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Mental Health and Learning Disabilities
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Mental Health and Learning Disabilities Research and Practice is jointly published by South West Yorkshire Mental Health NHS Trust and the University of Huddersfield. It is published twice a year. Online articles: abstracts and articles can be viewed online at: www.hud.ac.uk/hhs/research/mhrg/journal/issue1.pdf or www.southwestyorkshire.nhs.uk/journals where full text current and past articles can be downloaded.

Aims and Scope of the Journal

Mental Health and Learning Disabilities Research and Practice is a joint publication between South West Yorkshire Mental Health NHS Trust and the University of Huddersfield. *Mental Health and Learning Disabilities Research and Practice* will encourage a wide range of material which is accessible to a broad audience. It will appeal to a wide range of mental health practitioners, social care practitioners, researchers, educators, users of mental health services, carers, and voluntary sector workers.

The function of the journal is to:

- Disseminate research findings related to mental health and learning disabilities;
- Provide an opportunity for practitioners to:
  - share research findings, service developments, and educational developments,
  - write review papers

that are relevant to mental health and learning disabilities.

Mental Health and Learning Disabilities Research and Practice aims to be a good quality peer reviewed journal with well presented material. The journal aims to be inclusive as possible and supportive of first time or novice researchers and writers.

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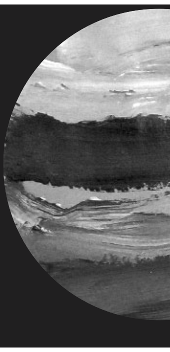

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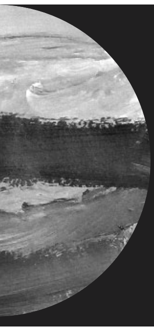


Foreword

Colleagues,

We are delighted to introduce this exciting new journal. The University of Huddersfield and South West Yorkshire Mental Health NHS Trust have a commitment to develop excellent services based on the most contemporary evidence and underpinned by a spirit of enquiry. The University and Trust believe that research must inform us all of what works best to meet the needs of the people who use our services, improve our interventions and support their recovery. We must ensure colleagues have easy and rapid access to evidence that will improve the experience of the people we serve and our own working lives. Both organisations are committed to encouraging research that develops and expands the evidence base and to evidence based practice that utilises the best research evidence available. Wherever possible we actively engage those who use our services in that process. We are also committed to ensure education and training meets the needs of the workforce and supports the modernisation of services.

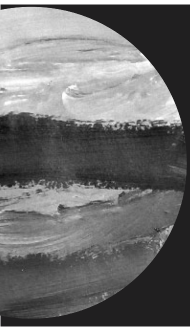
We are always learning from our own experience and from research evidence about ways to improve the experience of people with mental health problems and learning disabilities. It is essential that we have ready access to the findings of the latest research evidence and it is particularly exciting when that evidence is being generated in our own services, locally, and through our collaborative programmes of research. This journal is intended to capture such evidence and share it in ways that will help you to inform and transform everyday practice. In this way we will help to make a difference to the lives of the people we serve.

Both the University and the South West Yorkshire Mental Health NHS Trust are keen to work in partnership with other organisations to achieve their aims in relation to research and scholarship that underpins excellent practice and service development. This includes working with a range of organisations such as National Institute for Mental Health England (NIMHE) and other Universities across the North of England including York, Leeds and Sheffield. Such partnerships help us in developing knowledge that ensures that wherever people use our services there is a coherent programme of support which helps them stay in control of their lives and the choices they make. This extends to research partnerships with other health and social care organisations including Calderdale & Huddersfield NHS Trust, Mid Yorkshire Hospitals Trust and West Yorkshire Primary Care Trusts as well as other providers across the northern region. Increasingly our key partners are also Local Authorities, Education Services, Community Justice agencies and Employment and Leisure services. We hope this journal informs and includes colleagues across all of these partnerships.

This journal has been possible because of the joint work between the University of Huddersfield and the South West Yorkshire Mental Health NHS Trust. The journal provides some examples of the opportunities that have been created for people from both organisations and the people who use services to develop research projects, some of which are partnerships with other health and social care providers. Developing the journal has required commitment from the editorial team and reviewers. It is this fantastic spirit of endeavour that provides the energy to make this new journal successful in making a real contribution to our practice locally and inform the wider regional and national community. This is your journal created and owned by local staff and services. I hope that you enjoy reading it and will make an active contribution by sharing your thoughts, ideas and experiences in future editions. Congratulations to all of the team that have brought to fruition such a timely and appropriate way to share local and national work with colleagues, partners, and those who use our services.

Professor Sue Frost
Dean of Human & Health Sciences
University of Huddersfield

Judith Young
Chief Executive
South West Yorkshire Mental Health NHS Trust



Editorial

This new peer reviewed journal has been introduced to disseminate examples of research, evaluation and service developments in mental health and learning disabilities. The emphasis is on practice based research and developments, with contributions from a range of practitioners, service users and carers and a range of service areas. We are also keen to consider reflective articles describing experiences and views of service users and carers.   The first issue reflects this range, including articles related to older people, learning disabilities, psychological therapies and mental health problems in the community and a personal perspective from a carer.

The journal has been developed jointly by the South West Yorkshire Mental Health NHS Trust and the University of Huddersfield as part of a strategy to increase the dissemination of quality research and service developments, to improve research capacity in the area and promote the links between research, education and practice. It also supports the NHS Research and Development, priorities and needs funded, programmes, in particular those linked to the modernisation of mental health and learning disabilities services. The two organisations collaborate with local, national and international partners and this is reflected in some of the papers in the first issue. Over time we hope the journal will increasingly include contributions from further afield.

The journal is intended to be accessible to a wide audience including mental health practitioners, social care practitioners, researchers, educators, users of mental health services, carers and voluntary sector workers.

Alcohol abuse in older people - presentation and scope of the problem - a clinical review

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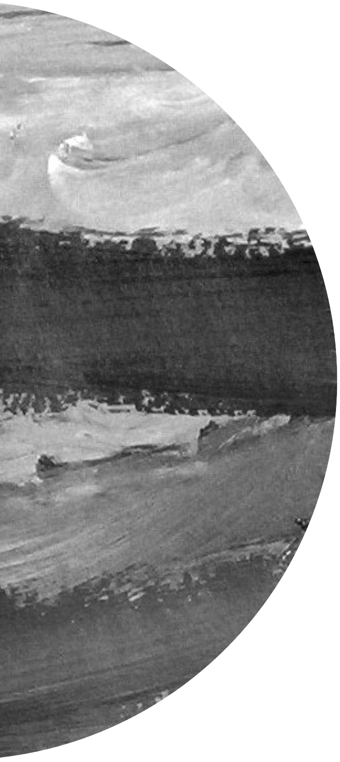
Alcohol abuse in older people – presentation and scope of the problem – a clinical review

Alan Hassey, Helen Wilkinson, James Newell, Hannah Rossall

Abstract



Alcohol abuse is recognised as a serious problem in the UK and there is a strong correlation between average consumption, the prevalence of heavy drinking and associated harm. Alcohol abuse disorders are thought to be common in older people and associated with impairments in physical, psychological, social and cognitive well-being. The effects of co-morbidity, medication and age may exacerbate the risks of alcohol abuse.

We conducted a review of published literature using a defined search strategy of electronic databases, including articles in English, between 1960-2004. This yielded 74 papers that matched the search criteria. Six papers were selected for detailed analysis.

Alcohol abuse in older people has a prevalence of between 1-4% in the general population, rising to between 7-22% in inpatients and 23-44% for psychiatric inpatients. The health-related effects of alcohol use in older people are still uncertain. Neither screening for elderly alcohol abuse in a general population nor the use of validated tools such as the CAGE questionnaire may not be effective in the general population. However, for rapid assessment in a clinical setting, the CAGE questionnaire, with a cut-off score of >=2, will effectively discriminate older patients with a history of drinking problems from those without such a history.

In the UK there has been little high-quality research reporting the prevalence, identification and treatment of alcohol use disorders in older people. There is a clear need for a specific research programme to address these issues in line with the government's Alcohol Harm Reduction Strategy and the NSF for Older People.

Keywords: Older people, alcohol abuse, alcohol dependence, screening, prevalence

Introduction

Alcohol abuse is recognised as a serious problem in the UK "across gender and age groups" (Plant 2004). The government have recognised this in the recent publication of their harm reduction strategy for England (Cabinet Office 2004), though this has recently been criticised in the BMJ as "the dampest of squibs" (Smith 2004). Alcohol consumption in Britain has increased by more than 50% in the last 30 years and alcohol related deaths, particularly liver cirrhosis, have risen as a result (Marmot 2004). Alcohol is also responsible for much morbidity, social disruption and failure. In their recent report, the Academy of Medical Sciences noted that there is a strong correlation between average consumption, the prevalence of heavy drinking and associated harm. In Britain the price of alcohol has fallen steadily in recent years, while consumption and alcohol related harm have risen (The Academy of Medical Sciences 2004).

Are we perhaps complacent about alcohol abuse and its effects? It is after all our favourite drug and as the Prime Minister states in the foreword to his strategy document "Millions of us enjoy drinking alcohol with few, if any, ill effects. Indeed, moderate drinking can bring some health benefits". Despite the correlation between alcohol consumption and poor health, there are few votes in being serious about alcohol reduction, especially when there are a million jobs associated with alcohol production, distribution and consumption in the UK.

Alcohol abuse disorders are thought to be common in older people and associated with considerable morbidity. The ageing of the population means that the absolute number of older people with alcohol use disorders will increase, even if the prevalence rate of abuse disorders remains constant. Alcohol abuse in older people is probably under-detected and misdiagnosed (O'Connell et al 2003). It is often associated with impairments in physical, psychological, social and cognitive well-being. The effects of co-morbidity, medication and age itself mean that recommendations about safe levels of alcohol use in older people are uncertain. It seems important that we try to better understand the likely presentation and scope of alcohol abuse disorders in our older patients.

We decided to conduct a study into the scope and presentation of alcohol abuse in older people in the form of a detailed literature review. This would run as one of two principal research projects within the Fisher Medical Centre Research Unit (FMCRU) during 2003/4. Once we had developed an outline project, this was presented to South West Yorkshire Mental Health Trust (SWYMHT) and the Medical Research Council General Practice Research Framework (MRC GPRF) and both organisations were supportive of the study. At this stage we formally linked this study to the SWYMHT "Modernising mental health and learning disabilities services" research programme through their ageing and mental health task group.

The Fisher Medical Centre research team includes Dr James Newell and Ms Hannah Rossall who provided expert statistical and information services advice respectively.

This paper is the report of our literature review study and will form the basis of a research protocol for a collaborative project between Fisher Medical Centre, SWYMHT and possibly the MRC GPRF.

Method

The Fisher Medical Centre is a research general practice based in Skipton, North Yorkshire. We have research links with several organisations including South West Yorkshire Mental Health Trust (SWYMHT) and the MRC GPRF. The practice population is 13,500 patients based in and around Skipton and the surrounding villages and dales. It is a popular retirement area and some 20% of our practice population are aged over 65 years.

This study arose from clinical general practice. The two GP authors were aware that they seemed to be seeing a lot of elderly patients with physical, mental, psychological and social problems where alcohol use seemed to be a significant factor. However, there did not seem to be much easily available information about the prevalence, presentation or scope of alcohol abuse in older patients, though anecdotally, most of the practice GPs felt that it was an important problem.

We defined the research question as "what is the presentation and scope of alcohol abuse in older people?" We used the standard definition of alcohol abuse and dependence provided by the Diagnostic and Statistical Manual of mental disorders (DSM IV – see Table 1). A systematic review of published literature was conducted using a defined search strategy (see Table 2) of electronic databases. The scope of the review was international but we only included articles in the English language. We decided to review the literature from 1960 onwards (1960-2004) to improve the prospects of us finding epidemiological/prevalence studies.

We defined older people as those aged 65 years and over. The GP authors would read abstracts of all papers that matched the search criteria and reach agreement on the list of articles to be included in the review (see Table 2). This review would include the full range of published articles that met our search criteria, not just experimental studies; therefore it was not our aim to perform any kind of meta-analysis of the data.

