer sex (12 items); Minimisation of HIV (6 items); Exposure to HIV (6 items); Fatalism (3 items) and Self esteem (4 items). Items included in each scale were derived from a variety of methods including: brainstorming of potential reasons why unsafe sex may be practised and the factors associated with working in HIV; an examination of the Sexual Risk Cognitions Questionnaire (Shah et al. 1998); a literature review of variables believed potentially significant together with comments made during the piloting of the questionnaire.

Throughout the questionnaire most information was elicited by Likert-type rating scales each comprising 5 or 7 points. This number of points was chosen rather than three as reliability has been indicated to improve in line with the increasing number of scale points presented (Nishisato and Torii, 1990).
Standardized Measures

(1) Psychological Distress

This was assessed by means of the 12-item version of the GHQ (The General Health Questionnaire - 12: Goldberg and Williams, 1988). The GHQ is a widely used screening tool for the detection of possible psychiatric disorder/psychological morbidity. Each item is endorsed on a 4-point scale from 0 to 3. Two forms of scoring were used: (i) 0,0,1,1 scoring to identify probability of caseness with a cut off criterion of 3 utilised and (ii) 0,1,2,3, Likert scoring to give a greater range of scores (0-36) for comparisons between groups. It was selected in preference to other measures because of its brevity. The GHQ-12 has been shown to have good reliability and validity (Goldberg and Williams, 1988).

(2) Occupational Stress/Burnout

Levels of stress and professional burnout were measured with a modified version of the Maslach Burnout Inventory (Maslach and Jackson, 1981). The MBI is a 22-item questionnaire, which assesses 3 aspects of burnout: emotional exhaustion (EE), depersonalisation (D) and lack of personal accomplishment (PA). EE refers to feelings of being exhausted and over-extended by work; D concerns the feeling of treating patients in an impersonal way; PA describes feelings of lack of competence and lack of personal achievement in dealing with patients. Each aspect is measured in relation to both its frequency and intensity. The frequency measures refer to how often a particular feeling of burnout is experienced, whereas the intensity measures refer to how severe these feelings are when they occur. High levels of burnout are indicated by high scores on the emotional exhaustion (EE) and depersonalisation (D) sub-scales, (frequency: EEf
\[30, Df \geq 12; \text{intensity: } EEi \geq 40, Di \geq 15\), and low scores on personal accomplishment (PA) sub-scales (frequency and intensity: \(PAf \leq 33, PAi \leq 36\)). Moderate levels of burnout are given by moderate scores on frequency and intensity in the 3 sub-scales (\(EEf: 18-29, Df: 6-11, EEi: 26-39, Df: 6-11, Di: 7-14, PAf: 34-39, PAi: 37-43\)). A low degree of burnout is indicated by low scores on Emotional Exhaustion and Depersonalisation frequency and intensity (\(EEf \leq 17, EEi \leq, Df \leq 5, Di \leq 6\)) and high scores on Personal Accomplishment intensity and frequency (\(PAf \geq 40, PAi \geq 44\)). In addition to the raw scores on the MBI, each person may be classified as either not burnt out or as a case of moderate or high burnout.

As the MBI was originally developed for use in occupational assessment, minor word adaptations were required (for example substituting the word ‘client’ for ‘patient’) to allow its use with the volunteer sample.

Research on the MBI has indicated that the inventory provides a valid way of measuring the burnout component of occupational stress (Belcastro, Gold and Hays, 1983). The internal reliability of the MBI has been found to be acceptable with split-half reliability coefficients for frequency and intensity having been determined to be .74 and .81 respectively (Maslach, 1981). Green and Walkey, (1988) have confirmed the three-factor structure and demonstrated the construct validity of the MBI by conducting a principal components analysis of previously published data followed by three and four factor varimax rotations. Reliability coefficients for the three separate subscales (Cronbach’s Alpha, \(n=1316\)) have been found to be: Emotional Exhaustion .90; Depersonalisation .79; Personal Accomplishment .71 (Maslach and Jackson, 1986).
The MBI can thus be seen to be a reliable, valid and useful tool with which to assess and quantify levels of burnout.

**Ethnical Committee Approval**

The study was approved by St. George’s Healthcare NHS Trust ethical committee.

In recognition that the questionnaire was seeking information on a sensitive and personal topic and in anticipation of participants’ potential concerns about the research, a cover sheet was attached to each questionnaire. This sheet informed participants of the sexually explicit nature of the questions and provided a contact telephone number for them to speak to the principal investigator if they required any further information or had any concerns. In total five calls were received. The primary concern for these callers was a misunderstanding that their profession (Health Advisors) was being targeted. Callers were reassured that the questionnaire was targeting a range of health care workers and not one profession, but to allay further anxieties on this count the cover sheet was amended to clarify this point.

**Study Design**

This study followed a two-cohort cross-sectional postal questionnaire design.

**Procedure**

Data collection took place between June 1997 and March 1998. Stamped self-addressed envelopes were attached for the return of each questionnaire. However reminders could not be sent due to the mode of distribution and the anonymous nature of the research. A
total of 550 questionnaires were distributed: 350 to health care workers and 200 to volunteers.

Data analysis
All data were analysed using the Statistical Package for the Social Sciences (SPSSWIN) and the level of statistical significance set at .05 for all analyses. Generally comparisons between volunteers and health care worker groups were analysed with non-parametric tests. Mann Whitney U tests and Spearman's rho rank correlation coefficients were used for non-parametric data. One way analyses of variance (ANOVA) performed for group comparisons on parametric data.

Reliability Analyses
All composite scales, (standardised scales and the Attitude Scale devised specifically for this study) were subjected to reliability analyses to ensure overall reliability of scales with this population. The items for the HIV Attitude Scale were further subjected to a principal components analysis to check the dimension structuring.
(1) Hypothesis 1 - (Individuals working within the HIV/AIDS field are less likely to engage in unsafe sexual behaviour for HIV/STDs than the general population) - was examined using descriptive statistics.

(2) Hypothesis 2 - Given the nature of HIV/AIDS work there will be high levels of (a) burnout and (b) psychiatric morbidity in this group, and those with most direct contact with people with HIV will exhibit higher levels of (c) burnout and (d) psychiatric morbidity, especially if they have symptomatic disease or mental health problems - was examined using descriptive statistics and Spearman rho correlations. Group comparisons were examined using Mann Whitney U-Test and $\chi^2$ for categorical data. Where $\chi^2$ tests were invalid, due to cell sizes being less than five, categories were collapsed as appropriate.

(3) Hypothesis 3 - There will be higher levels of (a) burnout and (b) psychiatric morbidity in professional health care workers than in volunteers - was examined by descriptive statistics, Mann Whitney U-Test and $\chi^2$ for categorical data.

(4) Hypothesis 4 - Workers (a) with lower self-esteem, (b) less positive attitudes to safer sex, (c) who are more immersed in their HIV work (d) who minimise the personal effects of HIV and (e) who are more fatalistic about HIV, will have higher levels of burnout and psychiatric morbidity and will be more likely to engage in unsafe sex - was examined by Mann Whitney U-Tests and Spearman rho correlations. The relationship between attitudinal scales and sexual practices
was analysed by one way analysis of variance (ANOVA) and post hoc least significance tests.

(5) Hypothesis 5 - Workers with higher levels of (a) burnout and (b) psychiatric morbidity will engage in higher levels of sexual risk taking - was examined by ANOVA.
RESULTS

Section 1 - Sample and Demographic Characteristics

1.1 Response Rate

Of the 550 questionnaires distributed, 218 (40%) completed questionnaires were returned, comprising 155 from health care workers (representing a 44% response rate) and 63 from volunteers, (representing a 32% response rate). These response rates, although fairly low, are comparable to other studies of sexual behaviour (McKusick et al. 1995) and are within acceptable limits and not unusual for a postal study and given the highly sensitive and personal nature of the questionnaire.

1.2 Sociodemographic characteristics

There were only 15 (7%) lesbian participants. In view of this limited data set and the fact that the primary risk behaviour examined was penetrative sexual intercourse with or without a condom and that female to female transmission is rare (Raiteri et. al., 1998), these participants were removed from the data set. This left a final sample of 203, comprising 143 health care workers and 60 volunteers. The gender, age, sexual orientation, race and educational characteristics of the sample are presented in Table 1 below.
Chi-square analyses revealed no significant differences between the health care workers and volunteers in age, gender, education or ethnic origin. However, there was a significant difference in sexual orientation ($X^2 = 5.2$ d.f. (1) $p=.02$) with a larger proportion of gay men in the volunteer group and of heterosexuals in the health care worker sample.
1.3 Occupational characteristics

Table 2 shows the main occupations reported by the participants. The 'other' categories in this table, comprises a variety of occupations cited by participants, but within which no category is represented more than twice.

Table 2 Participants self reported occupations

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Valid %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health care workers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Adviser</td>
<td>66</td>
<td>(33)</td>
</tr>
<tr>
<td>Nurse/doctor</td>
<td>23</td>
<td>(12)</td>
</tr>
<tr>
<td>Psychologist/therapist</td>
<td>17</td>
<td>(8)</td>
</tr>
<tr>
<td>Other paid worker</td>
<td>10</td>
<td>(5)</td>
</tr>
<tr>
<td>Health Promotion</td>
<td>6</td>
<td>(3)</td>
</tr>
<tr>
<td>Project worker</td>
<td>6</td>
<td>(3)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>5</td>
<td>(2.5)</td>
</tr>
<tr>
<td>Co-ordinator</td>
<td>4</td>
<td>(2)</td>
</tr>
<tr>
<td>Admin staff</td>
<td>3</td>
<td>(1.5)</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Volunteers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteer</td>
<td>24</td>
<td>(13)</td>
</tr>
<tr>
<td>Other unpaid worker</td>
<td>9</td>
<td>(5)</td>
</tr>
<tr>
<td>Helpline Volunteer</td>
<td>8</td>
<td>(4)</td>
</tr>
<tr>
<td>Volunteer-Co-ordinator</td>
<td>6</td>
<td>(3)</td>
</tr>
<tr>
<td>Buddy</td>
<td>4</td>
<td>(2)</td>
</tr>
<tr>
<td>Drop-in centre volunteer</td>
<td>4</td>
<td>(2)</td>
</tr>
<tr>
<td>Outreach worker</td>
<td>2</td>
<td>(1)</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>
The above table shows that the largest occupational grouping is made up of health advisers. Health advisers are workers employed within the field of genito-urinary medicine who probably have most direct contact with patients regarding discussions of safer sex. As such they may be viewed as experts on safer sex, HIV transmission and risks for sexually transmitted infections. Table 3 shows the total time participants had worked in the HIV field together with the number of participants working full or part time in their current work.

Table 3  Total time worked in HIV field and whether currently working full or part time

<table>
<thead>
<tr>
<th></th>
<th>Health Care Workers</th>
<th>Volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td><strong>HIV work/volunteering</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full Time</td>
<td>113</td>
<td>(79.6)</td>
</tr>
<tr>
<td>Part-Time</td>
<td>29</td>
<td>(20.4)</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Total time in HIV</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 years or less</td>
<td>63</td>
<td>(44.3)</td>
</tr>
<tr>
<td>6 years or more</td>
<td>79</td>
<td>(55.7)</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
Unsurprisingly, the groups differed on the basis of whether they were engaged in full or part time HIV work, with more volunteers working part time. In terms of total time spent within the HIV field, health care workers reported having spent significantly longer in the field than volunteers.

1.4 Geographical Distribution

Of the 162 participants for whom data was available on place of residence, an equal proportion in each group (50%), resided in London or Brighton, areas having the highest prevalence of HIV infections, with the remaining cases residing elsewhere in the UK.

1.5 Time in current post

Participants reported a very wide range (1-383 months) of time spent in their current position. Given this large range, means are not presented. Table 4 shows the median and inter-quartile range for the whole sample, along with those for the volunteer and health care worker sub-groups.

<table>
<thead>
<tr>
<th>Table 4</th>
<th>Length of time in current position (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Whole sample N=201</td>
</tr>
<tr>
<td>Median (Inter-quartile Range)</td>
<td>27(12.5,59)</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
</tr>
</tbody>
</table>
Health care workers had spent significantly longer in their current position than volunteers.

1.6 Amount of weekly time spent working with people affected by HIV/AIDS

Table 5 presents data on the length of time participants reported working in direct contact (a) generally with people with HIV disease, (2) individuals with symptomatic HIV and (3) individuals with HIV who also have mental health problems. There was a tendency for volunteers to report a larger proportion of their time than health care workers in direct contact with HIV.
<table>
<thead>
<tr>
<th>Time spent in direct contact with:</th>
<th>Health Care Workers</th>
<th>Volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>people with HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 25%</td>
<td>74 (54)</td>
<td>11 (20)</td>
</tr>
<tr>
<td>25-50%</td>
<td>21 (15.3)</td>
<td>5 (9.1)</td>
</tr>
<tr>
<td>50%</td>
<td>17 (12.4)</td>
<td>6 (10.9)</td>
</tr>
<tr>
<td>50-75%</td>
<td>12 (8.8)</td>
<td>11 (20)</td>
</tr>
<tr>
<td>Most of the time</td>
<td>12 (8.8)</td>
<td>22 (40)</td>
</tr>
<tr>
<td>Missing data</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Symptomatic people with HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 25%</td>
<td>85 (63.5)</td>
<td>17 (31)</td>
</tr>
<tr>
<td>25-50%</td>
<td>27 (20.1)</td>
<td>13 (23.6)</td>
</tr>
<tr>
<td>50%</td>
<td>8 (6)</td>
<td>8 (14.5)</td>
</tr>
<tr>
<td>50-75%</td>
<td>8 (6)</td>
<td>10 (18.2)</td>
</tr>
<tr>
<td>Most of the time</td>
<td>6 (4.5)</td>
<td>7 (12.7)</td>
</tr>
<tr>
<td>Missing data</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>PWHIV who have mental health problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 25%</td>
<td>106 (78.5)</td>
<td>44 (81.5)</td>
</tr>
<tr>
<td>25-50%</td>
<td>20 (14.8)</td>
<td>5 (9.3)</td>
</tr>
<tr>
<td>50%</td>
<td>4 (3)</td>
<td>3 (5.6)</td>
</tr>
<tr>
<td>50-75%</td>
<td>4 (3)</td>
<td>0 -</td>
</tr>
<tr>
<td>Most of the time</td>
<td>1 (0.7)</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>Missing data</td>
<td>8</td>
<td>6</td>
</tr>
</tbody>
</table>
1.7 **Index of time spent with people with HIV in current post**

Although health care workers were more likely to work full time, this may not mean that they have greater direct contact with people affected by HIV. To permit comparisons of hours spent in direct contact with people affected by HIV by volunteers and health care workers (whether full or part time) an index of time spent in HIV related work was calculated. The index of HIV related direct contact was calculated as follows:

**Stage 1 - Number of Hours Worked**

In order to establish the amount of direct contact with people with HIV the total number of hours worked was identified. For the full time workers a figure of 36 hours (a normal working week) was assumed, (health care workers n=81, volunteers n=3). Median figures of hours worked were calculated for part time workers which, for volunteers, was 6 hours and for health care workers, 14 hours. The respective medians were then substituted for missing data (Part Time Health care workers n=3, Part Time Volunteers n=6). One participant did not specify whether he worked full or part time and consequently a working hour figure could not be calculated for this individual.

**Stage 2 - Working time in direct contact with individuals with HIV**

Questionnaire items 11a-c provide data of participants’ estimate of time spent in direct contact with people with HIV. For each participant, ratings on these questions were multiplied by hours worked providing an index of time worked with people with HIV, time worked with people with symptomatic HIV, and time worked with people with HIV who also have mental health problems. The final index figure was calculated by dividing the figures gained above by 180 (the number of hours representing a full working week = 36 x 5= the maximum possible rating, i.e. those working/volunteering “most of the time” with people with HIV). This provided a proportion of hours per week
spent in direct contact with people with HIV for each participant thus enabling comparisons between samples. Table 6 compares groups on the time index scale.

**Table 6**  
**Time spent in direct contact with individuals with HIV (using time index)**

<table>
<thead>
<tr>
<th></th>
<th>HCW Mean (sd)</th>
<th>Volunteers Mean (sd)</th>
<th>Stat test/sig Mann Whitney U test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct contact with individuals with HIV (n=134)</td>
<td>36(29)</td>
<td>21(22)</td>
<td>z=-4.35 p=.01</td>
</tr>
<tr>
<td>Direct contact with Individuals with symptomatic HIV (n=133)</td>
<td>29(24)</td>
<td>15(14)</td>
<td>z=-4.96 p=.01</td>
</tr>
<tr>
<td>Direct contact with individuals with HIV and mental health problems (n=136)</td>
<td>21(19)</td>
<td>8(9)</td>
<td>z=-5.04 p=.01</td>
</tr>
</tbody>
</table>

Results show health care workers spent significantly more time in direct contact with all three categories of people affected by HIV than volunteers.

**1.8 HIV Status**

**1.9**

Participants' HIV antibody status is shown in table 7.

**Table 7**  
**HIV antibody status of participants**

<table>
<thead>
<tr>
<th></th>
<th>Whole sample n=203</th>
<th>Health care workers sample n=143</th>
<th>Volunteers n=60</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unknown but assumed negative</td>
<td>86 (42%)</td>
<td>69 (48%)</td>
<td>17 (28%)</td>
</tr>
<tr>
<td>HIV negative</td>
<td>80 (40%)</td>
<td>58 (41%)</td>
<td>22 (37%)</td>
</tr>
<tr>
<td>Unknown assumed positive</td>
<td>2 (1%)</td>
<td>1 (1%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>HIV Positive</td>
<td>12 (6%)</td>
<td>2 (1%)</td>
<td>10 (16%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>10 (5%)</td>
<td>7 (5%)</td>
<td>3 (6%)</td>
</tr>
<tr>
<td>Missing</td>
<td>13 (6%)</td>
<td>6 (4%)</td>
<td>7 (12%)</td>
</tr>
</tbody>
</table>

Only 7% of the sample were either diagnosed as HIV antibody positive or believed themselves to be HIV positive. HIV positive participants were differentially distributed between the groups with 16% of volunteers (n=10) HIV positive compared to 2% (n=2)
health care workers. The larger number of HIV positive volunteers may reflect the greater number of gay men in this group as well as the fact that some voluntary groups actively recruit HIV positive volunteers.

Section 2 - Reliability Analyses

A number of scales were used in this study. To establish the internal reliability of these measures before including them in further analyses, reliability analyses were performed on each scale.

2.1 Reliability analysis of standardised questionnaires

(i) General Health Questionnaire (GHQ-12)

To ensure the internal consistency of the GHQ-12 with the current population, a reliability analysis was performed. The alpha reliability coefficient for the GHQ-12 was 0.91 and confirms its item content structure as internally reliable.

(ii) Maslach Burnout Inventory (MBI)

Reliability analysis was also performed on each of the six sub-scales of the MBI to ensure the internal consistency of the sub-scales with the population under investigation. Table 8 shows the Cronbach alpha coefficients for each sub-scale.
Table 8  Reliability analysis Cronbach alpha coefficients for the MBI

<table>
<thead>
<tr>
<th>Maslach Burnout Inventory-sub-scales</th>
<th>Cronbach alpha coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Exhaustion - Frequency</td>
<td>.89</td>
</tr>
<tr>
<td>Emotional Exhaustion - Intensity</td>
<td>.86</td>
</tr>
<tr>
<td>Depersonalisation - Frequency</td>
<td>.71</td>
</tr>
<tr>
<td>Depersonalisation - Intensity</td>
<td>.83</td>
</tr>
<tr>
<td>Personal Accomplishment - Frequency</td>
<td>.77</td>
</tr>
<tr>
<td>Personal Accomplishment - Intensity</td>
<td>.83</td>
</tr>
</tbody>
</table>

The alpha reliability coefficients for all six sub-scales of the MBI confirm internal consistency of items.

2.2 HIV Attitudes Scale

Statements included within the questionnaire which were believed to be potentially related to risky sexual practices were divided into five main a priori categories labelled:

1. attitude to safer sex
2. minimisation of HIV
3. fatalism
4. self esteem and
5. immersion in HIV.

Actual scale items are presented below.
### Scale 1 - Attitudes to safer sex

<table>
<thead>
<tr>
<th>Attitude</th>
<th>Variable Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>I always engage in safer sex</td>
<td>Att1</td>
</tr>
<tr>
<td>Engaging in safer sex is difficult for me</td>
<td>Att2</td>
</tr>
<tr>
<td>Thinking about safer sex reduces my sexual enjoyment</td>
<td>Att3</td>
</tr>
<tr>
<td>If I talk about safer sex partner would think I am HIV positive</td>
<td>Att4</td>
</tr>
<tr>
<td>Alcohol/drugs affect my sexual risk taking</td>
<td>Att5</td>
</tr>
<tr>
<td>Slip-ups during sex happen sometimes</td>
<td>Att6</td>
</tr>
<tr>
<td>I dislike using condoms</td>
<td>Att7</td>
</tr>
<tr>
<td>My partner/s dislike condoms</td>
<td>Att8</td>
</tr>
<tr>
<td>During sex I am less rational about using condoms</td>
<td>Att9</td>
</tr>
<tr>
<td>During sex I think to myself &quot;I am taking a risk&quot;</td>
<td>Att10</td>
</tr>
<tr>
<td>I feel nervous talking about safer sex</td>
<td>Att11</td>
</tr>
<tr>
<td>I find talking about safer sex difficult</td>
<td>Att12</td>
</tr>
</tbody>
</table>

### Scale 2 - Minimisation

<table>
<thead>
<tr>
<th>Minimisation</th>
<th>Minimal</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV is not personally relevant to me</td>
<td>Minimal1</td>
</tr>
<tr>
<td>HIV does not pose a personal threat to me</td>
<td>Minimal2</td>
</tr>
<tr>
<td>HIV is not an issue for me in my personal life</td>
<td>Minimal3</td>
</tr>
<tr>
<td>I feel that I am not at risk for HIV</td>
<td>Minimal4</td>
</tr>
<tr>
<td>I try not to discuss my HIV work at home</td>
<td>Minimal5</td>
</tr>
<tr>
<td>I try not to think about HIV when having sex</td>
<td>Minimal6</td>
</tr>
</tbody>
</table>

### Scale 3 - Fatalism

<table>
<thead>
<tr>
<th>Fatalism</th>
<th>Fatal1</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe the future is out of my control</td>
<td>Fatal1</td>
</tr>
<tr>
<td>Contracting HIV is out of my control</td>
<td>Fatal2</td>
</tr>
<tr>
<td>I worry about contracting HIV</td>
<td>Fatal3</td>
</tr>
<tr>
<td>Scale 4 - Self esteem</td>
<td>Variable Name</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>I am a shy person</td>
<td>Selfest1</td>
</tr>
<tr>
<td>I am an anxious/nervous person</td>
<td>Selfest2</td>
</tr>
<tr>
<td>I am a confident person</td>
<td>Selfest3</td>
</tr>
<tr>
<td>I have a low self esteem</td>
<td>Selfest4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale 5 - Immersion in HIV</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I switch off to HIV when I leave work</td>
<td>Expose1</td>
</tr>
<tr>
<td>I have seen many deaths from HIV/AIDS</td>
<td>Expose3</td>
</tr>
<tr>
<td>I would like to stop my HIV work</td>
<td>Expose4</td>
</tr>
<tr>
<td>I feel totally surrounded by HIV</td>
<td>Expose5</td>
</tr>
<tr>
<td>Detaching myself from HIV work is difficult</td>
<td>Expose6</td>
</tr>
<tr>
<td>HIV affects my whole life</td>
<td>Expose8</td>
</tr>
</tbody>
</table>

### 2.3 Reliability analysis

(i) **Stage 1**

As an initial reliability check of these five scales, to identify incorrectly categorised items, two independent raters, both clinical psychologists, were presented with the total list of 38 statements together with the five a priori labelled categorisations. Raters were asked to place each item into their respective category. This initial check yielded an 87% inter-rater reliability with only 4 items positioned within a different category to the one expected. These four ambiguous items were examined and re-classified as follows: items 5 and 6 originally positioned within the ‘Self esteem’ category were recoded into items 11 and 12 of the ‘Attitude to safer sex’ scale and items 2 and 7 in the original
‘Immersion’ category were re-classified into items 5 and 6 on the ‘Minimisation’ scale, thus achieving face validity.

(ii) Stage 2

The internal consistency and accuracy of scale items were then analysed by performing reliability analyses on the items comprising each of the five scales. Negatively coded items were re-coded prior to the reliability analysis. The Cronbach Alpha Coefficients and Corrected Item-Total correlations produced by the reliability analyses are presented below.

(a) Scale 1 - Attitude to safer sex

<table>
<thead>
<tr>
<th>Variable</th>
<th>Corrected Item-Total Correlation</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATT1</td>
<td>.1441</td>
<td>.7826</td>
</tr>
<tr>
<td>ATT2</td>
<td>.5337</td>
<td>.7394</td>
</tr>
<tr>
<td>ATT3</td>
<td>.5628</td>
<td>.7354</td>
</tr>
<tr>
<td>ATT4</td>
<td>.4534</td>
<td>.7469</td>
</tr>
<tr>
<td>ATT5</td>
<td>.4053</td>
<td>.7503</td>
</tr>
<tr>
<td>ATT6</td>
<td>.2751</td>
<td>.7656</td>
</tr>
<tr>
<td>ATT7</td>
<td>.3744</td>
<td>.7648</td>
</tr>
<tr>
<td>ATT8</td>
<td>.4231</td>
<td>.7484</td>
</tr>
<tr>
<td>ATT9</td>
<td>.6059</td>
<td>.7293</td>
</tr>
<tr>
<td>ATT10</td>
<td>.3625</td>
<td>.7548</td>
</tr>
<tr>
<td>ATT11</td>
<td>.5121</td>
<td>.7433</td>
</tr>
<tr>
<td>ATT12</td>
<td>.4923</td>
<td>.7451</td>
</tr>
</tbody>
</table>

As the first variable on this scale failed to significantly improve the overall internal consistency of the scale and was unrelated to the other scale items, it was removed to increase the scale’s reliability. An 11 item scale was therefore used in all further analyses.
(b) Scale 2 - Immersion in HIV

<table>
<thead>
<tr>
<th>Variable</th>
<th>Correlation</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXPOSE1</td>
<td>.1129</td>
<td>.7370</td>
</tr>
<tr>
<td>EXPOSE3</td>
<td>.2751</td>
<td>.3070</td>
</tr>
<tr>
<td>EXPOSE4</td>
<td>.2500</td>
<td>.3322</td>
</tr>
<tr>
<td>EXPOSE5</td>
<td>.4180</td>
<td>.2806</td>
</tr>
<tr>
<td>EXPOSE6</td>
<td>.3333</td>
<td>.3018</td>
</tr>
<tr>
<td>EXPOSE8</td>
<td>.3773</td>
<td>.2680</td>
</tr>
</tbody>
</table>

The first variable was also removed from this scale creating a more internally consistent 5 item scale.

(c) Scale 3 - Fatalism

<table>
<thead>
<tr>
<th>Variable</th>
<th>Correlation</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>FATAL1</td>
<td>.1662</td>
<td>-.0925</td>
</tr>
<tr>
<td>FATAL2</td>
<td>.0669</td>
<td>.1411</td>
</tr>
<tr>
<td>FATAL3</td>
<td>.0244</td>
<td>.2883</td>
</tr>
</tbody>
</table>

Internal reliability on this scale was very low. These items were therefore excluded from any further analyses, thereby reducing the overall number of scales to four.

(d) Scale 4 - Minimisation

<table>
<thead>
<tr>
<th>Variable</th>
<th>Correlation</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>MINIMAL1</td>
<td>.4674</td>
<td>.6940</td>
</tr>
<tr>
<td>MINIMAL2</td>
<td>.5863</td>
<td>.6544</td>
</tr>
<tr>
<td>MINIMAL3</td>
<td>.6793</td>
<td>.6181</td>
</tr>
<tr>
<td>MINIMAL4</td>
<td>.5485</td>
<td>.6647</td>
</tr>
<tr>
<td>MINIMAL5</td>
<td>.3507</td>
<td>.7215</td>
</tr>
<tr>
<td>MINIMAL6</td>
<td>.1961</td>
<td>.7686</td>
</tr>
</tbody>
</table>

Variable 6 was removed from this scale to create a more robust 5 item scale.
(e) Scale 5 - Self esteem

<table>
<thead>
<tr>
<th>Variable</th>
<th>Corrected Item-total</th>
<th>Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>SELFEST1</td>
<td>.4019</td>
<td>.4934</td>
</tr>
<tr>
<td>SELFEST2</td>
<td>.5429</td>
<td>.3774</td>
</tr>
<tr>
<td>SELF3REC</td>
<td>.1559</td>
<td>.6796</td>
</tr>
<tr>
<td>SELFEST4</td>
<td>.4220</td>
<td>.4794</td>
</tr>
</tbody>
</table>

Variable 3 was removed as this did not improve the overall reliability of this scale.

(iii) Stage 3 - Principal Components Analysis

Following the inter-rater reliability checks and reliability analyses, the item structuring of the scale items comprising the remaining four scales were further examined. The remaining 24 scale items were entered into a principal components analysis. Factors were rotated by Direct Oblimin method with four factors forced. The actual four factors produced accounted for 46.5% of the variance. Table 9 shows the eigenvalues of the four factors and Table 10 the principal component analysis pattern matrix.

