

**Psychological impact of weight loss in HIV and AIDS: An
exploratory study of seropositive non-IVDU men
and
Research Portfolio**

Naomi Rai-Chaudhuri (BSc. MSc.)

**Submitted in partial fulfilment for the degree of
Doctorate in Clinical Psychology
Faculty of Medicine, University of Glasgow**

1996

ProQuest Number: 13818511

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest 13818511

Published by ProQuest LLC (2018). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code
Microform Edition © ProQuest LLC.

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 – 1346

Heir
10533
Copy



Acknowledgements

I am extremely grateful to the following people for their invaluable guidance and support throughout my research. For the major research project, thanks to Dr Anna Stallard and Louise McCombie for their inspiration, all the patients who took part and brightened up the research with their colourful anecdotes, Carole Noble for assistance with the weight graphs, the *Body Positive* crew and staff at Ruchill Hospital, Glasgow Royal Infirmary and Monklands District General Hospital in the recruitment of patients. For the small scale service evaluation project, my gratitude goes to staff at the NW Glasgow CLDT with big thanks to Jill Murray and Alistair Mathieson in the development of the CLDT questionnaire (especially the computer graphics!). For advice on the single clinical case research studies, I am grateful to Susan Boyle (1), Anne Douglas (2) and Sally Butler (3). The last three years would not have gone quite as swimmingly without the support of staff at the Department of Psychological Medicine (Glasgow University), my family, Graham, and lastly, a huge acknowledgment goes to to my groovy classmates; Louise, Alison, Julie, Stewart, Lindsay, Elizabeth and John.

Contents

CHAPTER 1: MAJOR RESEARCH PROJECT LITERATURE REVIEW	1
Psychological impact of weight loss in HIV/AIDS: A review	
CHAPTER 2: MAJOR RESEARCH PROJECT PROPOSAL	18
Psychological impact of weight loss in HIV and AIDS	
CHAPTER 3: MAJOR RESEARCH PROJECT PAPER	30
Psychological impact of weight loss in HIV and AIDS: An exploratory study of seropositive non-IVDU men	
CHAPTER 4: SMALL SCALE SERVICE EVALUATION PROJECT	51
Involving clients with learning disabilities in a review of services provided by a community team	
CHAPTER 5: SINGLE CLINICAL CASE RESEARCH STUDY (1)	66
Behavioural treatment of habitual caffeine use in a woman with moderate learning disabilities	
CHAPTER 6: SINGLE CLINICAL CASE RESEARCH STUDY (2)	79
Retarded ejaculation and fear of impregnation: Case report of a therapeutic assessment	

CHAPTER 7: SINGLE CLINICAL CASE RESEARCH STUDY (3)

89

Treatment of PTSD and facial scarring in an
adolescent boy assaulted with a knife

TABLES

3.1 Cause of weight loss in study sample & comparison with London sample	47
3.2 IMPWLQ items and rank positions of psychological impact	48
3.3 Subject ratings of weight loss	50
4.1 Ratings provided by clients about contact with CLDT member	65
5.1 Caffeine content of various common sources & guidelines for daily use	77

FIGURES

5.1 Miss H's daily caffeine intake during baseline treatment and F.U. phases	78
------------------------------------------------------------------------------	----

APPENDICES

Appendix 1: Major research project literature review	101
Appendix 2: Major research project proposal	109
Appendix 3: Major research project paper	115
Appendix 4: Small scale service evaluation project	119
Appendix 5: Single clinical case research study (1)	123
Appendix 6: Single clinical case research study (2)	125
Appendix 7: Single clinical case research study (3)	127

CHAPTER 1: MAJOR RESEARCH PROJECT LITERATURE REVIEW

Psychological impact of weight loss in HIV and AIDS : A review

This paper was written according to the guidelines of *AIDS Care*. A copy of the author notes and further relevant information can be found in Appendix 1.

Abstract

Weight loss is a major clinical consequence of infection with the human immunodeficiency virus (HIV). Whilst the medical aspects of weight loss have been relatively well documented, there is a dearth of literature relating to the psychological impact of weight loss in HIV infection. The purpose of this paper was to review the scarce literature on psychological aspects of weight loss which is primarily descriptive and concerned with seropositive males. There is tentative evidence to suggest that weight loss has psychological and social implications for patients and their families or carers. Weight loss causes feelings of unattractiveness, feelings of stigma and fears that being very thin will cause others to suspect seropositivity. Weight loss is also psychologically associated with illness progression and may lessen perceived control over illness. Pre-existing attitudes to weight loss are assumed to be important especially where the patient has a history of an eating disorder. It is concluded that the psychology of weight loss in HIV/AIDS is an underresearched area and further research is required to improve psychological and dietetic interventions.

Introduction

Many of those infected with the Human Immunodeficiency Virus (HIV) will experience a range of psychological problems including anxiety, depression, relationship difficulties, adjustment to HIV status, bereavement, sexual concerns, isolation and suicide (Hedge & Sherr, 1995). It has been suggested that often people infected with HIV suffer the psychological problems associated with HIV infection longer than they suffer the medical problems associated with it (Richardson, 1992). The initial trauma of an HIV diagnosis can lead to

adjustment reactions (acute stress reactions) and adjustment disorders (Miller and Riccio, 1990). Individuals can experience feelings of shock, despair, depression, fear, guilt and anger. Whilst similar reactions are commonly seen in response to diagnosis of other life threatening diseases, individuals infected with HIV have to cope with additional stress arising from stigma associated with gay lifestyles, drug misuse and society's fear of contagion (Maj, 1990; King, 1990). HIV infection causes advancing destruction of the key elements of the immune system (the CD4 cells) and the psychological response to HIV is usually described with reference to stage of infection.

During the early years of HIV disease when individuals are usually asymptomatic, the initial distress can recede into the background. With time however, HIV related symptoms begin to appear such as night sweats, thrush, muscle pains, diarrhoea and falling CD4 counts. These symptoms are viewed by patients as indices of disease progression and often lead to increased anxiety and depression (Chesney and Folkman, 1994). The HIV symptomatic period continues until the development of conditions that fulfil criteria for Acquired Immunodeficiency Syndrome (AIDS) such as opportunistic infections, weight loss or HIV dementia. Diagnosis and labelling of a patient as '*person with AIDS*' further increases psychological distress (Catalan, 1988; Hedge & Sherr, 1995). The incidence of major depression is high and arises from multiple losses i.e. loss of health, income, independence and relationships (Atkinson et al 1988).

As with other debilitating illnesses, alterations in body image are common in those suffering from AIDS. As the disease takes its physical toll, patients can experience severe weight loss, skin lesions (e.g. Kaposi's sarcoma, molluscum contagiosum), hair loss and blindness. The literature relating to psychological

aspects of HIV infection pays very little attention to the impact of altered body image. Sheridan and Sheridan (1988) describe psychological implications of AIDS and note that with progression of the disease, individuals can become depressed about decreasing control of their bodies and loss of physical strength, weight and attractiveness. Similarly, Green (1989, appendix 4) is one of the few authors to summarise psychological reactions in patients with AIDS and include reference to anxieties about physical appearance. He observed that particularly where there is great weight loss, patients will feel unattractive and have low self esteem.

Weight loss is perhaps one of the most common and debilitating features of HIV infection. It has been reported in 93 - 100% of AIDS patients (Keithley et al, 1992) and in Africa, AIDS is known as "slim disease" (Schwenk, 1993). Whilst the medical aspects of weight loss have been relatively well documented, there is surprisingly a dearth of literature relating to psychological aspects of weight loss in HIV. This is also true for other disease states where weight loss and wasting are complications, such as cancer. The literature relating to the psychology of weight is mainly concerned with the distress of weight *gain*. The aims of this paper are to describe weight loss in HIV infection, to review the scarce literature relating to its psychological impact and to comment on directions for future research.

Weight loss in HIV infection

Weight loss and loss of appetite are major clinical consequences of infection with HIV and there is strong evidence to suggest that weight loss is a significant contributor to morbidity and mortality (Coodley et al, 1994). Malnutrition and HIV are thought to form a vicious circle whereby malnutrition increases the severity of

HIV disease which in turn leads to a deterioration of nutritional status. In 1987, weight loss was included as a diagnostic criterion for AIDS in the widely accepted clinical classification of HIV infection produced by the American Centres for Disease Control (CDC, 1987). This was defined as involuntary weight loss of more than 10% baseline body weight. Although there are similarities between weight loss seen in AIDS and terminally ill cancer patients, AIDS related weight loss differs in its occurrence early in the disease, rapid progression and severity (Nahlen et al, 1993).

Different patterns of weight loss have been observed in HIV infection (Macallan et al, 1993). *Acute weight loss* may occur in short episodes lasting several weeks and is usually associated with secondary opportunistic infections such as pneumocystis carinii pneumonia (PCP). *Chronic weight loss* is typically progressive and unremitting persisting over several months or years and is often seen in people who have gastrointestinal disease. There are also patients who have periods of *weight stability* and *weight gain* usually due to recovery from acute weight loss or during intensive nutritional support.

Weight loss in HIV infection can be attributed to many factors including reduced nutrient intake, malabsorption of nutrients and altered metabolism (Macallan et al, 1992; Summerbell et al, 1993; Raiten, 1990). For many patients weight loss results from a combination of these factors (Schwenk, 1993). Reduced nutrient intake is thought to be the principal cause of HIV related weight loss (Macallan & Griffin, 1994) and causes include anorexia and nausea (e.g. effects of acute infection or medication); local oral or oesophageal infections (causing painful swallowing); psychological or neurological causes (depression, anxiety, dementia); and other causes such as fatigue, diarrhoea or constipation (Macallan & Griffin, 1994).

Nutritional support

Maintenance of adequate nutrient intake is very important in managing HIV infection and dietary counselling is therefore essential. It may be helpful to provide patients with nutritional supplements. Attempts to improve appetite in patients with AIDS have been made with use of appetite stimulants (e.g. megestrol acetate). However, where anorexia, nausea or local symptoms prevent adequate food intake, enteral feeding (i.e. through nasogastric tubes) may be required. In the presence of severe gastrointestinal disease, total parenteral nutrition (i.e. with a central venous catheter) is used. Recently, there has been evidence to show that use of anabolic steroids and growth hormone promotes weight gain in patients with AIDS (Macallan and Griffin, 1994).

■ *Nutritional support and quality of life*

Malnutrition during the course of HIV infection leads to decreased quality of life (Raiten 1990). In a study tracking the nutritional status of outpatients with AIDS over a three month period, Broderick and Nasset (1989, brief conference abstract) noted a positive correlation between nutritional status and quality of life. Successful nutritional interventions have been shown to increase quality of life for HIV patients. It was reported that patients had '*improved well being*' following treatment of weight loss with megestrol acetate which caused weight gain and improved appetite (Von Roenn et al, 1988). There was no comparison group in this study and the authors highlighted the need for controlled studies using formal quality of life measures. Use of low level anabolic steroids in HIV infected patients was found to improve lean body mass and quality of life (Strawford et al, 1994, brief conference abstract). It is not clear how quality of life was measured.

Similarly, parenteral nutrition has been shown to improve quality of life; resulting in more positive attitude, improved appetite, unassisted ambulation and increased energy levels (Weaver et al, 1990). It has been argued that artificial feeding with tubes and cumbersome apparatus can also be distressing for patients and cause them to feel helpless, dependent, angry and resentful (Wood, 1994).

Evidence linking weight loss with psychological distress

Whilst there is evidence to suggest a link between quality of life, nutritional status and weight loss; '*quality of life*' is a broad concept encompassing a range of human experience such as physical functioning, role functioning, cognitive functioning and mental health (Burgess et al, 1993). Little is known specifically about how mental health is affected by weight loss, not only in HIV but also in other illnesses where weight loss is a feature e.g. cancer. Psychological literature relating to HIV infection rarely discusses weight loss and the studies which do address the subject rely on qualitative information (Frierson & Lippman, 1987; Firn & Norman, 1995). This is surprising given that HIV is largely a disease of young people for whom body image, weight and physical appearance are likely to play a major role in self esteem.

In a study designed to identify psychological issues of concern, Frierson and Lippman (1987) studied 11 patients with AIDS (10 males and 1 female) over a 4 year period. The issues identified were social isolation, death and dying, sexual concerns and changes in body image. The commonest physical change was weight loss. The authors point out that such body changes are devastating in AIDS because of the rapidity of change. They found that some patients

scrutinised visitors for reactions to their appearance. Others voiced concerns that initiating new relationships would be hampered and feared that family members, particularly children would be frightened by their appearance. They noted that patients with depression had the poorest self image but it is unclear how the authors measured this.

The main psychological and emotional issues described by 7 hospital inpatients with AIDS (5 males and 2 females) were outlined in an article by Fim and Norman (1995). These included fear and rejection, dealing with loss of loved ones through AIDS and changes in body image. All the respondents in this study were concerned about physical changes. The visible aspect of weight loss was highlighted as an area of concern. The authors conclude that the impact of altered body image is underestimated in the literature and that further research is required to determine whether this is a significant factor in development of emotional distress.

In an unpublished pilot study (Rai-Chaudhuri, 1996), the impact of weight loss in HIV and AIDS was assessed by interviewing male seropositive patients who had experience of weight loss and by asking dietitians working in the HIV/AIDS field to complete questionnaires. The themes uncovered included association of weight loss with feelings of unattractiveness and stigma; fears that severe weight loss caused others to suspect their HIV status; beliefs that weight loss signalled illness progression, lessened the control they had over their illness, and increased thoughts about dying. However, patients who had regained weight appeared to have more positive views. All the patients interviewed described how difficult it was to cope with loss of appetite and complained about experiencing pressure to eat more. This often led to conflict within families. The patients employed a variety

of strategies to cope with weight loss such as wearing extra layers of clothes to disguise thinness or avoiding social occasions because they felt bad about their shape.

Although the sample groups in these studies were small and the information collected purely qualitative, there are indications that altered body image, particularly weight loss is a source of psychological distress in patients. The areas of concern include stigma, disease progression and relationships with families and carers.

■ *Stigma*

HIV and AIDS is an extraordinary illness in terms of the potential for multidimensional stigmatisation (Alonzo & Reynolds, 1995). Society responds negatively to HIV illness because it is associated with deviant behaviour; viewed as the responsibility of the individual; contracted via immoral behaviours; perceived as contagious or threatening to the community; associated with death and not well understood by the lay community. Patients who experience changes in body image may have to deal with expanding stigma (Alonzo & Reynolds, 1995; Price, 1990). The AIDS related conditions which are most visible are thought to have the greatest stigma. Vamos (1993) reviewed the literature on altered body image in a range of debilitating illnesses including rheumatoid arthritis, systemic lupus erythematosus, epilepsy, renal failure and AIDS. She concluded that physical appearance and visibility are important primarily because patients fear how other people will react. The visibility of weight loss in HIV infection is likely to be significant as it is strongly associated with general public perceptions of what AIDS patients look like. The visible effects of weight loss can

add to fears of identification as being HIV positive and potential stigmatisation and rejection.