Table 1 – definitions

DSM-IV Alcohol Abuse (1 or more criteria for over 1 year)

- Role Impairment (e.g. failed work or home obligations)
- Hazardous use (e.g. Driving while intoxicated)
- Legal problems related to alcohol use
- Social or interpersonal problems due to alcohol

DSM-IV Alcohol Dependence (3 criteria for over 1 year)

- Tolerance (increased drinking to achieve same effect)
- Alcohol Withdrawal signs or symptoms
- Drinking more than intended
- Unsuccessful attempts to cut down on use
- Excessive time related to alcohol (obtaining, hangover)
- Impaired social or work activities due to alcohol
- Use despite physical or psychological consequences

N.B. DSM-IV = Diagnostic & Statistical Manual of Mental Disorders

Table 2- search strategy

- (MeSH term applied where available)
- Alcohol Abuse (KW, MeSH 1960_) OR
- Alcoholism (KW, MeSH, 1960_) OR
- Alcohol Drinking (KW, MeSH, 1960_) AND
- Elderly (KW, MeSH 1960_) OR
- Aged (KW, MeSH 1960_) OR
- Old$ Person$ (KW, MeSH 1960_) OR
- Old$ People$ (KW, MeSH 1960_) AND
- Age - Aged 65 Yrs and Older (Filter) OR
- Age – Very Old 85 Yrs and Old (Filter) AND
- Prevalence (KW, MeSH 1960_) OR
- Diagnosis (KW, MeSH 1960_) OR
- Assessment Diagnosis (KW, MeSH 1960_) OR
- Detection (KW, MeSH 1960_) OR
- Substance Abuse Detection (KW, MeSH 1960_) OR
- Alcohol Abuse Detection (KW, MeSH 1960_) OR
- Alcohol Use Disorders Identification Test (KW, MeSH 1960_) AND
- English Language (Filter) AND
- Systematic Review$ (KW, Filter) OR
- Review$ (KW, Filter) OR
- Meta Analysis (KW, Filter) OR
- Literature Review (Filter) OR
- Review Articles (Filter)

KW = Keyword search

Results

1. Prevalence and presentation of the problem

The initial search of electronic databases yielded 68 papers that matched the search criteria. A further six were added from journal hand searches and personal contacts, making a total of 74 papers for initial review. Six of these papers were selected for detailed analysis, including two clinical review articles, two systematic reviews, one meta-analysis and one combined systematic review and meta-analysis.

The prevalence of alcohol use disorders in older people is generally accepted to be lower than in younger groups. Most prevalence studies have been carried out in North America and the diagnostic criteria used seem to vary considerably or are not clearly defined. There is general agreement that the prevalence is lower in community based studies than for older inpatients and those attending emergency departments. Among older people, socio-demographic factors associated with alcohol abuse include being; male, socially isolated and single, separated or divorced. Overall the prevalence in the general (US) population ranged from 1-4%, rising to between 7-22% of older inpatients and as much as 23-44% for psychiatric inpatients(Conigliaro, Kraemer, & McNeil 2000; Fiellin, Reid, & O'Connor 2000; O'Connell, Chin, Cunningham, & Lawlor 2003).

Alcohol abuse disorders may be undetected or under-diagnosed in older people for many reasons. Those commonly reported include; reluctance of older people to disclose the information, cognitive impairment and unreliability of history, atypical presentations (e.g. falls, confusion, depression, social failure), and a lower degree of health professional suspicion. There is no clear guidance on safe levels of drinking for older people and diagnostic/screening criteria tend to focus on current drinking rather than lifetime alcohol consumption (Conigliaro et al 2000; O'Connell et al 2003).

Alcohol use disorders in older people are associated with a wide spectrum of adverse effects in terms of physical, psychological, cognitive and social health. The effects of ever having been a heavy drinker have been shown to be long-lasting and have adverse effects on illness, perceived health status, mental health and social wellbeing. There is some evidence that moderate alcohol intake may be beneficial but there is insufficient data to exclude personality and social factors as being more important and there is uncertainty whether or not the magnitude of risk posed by alcohol increases with age (Carrington Reid, Boutros, O'Connor, Cadarin, & Concato 2002; Conigliaro et al 2000; O'Connell et al 2003).

One systematic review of the health-related effects of alcohol use in older persons (Carrington Reid et al. 2002;) assessed 91 exposure-outcomes in 84 articles, relating to four outcomes; falls, functional impairment, cognitive impairment and all cause mortality. The age criteria were not always clearly defined but 63% included only participants aged over 60 years. Two thirds of the studies measured the effects of alcohol on only one of these four outcomes, five studies measured the effects on two and only one measured the effects on three outcomes. Seventeen (20%) of the 84 studies demonstrated harm associated with increased alcohol exposure, 59 (70%) studies found no association between increased alcohol use and adverse effects and eight (10%) reported benefit from greater alcohol use. Studies that demonstrated harm did not have higher methodological scores than those that found no association or benefit from alcohol use. The reviewers commented that most studies had methodological limitations related to; problems with quantity-frequency measures, under-reporting of alcohol use, lack of information about past drinking behaviour and current drinking patterns (e.g. binge drinking). They concluded that the magnitude of the risk posed by alcohol among older adults remained uncertain and recommended prospective studies to better define the health-related effects of alcohol use in this age-group.

2. Screening for alcohol abuse in older people

Given the multi-faceted presentation of alcohol abuse disorders in older people – are there effective screening strategies to identify patients with alcohol problems in primary care settings? In their systematic review Fiellin et al (2000) found 27 studies that screened for alcohol abuse and dependence. This systematic review was not restricted to an elderly population. The reviewers found that the AUDIT (10 questions) and CAGE (four questions) diagnostic tools performed consistently better than other methods with the results varying by sex and ethnicity. The AUDIT tool was most effective at finding subjects with at-risk, hazardous or harmful drinking (sensitivity 51-97% and specificity 78-96%), while the CAGE tool was most effective for identifying alcohol abuse and dependence (sensitivity 63-70% and specificity of 82-91%) in older populations for a score of two or more. Unfortunately, most of the studies reviewed, inconsistently adhered to both methodological standards and reporting of alcohol intake by amount and duration.

In their clinical review Conigliaro et al (2000) assessed the CAGE, MAST-G and AUDIT tools for the screening and identification of older adults with alcohol problems in primary care. In populations over the age of 60 years, they found that the CAGE questionnaire was the most effective brief screen (sensitivity 70%, specificity 91%) for a score of two or more. However, they warned that CAGE may be less sensitive in elderly populations. The modified 24 item MAST-G scale was also a valid tool in older people with good sensitivity (95%) and specificity (78%) but was lengthy and time-consuming to use. The AUDIT tool was found to perform poorly in elderly populations.

These reviews would seem to suggest that alcohol abuse screening in older people may be feasible in primary care using the standard 4 item CAGE questionnaire with a score of two or more. However, two recent reviews have cast doubt on the value of the CAGE questionnaire for screening for alcohol abuse and dependence in general clinical populations (Aertgeerts, Buntinx, & Kester 2004) and the effectiveness of screening at all for excessive drinkers in general practice as a precursor to brief interventions (Beich, Thorsen, & Rollnick 2003).

Beich et al (2003) reported a systematic review and meta-analysis of screening in brief intervention trials targeting excessive drinkers in general practice. They reported that for every 1000 patients screened, 90 will require further assessment of which 25 will qualify for brief intervention and two or three can be expected to reduce their alcohol intake. They concluded that screening in general practice did not appear to be an effective precursor to brief interventions targeting excessive alcohol use.

Aertgeerts et al (2004) reported a diagnostic meta-analysis to evaluate the CAGE questionnaire in screening for alcohol abuse and dependence in general clinical populations. They identified 35 articles that used the DSM-IV criteria as the gold standard to test the diagnostic value of CAGE, 10 of which were included in the meta-analysis. They calculated that with a cut off score of two or greater, the pooled sensitivity of CAGE was far better in hospital inpatients (87%) than in primary care (71%) or ambulatory patients (60%). This ties in closely with the results reported earlier in this paper (Conigliaro et al 2000; Fiellin et al 2000; O'Connell et al 2003). They concluded that the diagnostic value of the CAGE questionnaire was of limited value as a screening test for alcohol abuse and dependence.

An analysis of pooled results comparing the different screening tools is shown below in Table 3.

3. Summary of results

Alcohol abuse disorders are probably common and important causes of morbidity and mortality in older people. They are likely to be unrecognised and under-diagnosed for a variety of reasons. There is no accepted safe level of alcohol intake in older people, but the effects of co-morbidity and medication may increase the risk of alcohol use and abuse in this population.

Unfortunately, there is no single screening test or tool that can be used to reliably detect alcohol abuse in older people across a range of settings (clinical and research) and populations (community, primary care, out-patients and in-patients). However, for rapid assessment in a clinical setting, the CAGE questionnaire with a cut off score of >=2 will effectively discriminate older patients with a history of drinking problems from those without such a history (sensitivity 70%, specificity 90%, positive predictive value 75% - see table 3).

Discussion

Alcohol abuse disorders are recognised as being important in the UK by both the health professions and the government. However, there is no agreement between the two on what measures are appropriate to combat alcohol abuse (Marmot 2004).

Alcohol abuse in older people is often associated with impairments in physical, psychological, social and cognitive well-being. The effects of co-morbidity, medication and age itself are likely to exacerbate the effects of alcohol, making it increasingly important that we improve our effectiveness at identifying and treating this under-detected and misdiagnosed problem.

Unfortunately, alcohol abuse disorders have a multi-faceted presentation (physical, psychological, cognitive and social) and the prevalence varies according to the setting where the patient is seen (from 1-44%). Screening tools such as the CAGE questionnaire can be useful diagnostic aids, even though the latest evidence-based reviews cast doubt on the effectiveness of screening and brief interventions for alcohol abuse in the general population.

Recommendations

In the community, alcohol disorders in older people are common and likely to be identified opportunistically. In clinical practice, clinicians should also ask questions about quantity, frequency and drinking patterns (e.g. binge drinking) as well as specific questions about the effects and consequences of alcohol use. Any elderly-specific alcohol screen needs to include questions on physical, psychological, cognitive and social well-being. Patients identified may benefit from a brief intervention approach such as simple advice and education to the patient delivered by a health or social care professional.

In secondary care, alcohol abuse disorders have a higher prevalence and screening or case-finding may be viable. The CAGE questionnaire is quick and easy to administer and should be considered as an initial screen for those presenting with symptoms or signs suggestive of alcohol use disorder in the community and should be considered as part of the standard assessment of all those older people in secondary care (in-patients and out-patients) because of the higher prevalence of alcohol problems in these populations.

Many of the questionnaires and screening tools discussed in this review have been developed and validated in younger populations. Future clinical care and research must find ways of consistently recording and quantifying current and past alcohol intake levels. Recommended alcohol intake, screening instruments and diagnostic criteria need to be redefined in older people.

There is a clear need for high-quality prospective research in a UK setting to improve our understanding of the prevalence, presentation, diagnosis and treatment of alcohol abuse disorders in older people across the social and ethnic spectrum. Future research in this area will benefit from increased adherence to explicit methodological standards. Clinical trials (intervention studies) should be based on the accurate

Table 3 – Pooled comparison of screening tools for diagnosis of alcohol dependence and abuse

Screening Tool	Sensitivity %	Specificity %	Positive predictive value %	Reference (Setting)
CAGE				Aertgeerts et al 2004
Score 1	87	68	54	(all studies)
Score 2	71	90	75	
Score 3	42	97	87	
Score 4	20	99	92	
CAGE				Fiellin et al 2000
Score >=2	43-94			(primary care)
(63-70)*	70-97			
(82-91)*				
AUDIT				
Score >=8	33-96	70-97		
S-MAST				
Score >=2	21-100	77-85		
CAGE				Conigliaro et al 2000
Score >= 2	70	91	79	(older people - primary care)
MAST-G				
Score >=5	95	78	89	
AUDIT				
Score >=8	33-80	89-91	69	

Key

* subset scores for older patients in review

Abbreviations

CAGE	= Cut, Annoyed, Guilty, Eye opener
MAST-G	= Michigan Alcohol Screening Test - Geriatric
S-MAST	= Short Michigan Alcohol Screening Test
AUDIT	= Alcohol Use Disorder Identification Test

identification of patients with alcohol abuse disorders, offering them a clearly defined intervention which in turn, is linked to explicit outcome measures.

In the meantime information, support and advice may be helpful, particularly within a trusting therapeutic relationship. All those involved in caring for older people might usefully consider appropriate lifestyle advice to their patients or carers and be on the lookout for the multi-faceted symptoms and signs of alcohol abuse disorders in older people.