**Table 9 Eigenvalues of the four factors in the HIV Attitudes Scale**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Eigenvalue</th>
<th>% of Variance</th>
<th>Cumulative %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4.21</td>
<td>17.5</td>
<td>17.5</td>
</tr>
<tr>
<td>2</td>
<td>3.12</td>
<td>13.0</td>
<td>30.5</td>
</tr>
<tr>
<td>3</td>
<td>2.10</td>
<td>8.8</td>
<td>39.3</td>
</tr>
<tr>
<td>4</td>
<td>1.73</td>
<td>7.2</td>
<td>46.5</td>
</tr>
</tbody>
</table>
Table 10  Pattern matrix of the principal components analysis of the HIV Attitudes Scale

<table>
<thead>
<tr>
<th>Labels</th>
<th>Factor 1 (Attfact)</th>
<th>Factor 2 (Minfact)</th>
<th>Factor 3 (Sefact)</th>
<th>Factor 4 (Expofact)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATT2</td>
<td>.63505</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATT3</td>
<td>.64053</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATT4</td>
<td>.56666</td>
<td></td>
<td></td>
<td>.31277</td>
</tr>
<tr>
<td>ATT5</td>
<td>.48514</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATT6</td>
<td>.37931</td>
<td>-.27867</td>
<td>-.27166</td>
<td></td>
</tr>
<tr>
<td>ATT7</td>
<td>.52118</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATT8</td>
<td>.53288</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATT9</td>
<td>.72365</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATT10</td>
<td>.50369</td>
<td>-.20731</td>
<td>-.20219</td>
<td></td>
</tr>
<tr>
<td>ATT11</td>
<td>.62839</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATT12</td>
<td>.64648</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MINIMAL1</td>
<td></td>
<td>.60022</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MINIMAL2</td>
<td></td>
<td>.78079</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MINIMAL3</td>
<td></td>
<td>.83828</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MINIMAL4</td>
<td></td>
<td>.74647</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MINIMAL5</td>
<td></td>
<td>.51065</td>
<td>-.22938</td>
<td></td>
</tr>
<tr>
<td>SELFEST1</td>
<td></td>
<td>.70110</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SELFEST2</td>
<td></td>
<td>.82539</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SELFEST4</td>
<td></td>
<td>.69327</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EXPOSE3</td>
<td></td>
<td></td>
<td>.59245</td>
<td></td>
</tr>
<tr>
<td>EXPOSE4</td>
<td></td>
<td></td>
<td>.54427</td>
<td></td>
</tr>
<tr>
<td>EXPOSE5</td>
<td></td>
<td></td>
<td>.79643</td>
<td></td>
</tr>
<tr>
<td>EXPOSE6</td>
<td></td>
<td></td>
<td>.71536</td>
<td></td>
</tr>
<tr>
<td>EXPOSE8</td>
<td></td>
<td>-.30833</td>
<td>.68628</td>
<td></td>
</tr>
</tbody>
</table>

The four dimensions that emerged from the factor analysis related directly to the four sub-scales originally devised. The factor composition supports the construct validity of the four scales and indicates that the four scales represent different dimensions about working within the HIV field and attitudes to safer sex.

\(^1\) Values less than .20 were suppressed
Section 3 - Sexual Behaviour

3.1 Relationship status

Table 11 shows the types of relationships participants reported they had engaged in within the past year.

<table>
<thead>
<tr>
<th>Type of relationships</th>
<th>Gay Men n=90</th>
<th>Heterosexual Women n=101</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No regular or casual partner/s</td>
<td>8(9)</td>
<td>15(14)</td>
<td>23 (11)</td>
</tr>
<tr>
<td>Only a regular partner</td>
<td>23(28)</td>
<td>71(70)</td>
<td>103 (51)</td>
</tr>
<tr>
<td>Only casual partners</td>
<td>22(26)</td>
<td>7(7)</td>
<td>29 (14)</td>
</tr>
<tr>
<td>Both regular and casual partners</td>
<td>33(37)</td>
<td>8(8)</td>
<td>3(25)</td>
</tr>
<tr>
<td>Missing</td>
<td>4</td>
<td></td>
<td>4 (2)</td>
</tr>
</tbody>
</table>

Results indicate that gay men were more likely to have casual partners or a combination of both casual and regular partners compared with heterosexual men and women who were more likely to have regular relationships.

Table 12 shows the total number of sexual intercourse encounters and unprotected sexual intercourse encounters reported for the past week, month and three months. Sexual intercourse (SI) was defined as ‘penetrative sex - either anal or vaginal’ and unprotected sexual intercourse (USI) as ‘penetrative sex - either anal or vaginal without using a condom’.
Table 12  Frequency of penetrative sexual behaviour during the past week, month and three months

<table>
<thead>
<tr>
<th>No. of episodes</th>
<th>Total Sexual Intercourse Encounters</th>
<th></th>
<th></th>
<th></th>
<th>Total Unprotected Sexual Intercourse Encounters</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Regular partner</td>
<td>Casual partner</td>
<td></td>
<td></td>
<td>Regular partner</td>
<td>Casual partner</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Past week</td>
<td>Past month</td>
<td>Past 3 months</td>
<td>Past week</td>
<td>Past month</td>
<td>Past 3 months</td>
<td>Past week</td>
<td>Past month</td>
</tr>
<tr>
<td>0</td>
<td>59</td>
<td>39</td>
<td>28</td>
<td>61</td>
<td>42</td>
<td>30</td>
<td>78</td>
<td>64</td>
</tr>
<tr>
<td>1</td>
<td>30</td>
<td>7</td>
<td>9</td>
<td>5</td>
<td>13</td>
<td>6</td>
<td>23</td>
<td>4</td>
</tr>
<tr>
<td>2-5</td>
<td>46</td>
<td>40</td>
<td>11</td>
<td>6</td>
<td>12</td>
<td>21</td>
<td>32</td>
<td>33</td>
</tr>
<tr>
<td>6-10</td>
<td>5</td>
<td>32</td>
<td>18</td>
<td>0</td>
<td>4</td>
<td>9</td>
<td>4</td>
<td>21</td>
</tr>
<tr>
<td>11-20</td>
<td>1</td>
<td>0</td>
<td>14</td>
<td>33</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>21-30</td>
<td>0</td>
<td>3</td>
<td>13</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>31+</td>
<td>0</td>
<td>1</td>
<td>17</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Missing</td>
<td>6</td>
<td>11</td>
<td>18</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Total*</td>
<td>82/141</td>
<td>97/136</td>
<td>101/129</td>
<td>11/72</td>
<td>29/71</td>
<td>40/70</td>
<td>59/137</td>
<td>70/134</td>
</tr>
<tr>
<td>N**(%)</td>
<td>(58)</td>
<td>(71)</td>
<td>(78)</td>
<td>(15)</td>
<td>(41)</td>
<td>(57)</td>
<td>(43)</td>
<td>(52)</td>
</tr>
</tbody>
</table>

* Engaged in relationships
** Denominator changes reflect varying missing data concerning information provided for sexual intercourse
The three month period provided the greatest range of scores for penetrative sexual intercourse. Given that increasing the time periods was related to an increase in the number of sexual partners and sexual intercourse encounters reported and that this study is particularly investigating sexual behaviour (whether protected or unprotected) with both casual and regular partners, the three month time period was taken as the optimum time interval to capture data on sexual activity and these figures were used in all subsequent analyses.

3.2 Unprotected sexual intercourse (USI)

Table 13 shows data for number of people reporting unprotected sexual intercourse by relationship status within the two occupational groups.

<table>
<thead>
<tr>
<th>Relationship type</th>
<th>Whole sample (n=203)</th>
<th>Health care workers (n=143)</th>
<th>Volunteers (n=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>USI with casual partner</td>
<td>USI with regular partner</td>
<td>USI with casual partner</td>
</tr>
<tr>
<td>No partner/s</td>
<td>n.a.</td>
<td>n.a.</td>
<td>n.a.</td>
</tr>
<tr>
<td>Regular partner only</td>
<td>n.a.</td>
<td>56/91 (62%)</td>
<td>n.a.</td>
</tr>
<tr>
<td>Casual partner only</td>
<td>3/29 (10%)</td>
<td>n.a.</td>
<td>3/20</td>
</tr>
<tr>
<td>Both regular and casual</td>
<td>8/44 (9%)</td>
<td>20/38^4 (53%)</td>
<td>7/28</td>
</tr>
<tr>
<td>Total applicable</td>
<td>11/73 (15%)</td>
<td>76/129 (59%)</td>
<td>10/48</td>
</tr>
</tbody>
</table>

^2 Fishers Exact Test of probability revealed no significant differences between health care worker and volunteer groups for each relationship type

^3 missing data for 3 month unprotected sexual intercourse information for 12 participants

^4 missing data for 3 month unprotected sexual intercourse information for 6 participants
Only 5% (11/203) of the total sample engaged in unprotected intercourse (USI) with a casual partner, (10 health care workers (7%) and 1 volunteer (1.6%)) . However, when missing data and participants who did not have any sexual partners or who only had regular partners were removed from the equation, an overall figure of 15% engaged in USI with their casual partner/s (11/73) during the last three months, comprising 21% (10/48) of health care workers and 4% (n=1) volunteers, who had sexual contact with casual partners.

The overall figure for participants engaging in USI with their regular partner was 37% (76/203), comprising 59 health care workers (41%) and 17 volunteers (28%) . When missing data and participants who did not have a sexual partner or who had only casual partner/s were excluded, 59% (76/129) overall engaged in USI with their regular partner, comprising 61% (59/96) of health care workers and 52% (17/33) of volunteers.

Of the 44 participants who engaged in both casual and regular relationships, 8 reported having engaged in unprotected sexual intercourse with their casual partner/s. Of these, 1 participant did not provide information about their regular partner but of the remaining 7 participants, only 2 used condoms within their regular relationship. Consequently 5 of 8 (71%) participants who had both regular and casual partner/s and had USI with casual partners engaged in USI with both their casual and regular partner/s. Looking at it another way, of the 38 participants who engaged in both casual and regular relationships and who had engaged in USI with their regular partner (N=20), 5 also engaged in USI with their casual partner/s. When further analysed by group, of the 6 out of 7 health care workers for whom information about
their regular partner was available, who had both casual and regular partners and engaged in USI with their casual partner/s. 4 of the 6 had USI with **both** their casual and regular partners. Of the 16 volunteers with both partner types, only 1 reported unprotected intercourse with casual partner/s although this person also had USI within his regular relationship.

Of the 14 volunteers who had engaged in sexual intercourse with both casual and regular partner/s, 6 reported USI within their regular relationship. Of these, 1 reported USI also with casual partners.

While the numbers of participants reporting unprotected intercourse with casual partners are too small to enable meaningful comparisons between groups to be made: the figures for unprotected intercourse overall suggest that health care workers may be more likely to engage in risky sexual behaviour than volunteers, irrespective of type of relationship/s engaged in.

Table 14 shows the number of participants who engaged in sexual intercourse and unprotected sexual intercourse by sexual orientation, permitting comparisons between sexual orientation and gender.
Table 14  Sexual intercourse (SI) and unprotected sexual intercourse (USI) encounters during the past three months, presented by regular and casual partners and sexual orientation.

<table>
<thead>
<tr>
<th>Regular Partner</th>
<th>Participants reporting any SI (n, %)</th>
<th>Participants reporting any unprotected SI (USI) (n, %)</th>
<th>Casual Partner/s</th>
<th>Participants reporting any SI (n, %)</th>
<th>Participants reporting any unprotected SI (USI) (n, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>gay men n=78</td>
<td>straight men n=12</td>
<td>straight women n=86</td>
<td>gay men n=78</td>
<td>straight men n=12</td>
</tr>
<tr>
<td>Regular Partner only</td>
<td>15/22 (65) *</td>
<td>6/7 (86) **</td>
<td>51/62 (82) ****</td>
<td>5/22 (23) *</td>
<td>6/7 (86) **</td>
</tr>
<tr>
<td>Casual Partner only</td>
<td>n.a.</td>
<td>n.a.</td>
<td>n.a.</td>
<td>n.a.</td>
<td>n.a.</td>
</tr>
<tr>
<td>Both Casual &amp; Regular Partners</td>
<td>21/31 (68) **</td>
<td>2/2 (100)*</td>
<td>6/7 (86) *</td>
<td>11/29 (38) ****</td>
<td>1/2 (50) *</td>
</tr>
<tr>
<td>No Partners</td>
<td>8</td>
<td>0</td>
<td>15</td>
<td>8</td>
<td>0</td>
</tr>
</tbody>
</table>

* = 1 case missing; ** = 2 cases missing; *** = 3 cases missing; **** = 4 cases missing; ***** = 9 cases missing
While direct group comparisons are inappropriate due to small cell sizes, results indicate that among those participants who engaged in sexual intercourse with their casual partner/s (n= 40/70), 27% (n=11/40) engaged in at least one episode of unprotected intercourse with them within the previous three month period. This compares with those who reported having engaged in sexual intercourse with a regular partner (101/129), 75% (n=76/101) having engaged in unprotected sexual intercourse with their regular partner. Tables 15a-b describe self reported sexual behaviour of gay men only, since this group is most at risk for HIV infection.

3.3 Sexual intercourse in gay men

Table 15a shows sexual intercourse figures for gay men.

<table>
<thead>
<tr>
<th>Partner type</th>
<th>N</th>
<th>n, (%) engaging in SI with casual partner/s</th>
<th>n, (%) having USI with CP of those who had SI with their CP</th>
<th>n, (%) engaging in SI with regular partner</th>
<th>n, (%) having USI with RP of those who had SI with their RP</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Sexual Partners</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Regular Partner only</td>
<td>23</td>
<td>N/A</td>
<td>N/A</td>
<td>15(68)*</td>
<td>5(23)*</td>
</tr>
<tr>
<td>Casual Partner(s) only</td>
<td>22</td>
<td>11(50)</td>
<td>3(16)</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Both Casual and Regular</td>
<td>33</td>
<td>19(63)***</td>
<td>4(12)</td>
<td>21(68)**</td>
<td>11(38)****</td>
</tr>
<tr>
<td>Partners</td>
<td>30/52(58)</td>
<td>7/30(23)</td>
<td>36/53(68)</td>
<td>16/36(44)</td>
<td></td>
</tr>
</tbody>
</table>

* = 1 case missing; ** = 2 cases missing; *** = 3 cases missing; **** =4 cases missing
N.B. percentages read sideways and calculated excluding missing cases (e.g. 19/(33-3)=63%).

Results reveal that of those gay men who engaged in sexual intercourse with casual partner/s (n=30), 7 engaged in USI with their casual partner/s and of those gay men engaging in SI with regular partner/s (n=36), 16 engaged in USI with their regular partner. A slightly larger proportion of those with regular partners only reported USI.
with this partner than those who had casual partners only. Among those reporting both types of partner, USI was less frequent with casual partners than with regular partners.

3.3.1 Comparison with other studies of gay men

Table 15b compares SI and USI figures with previously reported frequency of sexual intercourse in gay men from UK based studies. In order to make direct comparisons non responders in the Hope and MacArthur (1998) study were omitted and percentages of USI recalculated for those actually engaging in sexual activity.
Table 15b  Comparison of reports of sexual intercourse by gay men in the current study with data from other sexual behaviour studies of gay men conducted in the UK.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Time period</td>
<td>3 months</td>
<td>12 months</td>
<td>12 months</td>
<td>12 months</td>
</tr>
<tr>
<td>Total reporting SI with RP</td>
<td>36/53 68%</td>
<td>646/789 Bfd 82%</td>
<td>1110/1580 68%</td>
<td>69.5%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>510/780 Other RP 65%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>at least 1 episode of USI with RP (of those who had sexual intercourse with RP)</td>
<td>16/36 44%</td>
<td>276/646 Bfd 43%</td>
<td>466/1597 28.3%</td>
<td>29.4%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other RP 27% 138/510</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total reporting SI with CP/s</td>
<td>30/52 58%</td>
<td>490/775</td>
<td>612/1579 38.6%</td>
<td>41.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>at least 1 episode of USI with CP (of those who had sexual intercourse with CP/s)</td>
<td>7/30 23%</td>
<td>96/490</td>
<td>143/1591 8.9%</td>
<td>9.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
RP = regular partner; CP= casual partner; Bfd= boyfriend; SI = sexual intercourse; USI = unprotected sexual intercourse

The figures for SI and USI in this study are not strictly comparable with those of the other studies because of the longer time frames used in the other research reports. The denominators for percentages in this study are also very much smaller than those in the other three studies. With these provisos, the results suggest that (a) the proportions of gay men reporting SI with regular partners and casual partners are similar to those
previously reported and (b) USI with regular partners and casual partners is similar or higher to those rates previously reported.

3.4 Sexual intercourse in heterosexuals

Tables 16a-b shows sexual intercourse figures for heterosexual men and women.

Table 16a  Numbers and Percentages of heterosexual men reporting unprotected sexual intercourse within the last three months (n, %)

<table>
<thead>
<tr>
<th>Partner type</th>
<th>n</th>
<th>Total number SI encounters with casual partner/s (n,%)</th>
<th>Any USI with casual partner/s (n,%)*</th>
<th>Total number SI with regular partner (n,%)*</th>
<th>Any USI with regular partner/s (n,%)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Sexual Partners</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Regular Partner</td>
<td>9</td>
<td>N/A</td>
<td>N/A</td>
<td>6(86)**</td>
<td>6(86)**</td>
</tr>
<tr>
<td>Casual Partner</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Both Casual and Regular</td>
<td>3</td>
<td>1(33)</td>
<td>1(33)</td>
<td>2(100)*</td>
<td>1(50)*</td>
</tr>
<tr>
<td>Total Applicable</td>
<td>12</td>
<td>1/3(33)</td>
<td>1/1(100)</td>
<td>8/9(89)</td>
<td>7/8(88)</td>
</tr>
</tbody>
</table>

NB percentages read sideways & calculated excluding missing cases (e.g. 6/(9-2)=86%).
* = 1 case missing; ** = 2 cases missing

Table 16b  Numbers and Percentages of heterosexual women reporting unprotected sexual intercourse within the last three months (n, %)

<table>
<thead>
<tr>
<th>Partner type</th>
<th>n</th>
<th>Total number SI encounters with casual partner/s(n,%)</th>
<th>Any USI with casual partner/s (n,%)*</th>
<th>Total number SI with regular partner (n,%)*</th>
<th>Any USI with regular partner/s (n,%)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Sexual Partners</td>
<td>15</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Regular Partner</td>
<td>71</td>
<td>N/A</td>
<td>N/A</td>
<td>51(74)**</td>
<td>42(61)**</td>
</tr>
<tr>
<td>Casual Partner</td>
<td>7</td>
<td>5(71)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Both Casual and Regular</td>
<td>8</td>
<td>4(50)</td>
<td>3(38)</td>
<td>6(86)*</td>
<td>6(86)*</td>
</tr>
<tr>
<td>Total Applicable</td>
<td>101</td>
<td>9/15(60)</td>
<td>3/9(33)</td>
<td>57/76(75)</td>
<td>48/57(84)</td>
</tr>
</tbody>
</table>

NB Percentages read sideways & calculated excluding missing cases (e.g. 51/(71-2)=74%).
* = 1 case missing; ** = 11 cases missing

There were no significant differences between heterosexual men and women reporting unprotected sexual intercourse with regular partners. USI with casual partners was too infrequent for meaningful statistical comparisons to be made. Although figures for
casual partners and heterosexual men are very small, results show that of those who engaged in sexual intercourse with casual partners, one third (n=3/9) of heterosexual women and the single heterosexual man engaged in unprotected sexual intercourse with their casual partner/s. Of those engaging in sexual intercourse with regular partner/s 84% (n=48/57) of women and 88% (n=7/8) of men engaged in unprotected sexual intercourse with their regular partner. The implications associated with classifying sexual intercourse without condoms between heterosexuals in regular relationships as USI are discussed later.

3.4.1 Comparison with other studies of heterosexuals

Table 16c compares frequency of sexual intercourse and unprotected sexual intercourse with figures from other studies of heterosexual sexual behaviour. Data for heterosexual men are not presented due to the small sample size in the current study making comparisons inappropriate.
Table 16c Comparison of reports of sexual intercourse by heterosexual women in the current study with comparative data.

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>Present Study (n=103) ((n, %))</th>
<th>Johnson et al (1994) (n=10492) ((n, %))</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 months</td>
<td>57/76 (75%)</td>
<td>8911/10492 (85%)</td>
</tr>
<tr>
<td>12 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total reporting sexual intercourse with regular partner</td>
<td>48/57 (84%)</td>
<td>74%</td>
</tr>
<tr>
<td>n, (%) having at least 1 episode of USI with RP of those who had SI with RP</td>
<td>9/15 (60%)</td>
<td>Not presented</td>
</tr>
<tr>
<td>Total reporting sexual intercourse with casual partner/s</td>
<td>3/9 (33%)</td>
<td>Not presented</td>
</tr>
</tbody>
</table>

Figures for SI and USI for heterosexual women in this study are also not strictly comparable with those of other studies because of the longer time frames used in the other research reports. With this proviso, the results suggest that (a) the proportion of heterosexual women reporting SI with their regular partner/s are slightly less than those previously recorded by Johnson et al (1994) and for USI with regular partner rates are higher although this may be a factor of the small sample size. Rates for casual partners could not be compared due to insufficient data reported in other studies.
3.5 Summary

Individuals working within the HIV/AIDS field are at least as likely to engage in unsafe sexual behaviour for HIV/STDs as the general population. However numbers having unprotected sexual intercourse are small and as such percentages may be misleading. Therefore Hypothesis 1, which suggested that HIV workers/volunteers would be less likely to engage in unsafe sexual behaviour for HIV/STDs than the general population is not supported irrespective of sexual orientation. Health care workers may be more likely than volunteers to engage in risky sexual behaviour.
Section 4 - Occupational stress and burnout

4.1 Burnout

Table 17 shows the proportion of health care workers and volunteers having low, moderate and high burnout alongside comparable UK data for health service workers.

Table 17  Comparison of proportions having low, moderate and high burnout with other UK samples of health care workers and volunteers.

<table>
<thead>
<tr>
<th></th>
<th>Health care workers</th>
<th>Volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=143)</td>
<td>(n=171)</td>
</tr>
<tr>
<td>Emotional Exhaustion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low (0-16)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>35%</td>
<td>56%</td>
</tr>
<tr>
<td>Intensity</td>
<td>31%</td>
<td>46%</td>
</tr>
<tr>
<td>Moderate (17-26)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>42%</td>
<td>35%</td>
</tr>
<tr>
<td>Intensity</td>
<td>48%</td>
<td>31%</td>
</tr>
<tr>
<td>High (27 &amp; over)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>23%</td>
<td>9%</td>
</tr>
<tr>
<td>Intensity</td>
<td>21%</td>
<td>15%</td>
</tr>
<tr>
<td>Depersonalisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low (0-6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>52%</td>
<td>67%</td>
</tr>
<tr>
<td>Intensity</td>
<td>40%</td>
<td>30%</td>
</tr>
<tr>
<td>Moderate (7-12)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>32%</td>
<td>24%</td>
</tr>
<tr>
<td>Intensity</td>
<td>28%</td>
<td>34%</td>
</tr>
<tr>
<td>High (13 &amp; over)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>16%</td>
<td>9%</td>
</tr>
<tr>
<td>Intensity</td>
<td>32%</td>
<td>36%</td>
</tr>
<tr>
<td>Personal Accomplishment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low (39 &amp; over)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>26%</td>
<td>1%</td>
</tr>
<tr>
<td>Intensity</td>
<td>17%</td>
<td>1%</td>
</tr>
<tr>
<td>Moderate (32-38)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>42%</td>
<td>2%</td>
</tr>
<tr>
<td>Intensity</td>
<td>39%</td>
<td>5%</td>
</tr>
<tr>
<td>High (0-31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>32%</td>
<td>97%</td>
</tr>
<tr>
<td>Intensity</td>
<td>44%</td>
<td>94%</td>
</tr>
</tbody>
</table>

- The classification into low, medium and high burnout is based on the lower, middle and upper third distributions of Maslach's normative data.

Results in table 17 shows that a larger proportion of health care workers in the current study score within the high burnout categories on both emotional exhaustion dimensions and on depersonalisation-frequency but a lower proportion on depersonalisation - intensity and the two personal accomplishment scales of the MBI. Volunteers have similar levels of emotional exhaustion and depersonalisation but much higher levels on personal accomplishment. Hypothesis 2a therefore has only partial support given the mixed MBI profile.
4.2 Psychiatric morbidity

Table 18 shows the overall mean scores for psychiatric morbidity as measured by the GHQ-12. Data are presented along with normative figures for the UK population reported by Weich and Lewis (1998) and McGrath et al's (1989) data for British Nurses.

**Table 18 Caseness on the GHQ-12 compared to general UK population norms and a sample of UK nurses. Scores of 3 or above used to denote caseness**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Probable caseness</td>
<td>34%</td>
<td>25%</td>
<td>23%</td>
</tr>
</tbody>
</table>

The above data suggests that there is a relatively high level of psychiatric morbidity in this population and hypothesis 2b is therefore supported.

4.3 Relationship between burnout and level of direct contact

Burnout data was further analysed to examine the relationship with amount of direct contact with people with HIV and total time having worked in the HIV field. Results are shown in tables 19 and 20.
Table 19 Spearman correlations between level of direct contact (time index) with people affected by HIV and MBI scores.

<table>
<thead>
<tr>
<th></th>
<th>Direct contact with people with HIV</th>
<th>Direction contact with PWHIV and symptomatic</th>
<th>Direct contact with PWHIV and mental health problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Exhaustion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>$r = .29(183)$</td>
<td>$r = .31(182)$</td>
<td>$r = .33(182)$</td>
</tr>
<tr>
<td>p&lt;.001</td>
<td>p&lt;.001</td>
<td>p&lt;.001</td>
<td></td>
</tr>
<tr>
<td>Emotional Exhaustion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensity</td>
<td>$r = .27(182)$</td>
<td>$r = .28(181)$</td>
<td>$r = .23(181)$</td>
</tr>
<tr>
<td>p&lt;.001</td>
<td>p&lt;.001</td>
<td>p&lt;.01</td>
<td></td>
</tr>
<tr>
<td>Depersonalisation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>$r = .20(181)$</td>
<td>$r = .26(180)$</td>
<td>$r = .33(180)$</td>
</tr>
<tr>
<td>p&lt;.01</td>
<td>p&lt;.001</td>
<td>p&lt;.001</td>
<td></td>
</tr>
<tr>
<td>Depersonalisation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensity</td>
<td>$r = .10(180)$</td>
<td>$r = .15(179)$</td>
<td>$r = .15(179)$</td>
</tr>
<tr>
<td>ns</td>
<td>p&lt;.05</td>
<td>p&lt;.05</td>
<td></td>
</tr>
<tr>
<td>Personal Accomplishment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>$r = .15(184)$</td>
<td>$r = .20(182)$</td>
<td>$r = .24(182)$</td>
</tr>
<tr>
<td>p&lt;.05</td>
<td>p&lt;.01</td>
<td>p&lt;.001</td>
<td></td>
</tr>
<tr>
<td>Personal Accomplishment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensity</td>
<td>$r = .03(183)$</td>
<td>$r = .04(181)$</td>
<td>$r = .076(181)$</td>
</tr>
<tr>
<td>ns</td>
<td>ns</td>
<td>ns</td>
<td></td>
</tr>
</tbody>
</table>

The extent of direct contact with people with HIV is positively associated with all the MBI factors except for intensity of personal accomplishment and intensity of depersonalisation. Similar positive associations were found for extent of direct contact with those with symptomatic infection or mental health problems with, additionally, associations with intensity of depersonalisation.

The relationships with personal accomplishment -frequency, are not in the direction that would be expected, as higher levels of personal accomplishment are associated with greater levels of direct contact. This suggests that the personal accomplishment items of the MBI are not clearly associated with the overall burnout measure.
Table 20  Correlations between total time worked within the HIV field and burnout.

<table>
<thead>
<tr>
<th>Total time spent in HIV field (n=203)</th>
<th>EEF</th>
<th>EEI</th>
<th>DeperF</th>
<th>DeperI</th>
<th>PAF</th>
<th>PAI</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than 1 yr</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 yrs</td>
<td>12.4(7.5)</td>
<td>17.9(11)</td>
<td>3.1(2.5)</td>
<td>5(4.7)</td>
<td>28.4(9.2)</td>
<td>33.4(8.1)</td>
</tr>
<tr>
<td>3-5 yrs</td>
<td>15.3(7.2)</td>
<td>23.9(10.6)</td>
<td>3.9(3.3)</td>
<td>8.8(8.6)</td>
<td>32.6(8.9)</td>
<td>36.6(8.9)</td>
</tr>
<tr>
<td>6-9 yrs</td>
<td>19.5(10)</td>
<td>28.5(11.6)</td>
<td>5.1(4)</td>
<td>9.1(8)</td>
<td>33.6(8.7)</td>
<td>34.4(9.5)</td>
</tr>
<tr>
<td>10+ yrs</td>
<td>21.4(8.9)</td>
<td>29.8(11.5)</td>
<td>6(4.7)</td>
<td>10.2(7.5)</td>
<td>34.5(8)</td>
<td>37.3(9)</td>
</tr>
<tr>
<td>**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

KEY * = p<.05; ** = p < .01; *** = p<.001 by Kruskal-Wallis ANOVA

Total time worked or volunteered within the HIV field was also significantly correlated with all but one (personal accomplishment - intensity) sub-scales of the MBI, suggesting that the longer workers remained within the HIV field, the more likely they are to experience higher levels of burnout.

Hypothesis 2c is therefore largely supported.

4.4 Relationship between GHQ and level of direct contact

Tables 21 and 22 show the relationship between psychiatric morbidity and amount of direct contact with people with HIV and total time having worked within the HIV field.

Table 21  Spearman correlations between level of direct contact (timeindex) with people affected by HIV and GHQ scores.

<table>
<thead>
<tr>
<th></th>
<th>Direct contact with people with HIV</th>
<th>Direction contact with PWHIV and symptomatic</th>
<th>Direct contact with PWHIV and mental health problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Health Questionnaire -12</td>
<td>r=.02 (190)</td>
<td>r=.03(188)</td>
<td>r=.06(187)</td>
</tr>
<tr>
<td></td>
<td>ns</td>
<td>ns</td>
<td>ns</td>
</tr>
</tbody>
</table>

187
Table 22 Correlations between total time worked within the HIV field and GHQ.

<table>
<thead>
<tr>
<th>Total time in HIV field</th>
<th>GHQ-12</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than 1yr</td>
<td>10.8(7.8)</td>
</tr>
<tr>
<td>1-2 yrs</td>
<td>10.5(4.8)</td>
</tr>
<tr>
<td>3-5 yrs</td>
<td>10.7(4.6)</td>
</tr>
<tr>
<td>6-9 yrs</td>
<td>12.2(6.6)</td>
</tr>
<tr>
<td>10+ yrs</td>
<td>13.5(6.5)</td>
</tr>
</tbody>
</table>

Unlike burnout, time in direct contact with people with HIV and total time spent in the HIV field were unrelated to psychiatric morbidity. Hypothesis 2d is therefore not supported.

4.5 Group comparisons for burnout

Burnout and psychiatric morbidity scores were further analysed to examine differences between health care workers and volunteers. The mean differences on the MBI between volunteers and health care workers are presented in Table 23 and comparisons between the two groups were made using the Mann Whitney U test.