■ *Disease progression*

The psychological association of weight loss with illness and disease progression is also thought to be strong. Patients with HIV associate stable or increasing weight with being healthy and loss of weight with illness (Ramsay et al, 1992). Patients with AIDS frequently attach high importance to weight loss seeing it as their most obvious marker of disease severity and hence longevity (Vamos, 1993). This is not surprising given that severe weight loss is included as a criterion for diagnosis of AIDS. Knowledge of seropositivity can occasionally lead to deliberate weight gain. Smith and Birmingham (1990) found that some patients had history of marked weight gain after they became aware of their HIV status. They reported increasing their food intake deliberately in order to gain weight and improve their chances of living longer with HIV infection.

■ *Relationships with carers*

The psychological link between weight loss and illness is strong not only for patients but for families and carers. Food and eating have strong symbolic connections with survival and food intake can become a barometer of patients well being. Terminally ill cancer patients and their carers were interviewed by Holden (1991) who found that as patients deteriorate and are unable to eat, caregivers become obsessed with serving food. When a patient does not eat, the carer can feel personally rejected, frustrated and angry. The patient may be

accused of not trying. Patients would often prefer a less assertive approach to their eating and interventions should go beyond simple provision of dietary advice (Holden 1991; Holden 1993). Non-food ways of caring such as reading or massage have been recommended. Education for carers about weight loss and loss of appetite may help them to understand patient difficulties.

Pre-existing attitudes towards weight

A patient's response to weight loss will be affected by their previous attitudes towards weight e.g. patients who are overweight may in fact feel good about initial weight loss. Attitudes towards weight are likely to differ between seropositive homosexual/bisexual men, heterosexual men, intravenous drug users (IVDU) and women. Gay men are reported to have thinner body ideals than heterosexual men (Garcia et al, 1987). The incidence of eating disorders amongst gay men has also been queried by Ramsay et al (1992) who presented 4 case studies of HIV positive homosexual men with either anorexia nervosa or bulimia nervosa. They concluded that eating disorders need to be recognised in patients with HIV as their beliefs about weight make clinical management of weight loss difficult. Intravenous drug users are a group of patients at particular nutritional risk prior to HIV infection (McCombie et al, 1995; Raiten, 1990). IVDU are likely to view weight loss differently from non-IVDU. It is also reasonable to assume that female patients will respond differently from male patients to weight loss. Research involving HIV positive women should also consider that they are under represented in HIV related nutritional research which bases its conclusions on studies involving mainly homosexual or IVDU males. Future studies investigating psychology of weight loss should assess pre-existing attitudes towards weight and the *meaning of thinness* for patients.

Conclusions and directions for future research

The purpose of this review was to present the evidence for psychological impact of weight loss in HIV infection. Whilst the literature is scarce, there are indications that weight loss has psychological and social implications and it is clearly an underresearched area. From the available literature, it is reasonable to assume that weight loss can lead to feelings of low mood and unattractiveness, feelings of stigma, fears about identification as being seropositive and may lessen perceived control over illness. Whilst nutritional support is essential, psychological support may also be required not only for patients but for carers. Future research should try to quantitatively measure the distress caused by weight loss and identify the strategies patients use to cope with it. It is also crucial to assess preexisting attitudes towards weight and screen for a history of eating disorders in participants of future studies. The provision of further information about the impact of weight loss should help to highlight where dietetic and psychological interventions can be improved and may prove useful for other diseases where weight loss and wasting are complications.

References

- ALONZO, A. A. & REYNOLDS, N.R. (1995) Stigma, HIV and AIDS: An Exploration and Elaboration of a Stigma Trajectory *Social Sciences in Medicine* Vol 41 no. 3 pp 303-315
- ATKINSON, H., GRANT, I., KENNEDY, C.J. et al (1988) Prevalence of Psychiatric Disorders Among Men Infected with Human Immunodeficiency Virus *Archives of General Psychiatry* vol 45 pp 859-864

BRODERICK, B. & NESSET, J. (1989) Nutritional status parameters associated with psychological well being seen in AIDS/ARC clients at an outpatients clinic in San Francisco *Proceedings of 5th international Conference on AIDS*

BURGESS, A., DAYER, M., CATALAN, C. et al (1993) The reliability and validity of two HIV-specific health related Quality-of-Life measures: a preliminary analysis *AIDS* 7 pp 1001 -1008

CATALAN, J. (1988) Psychosocial and Neuropsychiatric Aspects of HIV Infection: Review of the Literature and Implications for Psychiatry *Journal of Psychosomatic Research* Vol 32 no 3 pp237-248

CENTRES FOR DISEASE CONTROL (1987) Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome. Council of State and Territorial Epidemiologists; AIDS Programme, Centre for Infectious Diseases. *MMWR* 36 (suppl 1) 1S-15S

CHESNEY, M.A. & FOLKMAN, S. (1994) Psychological Impact of HIV Disease and Implications for Intervention *Psychiatric Clinics of North America* Vol 17 no 1 March pp163-182

COODLEY, G., LOVELESS, M., & MERRILL, T. (1994) The HIV Wasting Syndrome: A Review *Journal of Acquired Immune Deficiency Syndrome* 7 pp 681-694

FIRN, S. & NORMAN, I. J. (1995) Psychological and Emotional Impact of an HIV Diagnosis *Nursing Times* Feb 22 Vol 91 no 8 pp 37-39

FRIERSON, R.L. & LIPPMAN, M.D. (1987) Psychologic Implications of AIDS
Archives of Family Physicians Vol 35 no.3 pp 113-116

GARCIA, M.E., COLLINS, C.L. & MANSELL, P.W.A. (1987) The Acquired Immune Deficiency Syndrome: Nutritional Complications and Assessment of Body Weight Status *Nutrition in Clinical Practice* 1 108-111

GREEN, J. (1989) Counselling in HIV Infection and AIDS in S. Pearce and Wardle, J (eds) *The Practice of Behavioural Medicine*, Oxford: BPS Books/Oxford university Press

HEDGE, B. & SHERR, L. (1995) Psychological Needs and HIV/AIDS *Clinical Psychology and Psychotherapy* Vol 2 no. 4 pp 203-209

HOLDEN, C.M. (1993) Nutrition and hydration in the terminally ill cancer patient; the nurse's role in helping patients and families cope. *Hospice Journal* 9 (2-3) pp 15-35

HOLDEN, C.M. (1991) Anorexia in the terminally ill cancer patient: the emotional impact on the patient and family. *Hospice Journal* 7 (3) pp 73-84

KEITHLEY, J., ZELLER, J.M., SZELUGA, D.J. & URBANSKI, P.A. (1992) Nutritional Alterations in Persons with HIV Infection *Journal of Nursing Scholarship* 24 3 pp 183-189

KING, M.B. (1990) Psychological Aspects of HIV Infection and AIDS - What have we learned? *British Journal of Psychiatry* 156 pp 151-156

MACALLAN, D., NOBLE, C., BALDWIN, C. et al (1993) Prospective analysis of patterns of weight change in stage IV HIV infection, *American Journal of Clinical Nutrition* 58 pp 417-424

MACALLAN, D. & GRIFFIN, G.E.(1994) Nutritional Aspects of HIV Infection *Medicine International* (UK Edition) Volume 22:10 pp 416-418

MAJ, M. (1990) Psychiatric Aspects of HIV-1 Infection and AIDS *Psychological Medicine* 20 pp547-63

MCCOMBIE, L., ELLIOT, L., FARROW, K., et al (1995) Injecting drug use and body mass index (letter to the editor) *Addiction* 90 pp 1117-1121

MILLER, D. & RICCIO, M. (1990) Editorial Review: Non-organic Psychiatric and Psychosocial Syndromes Associated with HIV-1 infection and Disease *AIDS* May 1 4 pp 381-388

NAHLEN, B.L., CHU, S.Y., NWANYANWU, O.C. et al (1993) HIV Wasting Syndrome in the United States *AIDS* 7 pp 183-188

PRICE, B. (1990) *Body image : Nursing Concepts and Care* Hemel Hempstead: Prentice Hall

RAI-CHAUDHURI, N. (1996) Psychological impact of weight loss in HIV and AIDS: A pilot study *Unpublished D.Clin Psy Thesis* Appendix 1 Glasgow University

RAITEN, D.J. (1990) *Nutrition and HIV infection: A review and evaluation of the extant knowledge of the relationship between nutrition and HIV infection*. Life Sciences Research Office Federation of American Societies for Experimental Biology

RAMSAY, N., CATALAN, J. & GAZZARD, B. (1992) Eating Disorders in Men with HIV infection. *British Journal of Psychiatry* 160 404-407

RICHARDSON, A. (1992) Psychological Factors in HIV Disease: The Edinburgh Experience *The Psychologist: Bulletin of the British Psychological Society* 5 pp 543-547

SCHWENK, A., BURGER, B., WESSEL, D. et al (1993) Clinical Risk Factors for Malnutrition in HIV-Infected Patients *AIDS* 7 pp 1213-1219

SHERIDAN, K. & SHERIDAN, E.P. (1988) Psychological Consultation to Persons with AIDS *Professional Psychology, Research and Practice* Vol 19 no. 5 pp 532-535

STRAWFORD, A., SHARPSTONE, D., BURGESS, A. et al (1994) Weight Loss in HIV/AIDS: the efficacy of anabolic steroids as a therapeutic option *Proceedings of Biopsychosocial Conference on AIDS* P143

SMITH, J. & BIRMINGHAM, CL. (1990) HIV seropositivity and deliberate weight gain. *New England Journal of Medicine*, 322 1089-1090

SUMMERBELL, C.D., PERRETT, J.P. & GAZZARD, B.G. (1993) Causes of Weight Loss in Human Immunodeficiency Virus Infection *International Journal of STD and AIDS* 4 pp 234-236

VAMOS, M. (1993) Body Image in Chronic Illness - A Reconceptualisation *International Journal Psychiatry in Medicine* Vol 23 (2) pp 163-178

VON ROENN, J.H., MURPHY, R.L., WEBER, K.M. et al (1988) Megestrol Acetate for Treatment of Cachexia Associated with HIV Infection *Annals of Internal Medicine* Nov 15 109 (10) pp 840-841

WEAVER, K. MINGOIA, L., EASTEY, S. & HICKEY, M.S. (1990) Aggressive Nutritional Intervention Improves Quality of Life for Persons with AIDS Diarrhoea (abstract) In: *Proceedings of the American Society for the Parenteral and Enteral Nutrition Fourteenth Clinical Congress* Jan 28-31 p425

WOOD, S. (1994) The Psychological Effects of Artificial Nutritional Support *Medicine International* (UK Edition) Volume 22:10 p 406

CHAPTER 2: MAJOR RESEARCH PROJECT PROPOSAL

Psychological impact of weight loss in HIV and AIDS

Further relevant information relating to this proposal can be found in Appendix 2

Research proposal

Title

Psychological impact of weight loss in HIV and AIDS

Applicants

Naomi Rai-Chaudhuri, Trainee Clinical Psychologist,
Greater Glasgow Community Mental Health Services NHS Trust,
Gartnavel Royal Hospital, Glasgow, G12 OXH.

Dr Anna Stallard (supervisor),
Clinical Psychologist,
Department of Psychological Medicine,
Gartnavel Royal Hospital, Glasgow G12 OXH.

Louise McCombie, Dietitian,
HIV Counselling and Support Team (CAST),
Ruchill Hospital, Bilsland Drive, Glasgow.

Summary

Weight loss and malnutrition are major clinical consequences of infection with the human immunodeficiency virus (HIV). Little is known about the psychological impact of weight loss in HIV or in other disease states where weight loss is a complication, e.g. cancer. This study is designed to research a new area - the

psychological impact of weight loss in HIV infection. There is evidence that weight loss can contribute to patient distress. Research has also shown that loss of appetite and weight loss in patients causes feelings of unattractiveness; fears that others will guess seropositivity; fears relating to illness progression and control over illness; affects relationships with carers who may put pressure on patients to eat more. The study aims to explore ways in which patients with HIV infection are distressed by weight loss and to identify the psychosocial factors and coping strategies that may influence this distress. Subjects in this study will be interviewed with structured and semi-structured questionnaires. A *Psychological Impact of Weight Loss in HIV/AIDS Questionnaire* has been developed from pilot interviews with male seropositive non-intravenous drug users (IVDU) and from a survey of dietitians working in the HIV/AIDS field. Other measures in this study will include socio-demographic data, current psychological status (Hospital Anxiety and Depression Scale), a measure of social support and a locus of control scale (Multidimensional Health Locus of Control Scale). The results will focus on psychosocial aspects of weight loss and strategies that patients use to cope with weight loss. The *Psychological Impact of Weight Loss Questionnaire* is being piloted and may be a potentially useful tool for assessing where dietetic and psychological intervention can be improved with patients experiencing difficulties with weight loss.

Introduction

Weight loss and malnutrition are major clinical consequences of infection with the human immunodeficiency virus (HIV) and there is strong evidence to suggest that weight loss is a significant contributor to morbidity and mortality (Coodley, Loveless and Merrill, 1994). Whilst the medical implications of weight loss have

received coverage in the literature, there is a dearth of literature relating to psychological aspects of weight loss not only in HIV but also in other disease states where weight loss and wasting are complications e.g. cancer. By contrast the psychological impact of weight gain has generally been well documented.

In the pilot interviews conducted for this study, patients with HIV infection expressed unhappiness about their physical appearance, particularly in relation to their weight loss. Weight loss was commonly seen as an indicator of illness and increased thoughts about death and dying. It is speculated that weight loss lessens perceived control over illness. In a series of case studies, Ramsay, Catalan and Gazzard (1992) report that patients usually equate stable or increasing weight with being healthy and loss of weight with illness. In addition, knowledge of seropositivity can lead to deliberate weight gain in patients who believe that weight gain will improve their chances of living longer with infection (Smith and Birmingham, 1990). In the pilot interviews, patients also talked about the stigma of being infected with HIV and expressed fears that weight loss could cause others to suspect their HIV seropositivity. It was observed that patients who experienced weight regain had more positive attitudes towards weight loss than those who had not.

The association between weight loss and illness is strong not only for patients but also for their carers. Weight loss and food intake is often used as a barometer of overall condition. Patients may experience pressure from family and friends to eat more and when patients choose not to eat because of reduced appetite, this can lead to conflict. Patients with cancer who have lost weight have reported that carers focus too much energy on eating (Holden, 1991). It has been suggested that carers need nutritional education and guidance in providing nurturing care for patients that does not necessarily involve food (Holden, 1993).

Patients employ a variety of strategies to cope with weight loss which can range from disguising thinness by wearing extra layers of clothes to avoidance of social occasions because they feel bad about their shape. Published studies have shown that behavioural and cognitive avoidance strategies do not protect people from feelings of distress whilst more active coping is positively correlated with psychological well being (Hedge, 1990). It is anticipated that patients who have experienced weight loss will adopt a range of avoidance and active coping skills.