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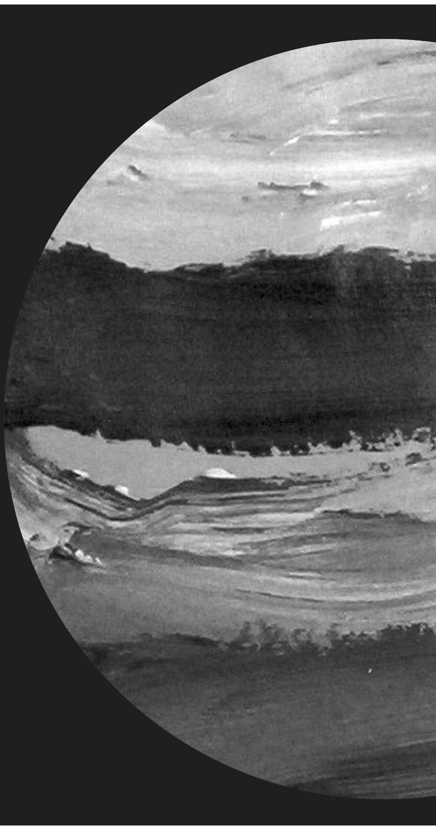

The dietary patterns of people with a mental illness who live in the community

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The dietary patterns of people with a mental illness who live in the community

Anne Hoyle & Julie Hazzledine

Abstract

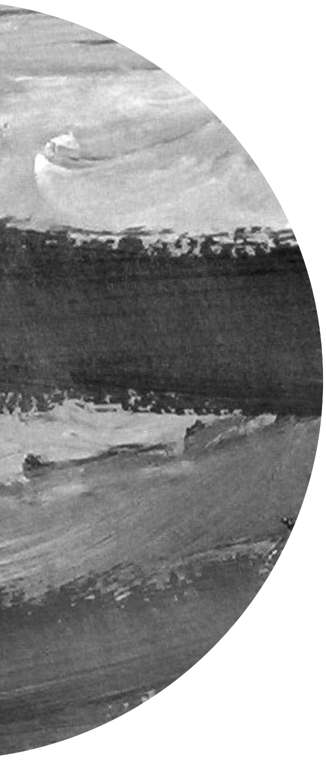
Background: People with mental health problems are known to have nutritional and physical health risks. This is due to the effect of mood on food intake, the side-effects of psychotropic medications, such as obesity and constipation, and the social issues affecting their food intake, such as poverty, homelessness and lack of motivation to shop for and cook food. Little is known about the actual dietary intake of this population. This study aimed to 1) establish the dietary patterns of a sample of community based mentally ill people, 2) compare their dietary patterns with the general population, 3) identify whether they follow the recommended healthy eating guidelines and 4) establish whether they are a group who require targeting for dietary education to prevent diet related health problems developing in the future.

Method: Twenty-two people with a mental illness, attending a local day centre, were weighed and questioned about their food intake, using a validated food frequency questionnaire.

Results: An analysis of the food frequency questionnaires demonstrated that the diets of mentally ill people differed little from the diets of the general population. Diets were generally low in fibre, due to a low intake of fruit and wholegrain foods, and high in saturated fat due to the frequent consumption of pies, pastries, chips and full fat milk (particularly by females). Refined sugar intake was primarily derived from sugar added to tea and coffee rather than sugared soft drinks or sugar containing foods. Over half of the subjects were overweight, smoked or exceeded the recommended level for alcohol intake.

Conclusion: This study demonstrated that although the diets of our sample of mentally ill people were similar to those consumed by the general population, their diets did not meet the government's healthy eating recommendations, in order to prevent cardiovascular disease, diabetes, obesity and cancer. Our sample of mentally ill people was therefore predisposed to the same risks of disease as the general population. Dietary and healthy lifestyle education programmes are thus required and should be targeted at individuals in this population who are most nutritionally at risk. Unfortunately, we were unable to establish which individuals were most at nutritional risk due to the small sample size. Larger studies, which allow for sub grouping according to diagnosis and psychotropic medication, are required in order to establish whether they have an effect on dietary intake patterns.

Key Words: Diet, Patterns, Food, Intake, Nutrition, Mental Illness



Introduction

People suffering from a mental illness are known to be at risk of poor nutritional status. There are several reasons for this. Firstly, psychiatric illnesses, including schizophrenia, mood disorders, eating disorders and substance abuse are known to adversely affect food intake, body weight and nutritional status (Gray, 1989). Secondly, drugs used to treat such disorders have effects on appetite and gastrointestinal function and interact with food and nutrients (Gray, 1989). Thirdly, social issues, such as poverty, homelessness and social isolation alter eating patterns, reduce food choice, and motivation to shop for, cook and eat food (Gelberg & Linn, 1988; Acheson, 1998).

Opportunistic eating, where people eat what they can get when it is available, is a way of life for many mentally ill people, and for others, chaotic eating is a part of a chaotic lifestyle (Evans & Dowler, 1999). Such poor eating patterns could lead to inappropriate food choices and the consumption of unhealthy diets. The physical consequences of such diets, for example, the development of cardiovascular disease, obesity, diabetes and cancer, are well known (WHO, 1990). The greater prevalence of morbidity and mortality documented in people with a mental illness is therefore not surprising (DoH, 1993a). Cardiovascular disorders are common in people with schizophrenia and their standard mortality ratio for all illnesses is two and a half times greater than the general population (Clinical Standards Advisory Group, 1995). The National Service Framework for Mental Health (DoH, 1999) has therefore prioritised health promotion in order to tackle this inequality in health.

Despite this link between diet and health, few studies have assessed the dietary intake of mentally ill people, and most of these have been performed in the elderly population due to their increased risk of malnutrition (Sindler et al, 1996: Gilbride et al, 1998). The nutritional intake of homeless and marginalised people attending day centres in London (which include the mentally ill) was recently determined (Evans & Dowler, 1999). Dietary intake patterns were found to be poorer than social classes IV and V, and nutritional intakes were found to be insufficient to meet the current dietary recommendations for many vitamins and minerals. Homeless adults with a previous psychiatric hospitalisation have also been reported to have the worst physical health of all homeless people studied (Gelberg & Linn, 1988).

Thomas (1990) examined the dietary intake of mentally ill adults living in different types of accommodation. However, only 37% of these were living in their own homes or with a relative. The remainder lived in care homes where food was provided, which had a positive influence on nutritional intake. Of the people living alone, only 60% ate three meals a day and Vitamin C intakes were 40% below the recommended amount due to the low consumption of fruit. This study however focussed mainly on nutrient intakes rather than dietary patterns and was performed in the South of England, where dietary intake is known to differ from that in the North (Gregory et al, 1990).

The move to community care means that many people with an enduring mental illness who used to receive hospital meals now live in the community where they have to provide and cook their own food (DHSS, 1975). However, there have been no studies to date that have examined the dietary patterns of mentally ill adults living in the North of England community. This cross-sectional exploratory survey therefore aimed to investigate the food consumption patterns and food choices of a cluster of mentally ill adults attending a local community day centre. The objectives were to: establish whether their intake is different from the general population; determine whether this population is following the recommended healthy eating guidelines (WHO, 1990); and identify whether they are a group who require targeting for dietary education and intervention in order to prevent physical health problems developing in the future.

Method

The target population was male and female mentally ill adults living in the community. The population studied was derived from individuals known to local Mental Health Services. From this study population, all individuals attending a day centre from 18 April to 28 August 2002 were selected for study. This cluster of people was required to meet the following selection criteria:

- Had a diagnosed Mental Health Disorder (ICD-10)(WHO, 1992).
- Had not experienced relapse in mental health condition, to the extent that they could not be interviewed.
- Had no severe memory problems (Dementia or Wernicke-Korsakoffs Syndrome) as this could have affected dietary recall.
- Were not following a prescribed therapeutic diet as this may have interfered with habitual dietary intake.
- Were not suffering from an eating disorder.
- Were aged between 18-65 years.

- Were not sectioned under the Mental Health Act (Buglass, 1993), due to ethical restrictions (DoH, 1993b).
- Were not of ethnic origin due to cultural differences in food intake and patterns of eating (e.g. fasting & religious restrictions).

All participants were provided with an information sheet detailing the purpose of the study and what the study would entail. Written consent was also obtained. Because both the dietitian and participant were not blind to the purpose of the study, these sheets were provided on the day of the interview, to avoid alteration of their usual food habits.

A nationally validated Food Frequency Questionnaire (FFQ) (Yarnell et al, 1983) was completed to establish patterns of food intake. Details of brand names and cooking methods were determined during the interview. Food portion size was determined using published standard food portion sizes (Crawley, 1988). Additional details were also requested including diagnosis, prescribed medications, living arrangements, cooking facilities, number of days lunch was eaten at the day centre, employment status and tobacco use. The frequency of the reported consumption of foods was compared with the reference figures for the general population obtained from The National Diet and Nutritional Survey: Adults aged 19 to 64 years (Henderson & Gregory, 2002).

The dietary interview was conducted at a local day centre on the participant's usual day of attendance in a relaxed, private setting. The date of the interview was unknown to the participant to avoid alteration of food intake the day prior to the interview. The same Dietitian (JH) performed all the dietary interviews in order to eliminate inter-observer error.

Dietary recalls considered incomplete or thought to be unreliable (e.g. due to memory problems) were excluded from analysis. People of an ethnic origin were excluded from the study

On the day of the dietary interview, the participant was also weighed (in light clothing) using portable Seca electronic scales (Manufacturer calibrated - Seca House, Birmingham) to the nearest 0.1 kg. Height was measured using a Seca stadiometer, to the nearest cm and Body Mass Index was calculated as weight (kg)/ Height (m^2).

Due to the small sample size, descriptive statistics (mean, standard deviation and percentage) were used to compare the food intake patterns between the mentally ill sample and the general population (Henderson & Gregory, 2002).

The research proposal was submitted to the Ethics Committee at Dewsbury NHS Trust for approval. Permission to include patients in the study was also requested from the Consultant Psychiatrists.

A pilot study was performed by selecting five people attending the same local day centre, who met the selection criteria, to establish the variability of outcomes, test the interview procedure and identify problems in the methodology. No changes were required to the methodology following the pilot study.

Results

Sociodemographic characteristics

Twenty two subjects met the selection criteria and were approached to participate in the study. No subject expressed a wish to be excluded. All 22 food records were considdered complete and reliable. Table 1 shows the socio demographic charateristics of the population studied.

Over half of mentally ill people living in the community lived alone, with more males living alone than females. However, despite only cooking for themselves, most people had adequate cooking and food storage facilities at home. Over half of the sample smoked and just under half exceeded the recommended intake for alcohol. Only one person was vegetarian. The unemployment rate was extremely high with no subject being in employment at the time the study was performed.

Table 1. Sociodemographic characteristics, psychiatric diagnosis and medications prescribed for the sample.

	Male	**Female**	**Combined**
	(n=14)	(n=8)	(n=22)
Age (years)			
Mean ± standard deviation	40 ± 11.4	27- 59	37 ± 16.3
Range	18 - 64	39 ± 13.1	18 - 64
Diagnosis % (n)			
Schizophrenia	43 (6)	0 (0)	27 (6)
Bipolar	7 (1)	0 (0)	5 (1)
Depression	14 (2)	87 (7)	41 (9)
Depression with alcohol abuse	7 (1)	0 (0)	5 (1)
Anxiety	7 (1)	13 (1)	9 (2)
Personality disorder with affective component	14 (2)	0 (0)	9 (2)
Pre senile dementia	7 (1)	0 (0)	5 (1)
Medication prescribed % (n)			
Atypical antipsychotics	29 (4)	13 (1)	23 (5)
Typical antipsychotics	14 (2)	13 (1)	14 (3)
SSRIs	43 (6)	50 (4)	45 (10)
Tricyclics	7 (1)	13 (1)	9 (2)
Other antidepressants	29 (4)	13 (1)	23 (5)
Lithium	7 (1)	0 (0)	5 (1)
Hypnotics:			
Benzodiazepine	7 (1)	37 (3)	18 (4)
Non-benzodiazepine	21 (3)	37 (3)	27 (6)
Beta blockers	14 (2)	0 (0)	9 (2)
Accommodation % (n)			
Lives alone	64 (9)	38 (3)	55 (12)
Lives with partner	29 (4)	25 (2)	27 (6)
Lives with relatives	7 (1)	25 (2)	14 (3)
Supported accommodation	0 (0)	13 (1)	4 (1)
Smokers % (n)	57 (8)	63 (5)	59 (13)
Alcohol consumption > recommended amount % (n)	43 (6)	50 (4)	45 (10)
Cooking facilities available % (n)			
Cooker	100 (14)	100 (8)	100 (22)
Microwave	86 (12)	100 (8)	91 (20)
Fridge	93 (13)	100 (8)	96 (21)
Number of days lunch taken at day centre per week			
Mean ± standard deviation	2 ± 1.6	2 ± 0.7	2 ± 1.3

Body weight

The sample appeared to be representative of the mentally ill population as mean BMI and percentage of people overweight were similar to those previously reported (Table 2). Surprisingly the prevalence of overweight in the sample was less than in the general population (Table 2). However, a third of participants reported weight gain in the 6 months prior to the interview.