Table 23 Comparison of volunteers and health care workers on the MBI

<table>
<thead>
<tr>
<th>Maslach Burnout Inventory</th>
<th>Volunteers mean (s.d.)</th>
<th>Health Care Workers mean (s.d.)</th>
<th>Test statistic</th>
<th>Significance level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Exhaustion</td>
<td>Frequency 14.1 (8.5)</td>
<td>22.7 (10.2)</td>
<td>t(192) 5.56</td>
<td>***</td>
</tr>
<tr>
<td></td>
<td>Intensity 21.5(11.8)</td>
<td>30.7 (10.8)</td>
<td>t(139) 5.2</td>
<td>***</td>
</tr>
<tr>
<td>Depersonalisation</td>
<td>Frequency 3.8 (4.0)</td>
<td>6.46 (4.8)</td>
<td>t(190) 3.46</td>
<td>**</td>
</tr>
<tr>
<td></td>
<td>Intensity 7.0 (7.7)</td>
<td>10.9 (8.0)</td>
<td>t(188) 3.06</td>
<td>**</td>
</tr>
<tr>
<td>Personal accomplishment</td>
<td>Frequency 29.4 (9.5)</td>
<td>35.6 (7.0)</td>
<td>t(193) 5.06</td>
<td>***</td>
</tr>
<tr>
<td></td>
<td>Intensity 33.8 (10.4)</td>
<td>36.9 (8.3)</td>
<td>t(192) 2.18</td>
<td>*</td>
</tr>
</tbody>
</table>

KEY * = p <.05; ** = p <.01; *** = p <.001 Mann-Whitney U test.
1 High scores indicate high burnout; 2 Low scores indicate high burnout.
There were significant differences between the two groups on all measures of burnout. The health care workers obtained higher scores for burnout on both frequency and intensity of emotional exhaustion and depersonalisation while volunteers exhibit higher levels of burnout on both intensity and frequency of personal accomplishment. Hypothesis 3a, which suggested that health care workers would have higher burnout scores than volunteers is partially supported.

To place data in perspective they were compared with figures from comparable UK based studies of volunteers (Claxton et al 1998) and health care workers (Catalan et al 1996), working with people with HIV infection. Results are presented in table 24.

<table>
<thead>
<tr>
<th>Maslach Burnout Inventory</th>
<th>Current Study (n=53) Volunteers - Buddies 3 n=267 mean (s.d.)</th>
<th>Current Study Health Care Workers (n=137) mean (s.d.)</th>
<th>Health Care Workers 4 n= 85 mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Exhaustion 1</td>
<td>Frequency 14.1 (8.5) Intensity 21.5 (11.8)</td>
<td>Frequency 13.4 (8.1) Intensity 21.0 (12.6)</td>
<td>Frequency 22.7 (10.2) Intensity 30.7 (10.8)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Frequency 22.0 (9.9) Intensity 28.0 (12.2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depersonalisation 1</td>
<td>Frequency 3.8 (4.0) Intensity 7.0 (7.5)</td>
<td>Frequency 2.9 (12.6) Intensity 6.0 (7.6)</td>
<td>Frequency 6.4 (4.8) Intensity 10.9 (8.0)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Frequency 7.7 (5.7) Intensity 9.2 (6.4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal accomplishment 2</td>
<td>Frequency 29.4 (9.5) Intensity 33.8 (10.4)</td>
<td>Frequency 28.0 (7.7) Intensity 34.1 (8.5)</td>
<td>Frequency 35.6 (7.0) Intensity 37.0 (8.3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Frequency 33.0 (9.8) Intensity 34.1 (10.2)</td>
</tr>
</tbody>
</table>

1 High scores indicate high burnout 2 Low scores indicate high burnout

3 Data from Claxton et al 1998 4 Data from Catalan et al 1996
Both the health care workers and the volunteers in the current sample have similar mean MBI scores to the comparable samples reported above.

4.6 Psychiatric morbidity

Overall 32% of health care workers and 38% of volunteers achieved GHQ-12 scores which would classify them as potential psychiatric cases. Similar proportions scored above the cut-off for caseness in each group ($X^2 = 0.7$ d.f. (1), N.S. Likert scoring (0,1,2,3) also indicated similar scores for health care workers (mean = 11.5, sd 5.9) and volunteers (mean = 12.0, sd 6.4).

To determine whether this level of psychiatric morbidity is typical for HIV/AIDS care workers and volunteers, level of caseness was compared with previously reported levels for comparable groups where GHQ measures have been used (see table 25). Previous studies assessing level of psychiatric caseness have most frequently used the 28 item version of the GHQ. However, both versions of the GHQ are derived from the same pool of scale items and are reported to have good inter-reliability.
Table 25 Psychiatric 'caseness' on the GHQ for HIV health care workers and volunteers.

<table>
<thead>
<tr>
<th></th>
<th>GHQ Version</th>
<th>Health care workers</th>
<th>Volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current study*</td>
<td>12</td>
<td>32%</td>
<td>38%</td>
</tr>
<tr>
<td>Catalan et al 1996 (n=85)</td>
<td>28</td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>Miller &amp; Gillies 1996 (n=103)</td>
<td>28</td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>Raphael et al 1990 (n=157)</td>
<td>28</td>
<td></td>
<td>37%</td>
</tr>
<tr>
<td>Guinan et al 1991 (n=72)</td>
<td>28</td>
<td></td>
<td>37%</td>
</tr>
</tbody>
</table>

*cut off of 3 utilised for 'caseness'

The rates of psychiatric morbidity found in the current study are similar to those reported among HIV health care workers and volunteers in other studies, although the two groups were not directly compared in previous research. Hypothesis 3b, which suggested that there would be a higher rate of psychiatric morbidity among health care workers than among volunteers was not supported.

4.7 Summary

Health care workers exhibit higher levels of burnout than volunteers on emotional exhaustion and depersonalisation but not personal accomplishment. Levels of burnout are generally related to level of direct contact with people with HIV and length of time worked in the field. There was no difference in overall level of psychiatric morbidity between groups and no significant relationships with level of direct contact or length of time working in the HIV field.
Section 5 - Factors associated with levels of burnout and psychiatric morbidity

5.1 HIV Attitude Scale

Mean factor scores on the HIV attitude scale are presented in table 26.

Table 26 Comparison of groups mean factor scores for the four attitude scales

<table>
<thead>
<tr>
<th>Attitude to Safer Sex Scale</th>
<th>Whole Group (n=155)</th>
<th>Health Care Workers (n=113)</th>
<th>Volunteers (n=42)</th>
<th>Mann Whitney U test / significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude to Safer Sex Scale</td>
<td>.00</td>
<td>-.11</td>
<td>.45</td>
<td>Z=-2.84(1) p&lt;.01</td>
</tr>
<tr>
<td>Minimisation Scale</td>
<td>.00</td>
<td>.12</td>
<td>-.21</td>
<td>ns</td>
</tr>
<tr>
<td>Immersion in HIV Scale</td>
<td>.00</td>
<td>.14</td>
<td>-.10</td>
<td>ns</td>
</tr>
<tr>
<td>Self Esteem Scale</td>
<td>.00</td>
<td>-.07</td>
<td>.34</td>
<td>ns</td>
</tr>
</tbody>
</table>

Volunteers held more negative attitudes to safer sex than health care workers but there were no other differences between the groups.

Correlations between burnout, psychiatric morbidity and HIV attitude scales are presented in table 27.

5 Data are not presented for the fatalism scale, as initial reliability analyses revealed this scale's unreliability.
Table 27  Spearman correlations between the MBI, GHQ-12 and HIV Attitude Scales

<table>
<thead>
<tr>
<th></th>
<th>Attitude to safer sex scale (factor score)</th>
<th>Minimisation scale (factor scores)</th>
<th>Immersion scale (factor scores)</th>
<th>Self esteem scale (factor scores)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq</td>
<td>Intens</td>
<td>Freq</td>
<td>Intens</td>
</tr>
<tr>
<td>Emotional Exhaustion</td>
<td>.02</td>
<td>-.07</td>
<td>.02</td>
<td>.04</td>
</tr>
<tr>
<td>Depersonalisation</td>
<td>-.04</td>
<td>-.08</td>
<td>-.03</td>
<td>.01</td>
</tr>
<tr>
<td>Personal Accomplishment</td>
<td>-.18*</td>
<td>-.20*</td>
<td>-.11</td>
<td>-.06</td>
</tr>
<tr>
<td>GHQ-12</td>
<td>.00</td>
<td>.15</td>
<td>.24**</td>
<td></td>
</tr>
</tbody>
</table>

KEY * = p<.05; ** = p <.01; *** = p<.001

Lower levels of self-esteem are associated with higher levels of burnout (emotional exhaustion - frequency and intensity) and with higher GHQ scores. Hypothesis 4a is therefore partially supported.

Attitudes to safer sex are not related to burnout and psychiatric morbidity, with the exception of higher levels of personal accomplishment being associated with more negative attitudes. Consequently hypothesis 4b is not supported.

Higher scores on immersion in HIV were associated with higher levels of burnout (frequency and intensity of emotional exhaustion and depersonalisation and lower levels of personal accomplishment) and higher GHQ scores. Hypothesis 4c is supported.
No relationship was found between minimisation of the personal risk of HIV and burnout or emotional distress. Therefore hypothesis 4d is not supported.

Results suggest that even if workers feel burnt out, attitudes to safer sex are not negatively affected and they do not minimise their personal risk of infection.

Section 6  Factors associated with unprotected sexual intercourse

6.1  Relationship between attitude scales and sexual practices

In order to determine whether those who engaged in risky sexual behaviour differed from others in their attitudes to HIV working and safer sex, two sets of one way analysis of variance were conducted. Each group’s mean scores are presented in table 28. In the first case the group was divided into those who had no sex, safe sex or unsafe sex. There were no significant differences between the groups with the exception of the minimisation scale (F=4.27 d.f. (2) p<.05). In the second set of analyses the sample were divided into those who engaged in no sex, safe sex, unsafe sex with a regular partner and unsafe sex with casual partner/s. Again, the only significant group difference was observed on the minimisation scale (F=4.9, d.f. 3,95, p<.01).
Table 28  One way analysis of variance scores (mean, s.d.).

<table>
<thead>
<tr>
<th>Group</th>
<th>Attitude to safer sex (factor scores)</th>
<th>Minimisation (factor scores)</th>
<th>Immersion (factor scores)</th>
<th>Self esteem (factor scores)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) No sex (n=8)</td>
<td>.4553(1.2)</td>
<td>-.2410(.90)</td>
<td>.5057(1.3)</td>
<td>-.0187(1.4)</td>
</tr>
<tr>
<td>(2) Safer sex only (n=19)</td>
<td>-.1145(1.1)</td>
<td>-.4004(.80)</td>
<td>.4860(1.1)</td>
<td>.1234(.81)</td>
</tr>
<tr>
<td>(3) Unsafe sex with regular partner (n=59)</td>
<td>-.0660(.90)</td>
<td>.3977(1.0)*</td>
<td>-.0257(.84)</td>
<td>.1137(.91)</td>
</tr>
<tr>
<td>(4) Unsafe sex with casual partners (n=10)</td>
<td>.3442(.80)</td>
<td>-.3774(.79)</td>
<td>.0074(1.3)</td>
<td>.0352(.34)</td>
</tr>
</tbody>
</table>

* Group 2 had significantly different (higher or lower) scores than groups 1 and 3.

On the minimisation scale analysis, post hoc least significant difference tests indicated that those who had unprotected sexual intercourse with their regular partner minimised the personal risk of HIV, compared with other groups.

Overall, results suggest, self esteem does not appear to be a factor in risky behaviour and that attitudes to HIV working and safer sex do not appear to be associated with sexual risk behaviour but that minimisation is associated with unsafe sexual behaviour with regular partners.

In relation to unsafe sexual practices, hypotheses 4a, b and c are not supported while there is support for hypothesis 4d.
6.2 Relationship between burnout, psychological morbidity and sexual practices

One way analyses of variance were performed in order to determine whether those engaging in unsafe sexual behaviours differed from others in terms of degree of burnout and psychiatric morbidity. Each group's mean scores are presented in tables 29 and 30.

Table 29 One way analysis of variance scores (mean, s.d.) for burnout and sexual practices.

<table>
<thead>
<tr>
<th>Group</th>
<th>EEF</th>
<th>EEI</th>
<th>DeperF</th>
<th>Deperl</th>
<th>PAF</th>
<th>PAI</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) No sex (n=10)</td>
<td>19.4</td>
<td>29.7</td>
<td>5.8</td>
<td>13.7</td>
<td>33.9</td>
<td>36.2</td>
</tr>
<tr>
<td></td>
<td>(7.4)</td>
<td>(13.4)</td>
<td>(4.0)</td>
<td>(10.4)</td>
<td>(7.9)</td>
<td>(11.1)</td>
</tr>
<tr>
<td>(2) Safer sex only (n=26)</td>
<td>22.9</td>
<td>31.8</td>
<td>5.7</td>
<td>9.2</td>
<td>35.8</td>
<td>37.7</td>
</tr>
<tr>
<td></td>
<td>(11.1)</td>
<td>(9.9)</td>
<td>(4.6)</td>
<td>(7.2)</td>
<td>(7.3)</td>
<td>(7.8)</td>
</tr>
<tr>
<td>(3) Unsafe sex with regular partner (n=66)</td>
<td>20.8</td>
<td>28.9</td>
<td>5.8</td>
<td>10.3</td>
<td>34.3</td>
<td>36.6</td>
</tr>
<tr>
<td></td>
<td>(10.1)</td>
<td>(11.3)</td>
<td>(4.2)</td>
<td>(7.7)</td>
<td>(7.6)</td>
<td>(8.3)</td>
</tr>
<tr>
<td>(4) Unsafe sex with casual partner(s) (n=9)</td>
<td>22.1</td>
<td>28.0</td>
<td>4.3</td>
<td>5.4</td>
<td>36.7</td>
<td>36.9</td>
</tr>
<tr>
<td></td>
<td>(12.0)</td>
<td>(9.3)</td>
<td>(2.6)</td>
<td>(3.4)*</td>
<td>(6.1)</td>
<td>(5.9)</td>
</tr>
</tbody>
</table>

Table 30 One way analysis of variance scores (mean, s.d.) for emotional distress and sexual practices.

<table>
<thead>
<tr>
<th>Group</th>
<th>GHQ-12</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) No sex (n=11)</td>
<td>2.3(3.7)</td>
</tr>
<tr>
<td>(2) Safer sex only (n=27)</td>
<td>3.0(3.6)</td>
</tr>
<tr>
<td>(3) Unsafe sex with regular partner (n=67)</td>
<td>2.3(2.9)</td>
</tr>
<tr>
<td>(4) Unsafe sex with casual partners (n=10)</td>
<td>1.8(2.1)</td>
</tr>
</tbody>
</table>

There were no significant differences between the groups in either extent of burnout (F= 0.40 (EEF); 0.52 (EEI); 0.33 (DeperF); 2.0 (Deperl); 0.48 (PAF); 0.14 (PAI),
Hypotheses 5a and 5b which suggested workers with higher levels of burnout and psychiatric morbidity would engage in higher levels of sexual risk taking, are not supported.

As a matter of general interest, participants who engaged in unprotected sexual intercourse with casual partner/s, generally agreed to be the most risky of sexual behaviours, were further examined to determine whether any variables were particularly represented within their group. Table 31 shows the characteristics of this group. Ten of the eleven are health care workers, and nine report a regular relationship as well as casual partners. Only six knew their HIV status and of the nine in regular relationships, four reported their partner's HIV status as positive or untested. Of the seven estimating their risk of contracting HIV, six thought it unlikely.
Table 3.1 Characteristics of participants who reported having engaged in unprotected sexual intercourse with casual partners

<table>
<thead>
<tr>
<th>Group</th>
<th>HIV status</th>
<th>Gender &amp; sexual orientation</th>
<th>In a regular sexual relationship?</th>
<th>Regular Partner’s HIV status</th>
<th>Frequency of UPI with RP in last 3 months</th>
<th>Frequency of UPI with CPs in last 3 months</th>
<th>Risk perception of contracting HIV within 1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCW</td>
<td>Assumed negative</td>
<td>Heterosexual female</td>
<td>yes</td>
<td>Negative</td>
<td>Missing</td>
<td>Without</td>
<td>7</td>
</tr>
<tr>
<td>HCW</td>
<td>Assumed negative</td>
<td>Heterosexual female</td>
<td>yes</td>
<td>Untested</td>
<td>Missing</td>
<td>Without</td>
<td>3</td>
</tr>
<tr>
<td>HCW</td>
<td>Untested</td>
<td>Heterosexual female</td>
<td>yes</td>
<td>Negative</td>
<td>4</td>
<td>Without</td>
<td>1</td>
</tr>
<tr>
<td>HCW</td>
<td>Assumed negative</td>
<td>Heterosexual male</td>
<td>yes</td>
<td>Untested</td>
<td>Missing</td>
<td>Without</td>
<td>4</td>
</tr>
<tr>
<td>HCW</td>
<td>Unknown</td>
<td>Gay male</td>
<td>no</td>
<td>n.a.</td>
<td>Missing</td>
<td>With</td>
<td>9</td>
</tr>
<tr>
<td>HCW</td>
<td>Unknown</td>
<td>Gay male</td>
<td>no</td>
<td>n.a.</td>
<td>0</td>
<td>Without</td>
<td>1</td>
</tr>
<tr>
<td>HCW</td>
<td>Negative</td>
<td>Gay male</td>
<td>yes</td>
<td>Missing</td>
<td>8</td>
<td>Without</td>
<td>2</td>
</tr>
<tr>
<td>HCW</td>
<td>Negative</td>
<td>Gay male</td>
<td>yes</td>
<td>Negative</td>
<td>20</td>
<td>No SI in last encounter</td>
<td>6</td>
</tr>
<tr>
<td>HCW</td>
<td>Negative</td>
<td>Gay male</td>
<td>yes</td>
<td>Positive</td>
<td>22</td>
<td>Without</td>
<td>3</td>
</tr>
<tr>
<td>HCW</td>
<td>Untested</td>
<td>Gay male</td>
<td>yes</td>
<td>Negative</td>
<td>0</td>
<td>With</td>
<td>1</td>
</tr>
<tr>
<td>Vol</td>
<td>Positive</td>
<td>Gay male</td>
<td>yes</td>
<td>Negative</td>
<td>12</td>
<td>Without</td>
<td>2</td>
</tr>
</tbody>
</table>
6.3 Summary of Results

6.3.1 Hypothesis 1  Individuals working within the HIV/AIDS field are less likely to engage in unsafe sexual behaviour for HIV/STD's than the general population.

This hypothesis is not supported. Results are presented in tables 11-16c. Among the 73 participants who reported having casual partners during the last three months, 15% reported USI with a casual partner. These were one fifth of health care workers and 4% of volunteers with such partners. Among the 129 participants who engaged in sexual intercourse with regular partners during the last three months, 59% reported USI. These comprised 61% of health care workers and 52% of volunteers.

In terms of the gay male sample, 44% (16 of 36) engaged in unprotected sexual intercourse with their regular partner and 23% (7 of 30) with casual partners. For heterosexuals, 84% (48 of 57) of women and 88% (7 of 8) of men engaged in unprotected sexual intercourse with their regular partners and 33% (3 of 9) of women and 100% (1 of 1) of men engaged in unprotected sexual intercourse with their casual partners. Overall health care workers and volunteers appear to engage in as much, if not more unprotected sexual intercourse than other samples reported in the literature. Caution is required, however, in interpreting these results due to small numbers comprising each group.

6.3.2 Hypothesis 2a, b, c & d  Given the nature of HIV/AIDS work there will be high levels of (a) burnout and (b) psychiatric morbidity in this group, and those with most direct contact with people with HIV will exhibit higher levels
of (c) burnout and (d) psychiatric morbidity, especially if they have symptomatic disease or mental health problems.

Hypothesis 2a was supported with results presented in table 17. Rates of burnout in this sample are at least as high as those reported in other comparable UK samples.

Hypothesis 2b was partly supported with results presented in table 18. Rates of psychological morbidity were higher than reported for normative UK samples and for British nurses but similar to those found among comparable groups of HIV workers. 34% of participants were classified as probable psychiatric cases on the GHQ-12. These comprised 32% of health care workers and 38% of volunteers.

Hypothesis 2c was also supported with results presented in tables 19 & 20. Significant associations were observed between burnout and level of direct contact with people with HIV and total time having worked in HIV field.

Hypothesis 2d was not supported. Results are presented in tables 21 and 22. No significant associations between psychological morbidity and level of direct contact with people with HIV and total time having worked in the HIV field were found.

6.3.3 Hypothesis 3a & b There will be higher levels of (a) burnout and (b) psychiatric morbidity in professional health care workers than in volunteers.

Hypothesis 3a was generally supported. Results are shown in table 23 & 24. Health care workers obtained significantly higher scores for burnout on both frequency and
intensity of emotional exhaustion and depersonalisation although volunteers scored higher on personal accomplishment sub-scales.

Hypothesis 3b was not supported. Results are reported in table 25. Similar scores on the measure of psychological morbidity were found in both groups.

6.3.4 Hypothesis 4a, b, c, d & e. *Workers (a) with lower self esteem, (b) less positive attitudes to safer sex, (c) who are more immersed in their HIV work (d) who minimise the personal effects of HIV and (e) who are more fatalistic about HIV, will have higher levels of burnout and psychiatric morbidity and will be more likely to engage in unsafe sex.*

Results for hypothesis 4 are presented in tables 26-28.

Hypothesis 4a is partially supported. Significant associations were observed between lower levels of self-esteem and higher levels of burnout (emotional exhaustion) and psychiatric morbidity. This hypothesis is not supported in relation to sexual behaviour as no associations were found between sexual risk taking and self esteem.

Hypothesis 4b is not supported. No significant associations were observed between attitudes to safer sex and burnout, psychiatric morbidity or sexual risk taking.

Hypothesis 4c is partially supported. Significant associations were observed between higher scores on immersion in HIV with higher levels of burnout and psychiatric morbidity but not with sexual risk taking.
Hypothesis 4d is partially supported. No significant associations were observed between minimisation of the personal risk of HIV with burnout or psychiatric morbidity but a significant association was found between the minimisation scale and risky sexual practices within regular relationships.

Hypothesis 4e was not examined due to the poor reliability of the fatalism scale.

6.3.5 Hypothesis 5a & b Workers with higher levels of (a) burnout and (b) psychiatric morbidity will engage in higher levels of sexual risk taking.

Hypothesis 5a & 5b were not supported. Results are reported in tables 29 & 30. No significant differences were observed between higher levels of sexual risk taking and burnout or psychiatric morbidity although minimisation of HIV risk was associated with unprotected sexual intercourse with regular partners.

7.0 DISCUSSION

The proposal that HIV workers would be less likely to engage in sexual behaviour placing them at risk for HIV and other sexually transmitted diseases was based on the assumption that two main factors would operate to make HIV workers more likely than the general population to adopt risk reduction, in relation to their own sexual behaviour. Firstly, they have a very high level of exposure to the morbidity and mortality caused by the virus. Secondly, they work in an environment in which safer sex messages are consistently present and in which they are involved in discussing, informing and advising on avoiding the risk of transmission with their clients.
Contrary to expectation, levels of self-reported unprotected intercourse appear to be as high as those reported among unselected samples of both homosexuals and heterosexuals. Overall, 15% (n=11) of those with casual partners reported unprotected sexual intercourse with such a partner over the previous three months and the proportion was higher among healthcare workers (21%, n=10) than among volunteers (4%, n=1). Among those with a regular partner, 59% (n=76) reported USI with this partner in the last 3 months, again with a higher proportion of health care workers (61%, n=59) than volunteers (52%, n=17).

Among homosexual men, who are at greatest risk for HIV transmission, almost half (n=16) of those with regular partners and almost a quarter (n=7) of those reporting casual partners had engaged in unprotected intercourse with their partners. Among heterosexuals the figures were 84% (n=48) of women and 88% (n=7) of men having unprotected intercourse within their regular relationship and one third of women and the only man within this group, with their casual partners. The results show that among the 44 participants with both regular and casual partners at least five engaged in unprotected intercourse with both partner types, four of whom were gay men. One of these was HIV positive and one had an HIV positive partner. Further comparison of volunteers' and health care workers' unsafe sexual behaviours was intended but the small numbers prevented further analysis.

Approximately one third of the participants had levels of psychological morbidity consistent with psychiatric caseness similar to levels previously reported among comparable groups of HIV workers (Guinan et al 1991; Raphael et al 1990) but higher
than those found in normative samples and among UK nurses (Weich & Lewis, 1998; McGrath, 1989). There were no differences between health care workers and volunteers and levels were unrelated to degree of direct contact or length of time having worked within the HIV field.

There were high rates of burnout in the sample as a whole with about two thirds experiencing moderate or high levels on all three sub-scales of the MBI. Mean scores however are similar to those reported in other comparable groups of HIV health care workers and volunteers in the UK (Catalan et al. 1996; Claxton et al. 1998). Burnout was generally positively associated with level of direct contact with people with HIV and with length of time working. The latter finding is consistent with those of Horstman and McKusick (1986) and Silverman (1993) who showed positive correlations between burnout and longer time employed within HIV. Unlike the other MBI scales, personal accomplishment was negatively associated with level of direct contact, where more contact was associated with higher levels of personal accomplishment. Health care workers had significantly higher levels of emotional exhaustion and depersonalisation although volunteers scored higher on the personal accomplishment dimension. This finding may be a consequence of the limited time volunteers spend volunteering or of their lack of perceived effectiveness within voluntary organisations.

The proportion of volunteers reporting high levels of burnout on the personal accomplishment sub-scale of the MBI were (frequency 66%, intensity 63%) and significantly higher than the rates (frequency 7%, intensity 11%) reported by Claxton.
et al (1998). Given the degree of difference, item coding on the personal accomplishment sub-scale was checked and found to be correct.

HIV health care workers have previously been described to be prone to higher levels of burnout than volunteers (Nesbitt et al. 1996). While the variables associated with burnout were not a focus of this study, possible reasons for high levels of burnout in HIV care staff have been suggested by other authors to include a variety of organisational, interpersonal, managerial and time related issues. A review of burnout in HIV care staff is presented in a special issue of AIDS Care Volume 8, 1996.

Examination of the constructs assessed by the specially designed attitudes to HIV and HIV working scale, showed significant relationships between lower self esteem and greater immersion in HIV with higher emotional exhaustion and psychiatric morbidity. No significant relationships were found between attitudes to safer sex or minimisation of the personal risk of HIV with burnout or psychiatric morbidity suggesting that however distressed or burnt out participants may be, this does not compromise their attitudes about safer sex or sexual risk taking behaviour.

It had been hypothesised that workers with lower self-esteem, less positive attitudes to safer sex, greater immersion in HIV work and greater minimisation of the personal effects of HIV would be more likely to engage in unsafe sexual behaviour. On this issue only one significant association was found, between minimisation of the personal effects of HIV and unsafe sexual behaviour. The finding that self esteem was unrelated to risky sexual practices contrasts with Horn et al's (1989) study, which highlighted an association between higher levels of unsafe sex with lower self esteem.
Participants who had unprotected sexual intercourse with their regular partners were more likely to minimise the personal risk of HIV compared with other groups. This finding makes intuitive sense and may partially explain why higher rates of unprotected sexual intercourse occur within regular relationships. This supports Horn et al’s (1989) finding that participants who denied risks of HIV to themselves were more likely to engage in risky sexual behaviours.

In contrast, no significant associations were found between levels of burnout or psychiatric morbidity and sexual risk taking, suggesting that risky sexual practices occur independently of level of occupational stress or mood disorders. This result contradicts the research by Kelly et al. (1991) and McKusick et al. (1990) who found positive associations between depression and high-risk sexual activity. However, the finding that psychiatric morbidity was unrelated to sexual practices is unsurprising given the contradictory results in the literature on the relationship between mood and sexual behaviour.

A number of methodological limitations to the current research are worthy of mention. The study was of course, limited in terms of the relatively small sample size and in particular the small number of heterosexual male participants, which prevented comparisons of this group with other studies. The overall response rate for the study was 40% which, although within acceptable limits for surveys addressing topics of such a sensitive nature, was low. The response rate gained was comparable to those reported for other studies of sexual behaviour (McKusick et al. 1985; Gruer et al. 1993) but nevertheless caution is required in making generalisations from these results.
to other populations of HIV workers and to more general surveys of sexual behaviour. While it would have been desirable to study the characteristics of non-responders, the anonymous nature of the study combined with the postal design and mode of distribution meant that no information about non-responders was available.

A major drawback to the interpretation of these results concerns a failure to include questions which assess changes in sexual behaviour, particularly whether the reported incidences of risk taking behaviours reflect a change from safe to unsafe behaviour and if so the reasons for this. It is also unclear what an incident of unprotected sexual intercourse actually meant for participants, for example whether this related to penetrative intercourse occurring for a few seconds before a condom was used or whether it meant intercourse to ejaculation.

The method of data collection in this study, namely approaching HIV/AIDS statutory and voluntary organisations to distribute questionnaire to their workers, has been used extensively elsewhere in the literature on AIDS (e.g. Calvert et al. 1991; Clary & Snyder, 1991; Omoto & Crain, 1995; Williams, 1988). However the limitations of this method have also been noted. Respondents were self-selecting, in terms of choosing to divulge highly personal details of their sexual and emotional lives. Results may therefore only reflect the behaviours of those workers who felt sufficiently comfortable to reveal this information or who perceived sexual behaviour within their profession as a cause for concern or perhaps not a cause for concern. Studies of intimate subject areas are, in any case, difficult to conduct and asking HIV workers about their own sexual behaviours, which possibly contrast with the information they provide to their clients and patients may cause greater distress and produce avoidance
in the form of non-response or under-reporting. The need to appear socially acceptable may also produce under-reporting of the true incidence of risky behaviours.