Aims of the study

Little is known about the psychological impact of weight loss in patients with HIV infection. The study is designed to research the psychological distress associated with weight loss in a group of seropositive, non-IVDU males and to explore the factors which may influence this distress. The results may highlight areas where dietetic and psychological support could be improved. There could also be wider implications for psychological aspects of weight loss in other disease states where weight loss and wasting are also prevalent.

Hypotheses

From the available literature and pilot interviews with patients a number of hypotheses can be put forward. It is hoped that this study will answer the following questions:

- Are patients who have experienced weight loss more distressed by weight loss than those who have not experienced weight loss?
- Are patients who have experienced weight loss more distressed by weight loss than those patients who have experienced weight loss but have subsequently regained weight?
- Is there a relationship between aspects of carer behaviour and distress caused by weight loss?
- Is there a relationship between perceived control of illness and distress caused by weight loss?
- What are the strategies used by patients to cope with their weight loss?

Plan of Investigation

Subjects

It is anticipated that around 40-60 patients with HIV infection will be recruited from Ruchill Hospital, Glasgow Royal Infirmary and the *Body Positive* organisation. Permission has been received from the Consultant Physicians at Glasgow Royal Infirmary, Ruchill Hospital and also from the management committee at *Body Positive*. All subjects will be non-IVDU males and seropositive for HIV. Suitable patients are being approached by a trainee clinical psychologist (NR-C) during out-patient or in-patient attendance. There are also recruitment posters at the locations where subjects are being recruited.

Measures

Socio-demographic data: information on age, employment status, family situation, sexuality and previous contact with psychiatric services

Weight history: information on current weight, ideal weight, history of weight change as well as details of non-HIV related weight loss eg weight loss which could be attributed to use of recreational drugs or presence of eating disorder.

Disease measures: CDC stage, CD4 cell count, time elapsed (months) since diagnosis of HIV

Psychological Impact of Weight Loss In HIV/AIDS Questionnaire (IMPWLQ): a semi-structured questionnaire has been developed from pilot interviews with 5 patients with HIV infection at Monklands District General Hospital (Lanarkshire) and from a survey of 10 dietitians who are working in the HIV/AIDS field. This has been piloted on a small group of subjects prior to the main study. The questionnaire comprises 26 items designed to elicit information from subjects on the following categories of information:

1. Distress caused by weight loss
2. Impact of weight loss and loss of appetite on relationships with carers
3. Relationship between weight loss and perceived control over HIV illness
4. Strategies that are used to cope with weight loss

As well as obtaining an overall measure of psychological impact of weight loss, there are 8 open-ended questions about attitudes towards weight loss and experience of weight loss e.g. What's the worst thing about weight loss?

Current Psychological Status: this will be measured with the Hospital Anxiety and Depression Scale (HAD) Zigmond and Snaith (1983) which has two subscales for anxiety and depression. The scale consists of 14 items

Social Supports (SS): this will be evaluated by means of a 3-item self rating scale rated on a 4 point scale as used by (Pergami, Gala et al 1994).

Locus of Control: this will be assessed by means of the Multi-dimensional Health Locus of Control Scale (MHLC) Wallston and Wallston (1978) . The scale measures the extent to which a person feels in control of their illness.

Design and procedure

Three groups of subjects will be studied for inter- and intra-group variation. Subjects will be assigned to one of three groups according to their weight history:

- *weight loss group*: patients who have experienced clinically significant weight loss since time of HIV diagnosis
- *weight regaining group*: patients who have experienced clinically significant weight loss since time of HIV diagnosis but who have subsequently regained weight
- *non-weight loss group*: patients who have experienced very little or no weight loss since time of HIV diagnosis

Subjects will be interviewed face to face by NR-C with structured and semi-structured questionnaires. Patients can choose where they would like to be interviewed (e.g.. at the out-patient clinic or at home). The questionnaires will take around 20 minutes but patients will be given the opportunity to spend up to 1 hour to talk about their experience of weight loss.

Data analysis

All information given by patients will be stored securely using a number rather than a name. The results will consist of both qualitative and quantitative data. The qualitative information will be analysed for themes. The quantitative data will be analysed using Statistical Package for Social Sciences (SPSS-PC). Potential analyses include:

- descriptions of distribution of the data across the three weight groups
(eg % patients in high IMPWLQ category)
- correlations between demographic variables and IMPWLQ scale (eg
sexuality or family situation)
- correlations between the IMPWLQ scale and theoretical counterpart
(i.e. the HAD questionnaire)

Timescales

The survey of dietitians and the pilot interviews have been completed at this stage. It is expected that the interviews for the main study will be completed in December 1995. Data analysis will be conducted between January and March 1996.

Purpose of study

The results of this study will be used to:

- identify whether distress caused by weight loss is of clinical significance in HIV infection
- pass on potential coping strategies to patients and carers
- use information to help patients, carers, psychologists and dietitians understand the psychological impact of weight loss. This perhaps would lead to more effective dietetic and psychological support for patients who are experiencing weight loss
- the questionnaire may prove to be a useful measure which could be developed further not only for patients with HIV but also for those with cancer

Ethical Considerations

Ethical approval has been received from Stobhill NHS Trust and Glasgow Royal Infirmary NHS Teaching Trust to conduct this study. Patients are required to give informed written consent. After each interview has been completed, patients will have the opportunity to discuss their experience of participating in the project in order to monitor any negative effects. There may be patients for whom psychological needs come to light as a result of the project. Arrangements have been made to have a named person to accept referrals from this project.

References

- COODLEY, G. LOVELESS, & M. MERRILL, T. (1994) The HIV Wasting Syndrome: A Review *Journal of Acquired Immune Deficiency Syndrome* 7 681-694
- HEDGE, B. (1990) The psychological impact of HIV/AIDS: The San Francisco Summaries. *AIDS Care*. 2 (4) 381-383
- HOLDEN, C.M. (1993) Nutrition and hydration in the terminally ill cancer patient; the nurse's role in helping patients and families cope. *Hospice Journal* 9 (2-3) 15-35
- HOLDEN, C.M. (1991) Anorexia in the terminally ill cancer patient: the emotional impact on the patient and family. *Hospice Journal* 7 (3) 73-84

MACALLAN, D., NOBLE, C., BALDWIN, C. et al (1993) Prospective analysis of patterns of weight change in stage IV HIV infection, *American Journal of Clinical Nutrition* 58 pp 417-424

PERGAMI, A., GALA, C., BURGESS, A. et al (1994) Heterosexuals and HIV Disease: A controlled investigation into Psychosocial Factors associated with Psychiatric Morbidity *Journal of Psychosomatic Research* 38 (4) 305-313

RAITEN, D.J. (1990) Nutrition and HIV infection: A review and evaluation of the extant knowledge of the relationship between nutrition and HIV infection. *Life Sciences Research Office Federation of American Societies for Experimental Biology*

RAMSAY, N., CATALAN, J. GAZZARD, B. (1992) Eating Disorders in Men with HIV infection. *British Journal of Psychiatry* 160 404-407

SMITH, J. & BIRMINGHAM, CL. (1990) HIV seropositivity and deliberate weight gain. *New England Journal of Medicine*, 322 1089-1090

WALLSTON, K. & WALLSTON, B. (1978) Development of the Multidimensional Health Locus of Control (MHLC) scales *Health Education Monographs* Vol 6 (2) 160 - 170

ZIGMOND, A.S. & SNAITH R.P. (1983) The Hospital Anxiety and Depression Scale. *ACTA Psychiatrica Scandinavica* 67 361-70

CHAPTER 3: MAIN RESEARCH PROJECT PAPER

Psychological impact of weight loss in HIV and AIDS: An exploratory study of seropositive non-IVDU men

This paper was written according to the guidelines of *AIDS Care*. A copy of the author notes and further relevant information can be found in Appendix 3

Abstract

This study investigated the psychological impact of weight loss in thirty seropositive non-intravenous drug using (IVDU) men who took part in semi-structured interviews. A 26 item *Psychological Impact of Weight Loss in HIV/AIDS Questionnaire (IMPWLQ)* was constructed for the purpose of this study. Additional measures used were the Hospital Anxiety and Depression Scale, Multidimensional Locus of Control Scale and Social Supports measure. Patients described how they were affected by weight loss and their coping strategies. 76% (n = 23) of the sample rated weight loss as a concern. The factors associated with this concern included feelings of unattractiveness; perceived deviation from usual weight; the meaning of thinness for individuals; fears about illness progression; and fears that others will suspect seropositivity. Patients with lower rates of disclosure about HIV status were significantly more distressed by weight loss. It was concluded that weight loss is distressing for patients and the IMPWLQ was found to be a valid measure. Recommendations have been made to improve dietetic and psychological interventions for patients with weight loss.

Introduction

Weight loss is a major clinical consequence of infection with the human immunodeficiency virus (HIV). It is perhaps one of the most common and debilitating features of HIV infection and indeed in Africa, AIDS is known as "*slim disease*" (Schwenk, 1993). Weight loss is widely recognised as a diagnostic criterion for AIDS (Castro et al, 1992) defined as involuntary weight loss of more than 10% baseline body weight. Weight loss in HIV infection can be attributed to

many factors including reduced nutrient intake (causes include loss of appetite, oral infections and depression), malabsorption of nutrients and altered metabolism (Macallan & Griffin, 1994). There is a dearth of literature relating to the psychological impact of weight loss but it has been suggested that weight loss in HIV infection is a source of psychological distress for a variety of reasons summarised below (Rai-Chaudhuri, 1996a):

- altered body image and feelings of unattractiveness
- fear that weight loss will cause others to suspect seropositivity
- psychological association between weight loss and illness progression
- weight loss and loss of appetite can affect relationships with carers

The aim of this study was to further explore the psychological impact of weight loss in men who were seropositive and non-IVDU. Attitudes towards weight loss were measured using a quantitative measure developed in a pilot study (Rai-Chaudhuri, 1996b). The research addressed the following questions: Are patients distressed by weight loss?, What is the nature of this distress?, What factors are associated with this distress (e.g. age, weight history, health locus of control, disclosure about HIV status and social supports)? and What strategies do patients use to cope with their weight loss?

Method

■ Sample

Thirty subjects took part in this study. The sample was drawn from 3 locations; Ruchill Hospital (via the HIV counselling and support team) (n = 17), Glasgow Royal Infirmary (Genito-Urinary Department) (n = 4) and the Glasgow branch of *Body Positive* (n = 9). Selection criteria were being male, seropositive for HIV, non-IVDU and with or without a history of weight loss. Potential subjects were approached and provided with information about the study. For those consenting to participate, a subsequent interview time was arranged. Subjects were interviewed on a face to face basis by a trainee clinical psychologist (NR-C) at home, on hospital ward, in hospital clinic or on *Body Positive* premises. Interviews lasted between 30 minutes and 1 hour.

Of the 30 men who were interviewed 25 (83.3%) were homosexual, 4 (13.3%) were heterosexual and 1 (3.3%) was bisexual. Using the expanded CDC classification (CDC, 1993) based on clinical events and CD4 count, 26 (86.7%) subjects in this study fulfilled criteria for diagnosis of AIDS. The mean time elapsed since diagnosis of HIV was 4 years 5 months (SD = 3 yrs; range 2 mths - 9 yrs 5 months). The mean age of the sample was 36.7 yrs (S.D. = 7.5; range 22 yrs - 47 yrs). Fifteen (50%) of the subjects lived alone, eight (26.7%) lived with their partner and 5 (16.7%) lived with their parents. Seven (16.7%) subjects were in employment (full time or part time) whilst 13 (43.3%) were on long term sick leave or not fit for work. Only 3 subjects had no experience of weight loss. One patient in the sample had a previous history (3 years prior to the study) of eating disorder (anorexia nervosa with binge eating and vomiting behaviour). The main cause of weight loss for patients in the sample are summarised in Table

1 and are comparable with figures from a London study of AIDS patients (Summerbell et al 1993).

■ Measures

Psychological impact of weight loss in HIV/AIDS questionnaire (IMPWLQ). A semi-structured questionnaire was constructed in exploratory interviews with HIV infected patients at Monklands District General Hospital (Lanarkshire) and from a survey of 10 dietitians working in the HIV/AIDS field. This was piloted on five subjects prior to the main study. The questionnaire comprised 26 items designed to elicit information from subjects on the following areas; distress caused by weight loss, impact of weight loss/loss of appetite on relationships with carers, psychological association between weight loss and illness and coping strategies. Patients were asked to rate each item on a 5 point scale ranging from never (scored as 0) to always (scored as 4). In order to control for item placement, the phrasing of 2 questions was reversed so that never scored as 0 and always scored as 4.

As well as obtaining an overall measure of psychological impact of weight loss, the questionnaire contained open-ended questions about attitudes towards weight loss including; *How has weight loss affected you?*, *What's the worst thing about weight loss?* and *How do you cope with weight loss?*

Weight history. Subjects were assigned to four weight categories using weight data was obtained from dietetic and medical notes. Individuals were categorised as having acute weight loss, chronic weight loss, stable weight or weight gain

using the classification system employed by Macallan et al (1993). Subjects were asked to estimate how much they deviated from their perceived usual weight in kilogrammes and were also questioned about their pre-existing attitudes to weight (i.e. prior to HIV infection).

Rating of weight loss

Subjects had to rate weight loss on a 3 point scale as shown below:

How would you rate weight loss? (Choose only one option)

1 = not of concern

2 = of concern but not as much as other problems

please specify other problems.....

3 = greatest concern

Current Psychological Status. This was measured with the Hospital Anxiety and Depression Scale (HAD) Zigmond and Snaith (1983) which has two subscales for anxiety and depression. The scale consists of 14 items and as a measure of psychological distress was viewed as a theoretical counterpart to the IMPWLQ.

Social Supports (SS). This was evaluated by means of a 3-item self report scale rated on a 4 point scale as used by Pergami et al (1994). Subjects were categorised into good SS (0 -5) and poor SS (6 - 12) .

Locus of Control. This was assessed by means of two scales (Powerful Others and Internal) from the Multi-dimensional Health Locus of Control Scale (MHLC) Wallston and Wallston (1978). The scale measures the extent to which a person feels in control of their illness.

Disclosure about HIV status. Subjects were asked to specify who they had disclosed their HIV diagnosis to from a list of options (i.e. partner, parents, siblings, friends, work colleagues and other). They were given a score between 0 - 12 and on the basis of the median score, subjects were classed as low disclosure (0 - 7) or high disclosure (8 - 12).

Results

■ *The Psychological Impact of Weight Loss Questionnaire (IMPWLQ)*

Scores on the IMPWLQ ranged from 2 to 86 (maximum possible score = 104). The mean score was 40.2 (s.d. = 19.9). As a descriptive summary of the psychological impact of each item in the scale, the items were ranked using their mean values as shown in Table 2. The internal consistency of the IMPWLQ was measured by reliability analysis and was found to be very high (Cronbach Alpha = 0.92). Removing each item in turn from the scale did not increase the scale's Cronbach alpha. It was concluded that a shorter version of the scale using 13 of the most clinically relevant items (1- 4, 9, 10, 12 - 15, 18, 19 and 25) was almost as reliable (Cronbach Alpha = 0.90).