Table 2. Body weight, body mass index (BMI) and self-reported weight change in the sample.

	Day Centre sample: Chronic mentally ill (aged 18-64)			General adult population		Chronic mentally ill population (aged 16-64)
	Male (n=14)	Female (n=8)	Both sexes (n=22)	Male	Female	Both sexes
BMI†						
Mean ± s.d	27 ± 5.1	26 ± 7.3	27 ± 5.8	25[†]	28[†]	27[*]
Range	21 - 42	18 - 41	18 - 42			
BMI >25 ie overw't (%)	57	50	55	68[‡]	56[‡]	55[*], 50[**]
Body weight Mean ± s.d	89 ± 19.8	67 ± 16.8	81 ± 21.2	76[†]	64[†]	-[a]
Range	66 - 42	45 - 99	45 -142			
Weight change in last 6 months% (n)						
Gain	43 (6)	25 (2)	32 (7)	-[a]	-[a]	-[a]
Loss	21 (3)	50 (4)	36 (8)			
Stable	36 (5)	25 (2)	32 (7)			

-[a] data not available

[‡] DoH Health Survey for England (2001)

[†] Gregory et al 1990

[*] Gopalaswamy & Gordon (1985)

**Thomas (1990)

Dietary Patterns

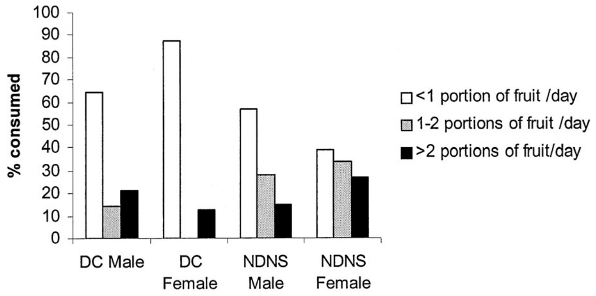
Fibre Intake

Eighty five percent of males and 63% of females consumed white bread. Females consumed a greater proportion of wholemeal bread than males (37% versus 15%). These trends were similar to those found in the general population (Henderson & Gregory, 2002).

A greater percentage of males ate breakfast cereal than females (91% versus 75%). Males had a slightly higher preference for low fibre cereals than high fibre cereals (50% versus 43%), whereas females were more likely to choose higher fibre than lower fibre ones (50% versus 38%). Again the figures are similar to those reported in the general population (Henderson & Gregory, 2002).

The average number of portions of fruit consumed per day was 0.8±0.9 portions for males and 0.9±1.0 portions for females. This is lower than reported in the National Diet and Nutrition Survey of 1.2 ±1.4 portions for males and 1.8 ±1.6 portions for females living in the North of England. The percentage of mentally ill females eating more than 2 portions of fruit per day was also slightly lower than the mentally ill males and the regional average for females and males (Figure 1). Eighty eight percent of females ate less than one portion of fruit per day.

Figure 1. Number of portions of fruit consumed



DC = Day Centre sample
NDNS = National Diet and Nutrition Survey (Henderson & Gregory, 2002) figures for the Northern Region

The average number of portions of vegetable/salad consumed per day was 1.5±0.9 portions for males and 1.4±0.5 portions for females. This was similar to that reported in the National Diet and Nutrition Survey of 1.3±0.9 portions for males and 1.3±0.9 portions for females living in the North of England. The percentage of mentally ill people eating more than 2 portions of vegetable/salad per day (35.7% of males and 12.5% of females) was greater than the regional average (1% of males and 0% of females).

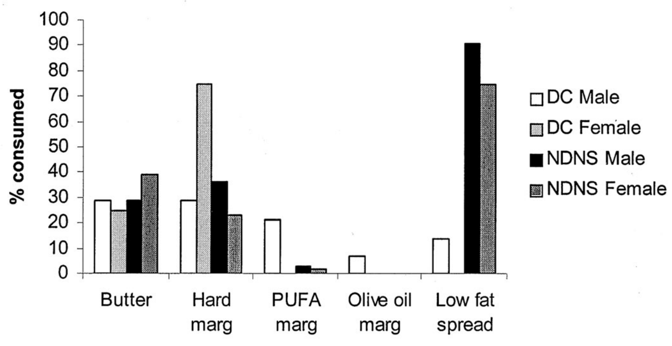
The average number of combined portions of fruit and vegetables/salad consumed per day was 2.4±1.6 portions for males and 2.3±1.0 portions for females, which was higher than the regional average of 2.1±2.0 portions for males and 1.9±1.8 portions for females. Only one male (this male was not the vegetarian) and no females met the recommended intake of 5 portions of fruit and vegetables/salad per day. This was below the regional figure of 13% for males and 15% for females (Henderson & Gregory, 2002).

The dietary intake of fibre from bread, breakfast cereals, fruit and vegetables/salad, was therefore low.

Fat intake

Forty three percent of males and 100% of females used a spreading fat, which was high in saturated fat (butter and hard margarine). Only 14% of males and no females used low fat spreads, unlike the general population, in which over 70% consumed low fat spreads (Figure 2).

Figure 2. Type of spread consumed

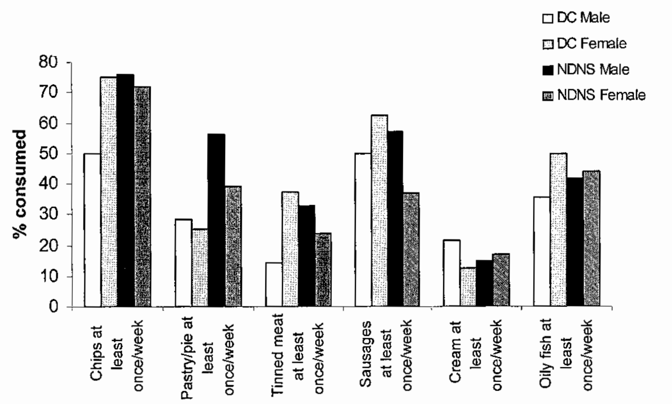


DC = Day Centre sample
NDNS = National Diet and Nutrition Survey (Henderson & Gregory, 2002) figures for the Northern Region
PUFA = Polyunsaturated fatty acids

All males and females used cooking oil for frying foods; hence, no participant used lard. A greater number of females than males ate fried foods more than twice a week (25% versus 14.%). Chips were eaten at least twice a week by 50% of females, but less so by males.

Other fatty foods that were commonly eaten (at least once a week) included sausages (55%) and pastry/pies (27%). The consumption of these fatty foods was less than the regional figures for males but higher than the regional figures for females for chips, sausages and tinned meat (Figure 3). Oily fish was eaten at least weekly by 41% of people, in line with the national intake of 43% (Henderson & Gregory, 2002).

Figure 3. Frequency of the consumption of fatty foods



DC = Day Centre sample
NDNS = National Diet and Nutrition Survey (Henderson & Gregory, 2002) figures for the Northern Region

Full fat milk was chosen in preference to semi-skimmed by females (50% versus 13%), whereas males consumed equal amounts of full fat and semi-skimmed milk (36%). Twenty one percent of males and 25% of females consumed skimmed milk, similar to the national intake of 21% for males and 26% for females (Henderson & Gregory, 2002).

The results therefore show that although the fat intake of the sample of mentally ill males was no greater (and in some cases less) than reported by the general population, the fat intake of the sample of mentally ill females was high and greater than reported in the general population.

Sugar intake

Biscuits and chocolate were eaten daily by 27% and 18% of the sample respectively. Only 23% of participants drank sugared squash and fizzy drinks which was below the regional average of 75%. Nine percent drank sugar free varieties, which was also below the regional average of 46% (Henderson & Gregory, 2002).

Sixty four percent of males and 38% of females drank in excess of the recommended amount of caffeine intake per day (300mg/d), with 36% drinking more than 6 cups of tea or coffee per day. Seventy three percent of these drinks had sugar added to them, with males more likely to add sugar to their drinks (86%) than females (57%). The sugar intake of the sample was therefore high but similar for females to the regional figure for the general population (56%)(Henderson & Gregory, 2002).

Discussion

Body weight

Being overweight is a major health hazard. In 1983 the Royal College of Physicians called for public health measures to counteract the widespread and increasing problem of obesity in the community. It has been suggested that weight gain, obesity and the associated physical consequences are likely to be an even greater issue for people with mental health problems (Gopalaswamy & Morgan, 1985). Furthermore, the incidence of obesity has been reported to be escalating with the advent of the newer atypical antipsychotic medications, which have the common side-effect of considerable weight gain (Taylor & McAskill, 2000).

The results from this study showed that over half of our mentally ill participants were indeed overweight, similar to that reported in other psychiatric populations (Gopalaswamy & Gordon, 1985; Thomas 1990). However, surprisingly, the population studied had a prevalence for being overweight which was less than in the general population. This may be because only a third of the participants reported weight gain over the previous six months. It is therefore possible that many patients who are on antipsychotic medications gain weight (37% of our sample were receiving such medications), but others with different diagnoses, such as depression, or substance abuse, may have a tendency to lose weight (Gray, 1989). The finding that a third of participants reported weight loss in the previous six months would support this hypothesis. The dietary patterns and weight change of this sample are therefore likely to be affected by differences in diagnoses. Unfortunately, it was not possible to establish this effect (by sub-grouping these variables) due to the small sample size. It is therefore likely that only a sub set of the local population will require targeting for dietary education to manage obesity, whereas others who may be malnourished may require dietary education on a balanced diet.

Dietary Patterns

Fibre intake

The overall intake of fibre containing foods was low. This was in accordance with the findings of others (McCreadie et al,1998; Evans & Dowler, 1999). Low fibre intakes are of particular concern due to the well-known side effect of constipation of many of the psychotropic medications with anticholinergic properties (Gray, 1989).

One reasons for the low fibre intake was the inadequate consumption of fruit and vegetables. A key feature of the Government's framework for reducing early deaths from coronary heart disease and cancer, and reducing health inequalities among the general population, is to improve access to, and increase the consumption of fruit and vegetables. The World Health Organisation (WHO, 1990) and the UK's Committee on Medical Aspects of Food (DoH, 1998) recommend eating at least five portions of fruit and vegetables a day. In this study only 7% of participants met this target, with 64% of men and 88% of women eating no fruit at all, with an average fruit and vegetable intake of only 2.4 portions a day. Other researchers have also reported low fruit and vegetable intakes in people with schizophrenia (Thomas, 1990; McCreadie et al 1998). As a consequence, the intake of the antioxidant vitamins A and C was likely to be low. This poor intake of fruit is of particular concern as a high proportion of our sample were smokers (59% compared to 32% in the general population; DoH, 2001) as smoking has been linked to higher lipid peroxide in people with schizophrenia and consequently higher risks of cardiovascular disease (Scottish Schizophrenia Research Group, 2000).

Fat intake

Despite the current health promotion messages across the UK to reduce fat intake, our sample was found to have high saturated fat intakes. This was in accordance with the findings of Thomas (1990) and McCreadie et al (1998). However, the males in our sample consumed fewer foods high in saturated fat than males in the general population (Henderson & Gregory, 2002). This finding was supported by the Scottish Schizophrenia Research Group (2000) who noted cholesterol levels in people with schizophrenia to be similar to those in the general population.

These results were surprising for two reasons. Firstly, all our participants were unemployed and were therefore likely to have limited resources for purchasing healthy food. Secondly, a higher proportion of males than females lived alone yet their diets were lower in saturated fat. When the source of the fat intake was examined, fat intake was mainly derived from the consumption of foods containing 'hidden' fats rather than fried foods, although the frequent consumption of chips was a particular problem in females. This is not unexpected since women with limited income have been reported to have a higher consumption of these fatty foods

(Henderson & Gregory, 2002). It is also likely that the younger mean age in the female sample than the male sample may have skewed the data slightly towards their higher consumption of chips and sausages, as this trend has been reported in young female adults in the general population (Henderson & Gregory, 2002).

One explanation for why the diets of the mentally ill were no worse than the general population may be because participants attended the local day centre on average twice a week, where a three course balanced cooked meal was provided. Their dietary intake of healthy food could therefore have been boosted by the wide choice of food available at the day centre. The importance of day centres in the provision of cooked nutritious food for the mentally ill and homeless has previously been emphasised (Rushton & Wheeler, 1993; Evans & Dowler,1999).