To reduce the possibility of biases due to social desirability and faking good, self-report questionnaires, rather than face to face interviews were used. While questionnaires cannot be expected to reveal the kind of individual and subtle responses that an interview could, the fact that the questionnaires were anonymous and that standardised instruments subjected to reliability analyses were incorporated, adds weight to the value of the results. The fact that MBI and GHQ scores are similar to those found in comparable HIV worker samples in research in which sexual information was not reported supports the likelihood that the current sample is not atypical. Comparable data on the prevalence of risky sexual practices for a three-month time interval were not found and comparisons are therefore made to studies which used a twelve-month time frame. While this is not ideal the figures reported here may reduce problems of recall bias associated with longer time frames. Coxon et al. (1999), in a comparison of self-report questionnaire surveys and qualitative methods of sexual behaviour collection (sexual diary keeping), over a one month period, concluded that answers about sexual behaviour collected via questionnaires are most likely to underestimate the incidence of unsafe sexual practices with retrospective bias being the most significant bias in reporting. Presumably the bias would be greater for a longer time frame. Although the figures reported here are likely to be more accurate than for a longer period, the fact remains that the prevalence of unsafe behaviour in the current sample is as high for a three month period as that reported in other studies over a much longer period. While it cannot be assumed that
the rates of unprotected intercourse would be higher for this sample if they had been asked about the previous 12 months, it is at least certain that they could not be lower than those reported. The similarity in levels of burnout and psychiatric morbidity in this study to those previously reported reduces the potential confounding effects of these variables on the reporting of sexual behaviour.

The most problematic aspect of comparisons with other data sets is the need to use proportions. In this sample the numbers having unsafe sex and denominators were very small in some categories, making percentages unreliable. In addition, because the amount of unsafe sex within each group was small, associations between unsafe sexual behaviour and other variables were examined using data for the whole group. This may provide inaccurate associations as in heterosexual relationships unprotected intercourse may not be viewed as risky behaviour given the relatively low prevalence of HIV in heterosexuals in this country. The exploratory nature of this cross sectional study consequently means analysis is necessarily limited. Multiple correlations make it likely that some of the positive findings may have occurred by chance, making Type 1 errors more likely.

Suggestions for future research

HIV and AIDS continue to infect and affect a broad segment of the population (Worden, 1991). Extensive work has now been conducted on sexual risk taking in a variety of populations although more frequently among gay men, people with HIV, intravenous drug users and to a limited extent heterosexuals. To date research has failed to examine the sexual behaviours of HIV workers and volunteers, the very people who, as a result of constantly being faced with the consequences of HIV
infection, might be expected to have changed and maintained their sexual behaviour in the direction of safer sex.

The present study was designed to investigate the prevalence of sexual risk taking, burnout and psychiatric morbidity. In testing the reliability of these results, future research would benefit from incorporating alternative methods of data collection, such as the use of sexual diaries which could provide useful qualitative data on individual's sexual behaviours over time (Coxon, 1999). Sexual behaviour is a complex phenomenon. Any explanation of high-risk sexual behaviours will be multi-factorial. While this study did not specifically address reasons for the continued practice of unsafe sex in this group, this will undoubtedly involve social, cognitive, environmental, interpersonal and personality variables. It remains unclear whether the prevalence of unsafe sex, detailed in the results, represents a relapse to unsafe sexual practices from previously held safer sex behaviour, or whether it is a reflection of a general inconsistent pattern of condom use. Many studies have reported that consistently maintaining safer sexual practices is difficult (Ekstrand and Coates, 1990; Stall et al. 1990; O'Reilly et al. 1990) with McKuster et al. (1992), describing 50% of their sample (130 out of 252) as "inconsistent maintainers".

Reasons for inconsistent condom use in Australian gay men have been reported by Grant et al (1989) who found the most common justifications for occasional risky sex to be: unprotected anal sex being considered safer if ejaculation did not take place; having made a judgement that their partner was uninfected; infrequent unsafe sex viewed as carrying an acceptable risk and a perception that condoms would "spoil the romance" or cause their partner/s to dislike them. Many also stated that the risk of
unsafe sex was one among many risks associated with everyday life. Horn et al (1989) has also found that some men describe being "tired of always practising safer sex and that they occasionally let themselves be swept away by passion".

A prospective study would allow an examination of workers' sexual behaviour over time and fluctuations in risk taking. A wider range of risky sexual behaviours should be investigated rather than only focussing on unprotected sexual intercourse. The context within which workers' sexual risk taking occurs should also be addressed to extend our understanding of risk taking in this group, for example to see whether it occurs in the context of 'negotiated safety' (Ridge et al. 1996), or in relationships believed to be concordant or discordant for HIV.

Conclusion

Having identified no previous reports examining the sexual behaviour of UK HIV workers or the relationship between sexual risk taking and burnout, psychiatric morbidity and attitudes to HIV, the present study sought to address these gaps in the literature. The results of this study suggest health care workers and volunteers are as likely to engage in high-risk sexual behaviours, which could place themselves and others at risk for the human immunodeficiency virus. Sexual risk taking does not appear to be related to attitudes to HIV or safer sex nor to burnout and psychological distress although minimisation of the personal effects of HIV was related to unsafe sex within regular relationships.

The finding that unprotected sexual behaviour is as prevalent in this group as in the general population supports previous findings that knowledge of the compromising
effects of HIV and its modes of transmission, is insufficient to protect against sexual
risk-taking. Considering the literature on behaviour change, these results should not be
wholly surprising. Research in the area of other health-related behaviours, such as
smoking, drinking and weight loss, has demonstrated that maintaining a new
behaviour is usually much more difficult than its initial adoption and may require very
different intervention strategies (Brownell et al. 1986; Marlatt and Gordon, 1985).
Although our understanding of the issues involved in safer sex maintenance has
improved during the last few years we still have much to learn and new strategies are
needed to encourage the long term and consistent maintenance of these behaviours.

It is of concern that anecdotal reports of workers continuing to engage in sexual risk
taking practices both within and outside of regular relationships and placing
themselves at risk for HIV have been confirmed by this study. While further research
is required to examine the reliability of these results, the implications of these findings
are that HIV workers who are deemed experts in the field of sexual behaviour and
HIV transmission (Holder et al. 1997), do not necessarily adopt safer sex advice
themselves and therefore represent a distinct group for health education which has not
previously been considered. Reaching health care staff is likely to be a difficult
exercise, possibly due to: fear in coming forward for help; perceived stigma from
colleagues for not heeding safer sex advice which they give to their clients or to
shame about being unable (or unwilling) to engage in safer behaviours. While the
factors influencing unsafe sexual behaviour in HIV workers are inevitably complex,
emphasis must now be placed on discovering which variables are most important and
susceptible to change if unsafe sexual behaviours in this group are to be reduced and
new cases of HIV are to be prevented.
References


Health Education Authority. (1990). *Young Adults' Health and Life Style.* Health Education Authority.


**XI International Conference on HIV and AIDS** (Vancouver, July 1996).


Terence Higgins Trust.


At St. George’s Hospital we are conducting a study to assess women’s views about breastfeeding.

All your answers are completely anonymous - we do not ask for your name or any other identifying information. Participation is entirely voluntary.

If you would like any more information about this study, please do not hesitate to contact the receptionist who gave you this questionnaire or John Church, the main researcher, who can be contacted on the above telephone number.

Thank you for helping us with our study.
Breastfeeding Questionnaire

This is a study looking at women's views about breastfeeding. We would be very grateful if you would help us by answering these brief questions. The survey is totally anonymous, we do not ask for your name or any other identifying information. Your participation is entirely voluntary.

QUESTIONS ABOUT BREASTFEEDING:
Please answer these questions by ticking Yes or No to the following questions.

1. If you had a baby would you want to breastfeed him/her?  Yes □ No □ Maybe □

2. Would you ever breastfeed someone else's baby? Yes □ No □ Maybe □

   If Yes or Maybe, please tell us under what circumstances you might breastfeed another woman's baby? ........................................................................................

3. HAVE you ever breastfed someone else's baby? Yes □ No □ (If Yes, please answer questions 3b & 3c below)

   Who did this/these baby/ies belong to? A friend □ A relative □
   A nanny □ Other □

   Please tell us the circumstances related to your breastfeeding this woman's baby?

................................................................................................................................................

. Has another woman EVER breastfed your baby/ies? Yes □ No □ I have no children

   If Yes, what relationship was this person to you? A friend □ A relative □
   Nanny □ Other □

   Please tell us the circumstances under which this person breastfed your baby

................................................................................................................................................

. WOULD YOU EVER let another woman breastfeed a baby of yours? Yes □ No □ Maybe □

   (If Yes or Maybe please answer 5b and 5c below)

   If Yes or Maybe, please tell us under what circumstances you might allow another woman to breastfeed your baby? ................................................................................................................

   Do you believe the circumstances you listed in question 5b above could occur in England/UK? Yes □ No □ Maybe □

   Do you know any woman who lets other women breastfeed her baby? Yes □ No □
Please tell us how true you believe the following statements are: Please tick or circle the number to indicate how you would answer: you most agree with:

A woman who has Sickle-cell can pass sickle-cell on to her baby by breastfeeding.

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A woman who has Diabetes can pass diabetes on to her baby by breastfeeding.

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A woman who has HIV (the virus that can cause AIDS) can pass this virus on to her baby by breastfeeding.

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A woman who has Cancer can pass cancer on to her baby by breastfeeding.

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BACKGROUND INFORMATION - PLEASE TELL US:-

1) Your Ethnic origin: (please tick one box) Black-African YES □ Black-Caribbean YES □ Asian YES □ White (UK) YES □ Other YES □ Other (please state) ..................

2) Your Country of Birth ..................

3) Your Age: ................ years

4) Your level of education/qualifications to date? (please tick one box)
   No qualifications □ CSE/O’level/GCSE □ A’Level □ Degree □

5) Do you work? Yes □ No □ If yes is this: Full time? □ or Part Time? □

6) How would you describe your HIV status?
   I don’t know, I have never been told □ I don’t know I have never been tested □
   I have been told I am HIV negative □ I have been told I am HIV positive □

THANKYOU FOR YOUR HELP
Please place this questionnaire in the survey box provided
Dear Volunteer

At St George's we are conducting a research study of volunteers and health care workers who work with people affected by HIV. We are particularly interested in how long you have been working in HIV services, your general health and about your sexual behaviour.

This is the first research of this type in the U.K. and we would be grateful if you would help us with our study, by completing the attached questionnaire.

Your answers are completely anonymous. We do not ask for your name, or place of work, in the hope that this will enable you to answer the questions as fully as possible. Of course, your participation is entirely voluntary.

To obtain as wide a sample of responses as possible this questionnaire is being sent to volunteers, doctors, nurses, health advisers working in a wide variety of HIV services.

If any of the questions concern you or if you would like any other information about the study please call me, John Church, in strictest confidence on 0181 725 3397/3617 at the Courtyard Clinic.

If you are able to distribute any more questionnaires to your fellow workers please telephone us and we will arrange for more to be sent to you.

We have attached a prepaid envelope for your completed questionnaire.

Once again thank you for helping us with this study.
SURVEY OF VOLUNTEERS WORKING WITH PEOPLE WITH HIV

As a volunteer working in HIV services we would be grateful if you would complete this questionnaire. Your answers are entirely anonymous and will be treated in strictest confidence. Please return this form in the prepaid envelope provided.

BACKGROUND INFORMATION - PLEASE TELL US YOUR:

(1) Sex: Male □ Female □

(2) Age: 16-24 □ 25-40 □ 41-54 □ 55-64 □ 65+ □

(3) Sexuality: Lesbian □ Gay (Homosexual) □ Straight (Heterosexual) □ Bisexual □

(4) Ethnic origin:
- Black-African YES □
- Black-Caribbean YES □
- Asian YES □
- White (UK) YES □
- Other YES □
- Other (please say) ..............................................

(5) Please tell us your level of education? (tick one box only)
- Secondary School - No qualifications □
- Secondary School - CSE/GCSE/GCE □
- A'Level □
- HNC/HND or vocational qualification □
- University/Polytechnic Degree □
- Post-Graduate Qualification □

Please tell us the nearest large town or city to where you live ..............................................

SECTION 2 - ABOUT YOUR VOLUNTARY WORK:

(6) Your current volunteering title? .................................................................

(7) Length of time volunteering in this post? ........... years ........... months

(8) Do you volunteer: - Full time □ or Part Time □
   (If part time, how many hours do you generally volunteer each week ........... hrs

(9) Have you previously volunteered or worked in the HIV field? Yes □ No □

(10) In total, how long have you volunteered/worked with people affected by HIV? Less than 1 year □ 1-2 years □ 3-5 years □ 6-9 years □ 10+ years □

Please answer question 11 by using the scale at the bottom of this page.

(11) What percentage of your current volunteering is spent in direct contact with: -

(11a) People with HIV?
   Answer = Number ......................

(11b) People with HIV who are unwell / physically symptomatic?
   Answer = Number ......................

(11c) People with HIV/AIDS who have mental health problems?
   Answer = Number ......................

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<td>Less than 25% of the time</td>
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<td>25-50% of the time</td>
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<td>About 50% of the time</td>
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<td>50-75% of the time</td>
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<td>Most of the time</td>
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(12) When you are not volunteering, in your social time, how often do you socialise with people who have HIV (as far as you are aware)?

- never □ - rarely □ - sometimes □ - often □ - always □

(13) If you do socialise with people who have HIV are these individuals:

- Friends Yes □
- Relatives Yes □
- Other volunteers Yes □
- Clients/patients Yes □
- Other Acquaintances Yes □
- Your sexual Partner/s Yes □
- Other/s (please comment) ....................................................................................

SECTION 3 - ABOUT YOUR SEXUAL BEHAVIOUR:

(14) In the last year have you had sexual intercourse (anal or vaginal penetrative sex) with:

- Men Yes □ No □
- Women Yes □ No □

(15) Do you currently have a regular partner? Yes □ No □
(If NO, please go to question 25)

ABOUT YOUR REGULAR PARTNER:

- By 'regular partner' we mean someone you have been with for at least one month, whom you have had sex with on more than one occasion and to whom you have some sexual commitment.

(16) What sex/gender is your regular sexual partner? Male □ Female □
(17) How long have you been with your regular partner? ....... Years ....... Months
(18) Have you ever asked your regular partner their HIV status? Yes □ No □
(19) What is your regular partner's HIV status?

- Unknown □ - Untested □ - Positive □ - Negative □
(19b) If negative when was he/she last tested? ............................................
(20) Are you married? Yes □ No □

- If you are a woman who has sex with other women please go to question 25.

(21) How many times altogether have you had sexual intercourse (penetrative sex - anal or vaginal), with your regular partner during:

- the last week? ........ times (b) the last month? ........ times (c) the last 3 months? ........ times

(22) How many times altogether have you had sexual intercourse (penetrative sex - either anal or vaginal), with your regular partner without using a condom during:

- the last week? ........ times (b) the last month? ........ times (c) the last 3 months? ........ times

(23) If you have ever had unprotected sexual intercourse in this relationship please tell us:

- How soon after entering the relationship you engaged in unprotected sex

- ......... years ......... months

- Your reasons for not using condoms? ....................................................................................
(24) How important to you is having safer sex (sexual intercourse while using a condom) to avoid the transmission of HIV with your regular partner? (tick one only)

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ABOUT YOUR CASUAL PARTNER/S:

(25) Have you had sexual intercourse with a casual partner(s) in the last year?

Yes ☐ No ☐ If no, please go straight to question 35.

- Women who have casual sex with women please now go to question 32.

(26) Please tell us how many different casual partners you have had sexual intercourse with (anal or vaginal penetrative sex) during the:

(a) last week? .................. partners
(b) last month? ................ partners
(c) last 3 months? ............... partners
(d) last 6 months? .............. partners

(27) How many times altogether have you had sexual intercourse (anal or vaginal penetrative sex) with your casual partner/s during the:

(a) last week? .................. times
(b) last month? ................ times
(c) last 3 months? ............... times
(d) last 6 months? .............. times

(28) How many times altogether have you had sexual intercourse (anal or vaginal sex) with your casual partner/s without using a condom during the:

(a) last week? .................. times
(b) last month? ................ times
(c) last 3 months? ............... times
(d) last 6 months? .............. times

(29) How important to you is using a condom to avoid the transmission of HIV infection when you have sexual intercourse with your casual partner/s?

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(30) Did you have sexual intercourse with your last casual partner? Yes ☐ No ☐

(31) If Yes, was this sexual intercourse with or without a condom?

With a Condom ☐ Without a Condom ☐

(32) How often do you ask your casual sexual partner/s their HIV status?

Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always ☐

(33) How often do you definitely know the HIV status of your casual partner/s?

Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always ☐

(34) Did you know the HIV status of the last casual partner you had sex with?

Yes ☐ No ☐ If Yes please comment..........

...........................................
Oral Sex:

(35) Do you engage in receptive oral sex with a man/men (insertion of a penis into your mouth)?
   Yes □ No □ If No. go to question 40.

(36) Have you had receptive oral sex in the last six months? Yes □ No □

(37) Have you ever used condoms for oral sex? Yes □ No □
   If yes, please tell us on what occasions you might use condoms for oral sex and why?

(38) Generally speaking, do you let your partner ejaculate into your mouth?
   never □ rarely □ sometimes □ often □ always □

(39) Generally speaking how often do you insist on your partner putting a condom on before he inserts his penis into your mouth?
   never □ rarely □ sometimes □ often □ always □

(40) Have reports about the effectiveness of new anti-HIV medications influenced your sexual behaviour? Yes □ No □ (If Yes please comment on this)

(41a) Please describe your own HIV status?
   Unknown, assumed negative □ Unknown, assumed positive □
   Unknown (no assumption) □ HIV Positive □ HIV Negative □

(41b) If you are HIV positive, in which year were you diagnosed? ____________

(42) Do you know of any HIV health care worker or volunteer who has contracted HIV while working/volunteering in the HIV field? Yes □ If yes how many ..... No □

(43) Using the scale below, please estimate the probability of someone of your age, sex and sexual orientation contracting HIV in the next year through their sexual behaviour if he/she was:

   (a) chosen at random from the general population? Answer = Number..........  
   (b) a volunteer not working in HIV? Answer = Number..........  
   (c) a volunteer working in HIV? Answer = Number..........  
   (d) If you are currently HIV negative/untested, please estimate the probability of you contracting HIV in the next year through sexual activity Answer = Number..........  

<table>
<thead>
<tr>
<th></th>
<th>1</th>
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</thead>
<tbody>
<tr>
<td>Totally Unlikely</td>
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<tr>
<td>Slightly Unlikely</td>
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<tr>
<td>No Opinion</td>
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<td>Quite Likely</td>
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<tr>
<td>Extremely Likely</td>
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</tbody>
</table>
Only women who have sex with women should complete this section. All others please go to question 47.

(44a) Do you engage in penetrative sexual acts using sex toys/dildo’s with your sexual partner/s?  
Yes □ No □  If Yes please answer (b) & (c).

(b) If yes, do you share sex toys with your sexual partner/s?  
Yes □ No □

(c) If you share sex toys do you take precautions (for example: wash them or use a barrier such as condoms with them, before sharing them with:

- Your regular sexual partner?
  never □ rarely □ sometimes □ often □ always □  Not in a relationship □

- Your casual sexual partners?
  never □ rarely □ sometimes □ often □ always □  No casual partner/s □

(45a) Do you perform oral sex (your mouth/tongue to your partner’s genitais) with your sexual partner?  
Yes □ No □

(b) If yes, do use dental dams/other barrier protection for oral sex?  
never □ rarely □ sometimes □ often □ always □

(46) Do you take extra precautions if your sexual partner is menstruating?  
never □ rarely □ sometimes □ often □ always □

(46) How important to you is taking precautions during sex with your female partner/s to avoid the transmission of HIV infection?

<table>
<thead>
<tr>
<th>Not at all Important</th>
<th>A Little Important</th>
<th>Moderately Important</th>
<th>Very Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

EVERYONE TO COMPLETE THIS QUESTION

(47) Please rate how much you agree with the following statements (please circle one number 1-5 for each statement)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Totally Disagree</th>
<th>Totally Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I switch off to HIV when I leave my voluntary work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I try not to discuss my HIV voluntary work at home</td>
<td></td>
<td></td>
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<tr>
<td>I believe the future is out of my control</td>
<td></td>
<td></td>
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<tr>
<td>I am a shy person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV is not personally relevant to me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have seen many deaths from HIV/AIDS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would like to stop my HIV voluntary work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am an anxious / nervous person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am a confident person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a low self esteem</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please rate how much you agree with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Totally Agree</th>
<th>Totally Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel totally surrounded by HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detaching myself from my volunteering is difficult</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel nervous talking about safer sex before sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV does not pose a personal threat to me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I always engage in safer sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engaging in safer sex is difficult for me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contracting HIV is out of my control</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thinking about safer sex reduces my sexual enjoyment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV is not an issue for me in my private life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I worry about contracting HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I talk about safer sex my sexual partner/s would wonder if I have HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol / drugs affect my sexual risk taking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slip-up’s (unsafe sex) during sex happen sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I am not at risk for contracting HIV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I find talking about safer sex difficult</td>
<td></td>
<td></td>
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<tr>
<td>I dislike using condoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My partner/s dislike condoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>During sex I am less rational about using condoms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>During sex I think to myself “I am taking a risk”</td>
<td></td>
<td></td>
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<tr>
<td>I try not to think about HIV when having sex</td>
<td></td>
<td></td>
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<tr>
<td>HIV affects my whole life</td>
<td></td>
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</tr>
</tbody>
</table>

(49) The effectiveness of anti-HIV treatments have made me less concerned about using condoms during sex

Yes ☐ No ☐

(48) During the past year I have suffered a sexual assault

Yes ☐ No ☐

(50) As a child I received sexual advances from an adult

Yes ☐ No ☐
**The General Health Questionnaire**

We should like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions. Thank you very much for your co-operation.

<table>
<thead>
<tr>
<th>HAVE YOU RECENTLY:</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Less than usual</th>
<th>Much less than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 been able to concentrate</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>on whatever you're doing?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2 lost much sleep over</td>
<td></td>
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<tr>
<td>worry?</td>
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<tr>
<td>3 felt that you are playing</td>
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<td></td>
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<tr>
<td>a useful part in things?</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>4 felt capable of making</td>
<td></td>
<td></td>
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<tr>
<td>decisions about things?</td>
<td></td>
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<tr>
<td>5 felt constantly</td>
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<tr>
<td>under strain?</td>
<td></td>
<td></td>
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<tr>
<td>6 felt you couldn't</td>
<td></td>
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<tr>
<td>overcome your difficulties?</td>
<td></td>
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<tr>
<td>7 been able to enjoy</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>your normal day-to-day</td>
<td></td>
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<tr>
<td>activities?</td>
<td></td>
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<tr>
<td>8 been able to face up to your</td>
<td></td>
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<tr>
<td>problems?</td>
<td></td>
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<tr>
<td>9 been feeling unhappy and</td>
<td></td>
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<tr>
<td>depressed?</td>
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<tr>
<td>10 been losing confidence</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>in yourself?</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>11 been thinking of yourself as</td>
<td></td>
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<tr>
<td>a worthless person?</td>
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<tr>
<td>12 been feeling reasonably</td>
<td></td>
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<tr>
<td>happy, all things considered?</td>
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</tbody>
</table>

Thank you very much for your co-operation.
Please read the following statements carefully and circle the number that best represents the FREQUENCY and INTENSITY of your experience of them.

1. I feel emotionally drained from my volunteering.

<table>
<thead>
<tr>
<th>HOW OFTEN:</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>A few times a month</td>
<td>Once a month</td>
<td>A few times a week</td>
<td>Once a week</td>
<td>A few times a day</td>
<td>Every day</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HOW STRONG:</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>very mild</td>
<td>barely noticeable</td>
<td>moderate</td>
<td>Major</td>
<td>very strong</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. I feel used up at the end of the voluntary day.

<table>
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<tr>
<th>HOW OFTEN:</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>A few times a month</td>
<td>Once a month</td>
<td>A few times a week</td>
<td>Once a week</td>
<td>A few times a day</td>
<td>Every day</td>
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</table>

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<td>moderate</td>
<td>Major</td>
<td>very strong</td>
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</tr>
</tbody>
</table>

3. I feel fatigued when I get up in the morning.

<table>
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<tr>
<th>HOW OFTEN:</th>
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<td>Major</td>
<td>very strong</td>
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</table>

4. I can easily understand how my clients feel about things.

<table>
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<tr>
<th>HOW OFTEN:</th>
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<td>very strong</td>
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</table>

5. I feel I treat some clients as if they were impersonal objects.

<table>
<thead>
<tr>
<th>HOW OFTEN:</th>
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<th>3</th>
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<td>Major</td>
<td>very strong</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6. Working with people all day is really a strain for me.

<table>
<thead>
<tr>
<th>HOW OFTEN:</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>A few</td>
<td>Once a</td>
<td>A few</td>
<td>Every</td>
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<td>Once a</td>
<td>A few</td>
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</tr>
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</table>

| HOW STRONG: | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--------------|----------------|----------------|----------------|----------------|----------------|----------------|----------------|
| Never        | very mild      | barely         | noticeable     | moderate       | major          | very           | strong         |

7. I deal very effectively with the problems of my clients.

<table>
<thead>
<tr>
<th>HOW OFTEN:</th>
<th>0</th>
<th>1</th>
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<tbody>
<tr>
<td>Never</td>
<td>A few</td>
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| HOW STRONG: | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--------------|----------------|----------------|----------------|----------------|----------------|----------------|----------------|
| Never        | very mild      | barely         | noticeable     | moderate       | major          | very           | strong         |

8. I feel burned out from my voluntary work.

<table>
<thead>
<tr>
<th>HOW OFTEN:</th>
<th>0</th>
<th>1</th>
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<th>3</th>
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<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>A few</td>
<td>Once a</td>
<td>A few</td>
<td>Every</td>
<td>A few</td>
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<td>times a</td>
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</table>

| HOW STRONG: | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|--------------|----------------|----------------|----------------|----------------|----------------|----------------|----------------|
| Never        | very mild      | barely         | noticeable     | moderate       | major          | very           | strong         |

9. I feel I'm positively influencing other people's lives through my voluntary work.

<table>
<thead>
<tr>
<th>HOW OFTEN:</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>A few</td>
<td>Once a</td>
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<td>Every</td>
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| Never        | very mild      | barely         | noticeable     | moderate       | major          | very           | strong         |

10. I've become more callous toward people since I took the voluntary post.

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11. I worry that this voluntary work is hardening me emotionally.

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12. I feel very energetic.

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13. I feel frustrated by my voluntary work.

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14. I feel I’m working too hard on my volunteering.

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15. I don’t really care what happens to some clients.

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16. Working with people directly puts too much stress on me.

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17. I can easily create a relaxed atmosphere with my clients.

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Thank you very much for completing this questionnaire.<br>Please return in the envelope provided.
THE PSYCHO-SOCIAL CONSEQUENCES OF MEDICAL ACCIDENTS:
AN EXPLORATORY STUDY

SUBMITTED FOR THE DEGREE of M.Sc. in CLINICAL PSYCHOLOGY

BY:

JOHN ANTHONY CHURCH

UNIVERSITY COLLEGE LONDON
SEPTEMBER 1993
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>LIST OF TABLES</th>
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<tbody>
<tr>
<td>LIST OF GRAPHS</td>
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<td>Hospital Anxiety and Depression Questionnaire</td>
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<td>Assessment of Subjective Distress</td>
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<td>Impact of Event Scale</td>
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### RESULTS

#### SECTION 1 - SAMPLE CHARACTERISTICS
- Respondents
- In-patient stay

#### SECTION 2 - INJURIES, PHYSICAL EFFECTS, PAIN AND COSTS

**PAIN**

**COSTS OF INJURY**
- Initial effects on occupational and social functioning
- Long term effects

#### SECTION 3 - EMOTIONAL REACTIONS AND PSYCHOLOGICAL DISTRESS
- Reactions to the incident
- Effects on mental and physical functioning
- View of self
- Long term emotional response
- Bottling up feelings
- Anxiety and Depression
- Impact of Event Scale
- Coming to terms with the trauma
- Suicidal ideation

#### SECTION 4 - SOCIAL SUPPORT
- At time of incident
- Long term support and communication
- Support from legal proceedings

#### SECTION 5 - CHANGES IN RELATIONSHIPS WITH MEDICAL PROFESSION
- Patients perceptions of medical staff reactions
- Attitudinal Changes
- Avoidance
- Views on treatment received
- Explanations

#### ATTRIBUTIONS
- Risk
- Blame
SECTION 6 - VARIABLES CORRELATED WITH PSYCHOLOGICAL DISTRESS 61

I. DEMOGRAPHICS 61

II. PAIN 62

III. SOCIAL AND OCCUPATIONAL EFFECTS 62

IV. SOCIAL SUPPORT 63

V. ATTRIBUTIONS 65

VI. CHANGES TOWARDS THE MEDICAL PROFESSION 66

MULTIPLE REGRESSION ANALYSES 67

DISCUSSION 69

Level of psychological disturbance 69
Anxiety and depression 70
Interactions between anxiety and physical injury 71

PAIN 71

Predicting psychological distress 73
Relationship between blame and depression 74
Subjective distress 75
Relationship between other variables and distress 77

SOCIAL FUNCTIONING 77

SOCIAL SUPPORT 78

Who supports patients? 78
Professional support 79
Implications for informal carers 79

DOCTOR / PATIENT RELATIONSHIP 80

COMPENSATION 81

GENERALISATION TO OTHER ACCIDENT GROUPS 81

METHODOLOGICAL ASPECTS / GENERAL LIMITATIONS 81

Sample issues 81
Alternative interpretations of results 83
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>IMPLICATIONS FOR CLINICAL INTERVENTION</td>
<td>84</td>
</tr>
<tr>
<td>Mediating psychological distress</td>
<td>84</td>
</tr>
<tr>
<td>Patients complaints about their post incident treatment?</td>
<td>86</td>
</tr>
<tr>
<td>Why should doctors change their behaviour?</td>
<td>86</td>
</tr>
<tr>
<td>What forms can clinical interventions take?</td>
<td>88</td>
</tr>
<tr>
<td>What specific issues can clinical interventions address?</td>
<td>88</td>
</tr>
<tr>
<td>CONCLUSION</td>
<td>90</td>
</tr>
<tr>
<td>THE FUTURE</td>
<td>91</td>
</tr>
<tr>
<td>BIBLIOGRAPHY</td>
<td>94</td>
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<td>Correlations between time since incident and distress</td>
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</tr>
<tr>
<td>3</td>
<td>Initial emotional distress</td>
<td>43</td>
</tr>
<tr>
<td>4</td>
<td>Effects on physical and mental health</td>
<td>45</td>
</tr>
<tr>
<td>5</td>
<td>Effects on respondents’ self perception</td>
<td>46</td>
</tr>
<tr>
<td>6</td>
<td>Long term emotional responses</td>
<td>47</td>
</tr>
<tr>
<td>7</td>
<td>Who respondents would talk to</td>
<td>53</td>
</tr>
<tr>
<td>8</td>
<td>Degree of fear expressed</td>
<td>56</td>
</tr>
<tr>
<td>9</td>
<td>Respondents views on the way they were treated</td>
<td>57</td>
</tr>
<tr>
<td>10</td>
<td>&quot;Has the explanation remained stable over time?&quot;</td>
<td>58</td>
</tr>
</tbody>
</table>
LIST OF APPENDICES

Appendix 1 - Introductory letter

Appendix 2 - Semi-structured questionnaire

Appendix 3 - Hospital Anxiety and Depression Scale

Appendix 4 - Impact of Event Scale

Appendix 5 - Sarason Social Support Questionnaire

Appendix 6 - McGill Pain Questionnaire - Short Form

Appendix 7 - Raw data from reliability analyses
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ABSTRACT

Long term distress experienced by medical trauma patients was assessed for a sample of 29 patients who had experienced one of three types of medical accidents: injury during surgery, failure of diagnosis or medical mistreatment, and who had pursued a course of litigation against those responsible for their health care. Levels of psychological distress reported at 53 months mean time since incident (12-120 months), were considerable. 66% were found to be suffering from a state of anxiety and 45% from depression as measured by the HAD scale. 76% were deemed as either / or both, anxious or depressed overall. Impact of Event Scale scores indicated higher levels of distress than have been reported for serious life events and general accidents. Multiple regression analyses showed that a tendency to bottle up feelings and attributing the cause of the accident to doctor negligence were particularly associated with depression. Time since the incident approached significance and was positively correlated with psychological distress.