To test for validity, scores on the IMPWLQ were compared with subject responses to the the question "How would you rate weight loss?". Table 3 summarises data from this question. Subjects were divided into 3 groups according to their rating of weight loss (i.e. 1 = of no concern, 2 = of concern but not as much as.... and 3 = greatest concern). One way anova revealed that there was a significant difference ($p < 0.05$) between the mean IMPWLQ scores of the three groups. *Post hoc* comparison using Tukeys Honestly Significantly

Different test showed that the mean IMPWLQ score of group 1 (mean = 23.1) differed from both the mean score of group 2 (mean = 41.5) and group 3 (mean = 53.1). In order to see whether the IMPWLQ was a valid measure of psychological distress, the scale was correlated with the HAD anxiety and depression subscales using Pearson correlation. Significant correlations were obtained between the IMPWLQ and the HAD anxiety subscale ($r = 0.5$, $p = 0.008$) and also the HAD depression subscale ($r = 0.3$, $p = 0.04$).

■ *Weight history and IMPWLQ scores*

In the sample there were 9 subjects with acute weight loss, 11 with chronic weight loss, 6 with stable weight and 5 with weight gain. For statistical purposes the weight stable and weight gain groups were combined. One way anova showed that there was no significant difference in IMPWLQ scores across the three groups.

Weight categories defined by medical or dietetic criteria do not always correspond to the patient's perception of their weight history. Subjects were asked to estimate how much they deviated from their usual weight in kg. Subject responses ranged from -28kg to +6kg (mean = - 6.9, sd = 7.1). Deviation from usual weight was scaled from 0 - 28kg perceived weight loss. Four subjects had no perceived weight loss or had gained weight and were given a score of 0. No significant correlation was found between perceived deviation from usual weight and IMPWLQ score (Pearson correlation $r = 0.29$, $p = 0.06$). However, closer inspection of the data revealed three outliers. Two of these cases were patients who had high perceived weight loss (i.e. more than 20kg) yet had IMPWLQ scores at least one standard deviation below the mean i.e. low impact scores. In

both cases there was a previous history of being overweight. The third case was a subject who had no perceived weight loss yet had an IMPWLQ score one standard deviation above the mean i.e. high impact score. This patient had a history of eating disorder. The three cases were felt to^{be} unrepresentative of the sample. When they were omitted from the correlational analysis, perceived deviation from usual weight was found to correlate positively with IMPWLQ scores ($r = 0.32$, $p = 0.04$).

■ *Socio-demographic variables and IMPWLQ scores*

Pearson correlation was carried out to see whether age was associated with IMPWLQ scores. There was no significant correlation between these variables ($r = 0.08$, $p = 0.352$). Between subjects t-tests were conducted to see whether there was an association between IMPWLQ scores and living arrangements or employment. There was no significant difference between the means of subjects who lived alone vs those who lived with others such as partner or parents ($t = 0.17$, $p = 0.865$) nor was there a significant difference between subjects who were in full or part time employment vs those who were not working ($t = 0.01$, $p = 0.994$).

■ *Psychosocial variables and IMPWLQ scores*

Pearson correlation revealed that IMPWLQ scores were not significantly correlated with either *internal* ($r = -0.17$, $p = 0.3$) or with *powerful others* ($r = 0.02$, $p = 0.89$) locus of control subscales. There was no significant correlation (Pearson correlation $r = 0.0045$, $p = 0.982$) between level of social support and

IMPWLQ scores. Disclosure about HIV status was also examined. A between subjects t-test revealed that the mean of the *high* disclosure group (30.6) was significantly lower than the mean (49.8) of the *low* disclosure group ($t = 2.28$, $p = 0.031$). Therefore subjects with lower rates of disclosure had higher scores on the IMPWLQ.

■ Open-ended questions

All of the subjects interviewed were able to talk about how weight loss had affected them. For subjects who had no experience of weight loss ($n = 3$), there was worry about future weight loss. Examples of how patients described weight loss are *"Living with weight loss is like the opposite of anorexia nervosa, you constantly worry about being underweight and become obsessed that everyone else is bigger than you"*; *"I didn't feel I was HIV positive until I lost weight"*; *"in the nightclubs it used to be the thing to be skinny, now with AIDS anyone who is too thin is thought to have AIDS, I hardly go out anymore"* and *"loss of appetite is hard to deal with, the thinner I get, the more food is put on my plate which does not help me to eat"*.

Twenty five subjects responded to the question "What's the worst thing about weight loss?". Over half of the respondents ($n = 15$, 60%) gave responses relating to the physical aspects of weight loss including *"I hate the way my bones stick out"*, *"I look like a walking skeleton"* and *"looking in the mirror is an ordeal"*. Five of the subjects (20%) gave responses relating to other people's reactions to weight loss including *"people noticing and commenting is hard to deal with"*, *"it's the fact that others can see my sunken face, I can't hide it"* and *"other people know weight loss is a sign of AIDS, I'm sure people must be talking about me at*

work". Three of the subjects provided answers relating to worry about illness including *"weight loss is a sign of illness - it makes me worry about dying"* and *"I worry about where it will end, will I keep losing more and more weight?"*

Twenty three subjects described how they coped with weight loss. Ten (43.4%) subjects spoke about changing eating behaviour including trying to eat small regular meals rather than three large meals daily, adhering to healthy eating guidelines, trying to keep weight up even when not losing weight and using appetite stimulants such as cannabis (n = 5). Seven responses (30.4%) related to efforts to hide thinness including wearing extra layers of clothes, buying new fitted clothes or growing a beard. Five (21.7%) subjects described strategies to help deal with reactions from others, particularly family members such as pretending to eat more e.g. *"my mum would bring me a cooked breakfast. She would leave the room and I would pretend to eat it but I would really throw it out of the window. If I didn't do this, the rest of the day would be unbearable as she would nag me to eat"* Three subjects reported making up reasons for their weight loss to protect themselves from others suspecting HIV status e.g. rare lung disease.

When talking about previous attitudes towards weight, three subjects reported being overweight prior to HIV infection. In all three cases, initial weight loss was greeted with praise and positive comments from other people. Indeed patients of average weight also can feel pleased with initial weight loss e.g. *"at first it was interesting seeing myself look gaunt and I thought I looked quite good"*. Nine patients (39.1%) mentioned having a specific weight which they did not wish to fall below e.g. *"I was weighed at the hospital and they told me I had only lost 1kg but for me it was devastating because I had convinced myself that I wouldn't go below 80kg"*.

Discussion

The literature relating to HIV and AIDS makes little reference to the psychological impact of weight loss yet in this study, 76% (n = 23) of those interviewed rated weight loss as being either their greatest concern or of concern. Only 23% (n = 7) subjects rated weight loss as not of concern. It could be argued that the recruitment process employed in this study attracted patients who were more distressed by weight loss.

When looking at the nature of the distress caused by weight loss, over half of the sample reported that the worst thing about weight loss was the change in physical appearance i.e. looking so thin and not looking attractive. It could be speculated that younger patients may be more distressed by weight loss because of the importance of they place on body image but age was not shown to correlate with IMPWLQ scores.

It was initially hoped that a comparative study could be conducted either with different patterns of weight loss (i.e. patients with no weight loss vs those with weight loss) or patients at different stages of infection. Weight loss is however associated with later stages of infection. Indeed 86.7% of the sample fulfilled criteria for AIDS. Patients with no history of weight loss were difficult to access as they are relatively healthy and therefore less frequent attenders at hospitals.

Subjects were initially categorised by medical categories of weight loss i.e. acute, chronic and weight stable/weight gain but there were no differences across the three groups in terms of psychological impact of weight loss. Although patients meet criteria for weight stable or weight gain categories they may still be below their usual weight. It was found that perceived deviation from usual weight was

important. The more someone perceives themselves as falling below their usual weight, the more distressed they are by weight loss. This was not true for patients who had a previous history of being overweight or eating disorder. An individual who has been overweight and has tried for years to lose weight may respond positively to weight loss even when ill. For the patient with a previous history of eating disorder, weight loss was associated with memories of being ill with anorexia. For these patients the *meaning of weight loss* was very different from the rest of the sample. In addition, many patients referred to a specific weight barrier which they did not wish to fall below. This may be important to explore with patients as it can cause distress when being weighed.

From patient interviews, there appeared to be a strong psychological association between weight loss and illness progression. Four of the top 10 ranked IMPWLQ items related to illness progression. It was suggested that weight loss lessens perceived control over illness but locus of control was not significantly correlated with IMPWLQ scores. This may result from using the MHLC scale which is a general measure of locus of control and does not refer specifically to control over HIV (Durrance et al, 1991; brief conference abstract).

Distress also appears to relate to the effects of weight loss and loss of appetite on family relationships. Patients who live in parental homes appear to report greater conflict than those who live with partners or alone. It is interesting to note that 4 of the 5 subjects who lived with their parents had returned to the parental home after diagnosis of HIV which has inherent difficulties. It is distressing for family members to witness weight loss. Loss of appetite and not eating may be viewed as the patient not trying hard enough. Pressure to eat may lead to conflict especially where the individual has been used to living independently. Similar problems were encountered in a previous study with terminally ill cancer patients

(Holden, 1993). Mothers view caregiving as providing food and can become frustrated if patients don't eat. Due to the small sample size it was not possible to determine if living in parental home correlated with distress caused by weight loss.

It was also found that patients with low rates of disclosure had higher IMPWLQ scores. In addition, the IMPWLQ item *"I fear that weight loss will cause others to suspect that I am HIV positive"* had the fourth highest item mean. The visibility of weight loss contributes to fears of being identified as HIV positive. This will be greater where patients have lower rates of disclosing their HIV status to others. In this study, some patients who were not open about their HIV status invented other reasons for their weight loss to keep family or work colleagues from guessing seropositivity. Fear of disclosure can stem from fear of discrimination and a desire to conceal homosexuality (Hays et al, 1993). The visibility of weight loss can add to fears of disclosure and potential stigmatisation and rejection. Although disclosure has its advantages, Hays et al (1993) warn that the benefits of doing so must be weighed up alongside the potential costs.

The implications for dietitians and psychologists are that in addition to dietetic intervention, patients may need psychological support to cope with weight loss. Patients have to deal with feelings of unhappiness about appearance and low self esteem. When patients lose weight, they may need to discuss issues of disclosure as others question their loss of weight. Encouraging patients to employ active rather than avoidance coping strategies such as changing dress style may be helpful. Education about weight loss in HIV and AIDS should be available for carers in the form of leaflets. This may help them to understand that weight loss is part of the HIV illness and that it is not the patient's fault when they do not eat. In providing feedback about participating in the study, 63.3% (n =

19) patients reported that talking about weight loss was extremely helpful and therapeutic. Patients complained that both carers and healthcare staff underestimate how distressing weight loss can be. The general belief is that weight gain is far more distressing.

In conclusion, despite the limitations of this exploratory study (lack of comparative data, small sample size) there is strong evidence that weight loss is distressing for patients. The meaning of weight loss should be explored with patients especially where patients have previous history of being overweight or have eating disorder. The *Psychological Impact of Weight Loss in HIV and AIDS Questionnaire* (IMPWLQ) was found to be a valid measure of psychological distress. It compared well with subjective ratings of weight loss, correlated with the HAD and had excellent internal reliability. More studies are needed however to further evaluate the psychometric properties of the scale and the shortened 13 item version is recommended. Future areas of research could compare weight loss in HIV infected patients with cancer patients. There is also a gap in the literature relating to female attitudes towards weight loss in HIV and AIDS.

References

CASTRO, K.G., WARD, J.W., SLUTSKER, L. et al (1992) 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults *MMWR* 41 (RR-17)

DURRANCE, P., NEWMAN, S., FELL, M. et al (1991) The impact of perceived control over HIV and general health *International conference on AIDS* 7 (1) Jun 16-21 PG 410 (abstract no.MD 4081)

HOLDEN, C.M. (1993) Nutrition and hydration in the terminally ill cancer patient; the nurse's role in helping patients and families cope. *Hospice Journal* 9 (2-3) pp 15-35

HAYS, R.B., MCKUSICK, L.P., HILLIARD, R. et al (1993) Disclosing HIV seropositivity to significant others *AIDS* 7 pp 425 - 431

HOLDEN, C.M. (1991) Anorexia in the terminally ill cancer patient: the emotional impact on the patient and family. *Hospice Journal* 7 (3) pp 73-84

MACALLAN, D., NOBLE, C., BALDWIN, C. et al (1993) Prospective analysis of patterns of weight change in stage IV HIV infection, *American Journal of Clinical Nutrition* 58 pp 417-424

MACALLAN, D. & GRIFFIN, G.E. (1994) Nutritional Aspects of HIV Infection *Medicine International* (UK Edition) Volume 22:10 pp 416-418

PERGAMI, A., GALA, C., BURGESS, A. et al (1994) Heterosexuals and HIV Disease: A controlled investigation into Psychosocial Factors associated with Psychiatric Morbidity *Journal of Psychosomatic Research* 38 (4) 305-313

RAI-CHAUDHURI, N. (1996a) Psychological impact of weight loss in HIV and AIDS: A review *Unpublished D.Clin Psy Thesis* Chapter 1 Glasgow University

RAI-CHAUDHURI, N. (1996b) Psychological impact of weight loss in HIV and AIDS: A pilot study *Unpublished D.Clin Psy Thesis* Appendix 1 Glasgow University

SCHWENK, A., BURGER, B., WESSEL, D. et al (1993) Clinical Risk Factors for Malnutrition in HIV-Infected Patients *AIDS* 7 pp 1213-1219

SUMMERBELL, C.D., PERRETT, J.P. & GAZZARD, B.G. (1993) Causes of Weight Loss in Human Immunodeficiency Virus Infection *International Journal of STD and AIDS* 4 pp 234-236

WALLSTON, K. & WALLSTON, B. (1978) Development of the Multidimensional Health Locus of Control (MHLC) scales *Health Education Monographs* Vol 6 (2) 160 - 170

ZIGMOND, A.S. & SNAITH R.P. (1983) The Hospital Anxiety and Depression Scale. *ACTA Psychiatrica Scandinavica* 67 361-70

Table 1: Cause of weight loss in study sample and comparison with London sample*

	GLASGOW study sample n = 27	LONDON sample n = 59
opportunistic infection (e.g. PCP, T.B., diarrhoea)	n = 17 (63%)	n = 44 (74%)
psychological (e.g. depression, loss of partner, knowledge of seropositivity)	n = 4 (14.8%)	n = 6 (10.1%)
unknown	n = 2 (7.4%)	n = 7 (11%)
oral infection	n = 2 (7.4%)	not known
drug related	n = 1 (3.7%)	n = 2 (3.8%)
diarrhoea (i.e. restricting food intake to avoid diarrhoea)	n = 1 (3.7%)	not known