Sugar intake

Many psychotropic medications have the side effect of thirst and carbohydrate craving, particularly antipsychotic drugs due to their anticholinergic properties and ability to block dopamine, serotonin and histamine receptor sites (Bernstein, 1984). Patients with drug-induced dry mouth tend to consume large quantities of fluid in an attempt to quench their thirst. Consumption of large volumes of caloric soft drinks as well as sweetened coffee and tea, can add considerably to the daily caloric intake leading to obesity (Kalucy, 1983). The same trend for a high fluid intake was found in this study where a third of participants drank more than 6 hot drinks a day and three quarters took sugar in these drinks. This trend was particularly evident in males. It is possible that the higher consumption of fluid by males could be explained by the greater percentage of males prescribed antipsychotic medications than females (41% versus 26%). The intake of soft drinks however was surprisingly low. No other study has measured the intake of beverages in the mentally ill population living in the community, so there was no reference data available for comparison. However, Holt (1997) reported similar findings in lithium-treated inpatients. It is possible therefore that only people taking thirst-promoting medications drink large quantities of tea, coffee and soft drinks, and a number of people in this study were not on such medications. One of the limitations of this study was therefore the small sample size as we were unable to group participants according to medication type and diagnosis in order to establish whether different psychotropic medications influenced drink intake to different degrees.

Methodological problems

It is impossible to know precisely what free-living individuals eat. Dietary intake is inherently variable and no method can assess food intake without itself altering eating behaviour (Thomas, 2001). This study attempted to measure the dietary intake of mentally ill people using a FFQ. At the commencement of the study, we intended to cross-validate the FFQ with another method for measuring dietary intake, the 24 hour recall (Bingham, 1987; Bingham et al, 1988; Bingham et al, 1994) incorporating A Photographic Atlas of Food Portion Sizes (Nelson et al, 1997). However, during the course of this study, a publication in the Journal of Human Nutrition & Dietetics (Frobisher & Maxwell, 2003) concluded that the use of food photographs for estimating portion size along side a 24-hour recall was no longer a valid method for establishing energy and nutrient intake, particularly in populations where recall is a problem. Whilst we would not normally have changed the study design, based on the findings of one article, the authors of the paper were considered to have sufficient expertise in the field of dietary assessment techniques to accept their new findings. The 24-hour recalls performed were therefore not analysed in this study as originally intended in order to cross-validate the FFQ. The dilemma of whether to measure food intake in mentally ill people, at the risk of the data being invalid, or whether not to measure their intake at all, due to the pitfalls of dietary assessment, will remain. However, we felt that even if only trends and patterns of dietary intake could be determined, then this could be of some value. The results of this study must therefore be interpreted cautiously as FFQs can be inaccurate when used in small samples (Bingham, 1987). Nevertheless, the general agreement between the results of our study and those of other researchers who investigated the dietary patterns in mentally ill patients, indicate that our findings were likely to be valid.

Conclusions

This study demonstrated that the diets of our sample of mentally ill people were similar to those consumed by the general population. However, their diets did not meet the government's healthy eating recommendations in order to prevent cardiovascular disease, diabetes, obesity and cancer. Over half the sample of mentally ill patients smoked, was overweight and exceeded the safe alcohol intake levels. Females had a particularly high intake of fat and males a high intake of sugar. Both sexes had low intakes of fruit.

The study therefore revealed a number of diet and lifestyle factors, which could predispose mentally ill people to the same risks of disease as the general population (WHO, 1990). It appears that dietary and healthy lifestyle education programmes are thus required. Ideally this education should be targeted at individuals in this population who are most nutritionally at risk.

Recommendations

Assertive programmes to improve the diet are necessary in order to reduce the risk of heart disease, diabetes and cancer and to reduce the side effects of medication, such as obesity and constipation, in the mentally ill population. People with mental health problems have more contact with health professionals than the general public, so health professionals should not miss out on a useful opportunity for preventative work. In fact, even during this study, many of the subjects interviewed requested referral to a Dietitian for dietary advice on healthy eating, as they were keen to improve their diets. Education on correct dietary principles and the promotion of an active, healthy lifestyle have been found to be beneficial in this population (Merriman & Kench, 1993). It is likely that certain sub-groups are at greater risk of developing these physical complications than others, primarily those who gain weight as a side effect of their medication, those who smoke and young female adults with a high fat intake. Larger studies are required to determine whether diagnosis and type of prescribed psychotropic medication place some individuals at greater risk of poor dietary patterns. These potentially higher risk groups could then be identified and preferentially targeted for education. Healthy lifestyle programmes (called Meaningful Day) have recently been set up in many communities in order to manage drug-induced weight gain from the newer atypical antipsychotic medications. South West Yorkshire Mental Health Trust has already piloted such a programme and is currently planning to expand this research in to the inpatient unit at Fieldhead Hospital. The effectiveness of this new programme will be evaluated in due course.

From the dietary education aspect, it is recommended that the same key messages provided to the general population be also given to mentally ill people. However, it would be sensible to give these as four or five simple specific dietary changes rather than educate on the broad general principles of healthy eating due to the impaired cognitive abilities of some mentally ill people (Holt, 1997). Examples of these may include:

1. Replace biscuits with fruit
2. Cut down on the intake of pastry and chips
3. Choose semi-skimmed milk
4. Eat a high fibre breakfast cereal every morning
5. Avoid adding sugar to hot drinks, and replace soft drinks with diet varieties.

Day centres should continue to provide cooked nutritious meals. They may also wish to consider offering fruit to attendees mid-morning and mid-afternoon as an alternative to biscuits, where resources permit.

It is also recommended that larger studies be performed in the mentally ill population, using the FFQ, in order to provide further validity to the results found in this study.

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Psychosocial interventions in a medium secure unit for people with learning disabilities:
A service development

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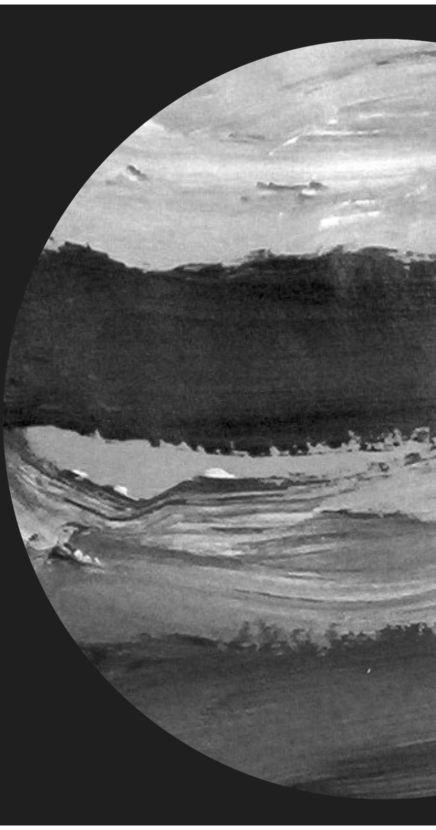

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Psychosocial interventions in a medium secure unit for people with learning disabilities:

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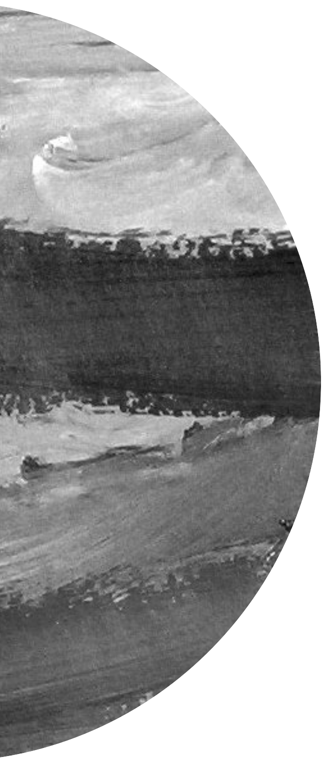
Abstract

Psychosocial Interventions (PSI), a whole systems approach, is an integral part of the agenda for modernising mental health services. It is advocated as an effective approach for services in promoting the recovery of people with schizophrenia and other psychoses. The literature relevant to the approach is reviewed. However there is a dearth of literature with regard to PSI in mental health services for people with learning disabilities. This absence is particularly marked in secure settings where there is no established evidence based model of care. This paper describes the implementation of PSI in such a setting, including the central tenets of individual and group therapy, family intervention and formulation based care planning. This is supported by group supervision, staff training and the explicit support of the centre's clinical management team. The implementation is still in progress. The evaluation strategy is also described.

Key words: learning disabilities, psychosocial interventions, secure services



Background

There is a dearth of literature with regard to the severe mental health problems of people with learning disabilities. Raghavan (2004) identifies this situation as being due to inconsistencies in assessment and diagnosis, and comparative paucity of published evaluation of intervention strategies. This lack of literature is even more significant for the learning disabled population cared for within secure psychiatric settings.

Services for people with learning disabilities have been dominated by the ideologies of normalisation and applied behavioural analysis and the training of nurses (RNMH/RNLD) has been in keeping with this (Gilbert, Todd and Jackson, 1998). However, it has been suggested that whilst behavioural technologies may tackle overt features of a person's presentation the underlying level of psychotic symptomatology remains unaffected (Tarrier, 1992). Psychosocial Interventions (PSI) have been advocated as a complement or alternative to behavioural and pharmacological models of intervention (McCann, 2001). What follows is a brief description of psychosocial interventions, their relevance to secure care for people with learning disabilities who have severe mental health problems and their implementation in a service for that population.

What are Psychosocial Interventions?

Psychosocial Interventions is a term which describes the use of psychological and social approaches alongside medical and pharmacological therapies in dealing with a variety of conditions (both physical and mental). With regard to services for people with schizophrenia, intervention may take many forms but they all rely on interpersonal interaction for therapeutic gain. They target people with enduring mental health needs to improve functioning and reduce distress. The interventions are drawn from the following areas; individual cognitive behavioural interventions, psycho-educational approaches for patients and carers (to increase recognition and understanding of signs and symptoms associated with schizophrenia and to maintain compliance with medication) and finally family interventions to reduce relapse (McCann, 2001). Combinations of these methods have been shown to promote mental health and well being (Pilling; Bebbington, Kuipers, Garety, Geddes, Orbach, Morgan, 2002), reduce burnout in nurses (Ewers, Bradshaw McGovern and Ewers, 2002) and to be in keeping with current policy frameworks (Williams, 2002; Department of Health, 1999). Recent Guidance from the National Institute for Clinical Excellence (NICE, 2002) states that these interventions should be available to people with schizophrenia and their families, but do not extend this directive to groups where there is 'co-morbidity' e.g. people with learning disabilities and concurrent mental health problems.

Psychosocial Interventions and People with Learning Disabilities

A comprehensive review by Hatton (2002) identifies a small literature relating to psychosocial intervention with people with learning disabilities, including those with psychosis and those in secure settings. The evidence is limited but positive with regard to the approach. However these two areas of literature do not overlap; the former consists of case study reports (Mace, Webb, Sharkey, Mattson and Rosen, 1988; Leggert, Hurn and Goodman, 1997) and the latter focuses mainly on offence related issues (e.g. Lindsey, Neilson, Morrison and Smith, 1998). Stenfert Kroese, Dewhurst and Holmes (2001) reviewed the literature relating to psychiatric diagnosis and prescription of psychotropic medication for people with learning disabilities. They found that relying solely on these interventions could be insensitive to the persons needs, intrusive and in many cases was not sufficiently supported by the evidence base. They advocated staff training and the use of psychosocial interventions as a more appropriate and ethically sound mode of intervention. Numerous small scale studies demonstrate that people with learning disabilities can engage in and benefit from Cognitive Behavioural Therapy (CBT) to deal with anxiety, depression and anger (Hatton, 2002). Caine and Hatton (1998) and Stenfert Kroese, Dagnan and Loumidis (1997) suggest ways in which the therapy can be adapted so that it can be used with this population. CBT forms the mainstay of work with individuals in the PSI framework; therefore using this approach with people with learning disabilities who experience psychosis seems appropriate. Many people with learning disabilities depend on substantial support to enable them to cope with everyday tasks therefore health services often intervene either with families (Bromley, 1998) or with residential services (McBrien and Candy, 1998). The established importance of this wider context supports the case for the applicability of PSI to systems of care for this client group

Psychosocial Interventions in Secure Services

The vast majority of published work in the field of PSI concerns community and acute inpatient psychiatric services (none of which addresses the needs of people with learning disabilities). A UKCC scoping paper into nursing in secure environments (1999) dismissed the evidence base in Forensic Nursing as ‘clinical anecdote’ (p.80). The paper recommended post registration training in PSI as a way to increase the competence of nurses in secure environments and to move forensic nursing away from practice based on incident and inquiry towards evidence based practice. Baker, O’Higgins, Parkinson and Tracey (2002) describe a pilot study of PSI implementation in a low secure service and anecdotal evidence of positive impact. They and McKeown, McCann and Forster (2002) identify a literature concerning problems in implementation of PSI in psychiatric services generally and in inpatient services in particular. They suggest systemic and organisational factors are crucial to deliver and maintain improvement, placing strong emphasis on training and supervision as well as managerial support. In general, inpatient services have been criticised for almost exclusive focus on the delivery of medication (SNMAC, 1999), it is hoped that the planned programme outlined below will demonstrate substantial developments beyond this.