The results suggest that both early and ongoing psycho-social interventions might benefit many victims of medical accidents. Suggestions for interventions are forwarded and indications for future research discussed.
THE PSYCHO-SOCIAL CONSEQUENCES OF MEDICAL ACCIDENTS: AN EXPLORATORY STUDY.

INTRODUCTION

Given the assertion that accidental injury is a major cause of disability and distress (Malt 1988), it is surprising that so little attention has been paid to the psychological sequelae of physical trauma. It has been reported, both empirically in the case of general accidents and anecdotally in the case of medical accidents, that accidental trauma can affect all aspects of a person's life (Rapheael, 1988, Hamilton, 1987, Shepherd, 1988). Accidents may lead to pain and disability which, in turn, can affect employment prospects and financial security. Changes in social relationships may occur, as well as psychological distress. Research examining the effects of accidents, indicate that resulting psychological effects may be both severe and prolonged (Malt, 1988; Landsman, 1990).

Despite a paucity of research examining wider effects of medical accidents, it is both relevant and useful to consider literature which examines the psycho-social reactions to other types of accidents. It is recognised, however, that certain features do set trauma of the medical type aside from these other groups. One striking difference, for example, is the fact that medical injuries have been caused by people who have been trying to help the victims and to whom the victims had gone voluntarily. Under such circumstances it could be hypothesised that any psychological reactions which result may be particularly powerful, both for the patients themselves and in terms of continuing relationships with health care professionals.
Psychological consequences of accidents and trauma

The impact of adverse medical events and the speed and extent of the recovery process will be dependent on a considerable number of different factors. Not least will be the extent and level of pain, physical injury and degree of subsequent disability, as well as its effect on the social and occupational functioning of individuals.

Clinical studies have been conducted on people involved in certain types of injury (head injury, burns; Lishman 1978, Malt 1980) and with specific accident situations (usually road traffic accidents, Thorsen, 1975), although these have been concerned primarily with the assessment and treatment of physical injuries. These studies, which typically involve more severely injured patients, indicate that between 20% and 30% of respondents suffer some form of long-term psychological impairment; with anxiety disorders, depression and organic brain syndromes being the most common psychological sequelae. However, as Malt (1988) notes, assessment of the psychological impact, and consequences of accidents, has not been the major focus of study and the assessment of psychological damage has been rudimentary.

In Malt’s (1988) prospective longitudinal study of a random sample of 107 patients, who presented to a hospital accident and emergency department with accidental injuries of varied severity, he found that 17% were judged to have a psychiatric disorder at six months, with 9% continuing to do so (predominantly depression and anxiety) at a two year follow up (meeting ICD 9 and DSM III diagnostic criteria). Somewhat surprisingly only one patient was diagnosed according to DSM III criteria as suffering a post traumatic stress disorder reaction, which was supported by the low Impact of Event Scale scores in his sample. Malt makes the general point that the levels of psychiatric disorder observed in his study are much lower than those reported after major disasters.
Some authors have commented that psychological distress after accidents, (Horowitz (1982)), is comparable to reactions reported in the bereavement literature, while others, in contrast, have reported consistencies between post accident reactions and post traumatic stress disorder (McCaffrey and Fairbank 1985). Commenting on the physical nature of accidents, Bulman and Wortman (1977) state that accidents resulting in physical injury may be perceived as nearly the worst imaginable trauma.

A few papers report studies which have focused specifically on the psychological morbidity associated with accidents. One such study is Shepherd et al's (1990). Shepherd examined 122 patients who had received fractures to the jaw, as a result of an assault or accident. They found that, three months after the incident, 19% were still considered to be at risk of a psychiatric disorder, with 17% remaining depressed at a three month follow up. A problem with Shepherd's study, however, was its lack of detail in relation to the extent of the injuries and the nature of the distress experienced. A further study conducted by Jones and Riley (1987) examined 327 people involved in civil accident litigation. They reported that only a minority of their sample had problems severe enough to warrant a psychological diagnosis, although most had some symptoms of depression, anxiety, irritability and sleep disturbance. Almost half the sample were considered to be pre-occupied with the injury they had suffered.

Landsman et al (1990) examined 137 patients who had gained severe injuries, resulting from road accidents, falls, pedestrian accidents, stabbings and gunshot wounds. Questionnaires were administered sixteen months after the accident. The response rate for this study was extremely poor however, with only 10% agreeing to participate. Nevertheless results showed a high frequency of intrusive images and memories for the event and higher levels of
psychiatric symptomatology than would be expected in the general population. However, the low response rate means that this study cannot provide a reliable assessment of the incidence of psychological disturbance. What is interesting despite methodological misgivings, is the analysis of the factors that predicted high distress in this population. Time since incident and the initial severity of the injury were not predictors of long-term distress. Distress was associated however with problems at work and a poorer family environment. The resultant disability, which could be argued is a more important predictor of long term adjustment was not assessed.

Post Traumatic Stress Disorder

Post traumatic stress disorder (PTSD) is a psychiatric disorder which typically follows an event that is 'outside the range of usual human experience (American Psychiatric Association, 1987). PTSD is characterised by three categories of symptoms: i) repeatedly reliving the traumatic event; ii) avoidance of cues reminding the patient of the event with a numbing of general responsiveness; and iii) increased arousal. These symptoms need to prevail for at least one month after the event. Stressors which are typically reported as aetiological agents in PTSD development include natural disasters, wars, rape and road traffic accidents (Shalev et al 1993).

The prevalence of PTSD associated with medically ill patients generally and medical accident victims specifically, is unknown. DSM III-R does not comment on the potential role of medical conditions or procedures as possible traumatic events even though these may, in some instances, (such as when things go wrong), be associated with sudden onset, feelings of being out of the patients control and a perceived threat to their life. These are all factors
which Green et al (1990) have commented are associated with a predisposition to the development of PTSD.

Despite the extremely low prevalence of PTSD reactions reported by Malt many others have reported much higher prevalences in a variety of disaster populations (Gleser, et al, 1981, Weisaeth, 1985, Rapheal, 1986). These studies generally report between 10% and 35% of subjects fulfilling DSM III criteria for PTSD. Shalev et al (1993) makes the point that there are indications that PTSD does occur in medical populations and more often than has been realised.

Accident literature summary

The above examination of the general accident literature, indicates that victims of accidents suffer a variety of psychological problems. Particularly prevalent are anxiety disorders and depression, along with intrusive and disturbing memories of the accidents. Figures of between 20% and 30% are generally reported as having psychological morbidity worthy of a psychiatric label, and many continue to be distressed for lengthy periods after the initial trauma. Given the similarity in the nature of some medical accidents with the above, for example in terms of the sudden impact and physical trauma (as in the case of injuries sustained during surgery), it could be hypothesised that similar psychological reactions could result. Other medical accidents are more dissimilar, such as delays in diagnoses or mistreatment, where onset may be gradual and any injuries sustained less clearly defined. The prevalence of psychological morbidity which might accompany this group is unknown.
Extreme caution is required in extrapolating from the research cited above to the medical accident population. However it seems plausible, given the amount of evidence of psychological reactions in these other groups, that the medical trauma population may also experience psychological distress, in addition to any physical injury or pathology they sustain.

Medical Accidents
Types
Index Medicus classifies accidents of various types, grouping them under several headings according to whether they occur in the home, at work, in the air, or on the roads. There are also sections on prevention and accident proneness. Surprisingly, however, medical errors and accidents do not merit special classification, but are subsumed within 'malpractice'. This clearly demonstrates the lack of investigation in this field to date.

Prevalence
Little is known about the prevalence of medical accidents in the United Kingdom. Although the protection societies keep information on annual rates of claims and complaints, this is but a fraction of the total number of accidents, as many will not involve negligence nor lead to litigation (Smith, 1988).

The nature of adverse events in medical practice
The Harvard Medical Practice study (Hiatt, et al 1989) recently estimated that 3.7% of the 2.7 million patients admitted to hospitals in New York State in 1984 sustained some kind of injury due to medical intervention, 27.6% of these being due to negligence. The authors
described a number of different types of adverse events, (which were defined as events that lead to measurable disability), the most common of which were drug complications, wound infections, complications during surgery and delayed diagnosis. The degree and duration of disability, over and above the pre-existing illness, was rated by the reviewing physicians. Unfortunately pain, psychological trauma and the effects on family and social life were not directly assessed in this study.

The great majority of adverse events examined by Hiatt et al did not result in serious disability, with more than half rated as having minimal impairment and who recovered completely within one month, and seventy percent rated as having completely recovered within six months. In 9% the resultant disability lasted longer than six months and in addition, a further 13.6% died, at least in part as a result of their injuries, though many were already seriously ill. 6.5% sustained some form of permanent disability. If these findings are applied to the approximately five million admissions per year in British hospitals (DHSS, 1985), this suggests 27,000 deaths and 13,000 cases of permanent disability are due wholly or partly to medical intervention. Little is known about the effects of such adverse events on the patients involved (Vincent 1989), even though there appears to be widespread concern about the litigation that may follow such injuries.

Current Literature
To date only one study has specifically addressed the psycho-social consequences of medical accidents (Vincent et al 1992). In this quantitative investigation, Vincent et al sent out postal questionnaires to 101 medical trauma patients who were contacted via the organisation 'Action for Victims of Medical Accidents' (AVMA). All respondents were surgical patients
who had been injured or severely distressed by their treatment, and who considered that their
treatment had been negligent and were currently involved in litigation against the medical
profession. Vincent's study examined the psycho-social effects of the accident on
respondents' lives as well as specifically examining the adequacy of explanations given pre
and post operatively. Standardised questionnaires were administered, to provide an indication
of the prevalence of psychiatric disorder and adjustment to their injuries. Results showed
considerable effects on patients lives. Scores obtained on the General Health Questionnaire
indicated that 77% of his sample could be suffering from a psychiatric disorder. Psycho-
social adjustment was found to be worse, as measured by the Psychological Adjustment to
Illness Scale, than for patients suffering from serious illnesses. On the issue of explanations
provided by medical personnel, respondents perceived these as extremely unsatisfactory -
lacking in information, unclear, inaccurate and given unsympathetically. Associations were
found between poor explanations and poorer adjustment. There were drawbacks to this
research however, in that this was a purely quantitative postal questionnaire study and several
fundamental variables were omitted as areas of study, such as the influence of social support,
patients attributions and any relationship between time of incident and subsequent distress.

Anecdotal reports suggest that medical accident are often associated with lengthy recovery
periods, if this is the case it would be interesting to examine any variables particularly
associated with long term distress, as well as any which could potentially ameliorate distress
over time.
Social Support

Social support has been suggested as one such variable that may mediate between disaster and long term distress. Smith and Hobbs (1966), expressing an official view of the American Psychiatric Association commented that, psychological distress is not the "private misery of an individual" but is intrinsically tied to the breakdown of natural sources of social support in an individuals life, involving family, job, friendship and religious affiliation. Since this time numerous researchers have forwarded views of psychological maladjustment which emphasise the central role of social support (Antonovsky 1979, Mechanic 1977). The mechanism for this, however, is not straight forward, with other more recent empirical data finding inverse relationships between support and indices of psychological distress (Andrews et al 1978, Henderson et al 1978).

Definitions of social Support abound but it has been loosely defined as "the presence of others, or the resources provided by them, prior to, during and following a stressful event". (Cohen and Wills 1985). The nature, meaning and measurement of social support however continues to be intensely debated. Despite this, claims for the positive effect of support has been reported on a wide variety of outcomes, including physical health, mental well being and social functioning. Many authors now argue that social support is a central psycho-social issue in health research (DiMatteo et al 1981).

Research on social support and health can be divided, roughly, into investigations of the structure (or quantity) of an individuals social network, and studies of the functions (or quality) of the support provided by those social contacts. Although it seems reasonable to suppose that the number of social contacts would be strongly related to functional support, studies that have examined this have found low correlations (from 0.20 to 0.30) between
structural and functional measures (for example, Sarason et al 1983), and consequently put a case for measuring both aspects.

Models of social support

During the 1970's the association between social support and health became increasingly recognised. It has been widely suggested, using a variety of population samples, that it plays an important role in protecting people from the effects of stress, preventing physical and mental disorders, and ameliorating illness and psychiatric symptoms. The results from studies of support and mortality provide evidence for a direct effect of social resources on health. The main effect model postulates that social resources are beneficial irrespective of whether a person is under stress. An alternative model proposes that support is related to health primarily for persons under stress; in other words, social support buffers (or protects) persons from the potentially adverse effects of life stress. Brown and Harris (1978) found evidence for a buffer model of social support in their study of depressive disorders among women. They found that support had no beneficial effect on depressive disorders unless subjects were exposed to high levels of life stress.

Cohen and Wills (1985) have suggested that buffering effects are demonstrated when social support is measured in terms of the perceived availability of social resources that are relevant to the stressful life event experienced. It might therefore play its protective role by attenuating or preventing an event from being appraised as harmful. In addition, support might alleviate the impact of a stress appraisal response (perceiving a life event as threatening) by providing a solution to the problem, or facilitating healthy behaviours. Such propositions implicate feelings of helplessness and loss of self esteem as critical factors in
the process linking social support to stress and illness. In this process social support may act by bolstering self esteem and minimising the sense of helplessness in the face of life stress.

**Measurement of social support**

Numerous scales have been devised which have been purported to measure the construct of social support and its role in health. The question arises, then, of what is the right measuring instrument. Orth-Gomer and Unden (1987) reviewed 16 instruments that were appropriate for the use with the general population. They found that there were two distinct groups of instruments; those that measured quantitative (or structural) aspects of social networks and social interactions, and others that assessed the quality, functions and adequacy of support. They commented that most instruments examined attempted to assess some qualitative aspects of support, including questions on the degree of satisfaction with members of the social network and how the network was perceived to work in times of crisis.

**Social support and the medical accident patient**

It could be postulated that the uncertainties and fears experienced by people who have suffered a medical accident are likely to result in an enhanced need for social support. When faced with a crisis, individuals have needs to be met by their social environment. For example there is often the need to talk about one's experience (Raphael, 1986). It is imperative therefore to have others available who are available and willing to listen, people who are supportive in both practical and emotional ways, and who do not make the person feel worse. In cases of physical illness generally, one can envisage the fundamental role which the medical and paramedical professions would have in supporting such individuals, in particular functioning to reduce their uncertainty and health related anxieties.
In the case of individuals suffering medical traumas, one could argue that such professional support would be even more important in aiding the restoration of their physical and mental functioning and in reducing any health related uncertainties. Ironically, however, because of the nature of these accidents and the effect and consequences that they may have on health care staff, this avenue of support may be denied, either directly, by the medics withdrawing from the patient through fear of litigation or embarrassment, or through fear, avoidance and / or loss of trust by the patients themselves. It is possible to envisage, therefore, that at a time when the need for support is possibly stronger than before, (for example while the patient is contending with coming to terms with what has happened by them, further unexpected medical appointments, fear of corrective surgery, coming to terms with new diagnoses, contending with physical trauma, anxieties about pain and any physical changes, etc), it is withdrawn or subjectively perceived as unavailable.

The potential effects of medical accidents on social relationships are largely unexplored, however it could be assumed, given evidence from the accident literature above, that these may be affected in this population. Thus both functional and structural aspects of support may be influenced. Consequently social support may be a valuable resource and significant variable for patients coping with physical injury, particularly if the consequences of the trauma are long lasting.

Communication

Literature on the effect of support in different populations indicates that communication problems between patients and health care providers is a common area of difficulty (Abrams 1966, Parkes, 1974). Vincent et al also found great dissatisfaction with communication, in
particular in terms of explanations and apologies offered by medical personnel. Papers which have reviewed the relationship between support and people diagnosed with cancer indicate patients particularly appreciate the opportunity to clarify their situation through discussion and supportive interactions with others. A removal of, or reduction in, support received from health professionals may, therefore, be interpreted as evidence of rejection by patients, at a very time when it is particularly important. As the process of coping with a medical trauma unfolds, communication problems and misunderstandings which may develop could potentially result in a difficult unsupportive interpersonal situation between the patient and health care providers.

Ironically, then, the occurrence of medical accidents may result in a reduction in social relationships with health professionals, relationships which may have been one of the strongest potential resources of helping patients cope with their injuries. The social relationships of these patients may not only fail to buffer them against any distress which derive as a result of their injuries, but may have the opposite effect, providing an additional source of distress. This may particularly be apparent if other social relations (for example with intimate partners or friends) are also adversely affected.

**Blame**

Studies of accident victims (Jones and Riley, 1987) have found that many express considerable bitterness about their injuries and often become preoccupied with the fact that another person is to blame for their misfortune. Tennen and Affleck (1990) have recently reviewed the relationship between blaming another for a threatening event and subsequent adaptation. In their examination of 22 studies where participants viewed another person as the cause of their misfortune or accident, 17 demonstrated an association between blaming
others and less successful adaptation. In none of these studies was blaming others associated with more positive adaptation. Across various samples, experiencing different threatening events, blaming others has been associated with poorer physical and emotional well being. Bulman and Wortman (1977) in their influential study of a wide range of victims of accidents which had all resulted in spinal cord injuries and some degree of paralysis, were interested in the relationship between successful coping and the ways in which the causes of the accident were perceived. They reported that victims who blamed others were viewed as poorer copers by the rehabilitation staff and that self blame was associated with better coping.

Tennen and Afflect propose a model in which blame is likely to occur if the outcome is severe and the event or accident is associated with the clear involvement of one person of high authority, especially if they are not well known or well liked. This suggests that an adverse outcome during medical treatment is an occasion where, rightly or wrongly, blame is highly likely to be attached to the doctor involved, especially if there is not a good rapport between doctor and patient. In this model they propose, firstly, that preoccupation with blaming another may interfere with efforts at coping with the trauma and distract them from efforts to solve their problems. Additionally blaming others may challenge cherished and deeply held views which may in itself be threatening, for instance people with serious illnesses may place a great deal of faith in the ability of their doctors to help them; to blame them for failing, is to leave themselves feeling vulnerable and unprotected; and thirdly blaming others may deprive one of the support of other people. To blame the doctor who is treating you, or worse, to blame health professionals generally, may deprive the patient of support and help at the very time when they need it most.
Self versus other blame

There is an increasing awareness of the differential effects associated with the attribution of blame. Abrams and Fineseger (1953), in their study of a largely female sample of cancer patients were interested to understand the attributions they held for why they had developed their illness. They were surprised by the number who believed it was the result of punishment of their own misdeeds. Finesinger and Abrams were of the opinion that those patients who felt guilty and blamed themselves for their misfortune coped least well. The literature on bereavements and abnormal grief reactions somewhat supports this. Parkes for example, notes that individual who have strong tendencies for guilt and self blame are prone to more marked pathological reactions. This seems somewhat contradictory to more recent assertions that self blame may be functional rather than dysfunctional in helping people come to terms with adverse events.

With respect to medical accidents, Vincent et al (1992) found that many patients blame the doctors for their accident and often one doctor in particular. Although the findings for the effect of self or other blame appears inconsistent, one could hypothesise that blaming doctors, combined with the ability to change doctors or hospitals could aid adjustment, as post trauma control is with patients.

One must be very cautious in making any statements of causality in relation to blame leading to increased psychological distress. There is much evidence to suggest, for example, that depression is correlated with a tendency to self blame for negative outcomes (Klein et al 1976). Self blame may therefore be one symptom of depression rather than being an attributional style which leads to psychological distress.
Doctor / Patient Relationship

Once an accident has occurred, remedial medical treatment will be instituted. However it may also be necessary to address the psychological needs of the patients, particularly their need to know exactly what has happened. The general dissatisfaction of patients with their medical consultations during the course of routine treatment is well known (Ley 1989), in particular the lack of a clear explanation and information about their treatment. In cases of medical accidents it could be hypothesised that the lack of a clear, convincing explanation may contribute to increased distress and be a spur to litigation. Action for Victims of Medical Accidents (AVMA) has suggested that many patients turn to litigation primarily because they failed to obtain a clear explanation of what had happened (Simanowitz, A 1985).

Ley (1989) has also discussed the importance of clear doctor / patient communications. He has shown that in general, patients want information about their condition and treatment but many do not feel they are told enough, do not understand what has been said or remember what they have been told. This has also been found in the case of news which may be distressing such as diagnosis of cancer, or information about the dangers and risks of treatment (Kalish and Reynolds, 1976, Ley 1988). Ley posits that speed and ease of recovery from illness may be adversely affected by a lack of information.

Summary

Most psychological work which has examined the effects of accidents and disasters has focused primarily on the symptomatology of post traumatic stress disorder (PTSD). In medical accidents, however, anecdotal reports from medico-legal experts suggest depression, anxiety and chronic pain are far more common outcomes.
Currently the psychological effects associated with medical accidents are relatively unknown, whether for trauma related to injuries received during surgery, through failures of diagnosis or though incorrect treatment being administered. This exploratory study set out to examine the long term distress experienced by this population and to identify factors which may account for any high levels of distress, which are anecdotally reported to persist. Vincents' postal questionnaire study went some way to provide information about psychiatric morbidity in this population, although this was limited by the restrictive nature of it's method of data collection.

This study utilises a semi structured interview format to enable greater detail of medical accident victims' experience to be gained. Given the evidence for the prolonged psychological effects associated with other forms of traumatic events, and the role of potential mediating variables in psycho-social recovery, this study gathered information in the areas of blame, communication, social support, doctor / patient relationship, explanations and effects on social and work lives. It is hoped this research will enable any similarities and differences between trauma of the medical type and other types of trauma to be delineated.

**Aims / Research Questions**

The literature review above highlights the under-researched nature of this area. In particular there is a lack of research examining psychological outcome in this population. Although the paucity of literature means detailed hypotheses cannot justifiably be predicted, a number of interesting research questions are addressed here. The primary focus of this study is, exploratory, with an emphasis on highlighting any long term effects. Potential mediating variables in adjustment are examined. It is hoped this study will prove a forerunner, enabling more specific hypotheses around long term adjustment to be examined in future work.
The exploratory nature of this research resulted in the generation of a wide array of research questions which originated from existing literature and anecdotal reports of the potentially significant variables. The present paper addresses six specific questions. These are:

1. What is the prevalence of psychological distress in this population (as measured by anxiety, depression and subjective stress).

2. What is the relationship between social support and psychological distress?

3. Is intrusion in work and social life associated with distress?

4. Is there a relationship between blame and long term distress?

5. Does this population suffer long term pain?

6. What are the consequences of incurring a medical accident on the relationship between patient's and the medical profession?
METHOD
METHOD

Overview

This paper reports on a cross sectional exploratory study examining the long term effects on twenty nine patients who were involved in a medical trauma. The types of medical accidents involved are: mishaps during surgery, failure of diagnosis and incorrect treatment. All respondents had decided to pursue a course of litigation against the doctors / hospitals involved in their initial treatment. A semi-structured interview format was used to collect basic demographic data and information on variables thought to be potentially significant in the long term adjustment to medical trauma. Standardised questionnaires were incorporated to measure current distress levels.

Respondents

Data was collected on 29 personal injury litigants (sample characteristics are presented in the results), who had recently been, or were currently in the process of litigation against their hospital or physician and who met the following inclusion criteria:

- Had been involved in some personal injury through medical mismanagement, failure to diagnose or injury during surgery.
- Indicated in Vincent’s earlier study they could be re-contacted.
- Were self suers (that is, they were suing the medical profession in their own right, as a result of an incident which happened to them, as opposed to suing on behalf of someone who had died or were cognitively impaired).

Design

A cross sectional design was used.
Procedure - Sample Selection

The sample were a sub-group of respondents who participated in an earlier postal questionnaire study conducted by Vincent et al (1992). This original sample (N=101) was recruited via firms of solicitors specialising in medical negligence. This route of contact and sample collection meant all subjects had recently been involved with, or currently engaged in, litigation through the UK Law Court system.

Vincent's study incorporated a question which elicited whether his respondents would mind participating in further research projects. All potential self-suers who met the inclusion criteria for this study and who stated they did not mind further participation, were sent a letter explaining the nature of the current study (N = 34). At this stage they were given the opportunity to decline their original offer of involvement (see Appendix 1). None of the potential respondents declined participation at this stage.

The initial explanatory letter was followed by a telephone call, (or letter to those non-contactable by telephone), from the author. A time and preferred location for the interview were arranged. The majority of interviews took place within two weeks of the author's initial contact with respondents.

Response Rate

Twenty nine of the thirty four people approached agreed to participate, representing an 85% response rate. The predominant reason given for non participation by the five decliners was a desire not to get distressed by recalling experiences.
Interview Schedule

A semi-structured interview was devised specifically for this study (see Appendix 2). This covered a comprehensive range of variables thought potentially pertinent to long term psychosocial adjustment. The interview schedule was piloted on three patients before its final inclusion, at which stage ambiguous questions were clarified and the most user-friendly presentation and question sequencing determined.

The semi-structured interview gathered information on basic demographic characteristics along with:

- anxiety and depression
- subjective distress
- pain
- initial reactions to the incident
- inpatient experiences
- attributions
- social support
- blame
- communication and explanation
- initial reactions by doctors
- attitudinal and behavioural changes
- compensation
- effects on work, social and recreational lives
- recommendations for future treatment.
Much of the above information was elicited from ratings on likert-type analogue scales. To avoid biases due to 'response set' (Messick and Ross 1962) the direction of some scales was varied such that a negative score was indicated by a score on the left for some of the questions and on the right for others. Open-ended questions enabled more general details to be gained.

Interview Setting

All except two respondents were interviewed in their own homes, despite being given the option of being interviewed in a London hospital. Reasons given for this were: physical discomfort associated with travelling; fear of hospitals; having too far to travel, or because the nature of their difficulties had already resulted in them spending a disproportionate amount of time within the hospital system. Two respondents were interviewed on London hospital sites.

Interview format

Interviews lasted between two and three hours. They began with introductions and an explanation of the aims of the study. Respondents were assured of the confidential nature of the research and because many were currently involved in litigation, they were informed the interview would have no bearing on their court case. They were told the interview would involve open and closed questions and self report questionnaires. Time was allowed for any questions which the above raised.

Before engaging in an open discussion, respondents were asked to complete the standardised mood and social support measures. This format was adopted to avoid introducing any mood
change bias resulting from the personal section of the interview. They were then asked to
give a history of their incident, giving as much detail as possible about their feelings and
experiences.

**Standardised questionnaires**

Standardised questionnaires measuring psychiatric state were incorporated into the study,
selected on the basis of proven reliability and validity.

**Mood Assessment**

1. **Hospital Anxiety and Depression Questionnaire (HAD, Zigmond and Snaith, 1983).**

The HAD was used to measure anxiety and depression (see appendix 3). This scale
comprises 14 items, half representing depressive and half anxiety related phenomenon with
items being intermingled. Each item is given a weighted score of either 0, 1, 2 or 3 where
a weighting of three indicates the presence of high anxiety or depression. Using a template
key, sums are calculated for each of the two sub-scales.

This questionnaire was chosen in preference to others as it has been shown to be a well
designed measure for the examination of medical patient populations. The major advantage
of the HAD over other anxiety and depression self report measures commonly used is its
claim to remain unaffected by physical symptomatology. It has been reported that physically
ill patients who were assessed as not having a mood disorder scored within the same range
as normal samples (Zigmond and Snaith, 1983). The HAD is also very quick and simple to
complete, this was an important qualification for inclusion given the length of the interview. A further advantage is that its reliability and validity have been well documented. It is said to perform well when compared with psychiatric ratings as well as having satisfactory internal consistency. When compared to other rating scales the validity of the HAD has received favourable support (Snaith and Taylor (1985) and Lewis and Wessely (1990)).

The sensitivity of the HAD as a screening device compared with other standardised measures is also well documented. Hamer, Sanjeev, Butterworth and Barczak (1991) found it performed well as a screening instrument when compared with structured clinical interviews in a sample of deliberate self harmers with a threshold score of 8 on the depression sub-scale giving a sensitivity of 88% with a positive predictive value of 80%. Similar results by Barczak, Kane, Conydon, Clay and Betts (1988) found the correlation between the HAD depression scale and the BDI and between the HAD anxiety scale and Clinical Anxiety Scale as satisfactory although correlations reported were better for the depression sub-scale.

Assessment of Subjective Distress


The IES is a 15 item scale which is used to assess current subjective distress for the effects of traumatic events, such as accidents and serious life events (see appendix 4). Particular life events under investigation are added to the top of the scale. The IES has been adopted as a standard screening instrument by researchers investigating the effects of accidents and disasters.
The IES yields two sub-scale scores, intrusion and avoidance. The intrusion subscale measures the extent to which unwanted distressing memories of the traumatic event continue to intrude into a person's mind. The avoidance sub-scale assesses the extent to which people need to avoid reminders of the original event. Ratings are made of such statements as 'I thought about it when I did not mean to' (Intrusion) and 'I tried not to talk about it' (Avoidance).

The IES is scored by giving each item a weighted score of 0, 1, 3 or 5 to the frequency categories. A score or 5 represents a high level of distress. The items are then summed to give a total IES score as well as the two sub-scales. The intrusion sub-scale is gained by adding items 1, 4, 5, 6, 10, 11 and 14) and for the avoidance sub-scale items 2, 3, 7, 8, 9, 12, 13 and 15.