*Figures taken from AIDS patients described in Summerbell et al (1993)

Table 2: Item means & rank positions of psychological impact

	item mean	rank position of psychological impact
25. I worry about losing weight	2.22	1
18. I see weight loss as a sign of deteriorating health	2.18	2
1. I feel unhappy about weight loss	2.14	5*
2. I worry that weight loss will cause others to suspect I am HIV positive	2.14	5*
3. I fear that weight loss will worsen the course of my HIV disease	2.14	5*
19. When I lose weight I feel I have less control over HIV illness	2.11	7*
21. Weight loss stops me from taking part in exercise please specify.....	2.11	7*
8. I feel I have control over my weight	2.03	8
10. I am constantly thinking about food and eating	1.77	9
12. Seeing my reflection in a mirror or window has made me feel bad about my weight	1.66	10
13. Weight loss makes me less sexually attractive	1.62	13*
20. My sex life is affected by weight loss	1.62	13*
7. I worry that I will not gain weight	1.62	13*
4. I experience pressure from family / friends to eat more	1.59	14

* = tied ranks

Table 2 contd: Item means & rank positions of impact

	item mean	rank position of psychological impact
9. If I eat poorly, others are angry with me or criticise me	1.55	15
15. I am distressed by others commenting on my thinness	1.51	16
11. I avoid situations where others may see my body e.g. swimming	1.44	17
17. I use appetite stimulants eg. alcohol medication, cannabis please specify.....	1.4	18
26. I disguise weight loss by wearing extra layers of clothe	1.11	19
14. I pretend to others that I am eating more than I actually am	1.18	20
5. I avoid social situations because I feel bad about my shape	0.96	22*
23. Weight loss makes it hard for me to do everyday things because of tiredness	0.96	22*
24. Family and/or friends pay too much attention to my weight	0.88	23
16. I avoid eating with groups of people e.g. family or friends	0.81	24
22. I can choose what I eat and when I can eat	0.74	25
6. I have felt so bad about weight loss that I have cried	0.62	26

* = tied ranks

Table. 3. Subject ratings of weight loss

HOW WOULD YOU RATE WEIGHT LOSS?	
1. not of concern	n = 9 (30%)
<p>2. of concern but not as troublesome as some <i>other problems</i> (please specify)</p> <p>actual responses to <i>other problems</i> were:</p> <p>pains in chest and back PCP - painful coughing memory loss herpes sexual problems T.B. Kaposi's sarcoma skin condition loneliness - loss of partner blindness from viral infection</p>	n = 10 (33.3%)
3. greatest concern	n = 11 (36.7%)

CHAPTER 4: SMALL SCALE SERVICE EVALUATION PROJECT

Involving people with learning disabilities in a review of services provided by a community team

This paper was written according to the guidelines of *Clinical Psychology Forum*.

A copy of the author notes and further information can be found in Appendix 4

Introduction

In Greater Glasgow, the phased 'Care in the Community' strategy has led to increasing opportunities for people with learning disabilities to receive health and social services in the community. In 1995, Greater Glasgow Community and Mental Health Services NHS Trust undertook a six month review of four Community Learning Disability Team (CLDT) services. Recent organisational changes in health services have placed greater emphasis on service evaluation in order to make services more responsive to client needs (Longley & Collins 1994). This is particularly important in community services for clients with learning disabilities. As well as giving feedback to service providers to help them achieve and maintain high standards of performance, it also ensures that vulnerable individuals and their families are not left stranded in the community (Bradley & Bersani 1990).

Whilst the involvement of clients is a crucial aspect of service evaluation, it is only recently that efforts have been made to seek views from people with learning disabilities. The inclusion of their views presents them as valued individuals and enables them to have a say about the services they receive. It is acknowledged that there are inherent problems in obtaining views from people with learning disabilities such as communication difficulties and response bias (Chapman & Oakes 1995). The general assumption is that people with learning disabilities are liable to response acquiescence (Shaw & Budd 1982; Clare & Gudjonsson 1993). However various question formats have been used successfully and it has been suggested that response bias in people with mild and moderate learning disabilities is overestimated (Dagnan & Ruddick 1995).

A number of methods have been used to enable people with learning disabilities to give feedback about services. Many people with learning disabilities have difficulty answering open ended questions (Sigelman et al 1982). However, it has been found that whilst closed questions allow high response rates, it is the open ended questions which allow more valid responses (Flynn 1988). Dagnan, Dennis and Wood (1994) outlined three formats (visual analogue, personal questionnaires and either/or questions) which were all useful in evaluating client satisfaction with community psychology services. Chapman and Oakes (1995) suggest that a combination of multiple choice and open ended questions should be used in surveying client satisfaction to allow a less interrogative interviewing procedure. Sigelman and Budd (1986) report that the use of symbols and written responses will increase the validity of responses and similarly March (1992) suggests that use of pictures will reduce response bias and decrease the verbal requirements of the interview.

As part of the CLDT review carried out by Greater Glasgow Community and Mental Health Services NHS Trust, a questionnaire was devised to obtain client views of services they had received. In this paper, the pilot study of the questionnaire is described. The aim of the pilot study was to assess the usefulness of the questionnaire as a tool for obtaining views from clients with mild - moderate learning disabilities and to address the following questions:

- could clients identify the CLDT members who came to help them from their photographs?
- could clients identify the primary area CLDT members helped them with?
- could clients express positive and/or negative views about CLDT services?

Method

Due to the time constraints of the review it was agreed that the client survey would be restricted to the North West Glasgow CLDT. Whilst some previous surveys of people with learning disabilities have involved asking team members to select cases from their caseload (e.g. Dagnan & Ruddick 1995) it was felt that this method could introduce bias into the results. For this study, clients were randomly selected from recent team reviews of care by a trainee clinical psychologist who was on placement with the team at the time. Following selection, care plans were consulted and in some cases, case coordinators were approached to assess client suitability for being interviewed.

Participants

15 people with learning disabilities were interviewed. The group consisted of 11 men and 4 women. All clients were classified as having a mild or moderate learning disability. Clients had been seen by 1 or more members of the team in the previous six months. Three clients had recently been discharged from the team. Clients were identified as receiving help from CLDT team members: speech therapy (n = 2); occupational therapy (n = 2); clinical psychology (n = 2); physiotherapy (n = 1); social work (n = 2); psychiatry (n = 1); home care assistant (n = 2); and community psychiatric nurse (n = 3). In addition, from discussion with client case managers, the primary area of help received was identified e.g. talking about feelings, help with cooking, help with planning a holiday etc.

Interview

The interviews took place over a six week period. Clients were interviewed in one session which lasted around 30 minutes. Interviews were conducted in the client's home (n = 8) or at client's place of work (n = 7). The interviews were carried out by a trainee clinical psychologist (NR-C) and an informal, conversational style was adopted to gain rapport with client. The purpose of the study was explained and additional reassurance was needed for 4 of the clients who were anxious about the nature of the survey.

Questionnaire

The questionnaire was devised specifically for the purposes of this study by the trainee clinical psychologist, the speech and language therapist and the senior nurse manager from the CLDT. It had never been used before. It consisted of 8 questions; 5 structured questions and 3 open-ended questions. It included photographs and colour pictures drawn with a computer graphics package to facilitate communication and reduce response bias. The order of the pictorial choices was alternated in questions 2, 4 and 5 to reduce positional response bias.

■ Structured Questions

1. *Who came to visit you?*

From a series of 22 'Polaroid' photographs of team members, the client was asked to identify the team member(s) who had come to see them.

The photographs included 4 team members who had recently left the team.

2. How did you get on with (the team member)?

Clients were asked to choose 1 of 4 responses; very good, okay, not so good and can't remember. Each response was said aloud, written down and had a pictorial representation (i.e. smiling face, neutral face, sad face and puzzled face).

3. What did (the team member) help you with ?

From a series of 17 pictures clients were asked to point to what team member(s) had helped them with. Information about each client's CLDT contact was obtained from care plans prior to the interviews. The pictures illustrated the different roles of team members. e.g. cooking, bathing, communication, medication, foot care, help with finding accommodation, talking about feelings etc). There was also an item to represent a response of "something else" for areas not represented by the pictures.

4. How did you get on with (area being helped)?

Clients were asked to choose 1 of 4 responses as in Question 2

5. How do you feel after (team member) helping you with (area being helped)?

Clients were asked to choose 1 of 3 responses; better, no change and worse. Each response was read aloud, written down and had a pictorial representation as in questions 2 and 4.

■ Open-Ended Questions

6. *What did you like about (team member) coming to see you?*
7. *What did you not like about (team member) coming to see you?*
8. *Do you have more ideas for how the community team could help you?*

Results

The information obtained was in the form of ratings and free comments. The ratings are expressed in terms of percentages. The free comments were studied for positive and negative themes.

■ Structured Questions

All clients were able to point to at least 1 team member that they knew. 13 (87%) clients correctly pointed to the team member(s) who came to help them and 11 of these people could name the team member. 2 clients (13%) did not recognise team member from their photograph but could name them. 11 clients (73 %) clients were able to correctly identify primary area(s) they had received help with. 2 clients identified other areas and 2 clients were unable to answer the question. The ratings provided by clients about contact with team member(s) are shown in Table 1.

■ Open-Ended Questions

Positive themes

Thirteen clients mentioned social aspects of contact with the team member as something they liked. Responses included: "someone to talk to", "(team member) listens to me" and "(team member) is a good friend"

Five clients mentioned issues related to support from the team member. Responses included: "it's good to have support", "I can contact (team member) at any time if I need help", "I can phone if I have a problem" and "I see (team member) a lot"

Two clients mentioned specific qualities of team member i.e. "patience", "understanding"

Two clients spoke of help to be independent e.g. "shows me how to do it myself"

One client reported an association between team help and living in the community i.e. "if I learn to do this, I won't have to go back to hospital"

Negative themes

Two clients reported that they were unhappy when team members moved on. One of these clients complained that he had discussed something important with a team member who subsequently left the team. The client was now unsure about what was going to happen.

One client felt that he did not know what was happening with their team member contact

One client felt that she would like to spend more time with team members when they visited

One client mentioned that he would like more regular contact with the team

Discussion

The results show that clients in this study were able to provide both positive and negative feedback although the positive feedback was far greater than the negative feedback with only 4 (26%) clients volunteering negative comments about the team. No client rated team member contact as "not so good" or their help as making them feel "worse". The results are a favourable reflection of the CLDT services although it is also suspected that in learning disabilities (as in medical and psychiatric settings) clients generally say they are satisfied with services (Chapman and Oakes 1995).

A substantial proportion of clients reported that they liked social aspects of team contact. This is particularly relevant for individuals with learning disabilities as their social contacts are often limited (Legault 1992, Shanly and Rose 1993). Increasing the social networks and enhancing the community presence of clients with learning disabilities are accomplishments that community services should strive to achieve (O'Brien, 1990). The therapeutic nature of social contact can make it difficult for clients when team members move away from the team (as

reported by 2 clients in this survey). Whilst staff turnover is inevitable, it is important that clients are prepared for the team member leaving. One technique employed by a former team member was to write to clients individually prior to leaving the team.

The use of photographs of team members was extremely useful. Every client who was interviewed responded to the photographs with speech or signing. The photographs helped to focus the interview and in 10 of the interviews, simply seeing the photograph prompted clients to talk about the team member and the help they had received in an informal manner before the rest of the questions had been asked. It is also interesting to note that 8 (53%) clients were able to name additional team members that they had not worked with but knew in passing.

The results also show that clients were able to answer both structured and open ended questions although the structured format had a much higher response rate (only 3% questions were unanswered) compared to the open ended questions (38% were unanswered). Question 8 which was the most open ended of the questions had the lowest response rate with only 2 clients responding. However some clients clearly found it easier to answer questions which were more verbal and open ended. For some clients, structured questions are seen as having "right" or "wrong" answers (Dagnan & Ruddick, 1995). At least 6 clients found it difficult to focus on the survey either because they were easily distracted or wanted to talk to the interviewer about other matters that were concerning them. Repetition of questions was used to keep the focus of the interview.

When interviewing clients with learning disabilities, a flexible approach is necessary as individual variation makes it difficult to create standardised

measures. The simple, concrete nature of this questionnaire and the almost universal ability to recognise photographs make it possible to use this method with a range of clients who are seen as having mild or moderate learning disabilities. It can be used with clients whose verbal skills are limited and also act as a framework for those clients who are more verbally skilled.

Future work

The questionnaire was a successful method of obtaining both positive and negative views of CLDT services from clients with mild to moderate disabilities which could be fed back to service providers. It is anticipated that the questionnaire will be incorporated into the ongoing CLDT review process although the expense of this technique is acknowledged in terms of time spent interviewing and in updating team photographs. Time constraints restricted this survey to one aspect of client satisfaction with community services. Future review processes could perhaps employ techniques to include the following areas which this study did not address:

- views from clients about satisfaction with life in the community in a wider sense than this survey
- views from carers, relatives and advocates which could be used in addition to views from clients
- views of clients with severe or profound disabilities via their carers, relatives or advocates

References

BRADLEY, V.J. & BERSANI, H.A. (1990) **Quality assurance for individuals with developmental disabilities: it's everybody's business.** Paul H Brookes Publishing Co. Baltimore, Maryland

CHAPMAN, K. & OAKES, P. (1995) Asking people with learning disabilities their view on direct psychological intervention **Clinical Psychology Forum** July 28 - 33

CLARE, I.C. & GUDJONSSON, G.H. (1993) Interrogative suggestibility, confabulation and acquiescence in people with mild learning disabilities **British Journal of Clinical Psychology** 32 (3) 295 - 301

DAGNAN, D, DENNIS, S. & WOOD, H. (1994) A pilot study of the satisfaction of people with learning disabilities with the service they receive from a community Psychology Service. **British Journal of Developmental Disabilities** 40 38 - 44

DAGNAN, D. & RUDDICK, L. (1995) The use of analogue scales and personal questionnaires for interviewing people with learning disabilities. **Clinical Psychology Forum**, May 21 - 24

FLYNN, M. (1988) Adults who are mentally handicapped as consumers: issues and guidelines for intervention. **Journal of Mental Deficiency Research** 30 369 - 377

LEGAULT, J.R. (1992) A study of the relationship of community living situation to independence and satisfaction in the lives of mentally retarded adults **Journal of Intellectual Disability Research** 36 (2) 129 - 141

LONGLEY, S. & COLLINS, J. (1994) The development of a nonverbal satisfaction measure for use with people who have severe or profound learning disabilities **British Journal of Developmental Disabilities** Vol XL 2 no79 143 - 149

MARCH, P. (1992) Do pictures help adults with severe mental handicaps make choices? **British Journal of Mental Subnormality** 37 122 - 8

O'BRIEN, J. (1990) Developing High Quality Services for people with developmental disabilities In

Bradley, V.J. & Bersani, H.A. (Eds) **Quality assurance for individuals with developmental disabilities: it's everybody's business.** Paul H Brookes Publishing Co. Baltimore, Maryland

SHANLY, A. & ROSE, J. (1993) A consumer survey of adults with learning disabilities currently doing work experience **Mental Handicap Research** 6 (3) 250 - 262

SHAW, J.A. & BUDD, E.C. (1982) Determinants of acquiescence and naysaying of mentally retarded persons **American Journal of Mental Deficiency** 87 108 - 10

SIGELMAN, C.K. et al (1982) Evaluating alternative techniques of questioning mentally retarded persons **American Journal of Mental Deficiency** 86 511 -518

SIGELMAN, C.K. & BUDD, E.C. (1986) Pictures as an aid in questioning mentally retarded persons **Rehabilitation Counselling Bulletin** 29 173 - 181

Table 1: Ratings provided by clients about contact with CLDT member

	very good	okay	not so good	can't remember
2. How did you get on with (team member)?	13 (87%)	2 (13%)	0	0
4. How did you get on with (area being helped)?	11 (73%)	3 (20%)	0	1 (6%)
	better		no change	worse
5. How did you feel after (team member) helping you with (area being helped)?	13 (87%)		2 (13%)	0

*ratings provided as number of clients with percentages in brackets

CHAPTER 5: SINGLE CLINICAL CASE RESEARCH STUDY (1)

Behavioural treatment of habitual caffeine use in a woman with moderate learning disabilities

This paper was written according to the guidelines of the *Journal of Behaviour Therapy and Experimental Psychiatry*. A copy of the author notes can be found in

Appendix 5

Abstract

This case report outlines the behavioural treatment of habitual caffeine use in a woman with moderate learning disabilities. Initial stages involved education about the sources and effects of caffeine and self monitoring of daily caffeine intake. A changing criterion design was successfully used to gradually reduce daily caffeine intake by 75% from an extremely high to a moderate level of consumption. Strategies were introduced to help prevent relapse and treatment gains were maintained at 6 month and 12 month follow-up.