Implementing PSI in the Medium Secure Service for People with Learning Disabilities

The service described is a specialist inpatient facility for 10 men with mild/borderline learning disabilities (IQ = 60-80) all of whom are detained under the Mental Health Act 1983. All the men have a psychiatric diagnosis of schizophrenia or another psychosis, though they may have other additional and complex physical and mental health needs.

PSI is a ‘whole systems approach’ rather than a discrete intervention. A person’s care is informed by Formulation, a theoretically informed integration of information drawn from a holistic assessment process. Formulation provides a way of understanding how problems developed and are maintained. It also points to how one should intervene to promote well being. This understanding informs nursing care plans which allow a broadly consistent approach and the use of targeted interventions by all members of staff.

Patients

In addition to routine care informed by the approach patients can also participate in individual psychological intervention and/or a Mental Health Issues Group. The primary purposes of this are for patients and professionals to develop a shared understanding of the patient's difficulties in context, and empower them to use coping strategies to improve and maintain their mental health. The individual and group work relies on a slower pace, careful work to establish a common language, pictorial representation, repetition and more attention to behavioural signs and behavioural experiments. Caine and Hatton (1998) write of the effectiveness of simplified CBT techniques such as self instruction and cognitive restructuring. Some time has to be spent to understand the impact of the person's learning disability on their illness and vice versa. This contextual understanding can be important e.g. auditory hallucinations where voices talk about 'being stupid' or looking different may be connected with experiences of bullying. Less ability to communicate coupled with suspicion can lead to isolating, impulsive and self destructive behaviours.

Families

Interventions with key members of a patient's family are integral to the approach and comprise tailored psycho-educational components. These are underway with the families of several patients at present. The service is fortunate to have a high level of involvement by families and carers in patient care and following a pilot group a carer support group will be established that will have a psycho-educational and supportive function. There is strong evidence that high Expressed Emotion (EE) within families; meaning strong articulation of hostility, criticism or overprotection, is detrimental to mental well being and increases the risk of relapse. The context of having a family member with a learning disability has to be considered (Bromley, 1998) including the difference this makes to levels of stress and ways of coping.

Staff

A Training Needs Analysis of current members of staff has been conducted using the 'Management of Schizophrenia Questionnaire' (Berkowitz and Heinl, 1984). This asked direct care staff (N=13) to write an account of how they would respond to a range of situations that may be experienced in working with people with schizophrenia. The responses have been analysed using a qualitative methodology based on Grounded Theory (Strauss and Corbin, 1998). The findings will be presented in a subsequent paper; but briefly members of staff used strategies to explore the situation and to reassure, support and direct patients. When one compares this to a PSI approach the latter gives patients more ownership of the strategies and, one could speculate, is based on a more sophisticated understanding of mental health. Also relevant is the fact that qualified nursing staff are predominantly trained in Learning Disability Nursing (RNLD/RNMH) rather than in mental health. Despite this there were also examples of good practice within staff responses. These findings will inform the training programme that will support the implementation of the approach. Following the training period ongoing supervision will be provided to all levels of staff to refine formulation and intervention.

Organisation

Crucial to the continued momentum of this initiative is the support of the organisation as a whole for the clinical team in its widest sense at ward level (Baker et al., 2002). An ongoing commitment to post registration training by the service will ensure that the 'critical mass' of committed and competent staff is maintained. Also, flexibility in the staffing profile will allow a larger number of people to become involved in the full range of components of the approach, improving patient care and job satisfaction.

Evaluation of the Service

Given that PSI is an integrated approach with several modes for intervening identifying ways of evaluating the individual components in a relatively small service is not straightforward.

To measure the impact of family interventions the Knowledge about Schizophrenia Interview (KASI) (Barrowclough and Tarrier, 1992) and Relative Assessment Interview

(RAI) (Barrowclough and Tarrier, 1992) will be used. Individual and Group interventions will be evaluated by repeated measures of The Psychotic Symptom Rating Scale (PSYRATS) (Haddock, McCarron, Tarrier et al. 1999), the KGV (Modified) Symptom Scale, Version 6 (Lancashire 1998), The Liverpool University Neuroleptic Side Effect Rating Scale (LUNSERS) (Day, Dewey and Bentall 1995), The Brief Psychiatric Rating Scale (BPRS) (Overall and Gorham 1962), The Beck Hopelessness Scale (Beck and Steer 1987), The Rosenberg Self Esteem Scale (Rosenberg 1965), The Glasgow Depression Scale (Cuthill, Espie and Cooper 2003) and The Calgary Depression Scale (Addington, Addington and Maticka-Tyndale 1993).

To monitor the overall impact the Ward Atmosphere Scale (WAS) (Moos, 1974) will be used. This is a 100 item questionnaire comprising statements to which the respondents answer 'true' or 'false'. It will be completed by patients and staff at 6 month intervals (2 sets of data have already been collected). Though 30 years old the WAS is still widely used in clinical settings for programme evaluation. It has been identified as a positive step towards the objective measurement of the therapeutic environment provided by a ward (e.g. Smith, Gross and Roberts, 1996). The responses are clustered to provide scores on the following subscales; involvement, support, spontaneity, autonomy, practical orientation, personal problems orientation, anger and aggression, order and organization, program clarity, and staff control.

Service users have been consulted regarding the developments above and the implementation reflects their desire to understand their problems more clearly and to have increased control over symptoms. Additionally they wanted staff and their families to understand illness better and to appreciate the role the family played in maintaining good mental health.

The results of further evaluation will be added to the literature in this area, a field that is still very much in its infancy.

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Educational implications of the National Service Framework for older people: A brief report

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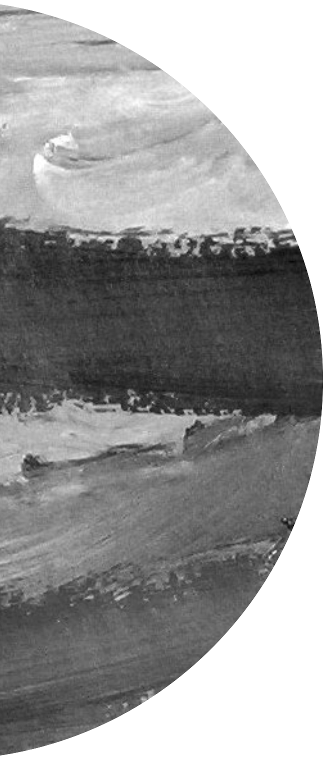

Abstract

This paper gives a short account of qualitative research undertaken with a large variety of stakeholders in the early days of the National Service Framework (NSF) for Older People. The aim of the work was to explore the educational needs arising from the NSF and to inform developments in education designed to address these needs. The study identified generally positive views on the NSF but few relevant training activities. There was a strong opinion that the elimination of age discrimination should be a major target and that cross agency and multidisciplinary training would be particularly helpful. The size of the staff groups involved, the need to address those who did not specialize in older people's care (but nevertheless spent a lot of time with older people), the generally fragmentary knowledge of the whole care system possessed by those working in parts of it and service pressures were seen as obstacles to training. A number of key areas for further progress were identified including the following:

- Mental health, palliative care and intermediate care
- Addressing the needs of staff not specializing in care of older people
- Increasing the health awareness of older people themselves
- Identifying leaders for developing specific education in each service area
- Developing guidelines and milestones to measure progress
- The need for an ongoing educational "campaign"
- Pervasive education to eradicate ageism, starting in schools.

Introduction

National Service Frameworks (NSFs) are an attempt to introduce equity of provision into the NHS and to encourage clinical excellence. They are based on clinical evidence and expert opinion and depend for their implementation on managerial effectiveness and educational initiatives. This is a brief summary of a project that examined the educational implications of the NSF for older people. It will be used locally to inform a workshop involving University, Social Services and NHS staff responsible for education. More widely, it will be of interest to anybody wrestling with the educational imperatives of turning the standards of the NSF into clinical reality. A full version of the report is available on the Ageing and Mental Health research Group Website at the University of Huddersfield http://www.hud.ac.uk/hhs/research/amh/index.htm. This includes a fuller report of the findings including a more detailed breakdown standard by standard and an analysis of views expressed by different stakeholders or stakeholder groups.

Background to National Service Frameworks

In 1997 a radical reforming Labour government came to power. A range of reforms and programme of modernisation were introduced in both health and social care. In December 1997 a White Paper "The new NHS: Modern, Dependable" (Department of Health 1997) outlined a comprehensive new vision for the NHS. Priorities guidance on modernising health and social service (Department of Health, 1998a) extended parallel reforms to social services. Much of this emphasis on social services modernisation and the subsequent injection of funding addressed the needs of older people

At the same time that vision and values were being laid down, performance management techniques were introduced across the range of health and social provision. The quality framework involved a three-layer approach (Department of Health 1998b). National Service Frameworks (NSFs) and a National Institute for Clinical Excellence (NICE) were to set clear standards for services, technology and treatments. The NHS was to make local delivery of services dependable by professional self-regulation, lifelong learning and clinical governance (Department of Health 1999) Clinical governance placed obligations on NHS Trusts to monitor and continuously improve the quality of health care that they provided. Wattis and McGinnis (1999a) emphasized the strong link between clinical governance and continuing professional development. A National Performance Framework, an inspectorate (the Commission for Health Improvement, now the Healthcare Commission) and a National Patient and User Survey underpinned Clinical Governance. This ambitious vision for change and its detailed prescribed implementation set a massive agenda for change and demanded radical shifts in the management and clinical cultures of the NHS (Wattis and McGinnis 1999b). This is the background against which the NSF for older people, the third NSF to be introduced, was developed and released. It was intended to promote high standards for the care of older people throughout the NHS.

Do we need an educational strategy?

The NSF is so hedged about with targets and administrative deadlines, that it is tempting to question the need for an educational strategy. It might be argued that the detailed targets by themselves are sufficient to generate the required change. Our local experience with the implementations of the educational recommendations arising from the “Forget-me-not” audit of older people’s mental health services suggested that even when specific areas for action were identified by District Audit, little happened without a conscious strategy to make it do so. This was in accordance with modern management theory that the best results are to be obtained not only by setting objectives but also by paying attention to process and people (Johnson and Broms 2000). It seemed reasonable to assume that the absence of a specific educational strategy and processes would at least reduce the speed of change in areas such as staff and management attitudes, knowledge and skills, and present an obstacle to implementing the NSF. This would delay or reduce the benefit to older people.

The rationale for the study and methods used

We were left with the question of what a strategy should contain. It would have been easy simply to turn to the “educational” experts but we wanted also to consider other points of view. With the aid of a grant from School of Human and Health Science’s Innovation Fund at the University of Huddersfield we systematically sought the views of a wide variety of stakeholders to develop a robust view of what needed to be done. We planned to identify areas of progress and good practice and areas that needed special attention as a first step towards developing an educational strategy

Choice of qualitative methodology

We chose qualitative methods in order to:

- be open to a variety if views, reducing the effect of pre-conceived ideas
- examine the issue from a number of different viewpoints to see whether any consensus emerged
- draw upon the experience of people who had grappled with the real-life implementation of NHS policy in the past
- ensure that what emerged would provide new ideas as well as perhaps confirming or refuting some pre-conceptions.