Horowitz, et al (1979) provide information about the scales psychometric properties. The split half reliability was high (r=0.86). Internal consistency of sub-scales using Chronbach's Alpha was also high (intrusion = 0.78, avoidance = 0.82). A separate study by Zilberg, Weiss and Horowitz (1982) reported similar figures. A correlation between the two sub-scales of .42 is reported, a figure low enough to suggest substantial independence of the item sets while also indicating some degree of co-variation. Test-retest reliability is good with 0.87 for the total stress scores, 0.89 for the intrusion and 0.79 for the avoidance sub-scales.
Social Support Assessment


The SSQ is a 27 item self administered questionnaire which has been devised to quantify the availability of, and satisfaction with, social support (see appendix 5). Each question requires a two part answer. Respondents are asked to list people to whom they could turn and on whom they could rely in specified sets of circumstances (availability), to a maximum of nine supports per item, and to rate how satisfied they are with their perceived available support (Satisfaction). Satisfaction levels are rated on six point scales for each question running from very satisfied to very dissatisfied.

For example:

Whose lives do you feel that you are an important part of?

Supports

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>3</td>
<td>6</td>
<td>9</td>
</tr>
</tbody>
</table>

How satisfied?

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

very fairly a little a little fairly very satisfied satisfied satisfied dissatisfied dissatisfied dissatisfied

A support score for each item is derived from the number of support persons listed. The mean of these 27 scores gives an overall support score (SSQN). A satisfaction score (SSQS) is gained by taking the mean of the 27 satisfaction scores.
Psychometric properties have been reported on this scale by Sarason et al (1983). The alpha coefficient of internal reliability was 0.97 for the number scores and 0.94 for the satisfaction scores (N=602). Test-retest correlations of 0.90 for the overall number score and 0.83 for the satisfaction score were obtained from 105 students after a four week interval.

In terms of validity Sarason et al (1983) have reported for both the SSQN and SSQS a strong first factor identified by factor analysis accounting for 82\% of the variance in the numbers score and 72\% in the satisfaction score. Sarason et al concludes that the two scores represent independent dimensions of social support. Criterion validity has been investigated derived from samples of psychology students showing significant negative correlations between the SSQ and a depression scale. McDowell and Newell (1987) in their review of social support measures comment that the SSQ is one of the most adequate research instruments for measuring this construct.

Pain Assessment

4. The McGill Pain Questionnaire - Short Form (Melzack, R. 1987)

The McGill Pain Questionnaire (SF-MPQ) is a self report measure consisting of 15 pain adjectives which assess the sensory and affective aspects of pain (see appendix 6). Each pain descriptor is ranked on an intensity scale of 0 = none, 1 = mild, 2 = moderate, and 3 = severe. The sensory dimension of the pain experience is calculated by summing answers to the first eleven items, and the affective dimension by summing responses to the last four items. The present pain intensity and visual analogue scale from the long form MPQ are also incorporated into the SF-MPQ.
The SF-MPQ has been shown to correlate very highly with the long form MPQ, which itself is described as having good test/retest reliability of 0.76 (Hunter et al 1979) and has been appraised as having acceptable face, construct, discriminant and concurrent validity (Reading, 1983).

Procedure adopted for the results

Answers which required ratings on seven point analogue scales, for example:

"The doctor's are solely to blame for what happened"

Not at all 1 2 3 4 5 6 7 A Great Deal

have been grouped, so that, in the above example, ratings of 1, 2, and 3 are reported as indicative of no or slight blame and ratings of 5, 6 and 7 as indicating, much / a great deal of blame, etc., unless otherwise stated.

Multiple regressions

Multiple regression analyses were performed to determine the extent to which affect (measured by the HAD anxiety and depression scales) and subjective distress (measured by the Impact of Event Scale intrusion and avoidance scales) as dependent variables, were associated with other independent variables. Independent variables included: time since the incident, bottling up feelings, degree to which they had come to terms with incident, pain severity rating, age, fears for future physical health and disfigurement, doctor negligence, degree to which they feared pain and the standardised social support measure.
To reduce the number of variables entered into the analyses three scales were created by grouping variables which were deemed, a priori, to measure the same construct.

The first scale was an overall support scale which consisted of ten social support and communication questions.

These were:-

- How supportive would you rate your family at the time of the incident?
- How supportive would you rate your friends at the time of the incident?
- How important do you feel the initial support was which you received immediately after the incident?
- Having someone to talk to at the time of the incident helped me cope with the incident.
- Having someone to talk to over the months which followed helped me cope with / adjust to the incident.
- Have you received any support from other people who have experienced similar incidents?
- Do you talk about the effect it has had on you?
- Do you talk about the effect the incident has had on your relationship with your partner?
- How satisfied were you with the amount you talked about the incident at the time it occurred?
- How satisfied are you with the amount you talk about the incident now?

Reliability analysis for this scale provided a Cronbach’s alpha of .66.

The second scale consisted of the eleven items pertaining to the doctors initial reactions. These were the degree to which doctors were perceived as sympathetic, understanding,
empathic, citing facts only, degree of denial, embarrassment, degree to which perceived as having given no details, defensive and accepting responsibility. Reliability analysis resulted in a Cronbach's alpha of .83 for this scale.

The third scale, which comprised 14 items, consisted of variables examining initial effects on social and occupational functioning. These were the degree to which their work, seeing friends, going out, sex life, intimate relationship, self esteem, body image, independence, sociability, finances, physical health, mental health, self confidence and alcohol use, had been initially affected. The Cronbach's alpha for this scale was .91.

Overall the reliability of these scales was moderate to good with Cronbach's alpha's of above .65 obtained for all three (Appendix 7 provides details of actual reliability analyses).

These scales were then entered into the regression equation along with the other variables listed above, after checks for co-linearity. Measures of psychological distress were not entered as independent variables to reduce problems of co-linearity and potential circularity in interpreting results.
RESULTS
RESULTS

The results of this study are described in six sections. Section one provides descriptions of the characteristics of the sample; descriptions of injuries sustained, physical effects, pain and costs are presented in section two; section three focuses on the emotional reactions and level of psychological distress, section four presents descriptive data on social support and section five examines changes in the doctor / patient relationship. Section six presents correlational data between psychological distress and other variables along with results from the multiple regression analyses. All results were derived from analyses performed using the SPSSPC statistical package.

SECTION 1 - SAMPLE CHARACTERISTICS

Respondents

Twenty nine personal injury litigants were interviewed. The majority were female (86% N=25). The mean age at time of interview was 45 years (sd 13.89; Range 21-72) of whom 17% were aged 30 or younger, 73% were between 30 and 65 and 10% were over 65. The mean time since the medical incident was 53 months (sd 26.60; range 12-120). Two thirds (65.5%) were currently engaged in legal proceedings. The remainder had either abandoned their litigation or their case had been settled.

In terms of marital status, 65% were married or cohabiting, 14% single and 21% divorced. Overall 76% were in an intimate relationship and therefore had some form of support at home. At the time of the incident 86% of the sample had between one and three dependents.

Education level was rated according to age at which they left school and using this categorisation, 59% left school aged 14 or below, 21% between 14 and 16 and 20% at 18 years or older, having remained in further education.
Two thirds (65%) had been working immediately prior to their incident, which compared with 28% who were currently employed. All commented their unemployed status was the direct result of a deterioration in physical and/or mental health caused by the incident. One patient was currently engaged in psychiatric treatment.

In-patient stay

The mean duration of hospital stay for inpatients (N=22) was 33 days (range 1 - 84 days). This compared with the mean expected stay of 9 days (range 1 - 28 days). When only those patients who remained in hospital longer than initially expected (N=13), the actual mean duration of stay was 49 days (range 7 - 84 days), which compared with their expected mean duration of stay of 11 days (range 2 - 28 days).

SECTION 2 - INJURIES, PHYSICAL EFFECTS, PAIN AND COSTS

Table 1 shows the percentage patients falling into each of the three accident categories.

Table 1

<table>
<thead>
<tr>
<th>TYPES OF MEDICAL NEGLIGENCE</th>
<th>CATEGORY OF INCIDENT</th>
<th>NUMBER (N)</th>
<th>PRIVATE TREATMENT</th>
<th>NHS TREATMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>INJURY DURING SURGERY</td>
<td>62% (N=18)</td>
<td>2</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>FAILURE TO DIAGNOSE</td>
<td>10% (N=3)</td>
<td>-</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>MISTREATMENT</td>
<td>28% (N=8)</td>
<td>1</td>
<td>7</td>
<td></td>
</tr>
</tbody>
</table>
The exact nature of the medical incidents was varied. The 'injury during surgery' category comprised: injuries to organs and nerves, perforations and damage gained through various gynaecological procedures. Within the 'failure to diagnose' category were: misdiagnosis of carcinoma and non detection of fractures and within the 'mistreatment' category were; inappropriate drug treatments and poor childbirth care.

Table 2 provides a list of the areas damaged as a result of the medical incident.

Table 2

<table>
<thead>
<tr>
<th>RESULTANT TRAUMAS / INJURIES SUSTAINED</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>SITE OF INJURY</td>
<td></td>
</tr>
<tr>
<td>GYNAECOLOGICAL PROBLEMS</td>
<td>8</td>
</tr>
<tr>
<td>BILE DUCT SEVERED</td>
<td>1</td>
</tr>
<tr>
<td>TRAUMA'S DURING CHILDBIRTH</td>
<td>3</td>
</tr>
<tr>
<td>EAR AMPUTATION</td>
<td>1</td>
</tr>
<tr>
<td>FAECALLY INCONTINENT</td>
<td>1</td>
</tr>
<tr>
<td>SPINAL INJURY</td>
<td>1</td>
</tr>
<tr>
<td>FRACTURES</td>
<td>6</td>
</tr>
<tr>
<td>DROPPED FOOT</td>
<td>1</td>
</tr>
<tr>
<td>TORN LIGAMENTS (FELL OFF OPERATING TABLE)</td>
<td>1</td>
</tr>
<tr>
<td>FALLOPEAN TUBES REMOVED</td>
<td>1</td>
</tr>
<tr>
<td>COMA</td>
<td>1</td>
</tr>
<tr>
<td>DAMAGE TO BREASTS</td>
<td>2</td>
</tr>
<tr>
<td>DRUG ERRORS</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 3 provides a selection of extracts from patients' descriptions of their incidents.

**Table 3**

<table>
<thead>
<tr>
<th>EXTRACTS FROM PATIENTS' DESCRIPTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>During my ventrosuspension my bowel was stitched in. No action was taken, they told me it was wind. It was 5 days before they operated to investigate.</td>
</tr>
<tr>
<td>Went in for removal of gall bladder stones but they clipped my bile duct. I was in great pain, it turned into a major infection. I went into ITU after going into total kidney failure. I was given a tracheotomy and my chances of survival were 20%.</td>
</tr>
<tr>
<td>I had a major spinal injury, the doctors failed to operate immediately and when they did they performed a very dangerous mobilisation which resulted in paralysis of both legs.</td>
</tr>
<tr>
<td>Went in for a simple hernia operation. After the operation my left leg wouldn't move, my stomach was swollen and numb and I was incontinent. It turns out I fell off the operating table.</td>
</tr>
<tr>
<td>I got pins and needles in my leg after my varicose veins operation. The wrong size elastic stocking was put on for too long and in the wrong place which left me with a dropped foot. I can't walk without a stick now.</td>
</tr>
<tr>
<td>I had a t-tube stitched in, when it was pulled out it ripped my bowel.</td>
</tr>
<tr>
<td>After the operation on my right ovary I was persistently sick and in pain. I had difficulty passing urine for two years. After numerous investigations and being told nothing was wrong they found out I had a blockage in my urethra.</td>
</tr>
<tr>
<td>My ear was amputated after a misdiagnosis of angiosarcoma.</td>
</tr>
<tr>
<td>My urethra was stitched almost closed during a repair to my bladder which was also damaged during a hysterectomy.</td>
</tr>
<tr>
<td>The neck of my femur cracked when I was giving birth. I was not allowed a cesarian even though I had brittle bones.</td>
</tr>
<tr>
<td>After considerable bowel surgery Gentamycin was given and not monitored in any way causing chronic kidney disease and destroying my balance in both ears.</td>
</tr>
<tr>
<td>I went into hospital thinking I was going to have minor surgery. I was not told I was going to major surgery or the true nature of the surgery. After extensive surgery I had severe pain and could not void urine spontaneously for a month.</td>
</tr>
</tbody>
</table>
PAIN

Of the 90% who completed the question asking for their current level of pain only 10% stated they had no pain at the time of the interview. 38% scored 1, 2 and 3 and 42% gave scores of 4, 5 or 6. This confirms anecdotal reports that chronic pain is a long term consequence for a significant number of these patients.

Twenty respondents completed the Short Form McGill Pain Questionnaire. Mean scores for pain intensity gained from the sensory and affective scales are given in Table 4, alongside scores provided by Melzack in his original study of unmedicated surgical patients in the days following their operation. These results show medical accident patients have, after 53 months, higher levels of pain to those of unmedicated patients recovering from surgery.

Table 4

<table>
<thead>
<tr>
<th>RESULTS FROM THE McGill Pain Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>MPQ SENSORY SCALE</td>
</tr>
<tr>
<td>MPQ AFFECTIVE SCALE</td>
</tr>
<tr>
<td>MEAN TIME LAPSED</td>
</tr>
</tbody>
</table>

48% rated their pain as distressing, horrible or excruciating, along with 59% who greatly feared long term pain and two thirds who had a great fear of lasting disfigurement.
COSTS OF INJURY

Initial effects on occupational and social functioning

High levels of negative effect were apparent in all spheres of employment, domestic and social life in the first three months after the incident (see graph 1). It is unclear however whether these effects were the result of the injury per se or hospitalisation in the early period. 79% rated sociability as having been deleteriously affected, along with the amount they left the house and associated with others. In terms of changes in intimate relationships 52% said this had been affected. Severe effects are seen on sexual activities.

Long term effects

In the longer term many avenues of life continue to be adversely affected. At interview financial costs and costs in terms of social relations were more affected than in the initial period. 42% experience continuing effects on their relationship with 64% commenting sexual activities were still affected (See graph 2).

SECTION 3 - EMOTIONAL REACTIONS AND PSYCHOLOGICAL DISTRESS

Reactions to the incident

Initial reactions to the incident were assessed by asking respondents to rate the degree of shock, emotional numbness, disbelief, etc., that they felt (all questions asked are reported in the interview schedule in appendix 2). Graph 3 shows considerable emotional distress was experienced at the time of the original incident. 59% experienced a great sense of shock and 69% extreme worry, with almost half saying they could not believe it was happening to them. 53% commented that in retrospect they felt they had experienced emotional numbing at the time of the incident.
Initial Effects on Social and Occupational Functioning

Graph 1

- Work
- Sociability
- Going Out
- Sex
- Relationship

A Great Deal
None / Mild
Long Term Effects on Social and Occupational Functioning

Graph 2

- Work
- Sociability Going Out
- Sex
- Relationship

- A Great Deal
- None / Mild
Initial Emotional Distress

Emotional Reactions

Graph 3

Disbelief  Numb  Extreme  Worry  Shock
Effects on mental and physical functioning

Graph 4 highlights the short and long term physical and mental effects experienced by respondents. It is apparent that over half continue experiencing effects on their mental health with 65% also reporting lasting physical effects.

View of self

Graph 5 highlights the severity of the traumas' initial and continuing effect on respondents' view of themselves in terms of self esteem, body image, self confidence and independence.

Long term emotional response

Reported long term emotional responses are shown in graph 6. The majority expressed considerable anger, bitterness and sadness. Nearly a third (31%) also expressed owning feelings of retribution. Comments made during interviewing suggest these developed because of their post incident treatment by the medical profession rather than developing naturally as a consequence of the initial incident per se.

Bottling up feelings

Related to mental functioning respondents were asked whether they bottled up their feelings about the incident, and any reasons for this. 45% reported bottling up their feelings often or always. Reasons for why they did this were because; they didn’t want to continue burdening friends and family (35%); a belief that others were fed up hearing about it (20%); preferring to keep it to themselves (31%) and feeling it was a private matter (31%). Only 14% said they believed talking didn’t do any good.
Effects on Physical and Mental Health

Graph 4

Physical

Mental

3 Months

53 Months
Effects on Respondents' Self Perception

Graph

Confidence Body Image Esteem Independence

Initial Effect

Long Term Effect
Long Term Emotional Responses

Graph 6

Bitter
Sadness
Upset
Anger
Revenge

Percent

0 20 40 60 80 100
Anxiety and Depression

The Hospital Anxiety and Depression Scale provides scores for anxiety and depression. The range of scores on the anxiety sub-scale was 3 to 19 with a mean of 10.03 and standard deviation of 4.6. For the depression sub-scale the range was 1 to 19 with a mean of 8.83 and standard deviation of 4.9. Norms (used by Barczak et al, 1988, for example) use a cut off point on the HAD of 7/8 (that is, a score of seven does not count as a 'case', whereas scoring eight is a 'case'). Using this cut-off point, 66 per cent count as 'cases' of anxiety and 45 percent as 'cases' of depression. The number counting as 'cases' of either anxiety or depression, that is the number with a psychological disorder, is 76 per cent. Other author's, however, (for example, Lewis and Wessely, 1990) have argued for more conservative cut off criteria, that is, use of a 10/11 point cut off for 'caseness'. If these criteria are used then 38 per cent of respondents count as 'cases' of anxiety and 41 per cent as 'cases' of depression, with 55 per cent having either or both anxiety and depression (see table 5).

Table 5

<table>
<thead>
<tr>
<th>'CASES' OF ANXIETY AND DEPRESSION DERIVED FROM THE HAD</th>
<th>ANXIETY</th>
<th>DEPRESSION</th>
<th>ANX &amp;/OR DEP</th>
</tr>
</thead>
<tbody>
<tr>
<td>7/8 CUT OFF</td>
<td>66%</td>
<td>45%</td>
<td>76%</td>
</tr>
<tr>
<td>(N = 19)</td>
<td>(N = 13)</td>
<td>(N = 22)</td>
<td></td>
</tr>
<tr>
<td>10/11 CUT OFF</td>
<td>38%</td>
<td>41%</td>
<td>55%</td>
</tr>
<tr>
<td>(N = 11)</td>
<td>(N = 12)</td>
<td>(N = 16)</td>
<td></td>
</tr>
</tbody>
</table>
Impact of Event Scale

Total IES scores along with intrusion and avoidance sub-scale scores are presented in Table 6. These are reported alongside IES figures which have been reported for other accidentally injured samples (mostly road accidents), (Malt, 1988), people suffering serious life events (bereavements and assaults), (Horowitz, 1979) and for victims involved in the Jupiter cruise ship disaster (Joseph et al, 1993). This is presented to enable comparisons between the present sample and other trauma populations. Durations between the incidents and IES completion for the three populations are also reported.

Table 6

<table>
<thead>
<tr>
<th>PSYCHOLOGICAL IMPACT OF ACCIDENTS AS MEASURED BY IES</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEDICAL ACCIDENTS</td>
</tr>
<tr>
<td>INTRUSION</td>
</tr>
<tr>
<td>AVOIDANCE</td>
</tr>
<tr>
<td>TOTAL</td>
</tr>
<tr>
<td>TIME SINCE INCIDENT</td>
</tr>
</tbody>
</table>

Mean Scores (S.D.)
*Higher IES scores indicate greater subjective impact.

There is no categorical cut-off for distress as measured by the IES. However level of distress has been categorised by some authors, (Horowitz, 1982, Malt 1988) using the following criteria: scores of 0-8 considered as low distress, 9-19 as medium distress and 20 or above
as high distress for each sub-scale, and these will be adopted here. Table 7 presents IES results for the three distress levels, alongside figures reported for Malt’s sample.

Table 7

<table>
<thead>
<tr>
<th>PERCENTAGE OF PERSONS AT THREE LEVELS OF DISTRESS ON IES</th>
<th>PERCENTAGE AT 3 LEVELS OF DISTRESS</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERCENTAGE AT 3 LEVELS OF DISTRESS</td>
<td>LOW (0-8)</td>
</tr>
<tr>
<td>MEDICAL ACCIDENTS</td>
<td></td>
</tr>
<tr>
<td>INTRUSION SUB-SCALE</td>
<td>14%</td>
</tr>
<tr>
<td>(N=28)</td>
<td>(N=4)</td>
</tr>
<tr>
<td>AVOIDANCE SUB-SCALE</td>
<td>21%</td>
</tr>
<tr>
<td>(N=28)</td>
<td>(N=6)</td>
</tr>
<tr>
<td>GENERAL ACCIDENTS (MALT)</td>
<td></td>
</tr>
<tr>
<td>INTRUSION SUB-SCALE</td>
<td>85%</td>
</tr>
<tr>
<td>AVOIDANCE SUB-SCALE</td>
<td>65%</td>
</tr>
</tbody>
</table>

The above table highlights a great disparity between the results and Malt’s figures, with the medical sample showing a much higher level of distress. This is particularly striking when one examines the mean time lapsed since incidents between the groups. The medical group completed their IES scale on average at almost twice the length of time post incident as the general accident group.

Coming to terms with the trauma

When respondents were asked whether they had come to terms with what had happened to them, 48% said 'not at all' or 'very slightly'. One third rated themselves as having 'totally' come to terms with their incident.
Suicidal ideation

Unfortunately this aspect of adjustment to the trauma was not formally examined although three respondents mentioned suicidal ideation. The author was also informed that one of the interviewees has since committed suicide.

SECTION 4 - SOCIAL SUPPORT

At time of incident

65% rated their family, and 68% their friends, as having been very supportive in the period following their incident. This early support was perceived for 84% as having been very important.

For 59% having someone to talk to helped them cope, though interestingly a quarter said talking didn’t help them. Talking helped 79% cope in the following months. In terms of satisfaction with levels of communication a third were moderately to very satisfied initially and 41% had been very dissatisfied.

Support from the medical profession was largely lacking. 62% did not receive a follow up appointment to discuss their situation and the vast majority (90%) did not talk at all, or very little, to the doctors about what had happened. 80% did not receive any form of professional help but the 20% who did, indicated it had been very helpful. 48% expressed (retrospectively), their need for professional help in the initial stages.
Long term support and communication

Half of the sample never or rarely currently talk about their incident. Only 10% continue talking a great deal. Not talking is not, however, necessarily a negative reaction, and they were therefore asked about satisfaction with the amount they currently talk. 72% said they were very satisfied.

Support from legal proceedings

Some elements of the litigation process were viewed as emotionally supportive. 65%, for example, found reading expert reports proved a positive experience and 72% found talking to medical experts beneficial. This may possibly have been because talking to medics was usually an area largely restricted through the instigation of legal proceedings or through their high levels of fearfulness and avoidance. Talking to independent experts as part of the legal process, might therefore have helped them express and validate their feelings.

Graph 7 shows who respondents would currently turn to for support. This highlights ‘female friends’ as the single largest category to whom respondents would turn, possibly reflecting the predominantly female sample. Spouses / partners are seen as the most likely support for 31%, even though 76% were in an intimate relationship. Other family members were rated by 7% as the first port of call for support and 3.4% stated professional helpers as people who they would turn to if they felt like talking. 3.4% did not have anyone to turn to for support.
Who respondent’s would talk to

- Female Friend: 51.7%
- Spouse: 31.0%
- No one to turn to: 3.4%
- Male Friend: 3.4%
- Family: 6.9%
- Psychologist: 3.4%

Graph 7
SECTION 5 - CHANGES IN RELATIONSHIPS WITH MEDICAL PROFESSION

Patients perceptions of medical staff reactions

Views on doctor's reactions revealed 58% stated they were not at all sympathetic, (only 7% rating their physicians as 'extremely sympathetic'). In terms of empathy, for 83% doctor's were viewed as not at all empathic and in terms of their being perceived as understanding to their plight they were rated as 'not at all' or 'only slightly' by 79%. On the issue of apologies 80% had not received one at all, and 13% said a mild apology had been made. For responsibility, 90% responded 'not at all' (checked number "1"), to the question, 'Did the doctors accept responsibility for what happened to you?'. Doctor's behaviour was viewed as defensive by 79% and a third felt they were moderately to very embarrassed by events.

Given the unexpected nature of the injuries sustained, they were asked whether they had been given the opportunity to ask questions about their condition and subsequent treatment, 83% reported the doctor's did not welcome their questions. In addition to this lack of opportunity to ask questions 69% also reported that their doctors had failed to provide them with any details of the incident of their own accord.

Attitudinal Changes

Views towards the health profession generally, and doctors specifically, were examined. Although attitudes were rated extremely positive for 72% prior to the trauma, post trauma views had changed markedly with 69% rating their current view as much more negative. For 31% relationships with general practitioners had changed for the worse, often resulting in transferring GP practice's.
Avoidance

Given the nature of the incidents, medical follow up was often required, despite this half actively avoided further medical encounters, even when they believed something was physically wrong. Two thirds reported feeling very afraid of future doctor / hospital visits (see graph 8). For over half of the sample (58%) their medical fear had generalised, to encompass the whole profession.

Views on treatment received

Graph 9 highlights respondents’ views on their treatment by the medical profession. 76% expressed having felt cheated, 79% treated unjustly and 78% they had been treated unsympathetically. 72% reported having lost trust in those directly responsible for their health care, and 55% had lost trust more generally in the medical profession as a whole. This is not surprising given the treatment which many of these patients reported. For example half the sample stated that their medical notes had been mislaid for extended periods of time (after they were requested by the legal profession) and that medical notes had been tampered with, for example letters having been removed or retyped.

Explanations

Graph 10 highlights the percentage of those who did not receive an explanation. This could possibly indicate medical staff’s detachment from the incident maybe to avoid embarrassment, or incrimination. A selection of quotes received in relation to the lack of explanations are presented below.
Degree of Fear Expressed

Graph 8
Not at all / Mild  A Great Deal
Percent
Respondents Views on the way they were treated
"Has the explanation remained stable over time?"

- Yes: 24.1%
- No: 6.9%
- No explanation given: 69.0%

Graph 10
"I would be a different person now if they had talked to me rather than let me find out for myself. They tried to cover it up hoping I would go away".

"If they had just been honest with me and said 'don't worry we will sort it out', I would have coped much better".

"It would have been nice if he had said, 'I'm sorry about what has happened....', it would have stopped me taking out the lawsuit".

"Even if it was not the doctors fault they could have just turned around and explained what went wrong; that it did not go as well as it could have".

"No one spoke to me about it, even when I asked. They chose to ignore the problem".

"A different surgeon agreed I was right, he reassured me, something which no other professional had done. He was human".

"If he had said a mistake had been made at the beginning it would have made it much easier for me. If only they had been open and honest, it would have meant a lot".

"No one would give me any answers, no one wanted to know. They were avoiding me even though they knew what I was going through".

"The doctors totally dismissed the idea that an accident had happened. I did not want to push it because at the end of the day I was still in their hands".

"They don't treat you as an intelligent adult. If you ask questions you are viewed as a difficult patient and create ill feelings".

"I needed someone to believe in me at the time".

"I feel everything that occurred could have been avoided but the ones who could help (the nurses) were not in a position to do anything".

"I was continually told that I was worrying about nothing. I never saw the same doctor twice".

"I will never forget this incident, especially the way I was treated by the staff".

"They should be more aware of the effect of an accident on the patient's life".

"I put my total trust in their hands and then they treated me like this".

"I feel in retrospect that the most important thing would have been for me to have felt that I was being believed".

"When I look back I can understand. I think they didn't really know what to say so they avoided the issue".
ATTRIBUTIONS - Risk

Perceptions of treatment related risk showed 69% perceived no risk. A further quarter perceived risk as minimal. 62% said explanations of risk by medical staff were definitely insufficient.

Table 8

<table>
<thead>
<tr>
<th>CAUSAL ATTRIBUTION</th>
<th>AGREE STRONGLY / A GREAT DEAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>RESULT OF DOCTOR NEGLIGENCE</td>
<td>93% (1)</td>
</tr>
<tr>
<td>PUNISHMENT FOR OWN MISDEEDS</td>
<td>14% (5.5)</td>
</tr>
<tr>
<td>A MEDICAL COMPLICATION</td>
<td>38% (2)</td>
</tr>
<tr>
<td>LIMITED HEALTH SERVICE RESOURCES</td>
<td>35% (3)</td>
</tr>
<tr>
<td>AN ACT OF GOD</td>
<td>14% (5.5)</td>
</tr>
<tr>
<td>AN ACCIDENT</td>
<td>21% (4)</td>
</tr>
<tr>
<td>AN UNEXPECTED COMPLICATION</td>
<td>10% (7)</td>
</tr>
</tbody>
</table>

Table 8 highlights the causal attributions most frequently cited as reasons for the incidents. The most frequently endorsed item was 'doctor negligence' followed by medical complication and limited health service resources. Surprisingly few respondents held firm beliefs that incidents were the result of an accident.
Blame

Doctors were viewed as totally to blame for the vast majority (86%) of respondents, with the same figure blaming a particular individual, (usually the surgeon or consultant primarily in charge of their care). The hospital was blamed generally for 55%. In terms of stability of who was blamed, 93% commented that it had remained stable since the incident had occurred. For self blame 79% did not blame themselves although it is noteworthy that a fifth strongly did blame themselves.

SECTION 6 - VARIABLES CORRELATED WITH PSYCHOLOGICAL DISTRESS

I. DEMOGRAPHICS

Most demographic variables were unrelated to psychological distress. The two exceptions were, time since incident (see table 9) and number of dependents at time of incident.

Table 9

<table>
<thead>
<tr>
<th>CORRELATIONS BETWEEN TIME SINCE INCIDENT AND DISTRESS</th>
<th>HAD DEPRESSION</th>
<th>HAD ANXIETY</th>
<th>IES AVOIDANCE</th>
<th>IES INTRUSION</th>
</tr>
</thead>
<tbody>
<tr>
<td>TIME SINCE INCIDENT</td>
<td>0.42**</td>
<td>NS</td>
<td>NS</td>
<td>0.47**</td>
</tr>
</tbody>
</table>

** P < .01 All correlations are two tailed

Longer duration since incident is positively correlated with higher rates of depression and subjective distress (intrusion), but unrelated to anxiety and avoidance. The number of dependants at the time of the incident significantly correlated with depression (r = 0.50; P < .01).
II. PAIN

Correlations between pain and psychological distress are given in Table 10. These show that ratings of level of pain at interview is significantly correlated with measures of subjective distress and depression.