Introduction

Caffeine is the most widely used drug in the world (Hughes et al 1992) and whilst in low doses caffeine may improve concentration and attention, there is growing evidence that prolonged use may produce deleterious effects on health e.g. heart disease, peptic ulcers and cancer in the kidneys or bladder (Gilliland & Bullock, 1984). Common sources of caffeine and guidelines for daily use are outlined in Table 1. Whilst some individuals display dependence on caffeine and exhibit tolerance, there was insufficient evidence for these symptoms to fulfil the criteria for Substance Abuse or Substance Dependence in DSM-IV (Hughes et al, 1992). High caffeine consumption is however associated with a group of symptoms defined in DSM-IV as caffeine intoxication (caffeinism). The symptoms include restlessness, nervousness, insomnia, flushed face, diuresis and gastrointestinal disturbance which can make caffeinism indistinguishable from anxiety disorder.

Behavioural treatments have been shown to be effective in reducing caffeine intake (Foxy & Rubinoff, 1979; James & Stirling, 1983). A behavioural approach to

treatment should incorporate education about the sources and effects of caffeine, self monitoring of caffeine intake and then gradual reduction of caffeine intake by substitution with other beverages (Gilliland & Bullock, 1983). A changing criterion design was used by Foxx and Rubinoff (1979) to gradually reduce daily caffeine intake in 3 subjects. Caffeine was reduced from a daily average intake of 1100mg per day to less than 350mg per day and this reduction was maintained at 40 month follow-up. Abrupt cessation of caffeine is ill advised especially in heavy users as caffeine withdrawal is a recognised syndrome in DSM-IV. This includes headaches, fatigue, nausea, anxiety, depression and a strong desire for caffeine which can last up to two weeks after abstinence.

Excessive caffeine intake is especially prevalent among psychiatric inpatients (Hughes et al, 1992). It is reasonable to assume that caffeine use is also higher in clients with learning disabilities who have lived in institutions as ward routines often build in tea and coffee consumption. The literature does not appear to refer specifically to caffeine consumption in clients with learning disabilities. This case report outlines adaptation of behavioural treatment of habitual caffeine use for a woman with moderate learning disabilities, "Miss H".

Case history

Miss H was a 38 year old woman with moderate learning disabilities who for two years had been living in a supported housing project where clients had access to staff support in a nearby flat. Miss H had previously lived in a long stay hospital for people with learning disabilities and was reported to be coping well with the demands of independent living. Although there had been no evidence of disturbed behaviour for 15 years, she was currently receiving a high dose of

antipsychotic medication (500mg/daily Chlorpromazine). In addition she had a speech dysfluency which made her speech difficult to understand.

Miss H was consuming an excessive amount of caffeine every day. It was estimated to be over 20 cups of coffee and 5 cups of tea. She was drinking the cheapest brand of powdered instant coffee in 100g packets and when this was finished she often "stole" coffee from her two flatmates. She knew this was wrong but insisted she was "dying for a coffee". Her desire for coffee was usually so strong that she could not wait for the kettle to boil resulting in her drinking cold coffee. At the day centre she attended, restrictions were placed on coffee drinking but Miss H bought small sachets of coffee to consume in secret with cold water in the toilets.

There was evidence of sleep disturbance and Miss H frequently got up in the middle of the night to make coffee which led to arguments with her flatmates. Miss H had a long history of gastrointestinal complaints. There appeared to be symptoms of anxiety including physical tension and chest pain which were either caused by or were being exacerbated by her caffeine intake. Miss H had attended a Speech and Language Therapist who felt that an anxious style of breathing could be contributing to Miss H's speech dysfluency. Miss H's symptoms did not fully meet the criteria for caffeine intoxication but it is recognised that caffeine intoxication may not occur despite high intake due to the effects of tolerance (American Psychiatric Association, 1994).

A strong desire for caffeine when she stopped drinking coffee maintained her high intake. Miss H lacked insight into the harmfulness of her caffeine intake and agreed to be seen because her keyworker had insisted on it. There had been no previous attempts to reduce caffeine intake.

Baseline Assessment

Self monitoring is increasingly seen as an important component of treatment for addictive behaviours to help increase awareness and self control. Although Miss H was also drinking tea, treatment focussed only on coffee consumption. As Miss H was able to read and write simple words, she was given diary sheets in which to record every cup of coffee she consumed. The diaries allowed a functional analysis of her drinking behaviour and confirmed that most of her coffee consumption was in the evenings at home. Unfortunately, as Miss H poured coffee straight from the packet into each cup without using a teaspoon, it was not possible to estimate how much coffee she was putting into each cup. Miss H was asked to hand in her empty coffee packets to staff on a daily basis so that her overall intake could be measured. Over the 4 week baseline period, Miss H was drinking an average of 140g coffee daily (estimated to be 2100mg caffeine) which would class her as an extremely heavy user of caffeine.

A pretreatment measure of anxiety was also obtained. Lindsay and Michie (1988) adapted the Zung Self rating Anxiety Scale (SAS) for people with learning disabilities. Miss H reported the presence of 9 of the 20 anxiety symptoms. There are no norms available for the Adapted Zung SAS.

Prior to treatment, medical advice was obtained from Miss H's general practitioner as there was concern about possible withdrawal effects. It was agreed that caffeine should be reduced in stages with monthly checks on Miss H's physical condition throughout treatment.

Treatment

The goal of treatment was to achieve a reduction of caffeine from a high to a moderate (i.e. 250 - 749mg/day) range of intake. Miss H showed no knowledge of why she should reduce her caffeine intake. The initial stage of treatment involved educating Miss H about the sources and effects of caffeine and she was given a simple information sheet. This contained pictures of the main sources of caffeine (coffee, tea, cola, over the counter analgesics, chocolate etc.) and included a drawing of the human body to highlight the physical effects of caffeine (palpitations, gastrointestinal complaints, diuresis, nervousness etc). She was also informed of the possible effects of withdrawal (nausea, fatigue and headaches). In view of her learning disability, feedback was obtained from Miss H about her comprehension of caffeine by asking questions such as "What is caffeine?" and "Why is caffeine bad for you?". She responded correctly to these questions and was very willing to participate in a reduction programme. Miss H was seen on a weekly basis for 20 weeks of treatment during which coffee intake was reduced in successive phases.

To facilitate caffeine reduction, decaffeinated coffee was used. This was mixed with ordinary coffee into one container. The 'mixed' coffee was weighed and administered to Miss H every morning by staff at the housing project. Miss H was to take responsibility for making the coffee last all day and was asked not to supplement this with extra coffee bought from the local shop. In treatment phases 1 and 2 Miss H was administered the same overall coffee as she had been drinking during the baseline phase (i.e. 140g) but in phase 1, 20g of this was decaffeinated coffee and in phase 2 this was increased to 40g. Miss H complied well with treatment and reported satisfaction with the taste of the mixed coffee. There was no evidence of withdrawal symptoms. The only lapse occurred

during phase 2 (week 6) when Miss H was on holiday with the day centre and staff had forgotten to provide her with a jar of mixed coffee. Miss H was unsure about what to do and during seven days supplied herself with coffee from the supermarket. This highlighted the importance of staff support throughout treatment

In phases 3 to 5, the overall bulk of coffee was reduced in stages (from 140g to 50g). Miss H was being presented with smaller overall amounts of coffee. In the beginning weeks of phases 3 and 4, she found it very difficult to make her coffee allowance last all day and as a result lapsed. On both occasions she went to the local shop and bought a large bag of coffee. She felt extremely guilty about her lapses and in addition experienced increased physical symptoms e.g. on one occasion she was unable to sleep all night after a binge of coffee and became extremely agitated and aggressive. The lapses were useful learning experiences as Miss H experienced direct negative effects of caffeine. She was reassured that a lapse did not mean a total relapse.

After 20 weeks, Miss H had successfully achieved a reduction of her caffeine intake. As she was now within the moderate range it was felt that no further reduction was necessary. The aim was to maintain Miss H at that level. As with any addictive behaviours, maintaining progress and identifying how to prevent relapse was important. Continued staff support was vital. High risk situations for coffee drinking were identified (e.g. being bored in the flat in the evening) and lifestyle changes recommended. Miss H was taught ways to resist the urge to drink coffee which Marlatt and George (1984) call "urge surfing" using distraction and relaxation. A simplified version of abbreviated progressive relaxation for people with learning disabilities was used (Lindsay & Baty, 1986). It was hoped that Miss H would build on the time waiting for the kettle to boil so that she

did not drink cold coffee. However, after treatment, Miss H still expressed a preference for cold coffee and was unwilling to drink hot coffee.

Results

The results are presented in Figure 1. Miss H successfully achieved a 75% reduction in her daily caffeine intake from an extremely high level (2100mg/day) to a moderate level (450mg/day) and there was no evidence of withdrawal symptoms. Miss H complied well with the treatment programme as did staff in the housing project. Miss H was aware of the dangers of heavy caffeine use and incorporated more non-caffeine drinks into her diet such as lemonade and blackcurrant tea. Rating with the Adapted Zung SAS revealed improvement as Miss H identified presence of 7 instead of 9 anxiety symptoms. At 6 month follow-up Miss H's progress had been maintained at 450mg caffeine daily with continued staff supervision. At 12 month follow-up, this was continued but there were no observable improvements in Miss H's sleep pattern, gastrointestinal problems or speech dysfluency.

Discussion

This clinical case study showed that a changing criterion design was successful in reducing habitual coffee drinking in a woman with moderate learning disabilities. Following education about the effects of caffeine, Miss H became motivated to receive help to reduce her intake. In this case, it was possible for staff to support administration of coffee on a daily basis. It is acknowledged that a different approach may be required where there is less staff support. Where clients are

not motivated to change, it may be necessary to employ a reward system to help them achieve each criterion.

When Miss H presented for treatment there was insufficient evidence for caffeine intoxication. This was partially due to the effects of tolerance but Miss H's medication, Chlorpromazine, was likely to be acting as a pharmacological antidote to the caffeine due to its sedative nature. Miss H's medication was kept stable throughout treatment and at 12 months follow-up, this was under psychiatric review. Interactive effects between caffeine and antipsychotic medication have been documented (Pilette, 1983). Dry mouth is often a side effect of medication and some patients may relieve this by taking tea and coffee. There is evidence however that caffeine intake can exacerbate disturbed behaviour and consequently lead to unnecessary increased doses of antipsychotic medication.

Treatment in this case did not lead to significant improvements in sleep pattern or gastrointestinal disturbance and there were only modest gains on the anxiety rating scale. However, it is interesting to note that during caffeine reduction when Miss H lapsed and increased her caffeine intake, she reported greatly increased sleep disturbance and agitation. A similar observation was noted by Searle (1984) who showed that removing caffeine from adults with severe learning disabilities did not lead to observable improvements on sleep or behaviour. However when caffeine was reinstated two weeks later, there was a significant increase in disturbed behaviour.

The health risks of excessive caffeine consumption should not be underestimated especially where there is evidence of other addictive behaviours (e.g. smoking)

which will compound the long term health risks (Pilette, 1983). Traditional hospital routines have encouraged habitual caffeine use in psychiatric and learning disabled clients. When clients are resettled in the community they often have fewer financial and social restrictions on supply of tea and coffee. In order to promote health in clients it is important to recognise overuse of caffeine and facilitate reduction of intake to within safe limits.