Twenty-seven people were interviewed. These included the following:
- representatives of social services (including a training manager)
- a representative of the housing department
- representatives of intermediate care
- representatives of NHS Trusts
- nursing and residential home providers
- university educators
- a representative of the voluntary sector
- carers
- members of the general public

All interviews were conducted by one of the authors (MM), trained and experienced in this type of work, in late 2001 to early 2002. Where necessary interviewees were provided with a summary of the NSF before the interview. We sought to discover general views about the NSF and for each standard to determine what educational activities were currently available, what gaps there were and what was needed to deliver on the standards. Interviews were recorded and transcribed before being analysed using the computer programme "N-VIVO" (Gibbs, 2002). As detailed in the main report we used this programme to analyse the data, developing themes linked to nodes by an iterative process. These could then be explored in a variety of different ways, for example standard by standard or stakeholder by stakeholder.
Research Governance and ethical considerations

This study was designed and commenced before the research governance framework was implemented. At that stage it was not considered necessary to seek ethical approval for studies involving consenting members of staff. However, the research design was subject to peer review within the University. When it became evident that the new Research Governance Framework (Department of Health, 2001) required Local Research Ethics (LREC) approval, the study was halted. The study was then submitted to the LREC and, once approval was granted, was recommenced.

Findings

The findings were analysed under five headings and key findings are summarised in Box 1 with supporting quotes in Box 2.

A standard by standard analysis showed that rooting out ageism, and person centred care were seen to be fundamental tasks. Intermediate care was a new area but one where education for inter-agency working was particularly important. In the general hospital there was particular concern about lack of education for dealing with mental health problems and about interest in the NSF outside specialist older people's services. Stroke and falls were areas where pre-existing initiatives had been strengthened by the authority of the NSF. Mental health was seen as an area where more knowledge and skills were needed not only in the general hospital but also in the community amongst home care and in residential and nursing care. Health promotion was a subject that needed to be tackled by all practitioners as part of their everyday work and education was needed to support them in this.

Box 1: Summary of emergent themes:

Views on the NSF generally

- The NSF was a good idea with much potential.
- Practical implementation was vital and required financial support
- It should address all staff and systems in health and social care.
- Those charged with implementation needed to be able to work with organisational complexity.

Current status of education and training for the NSF

- At the time of the study few relevant training strategies had been developed.
- Existing programmes might be adapted to this purpose.
- Training should arise as a result of immediate needs and should be focused.
- Cross-agency, interdisciplinary forums could improve mutual understanding.
- The elimination of age discrimination should be a major target

The gaps in and obstacles to education and training

- Target staff groups were large and consequently difficult to address.
- It was essential to reach those who did not specialise in older people's care.
- People tended not to be aware of all relevant aspects of the care system.
- The day to day operation of health care in general took priority over training.
- Joint learning, teamwork and attitude change were important targets.
- The care of older people should be promoted as an important field of study and development.
- There should be more training in areas specific to older people: e.g., dementia

Views on multi-disciplinary and inter-agency working

- There should be no 'grey areas' between separate health and social care organisations.
- We should acknowledge that these organisations worked in different ways.
- Existing rivalries must be overcome to promote integration.
- Separate budgets might be pulled together.
- Training must be related to the patients/clients needs.
- The biggest hindrance to development was claimed to be lack of coherence between health and social services.

Areas for further progress

- Mental health, palliative care and intermediate care required a special educational effort.
- Staff working in other areas needed knowledge about these areas in order to deal with the needs of older people that they cared for.
- Older people themselves need to be targeted, primarily by attempts to increase health awareness.
- Leaders ought to be identified and developed in each area of the service.
- Guidelines and milestones would help monitor progress.
- Senior staff needed an understanding of the "political" aspects of health and social care.
- Education and training should be ongoing.
- A cadre of specialist nurses could provide support and expertise as well as training.
- Education to eradicate ageism needed to start in schools and to be pervasive.

Box 2: Quotes to support emergent themes

General

"it cannot be done on the cheap and at the moment that does seem to be the way that it's expected to be delivered."
(Nurse consultant)

Current education and training

"…with the students that we take, we always ensure that they spend time with the district nurses and the therapists and the social workers, so it's very much done in-house - it's more of a shadowing rather than formal training, but that in itself has provided huge benefits because people have got a greater understanding of what each other's roles are…"
(Intermediate care provider)

Gaps and obstacles in education and training

"…I still get the feeling talking to my contacts that people who are specifically related to care services with older people see it as very relevant to them, but I am not convinced that other people or other practitioners where it really needs targeting, see it as being related to their care, because to me the Framework is talking about older people wherever they need care."
(University teacher)

Multi-disciplinary and inter-agency working

"…there is a sort of joint training and shared discussion because otherwise people don't understand the different assumptions that people from different professions and organisations are working to, and that's the only way to really resolve those."
(Voluntary organisation manager)

Areas for further progress

"I can't underestimate the value of front-line carers and equipping them to do a job that we are going to demand more and more in the future, so there has to be a recognition that it has to be as a career; they have to be trained and supported continually, and they have to be paid to do it."
(Intermediate care manager)

Conclusions

Particular areas of activity and need were seen in each of the agencies and groups studied and these are detailed in the full report. We concluded that to take forward the educational agenda for the NSF a strategic approach was needed that :

- Embraced different methods - personal agency and service design as well as courses.
- Included a variety of content - attitude-changing and technical.
- Crossed boundaries - health and social, mental and physical, caring and technical.
- Was co-ordinated - sharing resources and best practice.
- Was pervasive - starting in schools and involving all providers of health and social services.
- Was addressed to key groups - continually reminding commissioners, managers and providers of the needs of older people.
- Was persistent: - changing attitudes takes time, knowledge and skills need constant updating.
- Was well led - "champions" for the NSF in all relevant areas with support to facilitate delivery of the standards.

We plan a workshop in Huddersfield in autumn 2004 to consider the lessons to be learned from this study and from trying to develop education to implement the NSF. Our findings will be of interest more widely to those seeking to develop education to facilitate the shifts in attitudes, changes in organisations and gains in knowledge necessary to successful implementation of the NSF.

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The work itself remains the responsibility of the authors.

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Learning disabilities registers: Who should we register and why?

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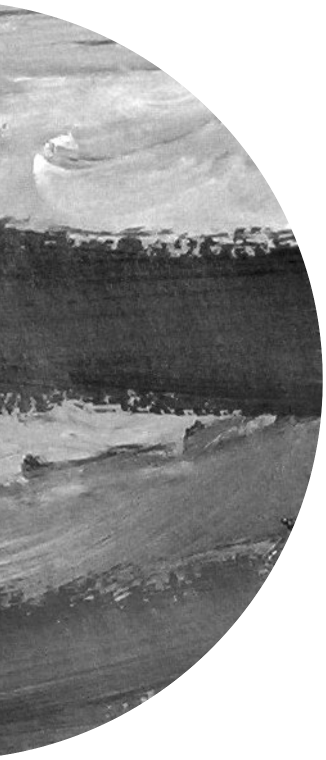
Learning disabilities registers: Who should we register and why?

Simon Whitaker

Abstract

The paper considers the advantages and disadvantages of setting up a register of people with learning disabilities. It is noted that one major problem in setting up such a register is that we do not know who the majority of people with a learning disability are. It is suggested that any register needs to define clearly who is being registered, have all or nearly all the people who fit that definition registered and have an appropriate update system for the register.

Key Words: Learning Disability, Registers, Prevalence



Introduction

In the 1990s I administered the Huddersfield register of people with a learning disability, and, in part because of this, I was recently asked by South West Yorkshire Mental Health NHS Trust to look at the use of registers in the region and the possible advantages and pitfalls of setting up such a register. This paper is based on this work and on current ideas about the nature and prevalence of learning disabilities.

There are numerous examples of computerised registers of people with learning disabilities both in this country (Farmer, Rohde and Sacks 1993) and abroad (Jacobson 1990). Within the South West Yorkshire area there are at least five registers which wholly or partly contain people with learning disabilities and there is currently a debate as to whether there should be an area wide register developed.

There are a number of advantages of holding a computerised register of people with learning disabilities in a particular location. It is able to store information on clients in such a way that it can be accessed easily. Information on a given individual could be obtained by simply typing a name into a computer. In this sense the register is a little like an electronic filing cabinet. However, the real advantage of computerised registers is their ability to provide detailed statistical information on the entire group of people on the register, or on specific sub sections, very quickly. This clearly has advantages for the planning and monitoring services. For example, a register of people with learning disabilities could be used to monitor compliance with the requirements of the White Paper Valuing People (Department of Health 2001), for example telling managers how many people had a Health Action Plan or had had a Person Centred Plan in the last six months. Similarly it could be used to aid planning by giving demographic information such as the number of people living with parents aged 70 or older. This would allow the service to run more efficiently and so hopefully have a beneficial effect on the people who are on the register.

There are, however, a number of ethical, practical and cost benefit considerations that should be taken into account before setting up such a register.

Ethical Issues

Setting up a register of people with learning disabilities is not without its ethical considerations. With any register there is the issue as to whether it is right to hold private information on individuals that could be potentially accessed by people they may not wish to have it, or could potentially be used against them for instance to withhold a service if they did not meet a criterion. These problems are greater for people with learning disabilities who may not understand the implications of agreeing to go on such a register, or providing information for the register. Ethical considerations are complex and it is not the primary aim of this paper to consider them. However, before setting up such a register, there needs to be consideration as to whether the clients on the register would benefit from being on it. If not the register must be ethically questionable.

Cost Benefit Considerations

In addition to considering if a register would have advantages for the individuals who are on it, one should also ask if the financial cost of setting up and operating a register would be recouped by the financial savings of having the register and/or the improvement in the service. Clearly if the benefits do not outweigh the costs then there is little point in having a register. This assessment may not be easy to undertake as it goes beyond simply looking at finances but should also include possible improvements to services that cannot be quantified. However, one factor that should be considered is whether the register can do what it is required to do. There are a number of potential problems with registers in general and with learning disabilities registers in particular, which could lead to them not being able to do what they have been set up to do. It is these that this paper will focus on.

The Need for Registers to be Inclusive

If a register does not have records of all the people, or nearly all the people, from a defined population, or a random sample of that population, then it will not be able to give accurate statistical information about that population. For example, as we are more likely to know of children with learning disabilities than adults due to their obvious failure at school, then a register could be biased to younger people. Such a register would not be able to provide information on elderly people with learning disabilities, or to provide an age distribution of people with learning disabilities. The need for a register to be inclusive, however, raises the issue as to whether people should be given a choice as to whether they should go on the register. Clearly it is ethically more sound to allow people choice, but if too many people do not wish to go on the register then the statistical information it provides will not be accurate.

The Need for Register to be Up to Date

If the information on any register is out of date then any statistical or individual information will also be out of date. In my experience simply relying on staff working with people on the register to provide information when circumstances change is not effective. There needs to be a mechanism whereby the client is contacted personally or a person familiar with them is contacted to confirm that the information is correct or to provide the updated information. To some extent, this can be done by asking service providers, such as day care or residential services, to do this for the people who are receiving such a service; however, one cannot do this with the people who, although known to services, are not currently receiving a service. When I managed the Huddersfield register I found that approximately half the people on it were currently not involved with services and required an annual visit from a member of the community team. There is therefore a requirement for these people to be visited and if necessary located on an annual basis, which clearly will have a cost implication.

Who Should be Registered?

Further problems specific to the registers of people with learning disabilities are inherent in the current definition of learning disabilities. Although there are a number of definitions of learning disability (British Psychological Society 2001; Department of Health 2001; American Association on Mental Retardation (AAMR) 1992; World Health Organisation 1985) all of them, including the White Paper Valuing People (Department of Health 2001), require the following three elements:

- Having an IQ below a critical point, usually 70.
- Having a deficit in adaptive skills or social function.
- That these deficits are present during the developmental period, usually taken to be before the age of 18.

One concern is whether we can actually assess IQ accurately enough for it to be used as a defining attribute of learning disability. I have proposed elsewhere (Whitaker 2003; Whitaker unpublished), that we cannot and that we should change our definition of learning disability so that it not longer specifies an IQ figure. However, I recognise that this is not likely to happen in the next few years and will be assumed that IQ will remain a key defining feature of learning disability.