Table 10

| CORRELATIONS BETWEEN PAIN AND PSYCHOLOGICAL DISTRESS |
|---------------------------------|----------|----------|----------|
| LEVEL OF PAIN AT INTERVIEW      | ANX      | DEPRESSION | INTRUSION | AVOIDANCE |
| NS                              | 0.43*    | 0.43*     | 0.39*     |           |
| (N=25)                          | (N=25)   | (N=25)    |           |

* P = > .05

The correlational nature of this data does not enable predictions of causality to be made. We do not know therefore whether psychological distress is a determinant or result of the experience of pain. For example affective disorder may reduce ones pain threshold and thereby increase the experience of pain. The inability to tease out the nature of the relationship between psychological distress and pain is compounded by the cross sectional nature of this study and the lack of pre incident measures.

III. SOCIAL AND OCCUPATIONAL EFFECTS

In terms of effects on social and occupational functioning, table 11 shows that all aspects are positively correlated with depression. Associations between anxiety and effects on mental health and how respondents generally view themselves were found. Mental health, self esteem and self confidence were correlated with both affect and subjective distress.
### Table 11

<table>
<thead>
<tr>
<th></th>
<th>Anxiety</th>
<th>Depression</th>
<th>Avoidance</th>
<th>Intrusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>LONG TERM EFFECTS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intimate Relationship</td>
<td>0.39*</td>
<td>0.61***</td>
<td>NS</td>
<td>0.34*</td>
</tr>
<tr>
<td>Alcohol use</td>
<td>0.51**</td>
<td>0.36*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Body image</td>
<td>0.33*</td>
<td>0.62***</td>
<td>0.39*</td>
<td>0.52**</td>
</tr>
<tr>
<td>Mental health</td>
<td>0.67***</td>
<td>0.63***</td>
<td>0.55***</td>
<td>0.73***</td>
</tr>
<tr>
<td>Sociability</td>
<td>0.35*</td>
<td>0.78***</td>
<td>0.32*</td>
<td>0.45**</td>
</tr>
<tr>
<td>Going out</td>
<td>NS</td>
<td>0.43*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Seeing friends</td>
<td>NS</td>
<td>0.43**</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Independence</td>
<td>NS</td>
<td>0.69***</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Physical health</td>
<td>NS</td>
<td>0.50**</td>
<td>0.41*</td>
<td>0.43*</td>
</tr>
<tr>
<td>Sex life</td>
<td>NS</td>
<td>0.47*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Self esteem</td>
<td>0.42*</td>
<td>0.66***</td>
<td>0.42*</td>
<td>0.62***</td>
</tr>
<tr>
<td>Self confidence</td>
<td>0.64***</td>
<td>0.65***</td>
<td>0.40*</td>
<td>0.41*</td>
</tr>
</tbody>
</table>

* P < .05; ** P < .01 *** P < .001  All correlations are two tailed

### IV. SOCIAL SUPPORT

Sarason scores are unrelated to the IES subjective distress scores although both quantity of and satisfaction with support are negatively correlated with anxiety and depression. Higher perceived satisfaction (SSQS) is therefore related to lower anxiety and depression but quantity of supports (SSQM) is only related to lower anxiety levels (See table 12). Highly significant correlations ( P > .001) between the HAD and self ratings of the degree to which respondents rated they had come to terms with their trauma are also apparent. Psychological distress is negatively correlated with respondents' satisfaction with the amount, both initially and currently, talked about the incident.
<table>
<thead>
<tr>
<th>RELATIONSHIP BETWEEN SOCIAL SUPPORT AND PSYCHOLOGICAL DISTRESS</th>
<th>ANXIETY</th>
<th>DEPRESSION</th>
<th>INTRUSION</th>
<th>AVOIDANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSQS (SATISFACTION WITH SUPPORT)</td>
<td>-0.34*</td>
<td>-0.38*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>SSQN (QUANTITY OF SUPPORT)</td>
<td>-0.43*</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>TALKING LONG TERM HELPED ME ADJUST / COPE</td>
<td>NS</td>
<td>NS</td>
<td>-0.52**</td>
<td>NS</td>
</tr>
<tr>
<td>TALKING INITIALLY HELPED ME COPE</td>
<td>NS</td>
<td>NS</td>
<td>-0.49**</td>
<td>NS</td>
</tr>
<tr>
<td>DEGREE TO WHICH HAVE COME TO TERMS</td>
<td>-0.56***</td>
<td>-0.59***</td>
<td>-0.39*</td>
<td>NS</td>
</tr>
<tr>
<td>BOTTLING UP FEELINGS</td>
<td>0.50**</td>
<td>0.53**</td>
<td>0.35*</td>
<td>NS</td>
</tr>
<tr>
<td>SATISFACTION WITH AMOUNT TALKED INITIALLY ABOUT THE INCIDENT</td>
<td>NS</td>
<td>-0.38*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>SATISFACTION WITH AMOUNT TALKED NOW</td>
<td>-0.35*</td>
<td>-0.34*</td>
<td>-0.41*</td>
<td>NS</td>
</tr>
</tbody>
</table>

* P < .05; ** P < .01; *** P < .001 All correlations are two tailed

Correlations between social support measures are given in table 13. Support was significantly associated with the degree to which respondents felt they had had control over their lives in the past week (P < .001). In addition both Sarason scores are related to higher ratings of having come to terms with their trauma.
**Table 13**

<table>
<thead>
<tr>
<th>RELATIONSHIP BETWEEN STANDARDISED AND OTHER MEASURES OF SOCIA SUPPORT</th>
<th>SSQS</th>
<th>SSQN</th>
</tr>
</thead>
<tbody>
<tr>
<td>NUMBER OF SUPPORTS</td>
<td>0.49**</td>
<td>0.51**</td>
</tr>
<tr>
<td>SATISFACTION WITH AMOUNT TALKED INITIALLY</td>
<td>NS</td>
<td>0.35*</td>
</tr>
<tr>
<td>SATISFACTION WITH AMOUNT TALK NOW</td>
<td>0.45*</td>
<td>0.36*</td>
</tr>
<tr>
<td>SUPPORTS FROM OTHERS WHO HAVE HAD MEDICAL ACCIDENTS</td>
<td>NS</td>
<td>0.40*</td>
</tr>
<tr>
<td>PERCEIVED CONTROL IN PAST WEEK</td>
<td>0.70***</td>
<td>0.71***</td>
</tr>
<tr>
<td>COME TO TERMS WITH INCIDENT</td>
<td>0.49**</td>
<td>0.46**</td>
</tr>
</tbody>
</table>

* P < .05; ** P < .01; *** P < .001  All correlations are two tailed

**V. ATTRIBUTIONS**

The only significant correlation between causal attributions and measures of distress were positive associations between: a belief in an act of God with anxiety (r=0.32; P < .05) and depression (r=.50; P < .01); the degree to which doctors are blamed for the incident with intrusion (r=0.33; P < .05) and blaming one doctor in particular with intrusion (r=0.33; P < .05). This suggests that blaming others, whether the doctors or spiritual forces, for their traumas results in higher distress levels. Self blame was not correlated with distress.
VI. CHANGES TOWARDS THE MEDICAL PROFESSION

Table 14 highlights correlations between psychological distress and changes towards the medical profession.

Table 14

<table>
<thead>
<tr>
<th></th>
<th>Anxiety</th>
<th>Depression</th>
<th>Intrusion</th>
<th>Avoidance</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOCTOR'S PERCEIVED INITIAL REACTIONS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SYMPATHETIC</td>
<td>NS</td>
<td>-0.64**</td>
<td>-0.45**</td>
<td>NS</td>
</tr>
<tr>
<td>UNDERSTANDING</td>
<td>NS</td>
<td>-0.46**</td>
<td>-0.42</td>
<td>NS</td>
</tr>
<tr>
<td>EMPATHIC</td>
<td>NS</td>
<td>-0.35*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>CITED FACTS ONLY</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>DEFENSIVE</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>-0.37*</td>
</tr>
<tr>
<td>EMBARRASSED</td>
<td>NS</td>
<td>-0.46**</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>CHANGES WITH MEDICAL PROFESSION</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AFRAID OF DOCTORS</td>
<td>0.40*</td>
<td>0.40*</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>LOST TRUST IN DOCTORS</td>
<td>NS</td>
<td>0.46**</td>
<td>0.39*</td>
<td>NS</td>
</tr>
<tr>
<td>LOST TRUST GENERALLY IN MED PROFESSION</td>
<td>0.39*</td>
<td>0.35*</td>
<td>0.42*</td>
<td>NS</td>
</tr>
</tbody>
</table>

* P < .05; ** P < .01 All correlations are two tailed

This table shows that the failure by doctors to express sympathetic reactions, or be perceived as understanding at the time of the initial incident, is related to higher levels of depression and subjective intrusion. In terms of post incident changes with the medical profession fear of doctors was associated with anxiety and depression and a loss of trust with higher anxiety, depression and subjective intrusion scores.
MULTIPLE REGRESSION ANALYSES

Four regressions were conducted, however only one, (using depression as the dependent variable), produced a significant predictive model. This model gave an overall adjusted $R^2$ squared of .65, that is, it predicted 65% of the variance in the depression score ($F = 3.9$ with $14,8 \text{ df, } P < .03$). Two significant predictor variables were drawn from the model. The first was the degree to which people bottle up their feelings ($\beta = .48, T = 2.5, P < .035$), and the second was the degree to which patients blamed their incidents on doctors negligence ($\beta = .41, T = -2.4, P < .045$). A third variable approached significance: time since the incident, ($\beta = .34, T = 2.2$ and $P < .055$). Unfortunately through missing variables on some items, six cases were dropped in these analyses.
DISCUSSION
DISCUSSION

This study used a semi-structured interview to explore the long term consequences of being involved in a medical accident. The sample consisted of patients who had been involved in a medical trauma and who were subsequently suing the health profession through the UK Law Courts for medical negligence. The mean time since the trauma was four years and five months.

An individual's psychological adaptation to a medical trauma will depend on several factors. These, for instance, may derive from the nature of the incident, any resultant disability and/or pain, as well as expectations and uncertainties for the future. Results show that initial reactions in this group are often characterised by extreme shock, worry and feelings of emotional numbing. Such an initial shock reaction may be followed by periods of continuing anxiety and depression which could originate from a variety of sources, including uncertainty around prognosis and course of any physical injury sustained as well as fear associated with effects of future treatment and disruption to domestic, social and occupational functioning.

Level of psychological disturbance

From the work on life stressors and life events (Finlay Jones and Brown 1981, Paykel et al 1969, Rahe 1974), we know that any major life event which involves the threat of loss can render the recipient prone to depression. The main findings of this study indicate that high levels of psychological morbidity, both in terms of affective disorders (as measured by the HAD) and subjective distress (as measured by the IES) are common. As a group, this sample experience levels of psychiatric symptomatology higher than that found in the general population. Goldberg and Huxley (1980) in a review of studies which examined the
prevalence of mental illness in the community found that the general population prevalence is between nine and twenty percent. Before one can comment on a raised prevalence of psychological morbidity in this population, however, some discussion of which criteria are most valid for measuring distress is required.

**Anxiety and depression**

Zigmond and Snaith (1983) in their original development of the Hospital Anxiety and Depression Questionnaire gave two cut off points for 'caseness' of anxiety and depression (as reported in the results section). They suggested that to reduce the number of false positive's in the assessment of the prevalence of psychiatric morbidity a conservative cut off of 10/11 should be adopted. They noted however, that a lower cut off could be used if the research priority was to include all possible cases of psychiatric morbidity. Many researchers have reported figures at both cut off points since this original report. One example is Barczak et al’s (1988) study of psychiatric disorder in genito urinary clinic attenders which reported the lower cut off as giving optimal sensitivity and specificity.

Given the exploratory nature of this research, and the original research question: 'What is the prevalence of psychological distress in this population?', reported figures show all potential 'cases' using both cut off points. The prevalence of depression, irrespective of which measuring criteria was adopted, remained consistent, with only one case dropped using the lower criteria. Difference in 'cases' of anxiety was more marked with a reduction by 28% (N=8) when the lower cut off was adopted. Overall three quarters of the sample were assessed as potentially having a mood disorder using the higher criteria and 55% using the lower. This prevalence is particularly high when the mean time since the trauma (53 months) is considered.
Unfortunately most studies of accidents fail to assess psychiatric morbidity in victims for any long period of time, most commonly cited follow up periods being six to twelve months. Given the considerable difference between time since trauma in this sample compared with others reported, group comparisons are not strictly possible as a variety of confounding factors must be taken into account, (one example would be the prevalence of post incident serious life events), as these would impact on outcome measures. Unfortunately recent life events were not assessed but should be considered in future research.

**Interactions between anxiety and physical injury**

A concern about loss of physical abilities is often a source of considerable distress for accident victims. In conjunction, a common feature of high levels of anxiety is a range of physical symptoms such as nausea, sweating, fever, shaking, muscle pain, weight loss and lethargy. Because these patients often have severe physical injury, and given the elevated anxiety levels, symptoms generated by the autonomic nervous system may be misinterpreted as signs of further physical deterioration, which in turn can sustain anxiety. Vicious cycles may develop which may subsequently lead to a depressive cognitive set.

**PAIN**

Chronic pain has often been reported as one of the most significant and troublesome symptoms for chronically ill patients. It is also well reported that the experience of pain itself can result in psychological distress, especially if it is perceived as uncontrollable. Levels of pain reported for this sample were high, being comparable to unmedicated post surgical patients. Ratings of pain severity was significantly correlated to depression and subjective distress. This was not surprising given the large literature reporting depression as a frequent accompaniment to chronic pain (Sternbach, 1974, Fordyce, 1976). There is considerable
controversy however concerning the extent to which pain and depression are associated, and an additional source of controversy concerns the possible causal relationship between the two conditions. Several contradictory hypotheses have been formulated about the nature of the pain-depression relation: i) depression evokes chronic pain by increasing pain sensitivity and lowering pain tolerance thresholds. According to Blumer and Heilbronn (1982), chronic pain reflects a muted depressive state in a pain prone individual (That is, pain may be a manifestation of a depressive state, which may be masked). ii) Secondary depression occurs as a reaction to chronic pain. Chronic pain may produce an incapacitating physical condition and depression develops as a function of the sustained reduction in physical and social functioning (Hendler, 1984, Sternbach, 1974). iii) An alternative hypothesis is that they occur simultaneously because they are related to similar psychological or biological foundations.

Lindsay and Wyckoff (1981) in their examination of patients' retrospective reports of the temporal relationship between pain onset and depression found that 38% of their sample (226 patients with co-existing pain and major depression) reported depression had developed after the onset of pain, 50% said the two syndromes had occurred simultaneously and 12% reported pain developed after the onset of depression. This study along with others, (for example Bradley 1963), suggests relatively few patients develop pain after the onset of depression and that a somewhat greater number develop pain and depression simultaneously than become depressed subsequent to the onset of pain.
Although pain and depression are related in this study, pain was not a significant predictor of depression in the regression analysis. Unfortunately onset of pain and depression were not examined making it difficult to speculate whether depression was followed by increased reports of pain or whether pain existed prior to depressive symptomatology.

Predicting psychological distress

Only one of the regression analyses provided a significant model. The results using depression as the dependent variable, found that the independent variables accounting for most of the variance were bottling up feelings and blaming doctors, with time since incident approaching significance. The former supports the well established conclusion that bottling up emotions can lead to later psychological morbidity.

The outcome that time since incident neared significance was initially surprising although on further examination at least three possible explanations might justify this. 1) It could be that this self selected group had long standing evidence of psychiatric disorder prior to their medical accident which has continued and/ or worsened as a result of this additional life event. Unfortunately because pre-morbid psychological status was not assessed firm conclusions about this can not be drawn. 2) As mentioned earlier, depression may be attributable to other significant life events (or a cumulative effect of them). 3) The nature of the accident, (which involves the continual reliving of the event by exposure to the medical and legal profession), may mean that unlike other accident groups the trauma period is extended. This could lengthen the process and period of recovery.
Relationship between blame and depression

The finding that blaming others was a significant independent variable is consistent with previous studies reporting that it is associated with less successful adaptation (Tennen and Affleck, 1990, Bulman and Wortman, 1977). Blaming others, particularly others who were previously well trusted, could lead to feelings of helplessness, uncontrollability and uncertainty, all factors known to be associated with higher levels of psychological distress and influential in long term recovery from chronic illness and physical injury. (Averill, 1973, Langer, 1983).

The relationship between blaming others and depression can be understood if Tennen and Affleck's model of blame related outcome is adopted. These patients seem to fulfil all the characteristics of this model in that outcome is often severe, concerned with the clear involvement of one person of high authority (the surgeon or consultant); who is often not well known or well liked (this may particularly be true if there has been little attempt to build a good doctor / patient relationship prior to the incident).

What is it then about blaming others which associates it with depressive symptomatology? Four potential explanations for this relationship are considered. Firstly it could be related to long term fears of being trapped. Unlike other accidents occurring away from the hospital environment this sample's incidents' are actually caused by the medical profession and remedial treatment for such trauma’s has to be conducted within the same or similar clinical environments. The perpetual need to rely on those who caused the accident may be one factor linking blame to depression. While it is recognised that patients do have the option of changing hospitals and doctors the results show that fear becomes generalised to all medical settings. This implies the medical profession may take on a new meaning for patients after
an adverse event: one of fear, mistrust, unsympathetic, untrusting and to be avoided. In such a scenario long term psychological difficulties may result and delay recovery. A second related explanation is that constant ruminations about blaming others may reduce patients personal resources and impede their efforts of coping with their trauma. This preoccupation may act in a detrimental way, by distracting them from otherwise positive attempts to solve the difficulties they encounter.

A third explanation could be that after these accidents, individuals beliefs in a 'just world' may be seriously challenged. The literature on the effect of loss generally shows that when a loss or event is untimely and/or unexpected it is especially likely to shatter assumptions that the world is just and orderly (Parke and Weiss 1983, Wortman 1983). The shattering of this belief may increase patients awareness that doctors are as fallible as anyone else and increase feelings of vulnerability or of being unprotected. The final explanation is more simplistic, this is that a preoccupation with blaming others over time may lead to a direct reduction in the number of professional supports available, supports which may be necessary to physical and / or psychological recovery.

**Subjective distress**

Subjective distress reported is severe. Scores on the IES reveal a similarity between scores for this group and those who have experienced recent serious life events (such as bereavements), and higher than scores for general accident populations and survivors of the Jupiter cruise ship disaster. This contrasts with Malt's finding that accidents do not result in raised levels of subjective distress. Which suggests there is something peculiar about the medical trauma population. Two possible explanations for this come to mind. 1) Increased distress may, in part, be an artefact of the length of time between assessment and incident.
The results suggest that the emotional impact related to receiving a medical accident may be profound and the consequences more serious than have been previously recognised. In certain instances the reaction of the patient to their trauma may result in the development of anxiety, depression and PTSD which continue to have an invasive influence for longer periods than is usually reported after other traumas. Although levels of distress earlier in the accident course were not assessed, the high levels of distress found suggest that the expected linear trend of high psychological symptomatology at time of crisis decreasing over time (Joseph et al 1993), does not occur in these patients which would appear to corroborate with Shalev et al’s (1993) results that PTSD is prolonged after medical events. This contrasts with Patterson et al’s (1990) findings that intrusive recollections and avoidance of stimuli associated with stressful events are time limited and self-remitting.

Relationship between other variables and distress

Several other variable had high correlations with the measures of psychological distress. These included social support, pain and changes in social and occupational functioning. Although these variables did not add to the predictive power of the regression model, their impact should not be overlooked.

SOCIAL FUNCTIONING

Changes in social and occupational functioning appear common. Results highlighted that all spheres of social functioning are adversely affected, both initially and in the longer term, with psychological distress related to continuing difficulties. The strongest correlations were with depression although again there is no evidence for the direction of these relationships, for example functional disability may interfere with work, socialising etc or alternatively individuals experiencing problems in psycho-social adjustment may find it more difficult to
return to pre-morbid levels of social functioning.

**SOCIAL SUPPORT**

The importance of social support networks in the facilitation of adjustment to physical illness is well known. In injuries caused through medical error there are many potential stressors that may test individual coping mechanisms and as such the role of support is likely to be critical to help buffer the effect of these stressors. Satisfaction and quantity of social support, satisfaction with talking and bottling up feelings were all related to anxiety and depression. Higher levels of support were also found to be associated with reports of having come to terms more with the incident and higher levels of perceived control. These results lend support to a hypothesis that higher levels of support may serve a protective function against the adversity of significant negative life events. Unfortunately actual levels of support received could not be compared to that measured in other studies due to lack of information.

**Who supports patients?**

In terms of who provides social support, 50% said 'female friend', 30% 'partners' and 7% 'other family members' as the major form of support. Only two respondents said they would turn to professionals and no one mentioned their family practitioner. These results differ from previous studies examining help seeking behaviour and sources of support. Barker et al (1990) found that although the main categories of support were partners (68%), other relatives (67%) and friends (43%), 41% also stated they would gain support from their family doctors. Cartwright and Anderson (1981) also report that 69% of their sample would contact their family doctor if they had been depressed for more than three weeks.
This study fails to support Barker et al's finding that doctors rank alongside friends and family as potential providers of support. Several reasons might explain this, an overriding one being differing methods of assessment. In the present study respondents were asked to state who they would use as their primary source of support, they were not provided with a list of potential sources of support and asked to rate whether they would use them. Despite this difference it could be hypothesised that as a group these patients would, nevertheless, be less inclined to seek support from doctors because of the origin of their trauma.

Professional support

The discrepancy between uptake of professional support and retrospective accounts of perceived need highlights the fact that patients often fail to ask for help. This should not be interpreted as not wanting or needing help. There are a number of possible reasons why professional help was not sought, these include:

1. Not wanting to be seen as, or confirmed as neurotic.
2. Wanting to be seen to remain strong for their families.
3. Fearfulness of all hospital based professions.
4. Resultant disabilities (difficulty travelling, etc).
5. Phobic responses towards hospital’s / all medical interventions.

Implications for informal carers

Families and friends assume the predominant role of support and are likely to be influential in the rehabilitation process. However, as has been shown in other physically ill groups, carers themselves are subject to stress and often in need of their own support. It is likely that
this would particularly be the case for those who live with the index patients. Stress associated with the caring role can result for a variety of reasons, for example, having to cope with changes in personality, cognitive functioning or behaviour, as well as more general relationship changes (such as role reversals, decreases in intimacy or sexual activity), or through restrictions in social and occupational functioning. The changes in physical and psychological functioning is often severe, resulting in great disruptions to normal routines.

DOCTOR / PATIENT RELATIONSHIP

Several changes in the doctor patient relationship are reported. These primarily are a loss of trust, generalised fear, avoidant behaviour patterns and changing general practitioners. Changes were associated with the distress measures, in that higher distress was associated with higher reported levels of fear and a reduction in trust. Depression, particularly, was negatively associated with perceptions of doctors initial reactions. This suggests doctors reactions, which are characterised by disinterest, lacking in sympathy, empathy or understanding, are associated with poorer long term adjustment. Facilitating change in the nature of these early communications might therefore mediate long term distress (see 'Implications for clinical intervention' section for recommendations on how this might be achieved).

Unfortunately through lack of information and the design of this study, a delineation of whether the changes reported are a consequence of the trauma itself, doctors reactions, subsequent care received, pursuing a course of litigation or an interaction between them is not possible.
COMPENSATION

The issue of compensation was not a major focus of enquiry in this research. Respondents were asked, however, whether their court case had been settled. No differences in distress were found between those whose cases were ongoing and those who had settled them.

GENERALISATION TO OTHER ACCIDENT GROUPS

This study has shown that accident populations cannot be viewed in blanket terms nor treated as a homogenous group, but that they will have some characteristics in common, others not. The difficulty with making comparisons across populations however, is that to date research has failed to follow patients for any lengthy period of time (generally no longer than one year). Consequently little is known about the natural course of difficulties and rates of psychological recovery in these people. This should be addressed in further prospective studies.

METHODOLOGICAL ASPECTS / GENERAL LIMITATIONS

Sample issues

This study was of course limited in terms of the small sample size and the limited number of male respondents which did not allow for comparisons between sexes. In terms of the representativeness of the sample, results cannot be generalised to the rest of the medical accident population. Respondents were self selecting, in terms of choosing to participate in this study, as well as having been motivated to take part in previous research. All patients were also suing those deemed responsible for the trauma experienced and as such we do not know how typical this sample is of the non suing population. One can only speculate that this population might be more seriously affected and therefore unrepresentative of the population.
as a whole, as it may be that respondents' involvement in litigation could have a biasing effect on self reports. Indeed it has been suggested that psychological reactions might be produced or maintained by a compensation claim, often referred to as 'compensation neurosis' (Weighill, 1983) although there is also contrary evidence that seeking compensation may be associated with less severe symptoms (Gleser, et al 1981).

High distress could also possibly be accounted for by the actual process of data collection, that is, only the most distressed participated. If those declining participation were coping better than those interviewed one would expect any problems in this sample to be over represented. This would not appear to have been the case for respondents recruited for this study however, as reasons given for non participation fails to support this reasoning. None of the reasons indicated that the incident was no longer an important issue or that they were not still currently affected by it. This limitation may have been more noticeable during the recruitment for the earlier study.

Given the complexity of factors which might influence long term recovery, it would be preferable to change the research design in future work to take account of the preferred position of aiming to track the course of recovery over time. A prospective study from onset of incident using a longitudinal repeated measures design would fulfil this. Ideally a matched control group of non injured patients could be used. This might then allow a clearer delineation than this paper has been able to provide of the relative importance of different factors associated with long term recovery, as well as transcending difficulties and biases associated with retrospective accounts, (a major drawback in work examining long term outcome). An investigation of the effect of continuing re-exposure to the threatening stimuli and taking out legal proceedings could then also be tracked.
A potential drawback to the results of this study is that results were collapsed across accident types (because of sample size). In addition there was no assessment of injury severity, which, if available, would allow a further examining of how far distress was due to injuries or to other factors. Future work should ensure that the respective influences of injury type and severity, over time, can be ascertained.

**Alternative interpretations of results**

One of the most serious threats to the validity of the results presented concerns the possibility that distress scores were artificially inflated because of the nature and context in which they were obtained. Respondents were interviewed after being told the aims of the research. One could envisage that this could have the effect of raising respondents' awareness of the issues, which may, under normal circumstances, be at the back of their minds. This criticism does not hold up in this instance however, given that outcome measures of distress were administered before the interview began to reduce any mood bias which might result.

Another criticism of all face to face interview studies is the issue of social desirability. It is possible that respondents exaggerated the level of distress experienced because they felt that this would be desirable or expected of them. Again, however, standardised measure of distress do not support this and indeed it could be argued that the most socially desirable response would in fact be one of acceptance or recovery given the lengthy time since original incidents. One must take care, however, to recognise that context effects can never totally be eliminated.
A major drawback to the interpretation of these results concerns a failure to include an assessment of pre-morbid functioning and any recent serious life events. Yule et al (1990) has reported evidence that suggests life-events subsequent to disaster help prolong the distress experienced by survivors. It could be argued that in the present study it is probable that other events may have occurred (given the average time of 53 months since incidents’) which may have altered the course of symptomatology. Reported levels of psychological stress cannot, therefore, be directly related to psycho-social status prior to the incident. This is particularly important in the case of medical accidents as, unlike injuries sustained in the workplace or in road traffic accidents, which often occur in otherwise healthy people, medical injuries generally occur in those who are already ill. Without some form of pre-morbid physical and psychological assessment, it would be difficult to distinguish disabling injuries caused by medical interventions from those attributable to the illness itself.

IMPLICATIONS FOR CLINICAL INTERVENTION

It's beyond this paper's scope to give an in-depth account of all possible interventions which could be applied to this population, however basic guidelines for potential changes in the doctor / patient relationship are forwarded.

Mediating psychological distress

The results indicate that victims of medical accidents experience considerable levels of long term psychological symptomatology, both in terms of mood disorders and subjective distress. Distress is particularly related to a tendency to bottle up feelings and blaming doctors, as well as pain, effects on social and occupational functioning and doctors immediate post incident reactions towards patients. Interventions which reduce the impact of these variables
might, therefore, help mediate psychological morbidity. Despite these levels of distress only one person was in receipt of professional psychological support. Why is this?

Goldberg et al (1976), in a study of psychological illness discovered that many people with functional disorders did not receive formal psychological help but tend to be cared for by their family physicians. In the present sample although, formal psychological support was not received, use of G.P’s as an alternative is also less likely, particularly given the prevalence of victims generalisation of fear and avoidance (a third had changed general physicians either because of unfavourable reactions or because of a loss of trust in them). These changes may result in a perceived inaccessibility of medical support, essentially culminating in support away from the medical profession and onto friends and / or family. Patient unresponsiveness to medical treatment following a medical accident should alert the medical profession to the possibility of co-morbid mental disorder.

A major difficulty in the support of this population is that those who should help, and are best placed to, are often the least forthcoming. It is ironic that when something goes wrong and patients need increased care, that care is, to a greater or lesser extent, withdrawn. In such circumstances we need to ask: What interventions are indicated for these patients given that many will experience psychiatric morbidity of a level which could warrant psychological intervention?
Patients complaints about their post incident treatment?

Respondents gave three main points related to doctors behaviour which they said should be included in any post trauma treatment. These are for doctors to:

i) Be honest, rather than try to hide the truth.

ii) Provide a frank and clear explanation of what happened and what was being done to put things right.

iii) Provide an apology or accept responsibility.

Why should doctors change their behaviour?

Vincent et al (1992), in his examination of the reasons why people turn to litigation, found that the majority of patients did not sue doctors so much because of financial compensation but more because of: i) altruism - wanting an assurance that the same thing will not happen to others, and ii) doctors negative post incident reactions, in particular a negation of their feelings and the lack of adequate explanations. These reasons for litigation suggest if the criteria above (for better treatment) were implemented, this might reduce long term distress along with the number of cases going to court. The adoption of these recommendations would, however, require a fundamental shift in the nature of the doctor patient relationship.