References

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders* 4th Edition (DSM-IV)

Foxx, RM & Rubinoff, A (1979) Behavioural Treatment of Caffeinism: reducing excessive coffee drinking. *Journal of Applied Behaviour Analysis* Vol 12 (3), 335-344

Gilliland, K & Bullock, W (1983) Caffeine: A Potential Drug of Abuse. *Advances in Alcohol and Substance Abuse* Vol 3 (1-2), 53-73

Hughes, JR Oliveto, AH Helzer, JE Higgins, ST & Bickel, WK (1992) Should Caffeine Abuse, Dependence or Withdrawal be Added to DSM-IV and ICD-10? *American Journal of Psychiatry* 149:1, 33-40

James, JE & Stirling, PK (1983) Caffeine: A Survey of some of the Known and Suspected Deleterious Effects of Habitual Use *British Journal of Addiction* 78, 251-258

Lindsay, WR & Baty, F (1986) Abbreviated Progressive Relaxation: its use with adults who are mentally handicapped *Mental Handicap* 14, 123-126

Lindsay, WR & Michie, AM (1988) Adaptation of the Zung Self Rating Anxiety Scale for People with a Mental Handicap *Journal of Mental Deficiency Research* 32, 484-490

Marlatt, GA & George, W (1984) Relapse Prevention: introduction and overview of the model *British Journal of Addiction* 79, 261-273

Pilette, W.L. (1983) Caffeine: Psychiatric Grounds for Concern *Journal of Psychosocial Nursing and Mental Health Services* Vol 21, no 8, 19-24

Searle, G (1994) The Effect of Dietary Caffeine Manipulation on Blood Caffeine, Sleep and Disturbed Behaviour *Journal of Intellectual Disability Research* 38 383-391

Table 1: Caffeine content of various common sources and recommended guidelines for daily use

CAFFEINE CONTENT IN VARIOUS COMMON SOURCES		
SOURCE	UNIT	CAFFEINE CONTENT
coffee (brewed)	cup	40-150mg
coffee (instant)	cup	30-120mg
tea	cup	10-90mg
chocolate	bar	approx. 25mg
soft drinks (cola etc)	12 oz	approx. 40-50mg
analgesic	tablets	16-100mg
(a range of caffeine levels is provided for each source due to product variation)		
GUIDELINES FOR DAILY USE		
0-249mg - low intake		
250-749mg - moderate intake		
750-1000mg - high intake		
> 1000mg - potentially harmful		
5-10g - fatal dose		

adapted from James & Stirling (1983) and Gilliland & Bullock (1984)

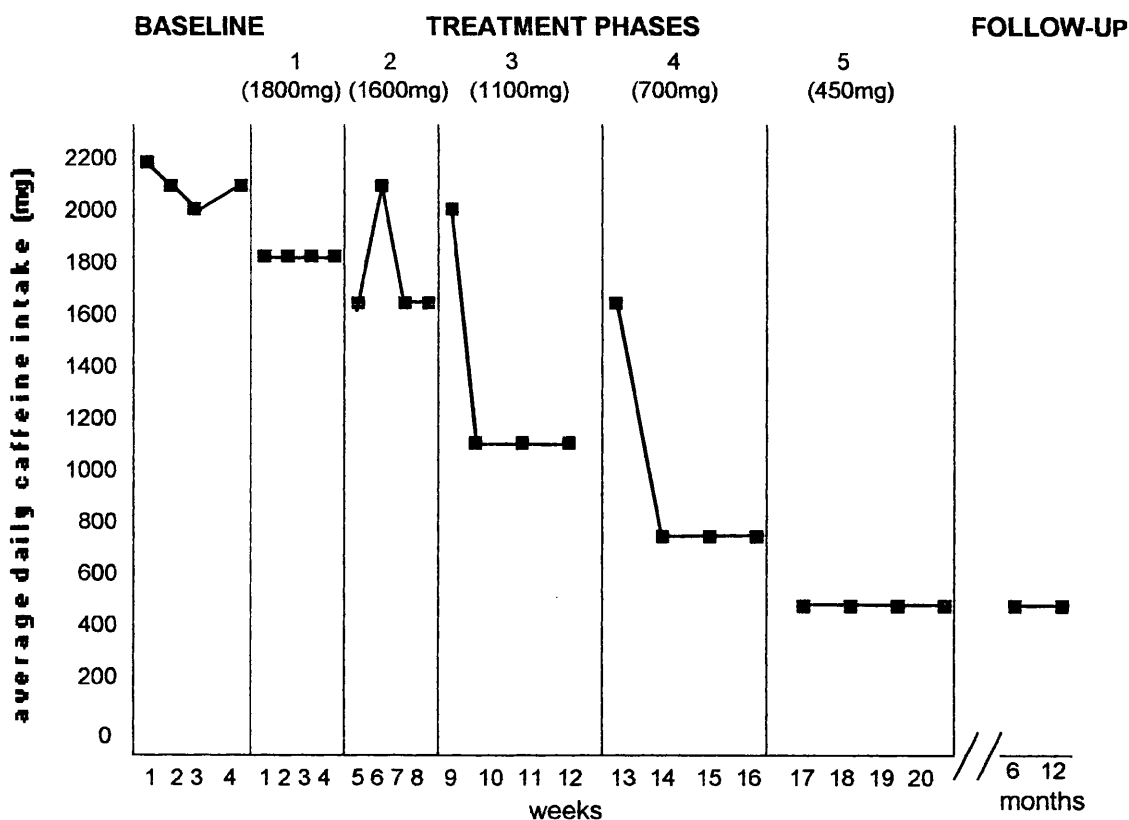


Figure 1: Miss H's average daily caffeine intake (mg) during baseline, treatment and follow-up phases.

Numbers in brackets indicate the criterion level for each phase. Daily caffeine intake was measured from coffee consumption by assuming every 2g coffee contained 30mg caffeine. These figures however must be viewed as underestimates as they did not include tea intake or decaffeinated coffee which contains a small amount of caffeine (approximately 2mg per cup).

SECTION 6: SINGLE CLINICAL CASE RESEARCH STUDY (2)

Retarded ejaculation and fear of impregnation: Case report of a therapeutic assessment

This paper was written according to the guidelines of the *Journal of Sex and Marital Therapy*. A copy of the author notes can be found in Appendix 6

Abstract

This report presents the case of a 22 year year old man diagnosed as having psychogenic retarded ejaculation. He had never ejaculated during intra-vaginal intercourse. Assessment revealed that a likely contributory factor was a fear of impregnating his girlfriend as no form of contraception was being used. Following introduction of contraception, intra-vaginal ejaculation was achieved. Retarded ejaculation is reported in the literature as being difficult to treat but in this case the problem started to resolve within three weeks. Progress was maintained at 3 month follow-up. The outcome of treatment is discussed in relation to the therapeutic nature of assessment.

Introduction

Retarded ejaculation or male orgasmic disorder is defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), [1] as *"persistent or recurrent delay in, or absence of, orgasm following a normal sexual excitement phase during sexual activity that the clinician taking into account the person's age, judges to be adequate in focus, intensity and duration."* It is viewed by some as the male counterpart to female orgasmic disorder [2]. Retarded ejaculation is the least researched and least often encountered male sexual dysfunction. This is reflected in the sparse literature which draws primarily from single case studies. Although there is no data about prevalence in the general population, the incidence of retarded ejaculation in clinical populations is estimated to be around 3% [3].

Causes of retarded ejaculation can be psychological, physical or a combination of both. Physical causes may be associated with specific diseases (e.g. diabetes), spinal cord injury, surgery involving the genito-urinary system and several classes of drugs such as antidepressants or narcotics [3]. Retarded ejaculation is however more frequently associated with psychogenic causes. The theory is that ejaculation is inhibited involuntarily, secondary to fears or anxieties associated with ejaculation. A variety of psychological causes have been suggested in the literature including fear of castration by the female genitalia, fear of impregnating the female partner, guilt about sexual intercourse secondary to a religious upbringing, fear of being interrupted during intercourse, lack of self assertion in relationships, hostility towards women, performance anxiety and positive reinforcement associated with self masturbation [3,4,5].

A spectrum of severity for retarded ejaculation exists with four levels: severe, moderate, mild and milder [6]. The severe condition means that an individual has never ejaculated under any conditions whilst the moderate level implies that ejaculation occurs only when the man is alone using masturbation. Mild cases are where he can ejaculate in the presence of another but not via vaginal containment. The milder condition indicates that the man can ejaculate intravaginally under certain conditions. Another classification method used is primary (denoting that retarded ejaculation was experienced from first attempt at intercourse) and secondary which indicates that ejaculatory functioning was previously adequate for a period of time [4].

In a review of treatments for psychogenic retarded ejaculation a variety of techniques were listed [4]. These included long term psychotherapy, medication, sex education, deep muscle relaxation, meditation, conjoint therapy with sensate focus exercises, directed masturbation and use of a sexual surrogate. Whilst

traditional approaches to the sexual dysfunctions have involved psychotherapy, there has been growing use of behavioural principles to treat sexual disorders [7]. Behavioural desensitisation to treat sexual problems is now the treatment of choice. For cases of retarded ejaculation, the aim is to work towards intra-vaginal ejaculation in a series of steps gradually approaching the goal [6]. The low incidence of retarded ejaculation has seriously hindered research [8] and treatment outcome studies have been limited to single case studies or uncontrolled small group studies. This single case study describes psychogenic retarded ejaculation in a young man 'Mr G', who presented for treatment with his girlfriend.

Case History

Mr G was a 22 year old unemployed man who sought treatment for retarded ejaculation. He presented with an inability to reach a climax during sexual intercourse with his 20 year old girlfriend, 'Miss A'. He could ejaculate during masturbation but never in front of his girlfriend. Mr G had been medically examined and there was no evidence for a physical causation. Mr G and Miss A were seen for two assessment sessions during which they were interviewed together and alone. A detailed sexual history was taken, the well known process of which is documented elsewhere [7].

Mr G had been going out with his girlfriend for 9 months and reported that this was his first sexual relationship. When they had intercourse for the first time he was unable to ejaculate and put this down to inexperience and anxiety about having sexual intercourse. As the months passed by and retarded ejaculation continued to be a problem, Mr G became increasingly anxious, moody and frustrated about

sexual intercourse. He experienced little enjoyment of their sexual relationship and only engaged in intercourse to please his girlfriend. The couple had tried various techniques during intercourse e.g. mutual masturbation but Mr G had never ejaculated in the presence of Miss A. As a consequence of his problem, he complained of depressed mood and lowered self esteem. He was unhappy about his life in general, particularly about being unemployed, which added to his feelings of not being "a worthwhile man".

Mr G was an only child whose father was a church minister and he described his parents as being very religious. Prior to Miss A, Mr G had one previous relationship for six months. This relationship ended when he discovered that the girl had sexual intercourse with his friend. As a result of this, she became pregnant and subsequently had an abortion. This was against Mr G's religious beliefs and he revealed extreme hostility towards his former girlfriend.

Mr G met his current girlfriend whilst doing voluntary work. Miss A asked him out and on their first date at her request, the couple had sexual intercourse. He believed that this was wrong and recalled being taken aback at how forward Miss A was. In describing his girlfriend he admitted he had mixed feelings towards her. On the one hand, he expressed love for her and a desire to get married. On the other, he resented the fact that she was sexually experienced and that he had heard rumours about her previous sexual relationships. He expressed hostile sentiments about promiscuous women. The couple were living in their respective parental homes and were having intercourse at Mr G's home when his parents were out. Mr G confessed to being anxious that his parents might return early and find them, particularly as they disapproved of sexual intercourse before marriage. Despite this, the couple were able to have intercourse at least four times a week. In addition, they had never used any form of contraception during

their sexual relationship. They both lacked awareness about sexual functioning and appeared unconcerned about transmission of sexually transmitted diseases. Behavioural treatment of sexual dysfunction is usually conducted as part of a wider treatment package based on the Masters and Johnson conjoint therapy approach [7]. The main elements of this are treating the problem as a joint problem, reducing anxiety by banning intercourse, setting sexual assignments i.e. sensate focus exercises, providing sex education and improving communication skills. During the second assessment session, treatment options were discussed with the couple. As they were living at home, they did not have privacy to carry out behavioural assignments. It was therefore inappropriate to embark on a behavioural programme. Given these circumstances it was agreed that the couple would be seen initially for four sessions of education and general guidelines about sexual intercourse and retarded ejaculation.

The issue of contraception was discussed in assessment. At the start of their relationship, the couple had never talked about using contraception. As the relationship progressed, they believed that Miss A could not pregnant as Mr G was not ejaculating. They were encouraged to consider that Mr G might not be ejaculating because of a fear of impregnating his girlfriend as they were not using contraception. Mr G agreed with this possibility especially because of the hostility he felt about his former girlfriend's abortion. He had not been assertive or experienced enough to ask Miss A about contraception. The couple were asked to imagine what would happen if Miss A did get pregnant given that they did not believe in abortion. In their current situation, i.e. both unemployed and living at home, it would be extremely difficult.

■ *Measures of assessment*

The Beck Depression Inventory (BDI) [9] was administered and Mr G's score of 22 indicated the presence of moderate depression. In addition the male and female versions of the Golombok-Rust Inventory of Sexual Satisfaction (GRISS), [10] were given to the couple. Mr G's overall score (66) indicated much greater sexual dissatisfaction than his girlfriend's score (25).

■ *Outcome*

The couple returned two weeks after assessment to start education about sexual functioning. When they returned, they reported that for the first time, Mr G had been able to ejaculate intra-vaginally. After the previous session, the couple had decided to start using contraception (condoms). On the first attempt there had been no change in ejaculatory functioning but on the second attempt Mr G had ejaculated intra-vaginally. Over the two week period, he had been successful in four out of six occasions. Mr G was overjoyed about this and when the couple were seen again at 1 month and 3 month follow-up, Mr G reported that he no longer experienced retarded ejaculation. In addition, at 3 month follow-up his overall GRISS score had improved from 66 to 21, indicating much greater satisfaction with intercourse his score of 5 on the BDI indicated presence of minimum or no depression.

Discussion

This was an interesting case for several reasons. Firstly, Mr G displayed many of the features typically seen in those with retarded ejaculation as suggested by the literature i.e. religious upbringing, lack of assertiveness, performance anxiety, hostile attitudes towards women, fear of impregnating his partner and fear of being interrupted by his parents during intercourse. Whilst fear of impregnating his girlfriend appeared to be the main anxiety, it does not explain his ejaculatory difficulties when masturbating in her presence. It is likely that all the factors had a part to play in maintaining his difficulties.

Secondly, retarded ejaculation has been regarded as difficult to treat. Campden-Main and Sara [2] wrote that *"cases where the male can ejaculate in some way in front of the female are difficult but those where he cannot are extremely difficult to reverse"*. Similarly it has been reported that in cases of primary retarded ejaculation (i.e. where the patient has never ejaculated intra-vaginally), prognosis is very poor. Mr G saw his problem resolve within two weeks despite presenting with primary ejaculation although it is acknowledged that Mr G had no experience of sexual intercourse with any previous partners.

Thirdly, as single case studies are the main source of information about treatment for retarded ejaculation, it is important to define the elements of success (or failure) in treatment of retarded ejaculation [6]. The factor that contributed to a successful outcome in this case was use of contraception. In addition, Mr G reported the importance of learning that numerous factors could account for his inability to ejaculate and that he was not "a freak". He described this as a huge weight being lifted from his mind which decreased his anxiety about intercourse. Mr G also found that talking about the problem in a joint session was helpful as

prior to assessment, the couple had not communicated about the problem in depth. Mr G put this down to his shyness about sexual matters. Seeing the discrepancy in their GRISS scores was informative for the couple as it highlighted the difference in their satisfaction with sexual intercourse. Miss A admitted she had not been aware that Mr G did not enjoy their intercourse.

Lastly, whilst generalisation from single case studies is limited, this case provides an example of a therapeutic assessment. The therapeutic aspects of being assessed should not be underestimated for any sexual dysfunction as often people present for treatment feeling embarrassed or ashamed. In this case, Mr G identified helpful aspects of assessment; talking in depth about the problem and not feeling that he was abnormal. This case also highlights the need for taking a comprehensive sexual history. The issues raised in assessment led to use of contraception and subsequent resolution of the problem. In this case, a less than comprehensive assessment could have led to an unnecessary lengthy treatment programme (as anticipated from initial referral letter) for a problem that for Mr G required a simple solution.

References

- [1] American Psychiatric Association: *Diagnostic and Statistical Manual for Mental Disorders 4th ed.*, (DSM-IV) Washington D.C. 1994
- [2] Campden-Main, BC & Sara, ML Retarded Ejaculation *Medical Aspects of Human Sexuality* vol 19, no 8 21-29 1985

- [3] Zgourides, GD & Warren, R: Retarded Ejaculation: Overview and Treatment Implications *Journal of Psychology and Human Sexuality* vol2 (2) 139-150 1989
- [4] Munjack DJ & Kanno PH : Retarded Ejaculation: A review *Archives of Sexual Behaviour* 8 (2), 139- 150 1979
- [5] Dow, MGT: Retarded ejaculation as a function of nonaversive conditioning and discrimination: A hypothesis *Journal of Sexual and Marital Therapy* 7(1) 49-53 1981
- [6] Shull, GR & Sprenkle, DH: Retarded ejaculation reconceptualisation and implications for treatment *Journal of Sexual and Marital Therapy* 6 (4) 234-246 1980
- [7] Bancroft, J: *Human sexuality and its problems* 2nd ed. Edinburgh, Churchill Livingstone 1989
- [8] Delmonte, M & Braidwood, M: Treatment of Retarded Ejaculation with Psychotherapy and Meditative Relaxation: a case report *Psychological Reports* 47 8-10 1980
- [9] Beck, AT: Beck Depression Inventory (BDI) Sidcup: The Psychological Corporation 1988
- [10] Rust, J & Golombok, S: *The Golombok-Rust Inventory of Sexual Satisfaction* Windsor NFER Nelson 1986

CHAPTER 7: SINGLE CLINICAL CASE RESEARCH STUDY (3)

Treatment of PTSD and facial scarring in an adolescent boy assaulted with a knife

This paper was written according to the guidelines of the *Journal of Traumatic Stress*. A copy of the author notes and further relevant information can be found in Appendix 7.

Abstract

Post-traumatic stress disorder (PTSD) was observed in a 15 year old boy who was assaulted with a knife. This resulted in a large facial scar. Cognitive behaviour therapy was used to treat his symptoms of PTSD which incorporated techniques to deal with the boy's anxiety about his facial scar. Treatment was successful in reducing intrusive imagery and improving self esteem. There was less success in reducing avoidance behaviour which remained high at 6 month follow up. The outcome of treatment is discussed in relation to the impact of both violent personal assault and facial scarring during adolescence.

Introduction

Post traumatic stress disorder (PTSD) has been more extensively studied in adults than in children or adolescents but it is now accepted that that they develop symptoms similar to adults (Pynoos et al, 1987; Terr, 1991; Joseph et al, 1993; Stallard & Law, 1993). The diagnostic criteria for PTSD include exposure to a traumatic event, intrusive memories of the event, avoidance of stimuli associated with the event, symptoms of increased arousal and numbing of responsiveness (American Psychiatric Association, 1994).

It is only recently that controlled studies of treatment for PTSD have been published but there is tentative evidence to suggest that a cognitive behavioural approach is effective (Scott & Stradling, 1992; Thompson et al, 1995). Recommended techniques include imaginal exposure to memories of the trauma, cognitive restructuring and desensitisation to avoided situations. For adolescents, cognitive behaviour therapy is thought to be appropriate generally for treating

emotional disorders (McAdam, 1986). The practical and directive nature of the approach (i.e. asking questions, summarising, providing feedback and homework exercises) helps to avoid long silences in sessions that make teenagers feel uncomfortable and self conscious.

Assault with a knife is extremely traumatic. It can lead to severe injury and long term scarring. Where individuals have facial scars, there are additional complications. As well as unhappiness about changed appearance and lowered self esteem, there may be real or perceived negative reactions from others (Macgregor, 1990). The face is the focus of social interaction and *Changing Faces* is a charity which was launched to raise awareness of the social impact of facial injury (Partridge et al 1994a). Whilst those who have been facially disfigured experience negative reactions from others, their own behaviour can contribute to their difficulties e.g. social withdrawal or social anxiety. *Changing Faces* developed a series of workshops for use with patients with facial injuries in the NHS drawing from traditional social skills training (e.g. education about social interaction and roleplay of social situations) (Partridge et al, 1994b).

This case report describes cognitive-behavioural treatment of PTSD in a 15 year old boy, 'C', who was a victim of a violent personal assault. The resultant facial scarring played an important role in exacerbating his symptoms of PTSD and the importance of addressing this in treatment is highlighted. Treatment outcome is discussed with reference to the impact of physical assault and facial scarring during adolescence.

Case report

■ *The Traumatic Event*

C had been walking with friends on a Saturday evening. Some older boys approached, one of whom without warning produced a knife and plunged it into the side of C's face. C ran to the safety of his home and he gave a vivid description of holding onto his face as he ran and feeling the fingers going inside his face. When he reached his home, his mother opened the door and found him drenched in blood. C was taken to hospital and a painful stitching procedure was performed that night. Since the assault, C had undergone four facial operations and as a result of the wound had a large scar stretching from his left eye to the corner of his mouth. C was able to name his attacker and the police subsequently arrested a youth who, following a court case was sentenced to three years imprisonment.

■ *Clinical Presentation*

C presented for treatment with his parents five months after the assault. He was experiencing intrusive thoughts and memories of the attack on a daily basis which were triggered by reminders such as seeing sharp knives. He experienced nightmares several times a week in which he dreamt of large knives or being chased by violent youths. C was frightened of being attacked again and did not feel safe when he was away from home. Consequently, he had stopped going out with friends in the evenings and during the day he travelled by taxi instead of taking the bus or walking. If he saw young men who resembled his attacker he felt frightened but reported few somatic symptoms of anxiety. There was no

evidence for suicide ideation or clinical depression. At school C was finding it hard to concentrate on preparation for his exams. He tried to avoid thinking about the attack but his scar acted as a constant reminder both for himself and for others. People he did not even know frequently commented on his appearance (e.g. strangers in the street, shopkeepers etc). Children in his school had been teasing him and calling him "Mars bar" (i.e. rhyming slang for scar). He spent hours looking at the scar in his bedroom mirror worrying about his physical attractiveness and was unable to look at photographs of himself before the attack. When he spoke to people he tried to hide the left side of his face and avoided eye contact so that he would not see them looking at his scar. He had tried using makeup to cover the scar but felt it looked worse.

Assessment

The *Revised Impact of Events Scale*, (IES, Horowitz et al, 1979) was used as a formal measure of PTSD. The scale measures the two central features of PTSD, intrusive imagery and avoidance of reminders. The IES has been used widely with adults and found to be suitable for use with children and adolescents (Stallard & Law, 1993). C obtained an overall score of 39 (intrusion 21, avoidance 18). Coping style is thought to be an important predictor of whether symptoms of PTSD are maintained (Scott & Stradling, 1992). To assess C's coping style the *Short Form Adolescent Coping Scale* was administered (Frydenberg & Lewis, 1993). This assesses the use of 18 active and passive coping strategies. C's profile of scores indicated that although he accessed social support from his family he more frequently spent time worrying about things without letting others know how he was feeling. C's difficulties were being compounded by his facial scar. In adolescence, facial scarring is thought to cause decreased self esteem

(Long and DeVault, 1990). The *Hudson Index of Self Esteem* (ISE, Hudson 1982) was used to measure self esteem. C's score of 34 indicated presence of a clinically significant self esteem problem (20 is the cut-off point for clinical significance).

Treatment

Most therapeutic approaches to PTSD involve rehearsal of the trauma story. This allows processing of the associated emotions in a relatively safe environment. C was given the opportunity to tell his trauma story from the day of his attack until his most recent facial operation. He provided a remarkably vivid account of events. He became distressed when reliving the attack and reported that it was the first time he had spoken in depth about the trauma as he had tried to protect his parents from his distress.

C was asked to monitor his intrusive thoughts in a diary. Cognitive restructuring was used to work through these and help C reassess the trauma. C had many "if only" type thoughts e.g. *"if only I had stayed in that night none of this would have happened"*. This was unrealistic as C had always gone out on a Saturday evening and walked the same route. C was able to accept that it was an unprovoked, unpredictable attack and that nothing could have done to prevent it. C was frightened about further attack and cognitive restructuring was used to help him reassess the degree of threat. Although there had been a spate of knife attacks reported in the newspaper, C acknowledged that knife attacks are reported in the press because they are relatively rare in nature. He was no more at risk than anyone else provided he took reasonable precautions to increase safety e.g. not walking alone in the dark late at night.

The fear of being attacked again resulted in C avoiding many activities he had enjoyed prior to the attack. A graded hierarchy of avoided situations that C could tackle in small steps was drawn up. This ranged from going record shopping on a Saturday afternoon to visiting a friend in the early evening alone.

■ *Anxieties about the scar*

Much of C's unhappiness related to his facial scar. His diary allowed expression of his feelings about the scar including: intense rage that he would be scarred for life whilst his attacker would be free in three years; concern that he was no longer attractive enough to have a girlfriend; fear that people thought he was a gangster or a thug; and concern about future job prospects as employers might not think he was trustworthy. C was maximising the effects of his scar and was encouraged to balance this by recording his strengths and capabilities. There were many examples of negative social interaction in C's diary. C felt very self conscious about his scar and believed that people were constantly staring at him. As a result he either put his head down or sometimes glared back. To help with this, some social skills techniques employed by *Changing Faces* were incorporated into treatment. This involved education about social interaction and role play of social situations from his diary e.g. C had gone to the shopping centre and felt that the security guard was watching him and staring at his scar. C wrote "*he's staring at my scar, he thinks I am a thief*". C was able to accept that his own behaviour (i.e. staring at the security guard and looking nervous) probably appeared very suspicious. There were many social encounters that C was avoiding. He learned that his anxious body language and avoidance of social encounters isolated him further.

Outcome

Following 10 sessions of cognitive-behavioural treatment, (which included two sessions with C's family), C showed significantly reduced IES scores for intrusive imagery (from 21 to 10) and less so for avoidance of reminders (from 18 to 16). He also showed improvement on the Hudson ISE with his score of 28 no longer being clinically significant. Although C was able to tackle the initial homework tasks on his behavioural hierarchy, he felt unable to practise and as a result could not continue with graded exposure for the later tasks. The problems in carrying out behavioural assignments related to feelings of not being safe.

At 6 month follow-up, C had left school and had been successful in securing an apprenticeship with a local firm which helped relieve his anxieties about future employment. The improvements on intrusive imagery and self esteem had been maintained. There were improvements on avoidance behaviour as C had started his first job and was travelling by bus alone during the day. C was still withdrawing from evening activities outside his home. His facial scar had physically improved following another plastic surgery procedure and although C felt better about his appearance, he hoped that when he was older cosmetic surgery could completely remove it.

Discussion

This case demonstrates the effectiveness of cognitive behaviour therapy in treating an adolescents symptoms of PTSD using monitoring of thoughts and emotions, cognitive restructuring and graded exposure work. The use of a diary to monitor negative thoughts was particularly helpful as it allowed C to sort out

difficulties and unhappiness in private. This was important for a male adolescent who tried to protect his family from his distress. Gender differences have been reported in child and adolescent responses to PTSD with girls more likely to show emotional expression than boys (Curle & Williams, 1996). Treatment was effective in increasing self esteem and reducing intrusive imagery but less effective for reducing avoidance behaviour. In practice, it has been found that achieving a strict hierarchy of fear provoking situations for victims of violent assault is difficult (Thompson et al, 1995). C had problems carrying out the graded hierarchy of tasks because he did not feel safe away from home. Prior to the attack he had only just begun to assert his independence. The assault disrupted this process by challenging his previously held belief that he was relatively invulnerable. Trauma in childhood or adolescence shatters basic trust and autonomy and leads to long term changed attitudes about people, life and the future which are difficult to alter (Terr, 1991).

C had no previous history of trauma and appeared to have a supportive family; these are indicators of good recovery from post traumatic stress (Scott & Stradling, 1992). C presented for treatment 5 months after his assault. His recovery process was being hindered by his facial scar which acted as a constant reminder of his assault both for himself and for others. When he attempted to distract himself, catching a glimpse of his reflection or someone commenting on his scar caused traumatic memories to flood back. Treating his symptoms of post-traumatic stress alleviated this to an extent. Much of his distress related to the change in his appearance and his perception of how others viewed him. This was addressed by incorporating cognitive therapy and simple social skills techniques into treatment. It was important to recognise the social impact of facial scarring within treatment of this adolescent's PTSD. He had endured teasing from classmates, felt extremely self conscious and feared being different

from his peers. Social withdrawal in teenagers may hinder the development of basic social skills and prevent the resolution of adolescent tasks before making the transition to adulthood. Long and Devault (1990) concluded that during adolescence, a phase of life when self concept, fear of rejection and conformity are at their peak, the impact of facial scarring can be devastating.

References

- American Psychiatric Association (1994) *Diagnostic and Statistical Manual for Detection of Mental Disorders* 4th edition Washington
- Curle, C.E. & Williams, C. (1996) Post Traumatic Stress Reactions in children: Gender differences in the incidence of trauma reactions at two years *British Journal of Clinical Psychology* vol 33
- Frydenberg, E. & Lewis, R. (1993) *Adolescent Coping Scale* Scanform Press,
- Horowitz, M.J., Wilner, N. & Alvarez, W. (1979) Impact of Events Scale: A Measure of Subjective Distress *Psychosomatic Medicine* 41 209-218
- Hudson, W. W. (1982) *Index of Self Esteem* The Dorsey Press Chicago
- Joseph, S.A., Brewin, C.R., Yule, W. & Williams, R. (1993) Causal Attributions and Post Traumatic Stress in Adolescents *Journal of Child Psychology and Psychiatry* Vol 34 No 2 247-253

Long, D. & DeVault, S. (1990) Disfigurement and Adolescent Development
American Journal of Forensic Psychology Vol 8(2) 3-14

McAdam, E. (1986) Cognitive Behaviour Therapy and its Applications with
Adolescents *Journal of Adolescence* Vol 9 (1) 1-15

Macgregor, F. (1990) Facial disfigurement problems and management of social
interaction and implications for mental health *Aesthetic Plastic Surgery* 14 249-257

Partridge, J., Lacy, K. & Rumsey, N. (1994a) Social Interaction Skills Workshop
for People Disadvantaged By Their Appearance *Clinical Psychology Forum* No
72 p2

Partridge, P., Coutinho, W., Robinson, E. & Rumsey, N. (1994b) Changing
Faces: Two Years On *Nursing Standard* Vol 8 No 34 54-58

Pynoos, R. (1987) Life Threat and Post Traumatic Stress in School Age Children
Archives of General Psychiatry Vol 44 1057-1063

Scott, M.J. & Stradling, S.G. (1992) Counselling for Post-traumatic Stress
Disorder *Sage Publications*

Stallard, P. & Law, F. (1993) Screening and Psychological Debriefing of
Adolescent Survivors of Life Threatening Events *British Journal of Psychiatry*
163 660-665

Terr, L. (1991) Childhood Traumas: An Outline and Overview *American Journal of Psychiatry* 148:1 10-20

Thompson, J.A., Charlton, P.F.C., Kerry, R. et al (1995) An open trial of exposure therapy based on deconditioning for post-traumatic stress disorder *British Journal of Clinical Psychology* vol 34 (3) pp 407 - 417