Although many difficulties exist in trying to change the nature of this relationship nonetheless some basic, (by no means exhaustive) but fundamental guidelines surrounding how these patients should be dealt with are presented on the next page:
i) Do communicate with the patient. Be honest and try not to conceal facts. This is particularly important given this is one of the major areas of patient dissatisfaction.

ii) Do provide an adequate explanation. This should be intelligible, clear, and couched in language appropriate to the patients level of understanding. Be aware that at times of stress patients’ recall and recollection is dramatically minimised, therefore check they have understood the information given.

iii) Do allow sufficient time for questions.

iv) Do respect and take seriously patients beliefs, feelings, emotions and fears.

v) Do empathize. It may be useful, for example, to explicitly acknowledge that patients must be feeling, confused, angry, bitter, etc, towards the doctors, and that it must be difficult for them to remain trusting. This recognition could free patients to talk about their fears more openly.

vi) Do arrange follow up appointments. Remember that fear, diminished trust or psychological difficulties may prevent them from returning, so follow them up.

vii) Do involve significant others.

viii) Do try to maintain consistency of the medical team, to minimise additional distress.

ix) Do not avoid patients or be defensive.
What forms can clinical interventions take?

Although a variety of techniques and methods of intervention could be relevant for use with this population, a discussion of these is beyond this paper's scope. However, one general point is given the estimated prevalence of these accidents (across specialties), a specialist counselling service is called for, or at the very minimum, direct access to psychologists working within a medical setting should be a priority. If service provision took this form it would benefit not only the patients themselves but also their families (in this sample 48% would have taken this up if it had been available at the time). In addition, the doctors and other hospital personnel may also benefit from this service.

What specific issues can clinical interventions address?

It must be recognised that mental health workers like general medical staff will be viewed in the first instance as yet another member of the hospital system and may therefore be viewed with suspicion or distrust. This is already indicated by the discrepancy between perceived need and uptake of professional services. As such, it is very important to build a good working therapeutic alliance. Intervention can help on a number of levels ranging from general counselling where patients are encouraged to talk about their thoughts and feelings, through to more specific management of circumscribed psychological disorders such as anxiety, depression, post-traumatic stress disorder, phobic responses, and the management of chronic pain. The important point, however, is the recognition of the possible co-existence of different forms of psychological morbidity, (anxiety, depression, PTSD, panic disorder, etc), whose prompt recognition and diagnosis will benefit the patient, enabling the most appropriate treatment to be implemented.
Where patients are experiencing symptoms of anxiety and depression these feelings are likely to be situation-dependent, and therefore it is likely that only a minority would benefit from drug therapy. It is more likely that they will benefit more from an approach where their problems are clearly identified, practical solutions sought and emotional support offered. Appropriate therapies might include problem solving, cognitive therapy and stress and anxiety management. Additionally it may not be necessary to offer all patients individual treatment. As with many other groups it is likely to be most cost and time effective to offer various levels of interventions. Examples of these might be:

**Level One**

Written material proffering advice and addresses of resources, including for example social services, legal aid, Community Health Council, Family Practitioner Committees, voluntary agencies, counselling services, details of complaints procedures and centres for alternative medicine.

**Level Two**

Closed support groups (that is, with a fixed and unchanging membership of up to twelve members and lasting for a minimum of eight sessions). Groups could be for patients themselves, their intimate carers or both.

**Level Three**

This encompasses all types of therapy that are designed to meet the needs of a particular individual or unit (couple or family).
To be effective this range of services needs to be backed by the appropriate range of professionals.

Psychological morbidity like physical injury needs to be taken seriously and addressed. Patients should be encouraged to communicate their feelings and helped to ask questions rather than leaving them to bottle their feelings up. Given the nature of these incidents priority should be given to this group not least because early intervention may ameliorate adjustment and preserve a trusting relationship with the medical profession.

CONCLUSION

Psychological intervention is strongly indicated for this population as these accidents have a major psychological impact. Long term distress is higher than that noted for other accident groups and for significant life events. Patients should be offered formal psychological help in addition to remedial treatment for any physical injuries sustained. This study has extended earlier work by providing a more detailed examination of the long term psycho-social consequences for this group. Further examination of time related recovery is required as this may improve our ability of predicting poorer adjustment, which would enable identification of particular needs and allow specific interventions to be tailored. The course of recovery from this type of trauma seems atypical to that of other accident populations and therefore worthy of more focused study.

The Patient's charter and rising costs of litigation and complaint management emphasise the general need to improve the handling of patient dissatisfaction. Injuries to patients caused by medical treatment are much more common than is generally realised. In the USA 3.7% of
patients admitted to hospital are injured by the treatment they receive, 1% negligently; 13% of these involved a death and 7% permanent disability. There are 8 times as many negligent injuries as claims. Extrapolating these results to the region in which this study was conducted (North West Thames Regional Health Authority) this would suggest there are 20,000 injuries, 2,500 deaths and 1,400 cases of permanent disability per annum.

The financial cost of such injuries is large with litigation costs for the NWTRHA currently running at £11 million per annum. Medical accidents also have a high human cost. This study has gone some way to describe the long term effect on patients but further research needs to address the causes and consequences of medial errors taking into account the experience of the medical staff, patients and their informal carers.

THE FUTURE
Clearly further research is required to substantiate this work. Results from this cross sectional descriptive study suggest a number of directions for future research as the data presented leaves a number of questions unanswered about the natural course of psychological disturbance. Normally it would be expected that psychological distress would be high in the initial trauma period with a linear trend reducing over time, however the results suggest this is not the case for this group. The major focus of this investigation was on the long term psycho-social effects, consequently the course of recovery could not be assessed. Studying from incident onset through time it may be possible to explicate the mechanisms linking medical accidents to subsequent psychological distress or recovery.
This work is being extended to allow a more thorough investigation of the nature and degree of the distress engendered in this population. This research will take the form of a prospective longitudinal study to enable an assessment of time related recovery and allow links between outcome and illness severity / type to be made. The discrepancy between the lack of professional psychological support received and the perceived need for it has also stimulated provisional plans for setting up a patient support group which will be evaluated for the health authority in which it will be conducted. It is hoped that in this way awareness of some of the needs of these patients may be increased amongst the medical services. At present there is a total lack of services for this patient group. Clinical audit and systematic enquiry into the causes of medical errors might help alleviate this situation. Our own feelings and fears of self preservation must not cloud professional judgements about the care of these patients as this is unprofessional and immoral.

I would like to finish with a quote from one of the respondents.

"There seems to be an all pervasive attitude that doctors are somehow above and beyond the normal constraints which the rest of humanity have to abide by; that when something has happened one should simply shrug your shoulders and carry on as before, after all, these things happen. When the door closes behind the patient a doctor's life carries on as normal but the person concerned lives with the consequences every minute of every day, for the rest of their lives."
BIBLIOGRAPHY
BIBLIOGRAPHY


APPENDIX
Dear

RE: Medico-legal research project

Thank you very much for completing the questionnaire. The study is going very well. Over 250 people will have taken part by the time we finish the first stage of the study at Christmas. As you know we will be writing again in 1993, with a second shorter questionnaire, to everyone who has taken part in the study.

I am writing now because an opportunity has arisen for us to extend the study and actually talk to people about their experience of medical treatment. My colleague, John Chuch, also a clinical psychologist, will be interviewing some of the people involved. While questionnaires are very useful, people can often put across their point of view more clearly by actually talking to someone face to face about their experiences. Although John will have a series of questions that he would like to ask he will also be extremely interested to hear your own personal views.

The interview should last between one and a half and two hours. John is able to visit you at your home, or you can meet him at St Mary’s Hospital if you prefer. The information you give in the interview will be completely confidential and will have no bearing on your case or your subsequent medical treatment. We will still send a second set of questionnaires in 1993 whether or not you feel able to talk to John.

John will telephone you in the next couple of weeks to answer any questions you might have and ask if you would be willing to be talk to him. I stress that even though you have completed the original questionnaires there is no obligation to take part.

As before I would be very happy to answer any questions myself. If you would prefer to speak to me I can be contacted at St Mary’s on 071-725-1990 (direct line) or a message can be left with my secretary Mrs Sandra Haynes on 071-725-1646.

Once again I am very grateful for your help so far. I hope you will not mind us contacting you again; please do not worry if you do not feel willing to be interviewed.

With best wishes

Charles Vincent
Lecturer in Psychology
Chartered Clinical Psychologist
Medico-Legal Interview Study

MEDICO-LEGAL INTERVIEW SCHEDULE

me ..........................  e ..... Sex  ........ Marital status  .................
te of incident ............ Interview date  ............
aim settled / unsettled  Outcome ..................
igion ........... Education ...... Ethnic origin .......
rtner Yes...... No....... Time together ..............
Dependents at time of incident ........

TIAL IMPACT
/ did this incident occur?

PATIENTS
soon after this incident did you leave hospital?

: you an inpatient longer as a result of this incident?

: much did you want the operation / drugs?
Not at all 1 2 3 4 5 6 7 A great deal

: necessary was/were the operation / drugs?
Not at all 1 2 3 4 5 6 7 Very necessary

: much choice did you have over the operation / etc?
None at all 1 2 3 4 5 6 7 A great deal

: you had any previous bad experiences with doctors/hospitals?

: you even been an in-patient prior to this incident? (If
: how did that go, what were your feelings about it, were
: medical staff any different on that occasion?)

...... NO ......
itive ...... Negative...... Neutral......

: worried were you about the operation before it was
ducted?
at all worried 1 2 3 4 5 6 7 Extremely worried

: you have any other physical problems before this incident?
...... No......
d Moderate  Severe

: any new physical problems occurred since this incident?
: you being treated for anything else?)

< 1 >
Medico-Legal Interview Study

s ........ No........ Mild Moderate Severe

s an explanation given to you when it happened? Yes / No

w much do you feel that the incident was a result of:

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>An act of God</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>Doctor negligence</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>Punishment for own misdeeds</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>Medical complication</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>Limited health service resources</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>An accident</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>An unexpected complication</td>
<td>1 2 3 4 5 6 7</td>
</tr>
</tbody>
</table>

at were your initial reactions at the time of the incident?

ock Not at all 1 2 3 4 5 6 7 A great deal
s belief Not at all 1 2 3 4 5 6 7 A great deal
mb Not at all 1 2 3 4 5 6 7 A great deal
rry Not at all 1 2 3 4 5 6 7 A great deal
dn’t know it had happened Not at all 1 2 3 4 5 6 7 A great deal
o ill to worry about it Not at all 1 2 3 4 5 6 7 A great deal

...............................................................

s the explanation which was given remained the same over
me?
me same ......... Changed ......... No explanation given.....
ease comment
...............................................................

ere and when were you told of the incident?
ile in hospital first time
ile in hospital subsequently
ile at home
aight away
ore left hospital
her time
ot told

o informed you that something may have gone wrong:
concerned
ther Dr
urse
licitor (AVMA)
dical experts
her
one

s this the best person to tell you?
s ........ No ........ Who should have?....

2
Medico-Legal Interview Study

there anything that you now know which you would have liked
have known at the time?

re the potential risks associated with this procedure
plained to you?
None at all A little moderate great deal

i this seem sufficient information to you at the time?
initely maybe not about maybe Definitely
; enough enough right enough enough

; any one else present when you were told?
ily Friends Medical staff No one

; a follow up appointment offered for you to discuss further
it had happened?
..... No..... If yes, was this useful/did you attend?.....

at all those who you found supportive at the time of the
incident - in supportive order.

Social Support

supportive would you rate your family at the time of the
incident?
Not at all supportive 1 2 3 4 5 6 Very supportive

supportive would you rate your friends at the time of the
incident?
Not at all supportive 1 2 3 4 5 6 Very supportive

important do you feel the initial support was which you
ceived immediately after the incident?
Not at all important 1 2 3 4 5 6 extremely important

ase rate how much do you agree/disagree with the following:
aving someone to talk to at the time of the incident helped
cope with the incident".

Strongly disagree 1 2 3 4 5 6 Strongly agree

aving someone to talk to over the months which followed
helped me cope with / adjust to the incident".

Strongly disagree 1 2 3 4 5 6 Strongly agree

ve you received any professional help / counselling in
lation to this incident? Yes..... No.....

an was this?..........................................................

m which profession?..............................................

< 3 >
Medico-Legal Interview Study

Was this useful?
Not at all 1 2 3 4 5 6 7 A great deal

In what way?

Would you have wanted to see a counsellor / psychologist if one was available at the time? Yes........... No..........

Have you received any support from other people who have experienced similar incidents?
None at all 1 2 3 4 5 6 A great deal

What would you say personally are the most important aspects of social support for you? (did you receive this?)

BLAME

Dr’s are solely to blame for what happened
Not at all 1 2 3 4 5 A great deal

blame one doctor in particular
Not at all 1 2 3 4 5 A great deal

blame the medical profession generally
Not at all 1 2 3 4 5 A great deal

blame myself
Not at all 1 2 3 4 5 A great deal

Why do you blame yourself for what happened?

Would have been more assertive Not at all 1 2 3 4 5 6 7

Did not need the treatment Not at all 1 2 3 4 5 6 7

Could not have trusted the
rs like I did Not at all 1 2 3 4 5 6 7

Had not have complained more Not at all 1 2 3 4 4 5 6

(do you blame the medical profession for what happened please)

ate below whether you have felt:

anger None felt 1 2 3 4 5 6 7 A great deal felt

sadness None felt 1 2 3 4 5 6 7 A great deal felt

itter None felt 1 2 3 4 5 6 7 A great deal felt

set None felt 1 2 3 4 5 6 7 A great deal felt

tribution None felt 1 2 3 4 5 6 7 A great deal felt

es your blame remained consistent over time?

Yes / No
Medico-Legal Interview Study

If your relationship has been affected what exactly has changed?

Income prior to this event.

- 5000pa £5-8000 £8-12000 £12-15000 15-20000 20-25000 25+

Income since this event.

- 5000pa 5-8000 8-12000 12-15000 15-20000 20-25000 25+

Communication

How often do you talk about the details of this incident and its effect on you?

Never 1 2 3 4 5 6 7 all the time

Do you discuss the effect it has had on your intimate relationships / marriage etc?

Never 1 2 3 4 5 6 7 all the time

How satisfied were you with the amount you talked about this incident when it occurred?

Not at all satisfied 1 2 3 4 5 6 7 Very satisfied

How satisfied are you with the amount you talk about the incident NOW?

Not at all satisfied 1 2 3 4 5 6 7 Very satisfied

Who would you mainly turn to to discuss the details of what happened if you felt like talking about it?

Male friend Female Friend Family Spouse/Partner

Did you talk about what happened with your family at the time it occurred? Yes..... No......

never / Rarely / A little / moderately / often / all the time

Did you talk about what happened with your friends at the time it occurred? Yes..... No......

never / Rarely / A little / moderately / often / all the time

Did you talk about it with the doctors when it happened?

Yes..... No......

never / Rarely / A little / moderately / often / all the time

What were the Dr's initial reactions?

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Not at all</th>
<th>1 2 3 4 5 6 7</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sympathetic</td>
<td>Not at all</td>
<td>1 2 3 4 5 6 7</td>
<td>A great deal</td>
</tr>
<tr>
<td>Understanding</td>
<td>Not at all</td>
<td>1 2 3 4 5 6 7</td>
<td>A great deal</td>
</tr>
<tr>
<td>Apologetic</td>
<td>Not at all</td>
<td>1 2 3 4 5 6 7</td>
<td>A great deal</td>
</tr>
<tr>
<td>Welcomed questions</td>
<td>Not at all</td>
<td>1 2 3 4 5 6 7</td>
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<tr>
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<tr>
<td>Denied responsibility</td>
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<td>1 2 3 4 5 6 7</td>
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<tr>
<td>Accepted responsibility</td>
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<td>1 2 3 4 5 6 7</td>
<td>A great deal</td>
</tr>
</tbody>
</table>
Gave no details Not at all 1 2 3 4 5 6 7 A great deal

**MEDICAL PROFESSION CHANGES**

Has your attitude changed towards health professionals since the incident?
  Much more positive 1 2 3 4 5 6 7 Much more negative

How would you describe your feelings towards doctors / the medical profession before the incident?
  Very negative 1 2 3 4 5 6 7 Very positive

How would you describe your feelings towards drs / medical profession since this incident?
  Much more positive 1 2 3 4 5 6 7 Much more negative

If there has been a change what effect has this had on subsequent:-
1. Dr’s appointments
2. Relationship with GP
3. Rehospitalisations
4. Corrective surgery
5. Clinic staff

Do you ever avoid going to the Dr’s since this incident happened? Yes ..... No ..... 

How afraid do you feel of going to the doctor or the Hospital?
  Not at all 1 2 3 4 5 6 7 A great deal

If Yes, is this just the Dr / hospital where this incident occurred or does it apply to all Dr’s / Hospitals?
  Specific .......... Generalised .......... 

How risky did you feel the operation / drug was going to be before surgery?
  Not at all 1 2 3 4 5 6 7 Very risky 
  risky indeed

Do you feel you have been cheated by the medical profession? Not at all 1 2 3 4 5 6 7 A great deal

Do you feel you have been treated unjustly by the medical profession? Not at all 1 2 3 4 5 6 7 A great deal

Do you feel you have been treated unsympathetically by the medical profession?
  Not at all 1 2 3 4 5 6 7 A great deal 

Do you feel you have lost trust in those directly responsible for your care?
  Not at all 1 2 3 4 5 6 7 A great deal
Medico-Legal Interview Study

Do you feel you have lost trust in the medical profession generally?
Not at all 1 2 3 4 5 A Great deal

Current thoughts and feelings

Over the past month have you spoken about this incident with anyone else, other than talking about me coming today?
Yes...........No...........How often..............

What have you spoken about in particular?

- Initial incident
- Effect on current life
- Effect on intimate relationships
- Effect on physical/mental health
- Fear of future
- Disability left with
- Court case

Have you found yourself so upset while thinking about this incident in the past month that you have cried?
Yes...........No...........If yes, how often?..............

What is it that makes you feel upset when you think about it?

COMPENSATION

How important is this law suit to you?
Not at all important 1 2 3 4 5 6 7 Very important

What has been the main positive effect of taking out this lawsuit for you?

Have you read any expert reports on your case?
Yes...........No.............

Have you spoken to any experts about your case?
Yes...........No.............

What has been the effect on reading expert reports about your case?
Def +ive Maybe +ive Neither + or -/ive Maybe -/ive Def -/ive

What has been the effect of talking to:
1) Medical experts:
Def +ive Maybe +ive Neither + or -/ive Maybe -/ive Def /ive

2) Psychological experts:
Def +ive Maybe +ive Neither + or -/ive Maybe -/ive Def /ive
In the first three months after the incident how much were the following affected for you personally? Your:-

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How much do you feel the incident STILL / CURRENTLY AFFECTS YOUR:

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</table>
Clinical Section

Can you think of any way in which the explanation given to you could have been improved or done differently? (any critical things you would have liked to have been told about).

What sort of support would have been most beneficial to you when you first learnt of this incident?

Did you receive this? Yes... No....

Were any of the medical personnel more supportive than others? If Yes what was it about these people that made you feel more supported?

What was most helpful about their behaviour / manner that felt right for you? (Eg stayed with you at night, tried to console you, were sympathetic, took time out to listen to you, etc).

If you felt that the Dr’s were unhelpful / unsupportive what was it about them that made you feel unsupported? (Eg their clinical manner, no time to talk, too busy, etc).

Would you describe the medical personnel as being emotionally supportive at that time?

What sort of support would be most beneficial to you now?

Are you receiving this? Yes... No....
HAD Scale

Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

feel tense or 'wound up':
Most of the time ...................................
A lot of the time ......................................
Time to time, Occasionally ...................
Not at all ...............................................

still enjoy the things I used to enjoy:
Definitely as much .................................
Not quite so much ..................................
Only a little ...........................................
Hardly at all ...........................................

get a sort of frightened feeling as if something awful is about to happen:
Very definitely and quite badly ...........
Yes, but not too badly ..............................
A little, but it doesn't worry me ...............
Not at all ..................................................

I can laugh and see the funny side of things:
As much as I always could ..................
Not quite so much now ............................
Definitely not so much now ..................
Not at all ..............................................

worrying thoughts go through my mind:
A great deal of the time ......................
A lot of the time ......................................
From time to time but not too often ......
Only occasionally .................................

feel cheerful:
Not at all ..............................................
Not often .............................................
Sometimes ..........................................  
Most of the time ...................................

I feel restless as if I have to be on the move:
Very much indeed ..................................
Quite a lot ............................................
Not very much ..................................
Not at all ..............................................

I look forward with enjoyment to things:
As much as ever I did .........................
Rather less than I used to ....................
Definitely less than I used to ................
Hardly at all ........................................

I get sudden feelings of panic:
Very often indeed ..................................
Quite often ..........................................
Not very often ..................................
Not at all ..............................................

I can enjoy a good book or radio or TV programme:
Often ..................................................
Sometimes .........................................
Not often ..........................................  
Very seldom ........................................

Do not write below this line
INSTRUCTIONS:
The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the person's initials and their relationship to you (see example). Do not list more than one person next to each of the letters beneath the question.

For the second part, circle how satisfied you are with the overall support you have.

If you have no support for a question, check the words "No one," but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all questions as best you can. All your responses will be kept confidential.

EXAMPLE:

Who do you know whom you can trust with information that could get you in trouble?

No one 1) T.N. (brother) 4) T.N. (father) 7)  
2) L.H. (friend) 5) L.H. (employer) 8)  
3) R.S. (friend) 6) 9

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied
1. Whom can you really count on to listen to you when you need to talk?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

2. Whom could you really count on to help you if a person whom you thought was a good friend insulted you and told you that he/she didn't want to see you again?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

3. Whose lives do you feel that you are an important part of?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

4. Whom do you feel would help you if you were married and had just separated from your spouse?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

5. Whom could you really count on to help you out in a crisis situation, even though they would have to go out of their way to do so?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

6. Whom can you talk with frankly, without having to watch what you say?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

7. Who helps you feel that you truly have something positive to contribute to others?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied
8. Whom can you really count on to distract you from your worries when you feel under stress?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

9. Whom can you really count on to be dependable when you need help?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

10. Whom could you really count on to help you out if you had just been fired from your job or expelled from school?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

11. With whom can you totally be yourself?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

12. Whom do you feel really appreciates you as a person?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

13. Whom can you really count on to give you useful suggestions that help you to avoid making mistakes?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

14. Whom can you count on to listen openly and uncritically to your innermost feelings?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied
15. Who will comfort you when you need it by holding you in their arms?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

16. Whom do you feel would help if a good friend of yours had been in a car accident and was hospitalized in serious condition?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

17. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

18. Whom do you feel would help if a family member very close to you died?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

19. Who accepts you totally, including both your worst and your best points?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

20. Whom can you really count on to care about you, regardless of what is happening to you?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied

21. Whom can you really count on to listen to you when you are very angry at someone else?

How satisfied?

6-very satisfied 5-fairly satisfied 4-a little satisfied 3-a little dissatisfied 2-fairly dissatisfied 1-very dissatisfied
22. Whom can you really count on to tell you, in a thoughtful manner, when you need to improve in some way?

How satisfied?

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<tr>
<th>6-very</th>
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23. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

How satisfied?

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<th>6-very</th>
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24. Whom do you feel truly loves you deeply?

How satisfied?

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25. Whom can you count on to console you when you are very upset?

How satisfied?

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26. Whom can you really count on to support you in major decisions you make?

How satisfied?

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27. Whom can you really count on to help you feel better when you are very irritable, ready to get angry at almost anything?

How satisfied?

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<thead>
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<th>6-very</th>
<th>5-fairly</th>
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TO SCORE SSQ:

1. Add total number of people for all 27 items. (Max. score is 243). This gives you SSQ Number Score, or SSQN.
2. Total Satisfaction scores for all 27 items (Max. = 162). This gives you SSQ Satisfaction score or SSQS.
3. You can also add up total number of people that are family members and that can give the SSQ Family score.

Reference for reliability and validity of SSQ in addition to 1983. Sarason, Lev Basham, and Sarason article:

PAIN QUESTIONNAIRE

Have you been left in pain as a result of the incident that led you to take legal action?

- Yes ( )
- No ( )

If yes, please complete this questionnaire. Circle the number which most nearly relates to the level of pain you have been experiencing. If no, please move on to the next questionnaire.

A. Please rate your usual level of pain on each of the following pain descriptions:

<table>
<thead>
<tr>
<th>Pain Description</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
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</thead>
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<tr>
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<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Shooting</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Stabbing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Sharp</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Cramping</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Gnawing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Hot-Burning</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Aching</td>
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<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Heavy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Tender</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Splitting</td>
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<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Tiring-Exhausting</td>
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<td>2</td>
<td>3</td>
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<tr>
<td>Sickening</td>
<td>0</td>
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<td>2</td>
<td>3</td>
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<tr>
<td>Fearful</td>
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<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Punishing-Cruel</td>
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<td>3</td>
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B. Please put a mark on the line that corresponds to your usual level of pain:

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<tr>
<th>Pain</th>
<th>______</th>
<th>______</th>
<th>______</th>
<th>______</th>
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<td>No Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Worst Possible Pain</td>
<td></td>
<td></td>
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</table>

C. Please tick the word that most corresponds to your usual pain:

- 0 NO PAIN
- 1 MILD
- 2 DISCOMFORTING
- 3 DISTRESSING
- 4 HORRIBLE
- 5 EXCRUCIATING
'VARIABLES MAKING UP SOCIAL SUPPORT SCALE'.

ABILITY /VARIABLES
 ?PFAM SUPPFRDS SUPPIMPT TALKHELP TALKMORE SAMEOTHR 
YOU TALKREL TALKSAT1 TALKSAT2

mary all.

11943

ELIABILITY SCALE SUBCOMMAND IS SPECIFIED—Scaling is applied to all
ified variables.

*** METHOD 2 (COVARIANCE MATRIX) WILL BE USED FOR THIS ANALYSIS *******

*** 1568 BYTES OF SPACE REQUIRED FOR RELIABILITY *******

66 VARIABLES MAKING UP SOCIAL SUPPORT SCALE

ELIABILITY ANALYSIS - SCALE (ALL)

SUPPFAM how supportive family at time of incident
SUPPFRDS how supportive friends at incident time
SUPPIMPT how important was the initial support
TALKHELP having someone to talk to at the time he
talks
TALKMORE having people to talk to over rest of mon
talk
SAMEOTHR have you received support from others me
TALKYOU do you discuss the details of incident a
TALKREL discuss effects on intimate relationship
TALKSAT1 how satisfied with amount talked at the
TALKSAT2 how satisfied with amount talked about i

67 VARIABLES MAKING UP SOCIAL SUPPORT SCALE

ELIABILITY ANALYSIS - SCALE (ALL)

# OF CASES = 29.0

MEANS

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>MEAN</th>
<th>MINIMUM</th>
<th>MAXIMUM</th>
<th>RANGE</th>
<th>MAX/MIN</th>
<th>VARIANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>1.4828</td>
<td>5.2414</td>
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<td>3.5349</td>
<td>1.5421</td>
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VARIANCES

<table>
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<tr>
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<th>MEAN</th>
<th>MINIMUM</th>
<th>MAXIMUM</th>
<th>RANGE</th>
<th>MAX/MIN</th>
<th>VARIANCE</th>
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<tbody>
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</table>

I-ITEM

I-ITEMS MEAN MINIMUM MAXIMUM RANGE MAX/MIN VARIANCE
RELIABILITY ANALYSIS - SCALE (ALL)

RELIABILITY COEFFICIENTS 10 ITEMS

\[ \alpha = 0.6509 \quad \text{STANDARDIZED ITEM \( \alpha \) = 0.6597} \]

100 VARIABLES MAKING UP SOCIAL SUPPORT SCALE

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
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<tbody>
<tr>
<td>DRSYMP</td>
<td>Sympathetic reaction from drs</td>
</tr>
<tr>
<td>DRUNDER</td>
<td>Understanding doctor</td>
</tr>
<tr>
<td>DRAPOLO</td>
<td>Dr apologetic</td>
</tr>
<tr>
<td>DRQUEST</td>
<td>Dr welcomed questions</td>
</tr>
<tr>
<td>DREMMPATH</td>
<td>Empathic dr</td>
</tr>
<tr>
<td>DFRFACTS</td>
<td>Dr cited facts only</td>
</tr>
<tr>
<td>DRDENY</td>
<td>Dr denied responsibility</td>
</tr>
<tr>
<td>DRACEPT</td>
<td>Dr accepted responsibility</td>
</tr>
<tr>
<td>DREMBA</td>
<td>Dr embarrassed</td>
</tr>
<tr>
<td>DRADDETAIL</td>
<td>Dr gave no details</td>
</tr>
<tr>
<td>DRENCENCE</td>
<td>Drs defensive when happened</td>
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100 VARIABLES MAKING UP DRS INITIAL REACTIONS SCALE

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</thead>
<tbody>
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<td>DRAPOLO</td>
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<td>DRQUEST</td>
<td>Dr welcomed questions</td>
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<tr>
<td>DREMMPATH</td>
<td>Empathic dr</td>
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<td>DFRFACTS</td>
<td>Dr cited facts only</td>
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<td>DRDENY</td>
<td>Dr denied responsibility</td>
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<td>DRACEPT</td>
<td>Dr accepted responsibility</td>
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<td>DREMBA</td>
<td>Dr embarrassed</td>
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<td>DRADDETAIL</td>
<td>Dr gave no details</td>
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<td>DRENCENCE</td>
<td>Drs defensive when happened</td>
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# OF CASES = 29.0

ITEM MEANS

<table>
<thead>
<tr>
<th>Item</th>
<th>MEAN</th>
<th>MINIMUM</th>
<th>MAXIMUM</th>
<th>RANGE</th>
<th>MAX/MIN</th>
<th>VARIANCE</th>
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ITEM VARIANCES

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<th>VARIANCE</th>
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INTER-ITEM

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ITEM-TOTAL STATISTICS

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### Reliability Analysis - Scale (All)

#### Reliability Coefficients

**Hα = .8197**

STANDARDIZED ITEM ALPHA = .8341

### Variables Making Up DRS Initial Reactions Scale

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<thead>
<tr>
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<th>Item Squared</th>
<th>Multiple Correlation</th>
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### Variables Making Up Initial Occupational and Social Effect

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</table>
### Multiple Regression

**Regression Number 1**

- **Dependent Variable:** HADD2 (HAD depression subscale score)

#### Multiple R

- Multiple R: 0.93394

#### Square

- Adjusted R Square: 0.64865

#### Standard Error

- Standard Error: 2.92388

```

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F Signif = 0.0295
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**Variables in the Equation**

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<th>Beta</th>
<th>T</th>
<th>Sig T</th>
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4/21/9

**Multiple Regression**

**Regression Number 1**

- **Dependent Variable:** HADD2 (HAD depression subscale score)

```

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<tr>
<th>Variable</th>
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<th>Beta</th>
<th>T</th>
<th>Sig T</th>
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Block Number 1: All requested variables entered.