The major problem for registering people who meet this definition is that we do not know who most of them are and there is no easy way of finding out. The White Paper Valuing People (Department of Health 2001) suggests that the prevalence of learning disability is about three percent of the population as a whole, a figure that agrees with a number of other estimates. Emerson et al (2001) suggested that the prevalence of mild learning disparity is between 2.5% and 3%. The World Health Organisation (1985) also put the figure of mild learning disability for children in industrialised countries at 2% to 3%. However, these estimates cannot be accepted uncritically. The IQ level below which someone can be regarded as having a learning disability is usually taken to be 70 (or 2 standard deviations below the norm). Assuming a mean IQ of 100 and a standard deviation of 15, about 2.3% of the population would meet the IQ criteria of learning disability. However, as the definition requires the individual to have both an IQ below 70 and a deficit in adaptive function it is likely that less than 2.3% of the population would meet the definition. Studies that have looked at the prevalence of learning disabilities in the population as a whole have produced a range of estimates but tend to support this. Those studies that only used IQ as the criterion have tended to come up with figures similar to 2.3%. For example, Birch et al (1970) found that 2.74% of eight to ten year old children in Aberdeen had an IQ below 75, and Rutter et al (1970) found that 2.53% of 10 year olds living on the Isle of Wight had intelligence levels that fell within the learning disabilities range when compared against their peers. In reviewing the literature Roeleveld et al (1997) found that the prevalence for children of school age with IQ less than 70 was about three percent. I have only been able to find one study that surveyed a whole population assessing people on both IQ and adaptive behaviour. Mercer (1973) surveyed 2661 households to assess coping abilities and then gave IQ tests to those that were screened as having low coping ability. She found that 2.17% had IQs below 70, but only 0.97% met the dual AAMR criteria for learning disabilities.

It seems to me that, although it is very difficult to come up with a precise figure for the prevalence of learning disability, it is probably between 1% and 3%, depending on the definition that is used (c.f., Whitaker 2004). If only IQ is used in the definition then the rate may be nearer 3%, whereas if the criterion of deficits in adaptive behaviour is also used then the rate may be nearer 1%.

Irrespective of definition, the number of people who meet the criterion for having a learning disability will probably be greater than the number who have been labelled. If this difference were small it would not matter a great deal; however, the evidence suggests that it is quite large. Whitaker and Porter (2002) surveyed learning disability services in West Yorkshire and found that they know of a number corresponding to 0.29% of the population as a whole. Although this study only covered a few districts in West Yorkshire, the finding is consistent with other studies. Farmer et al (1993) report on the register of people with learning disability held by NW Thames Regional Health Authority. This region had a total population of 2.69 million (about 5.3% of the population of England and Wales) yet had only 6625 people on the register or 0.23% of the population as a whole. In the US, the number of people registered as having a learning disability is similarly low. In California, Borthwick-Duffy and Eyman (1990) report that 78,603 people are registered as having a learning disability, which is 0.23% of the 33,871,648 people living in California (based on the 2000 census). Jacobson (1990) reports similar figures in New York State; the Developmental Disabilities Information System (DDIS), effectively a register of people with learning disabilities, had 42,479 people on it, which is 0.24% of the whole population of New York State of 18,976,457. The figures are considerably lower than the estimate of between 1% and 3% suggested as the true prevalence. It is therefore likely that we only know about between 10% and 25% of the people who could be considered to have a learning disability. The implication of this finding for registers of people with learning disabilities is that we cannot register everyone who meets the current definition of learning disability, as we do not know who they are. We therefore need to consider carefully who should be on a learning disability register. I would suggest that there are the following options:

The first option would be to register everyone labelled as having a learning disability, without acknowledging that this is only a small proportion of people who meet the current criterion for having a learning disability. This has several problems, not the least of which is that it is dishonest and therefore unethical. Not only would such a register not include the majority of people who fit the definition of learning disability, it would include a lot of people who, although known to services, do not currently require a service. The information from such a register would be both inaccurate and misleading. Any statistics produced from it would appear to relate to people with learning disability as a whole when in fact they only related to those that have been labelled. For example, if the register was to be used to monitor compliance with the recommendations of the White Paper, which are for “all people with learning disabilities”, it would only be able to give figures for those that are known about, but give the impression that the figures were for people with learning disability as a whole. Whereas this would produce much better figures for compliance with the White Paper’s recommendations than if all people with leaning disabilities were being considered, it is somewhat disingenuous to quote them as actual estimates of compliance with these recommendations. In addition, such a register could be difficult to maintain, as many of the people on it would not be in contact with services and have to be located and contacted on a regular basis in order to update their records. In short this option would be costly, ethically dubious, and have no clear benefits for people with learning disabilities.

Secondly, we could just register people who have a severe or profound degree of learning disability; that is people with IQs less than 40. This could have a number of advantages: All the people in this group would be in need of support in order to cope, so we would not be registering people who do not potentially need a service. It would also be easier to maintain a full and up to date register, as we know far more accurately who these people are and the majority of people will be in regular contact with services that could provide the information to update their records. However, there would still be problems deciding who fits the criterion of having an IQ below 40 as most IQ tests do not measure that low and there is still a substantial error of measurement. Also such a register would not include people with moderate and mild learning disabilities who, according to the White Paper, should be entitled to services such as Health Action Plans. If this approach were followed then there would have to be mechanisms in place to ensure that these other people with learning disabilities got the services they were entitled to.

Thirdly, only those people with a learning disability label who are currently in receipt of a service could be registered. This would include some people with moderate and mild learning disabilities, so these people would not be explicitly excluded. The register would be relatively easy to maintain as the services could provide the information for updating. However, it would not include those people, who were not able to cope without help not currently in receipt of a service, either because relatives were caring for them, or they were refusing to accept a service or a service was not available to meet their specific needs. It seems to me that to exclude people who are in need but not receiving a service is not only against what Valuing People says but also against the spirit of what it means.

A fourth option would be to register those people who have a learning disability label and currently need help in order to cope. These would be people who, without assistance, would not be able to provide a reasonable quality of life for themselves or their dependents. This would include all those people who were being provided with help by relatives instead of statutory services, all those who were refusing a service, and all those for whom a service could not be provided, as well as those who were currently in receipt of a service. It also includes people, such as parents with learning disabilities who may be able to meet their own needs but may be challenged in providing for their own dependents. However, it would not include people who do not currently need a service. As with the other options it does not include all the people who have a learning disability as defined in the White Paper, though to do this is not realistic. However, as the White Paper is about making sure that people with learning disabilities get the services they need, including people who are in need, this seems to be the best compromise. One disadvantage of this option is that as not all the people on the register would be in contact with services, the updating system would require those people not in contact with services to be contacted on a regular basis to ensure that the information on the register about them is correct, and so there would be a cost.

Conclusions

Setting up a register of people with learning disability is not a straightforward matter. If such a register is to be able to perform a useful function, the following steps should to be taken. Planners and managers need to outline what they require from the register, which will determine what information should be kept on the register and to some extent how often the information will require updating. However, in deciding what the register will be required to do, it is clearly important to be realistic in terms of what it is possible for a register to do: it is not possible for it to have information on everybody who has a learning disability. After it has been specified what information the register should provide a decision can be made as to which people are going to be registered and what information is to be recorded about them. I have suggested above that the group that should be registered are those that have a learning disability label and are currently in need of a service; however, this is only one of several options. What is important is that it is made explicit exactly which group is being registered so that statistics produced from the register can be clearly stated as relating to this group and not people with a learning disability as a whole. Once this has been carried out then a suitable updating system should be designed so that the information on the register is sufficiently in date to be useful. If this process is not thoroughly carried out when setting up the register then it is likely that the register will contain little useful up to date information and in effect will be an expensive white elephant. It may also be the case that once this planning process has been completed that it is felt that a register either could not fulfil the purposes required of it, or that it could only do this at an unacceptable cost, in which case there is the option of not having a register.

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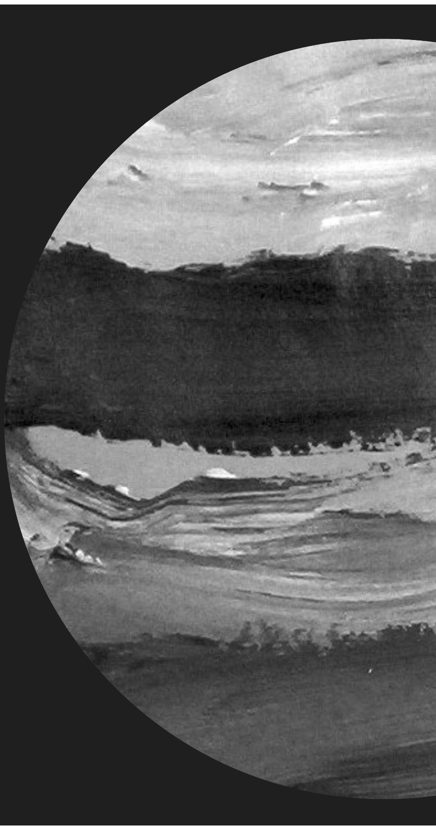

Evaluating Psychological Therapies Services: A review of outcome measures and their utility

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Evaluating Psychological Therapies Services: A review of outcome measures and their utility

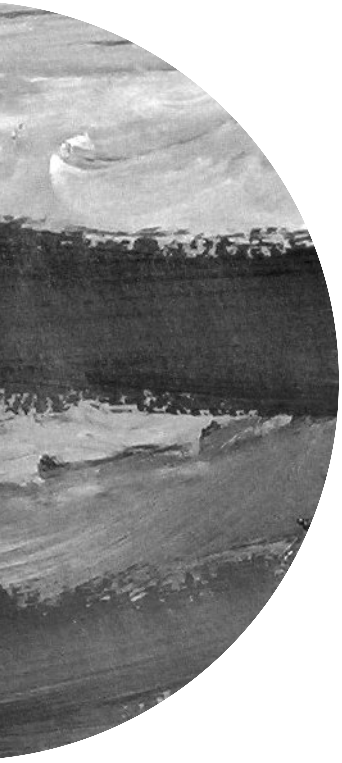
Chris Leach, Mike Lucock, Steve Iveson & Rachael Noble

Abstract

We describe the use of a number of outcome measures that have been used over the past eight years to evaluate adult psychological therapies services in the Wakefield & Pontefract locality of the South West Yorkshire Mental Health NHS Trust. The psychological therapies service now has a unique database of outcome measures completed by 5563 clients, which has been used nationally and internationally for service evaluation and research purposes. Internally, the database has informed the clinical service, allowing prioritising of referrals and feedback to clinicians and referral agencies on the quality of the service and appropriateness of referrals.

We describe the properties and intended use of the measures, the way results are fed back to the service and evaluate the usefulness of the measures in routine service settings. Implications for psychological therapies and other mental health services are discussed including:

- Choice of generic or specific outcome measures
- How the measures relate to one another
- Clinical usefulness of the measures, including risk assessment
- Interpretation of results, including availability of norms and how to assess change
- Practical utility, including cost



Keywords: psychological therapies; practice-based evidence;
CORE-OM; BDI; BAI; IIP-32; DES

Introduction

Background

The clinical governance and clinical effectiveness agendas in the NHS emphasise the need for routine service audit and evaluation (Department of Health, 2004, p. 30). There is considerable evidence of efficacy of psychological therapies from research trials (Roth & Fonagy, 1996), which has fed into evidence-based guidelines (Department of Health, 2004). However, this evidence is often obtained from research clinic settings, where, for example, therapists are required to deliver therapy strictly according to a manual and complex clients with multiple problems are excluded. To complement this evidence, there is a need to evaluate the effectiveness of psychological therapies services in "usual service conditions" (Department of Health, 1999, page 116), where a range of therapies is provided by a range of therapists to a range of clients with a range of problems. Effectiveness research in routine clinical settings is an example of "practice-based evidence" (Barkham, Margison, Leach, Lucock, Benson, Mellor-Clark, Evans, Connell, Audin & McGrath, 2001), which complements the evidence-based guidance and provides "a framework for using local evidence to support practice" (Department of Health, 2004, p. 29). Practice-based evidence can also be used within services to feed data back to clinicians to inform their practice, and to inform clients of their progress. This feedback is an important part of any applied research, audit or evaluation and is often missed out (Parry, 1992).

Since 1997, the Adult Psychological Therapies Service (APTS) in the Wakefield & Pontefract locality of the South West Yorkshire Mental Health NHS Trust (formerly Wakefield & Pontefract Community Health NHS Trust) has been collecting outcome data for all clients referred to the service as part of the routine service delivery. The service receives about 1200 referrals a year, mainly from general practitioners, but also from the wider mental health services, psychiatry and social services and more recently from the Primary Care Liaison, Assessment, Therapy & Training (PLATT) team. The service is multi-professional and has included clinical psychologists, psychotherapists, counsellors, cognitive behaviour therapists, counselling psychologists, and an art therapist. Clients are seen on three main sites (Wakefield, Pontefract and the Specialist Psychotherapy Team based at Horbury) as well as general practice clinics.

The collection of outcome data of various sorts has been part of service delivery for many years at the Wakefield and Pontefract sites, but the appointment of research staff in 1995 allowed such data to be collected more systematically, resulting in the development of a database that now (May 2004) includes data on measures completed by 5563 clients. The database has become an archive that is useful for local service evaluation and feedback to clinicians and referrers. For example, clinicians receive feedback on all their clients annually, as well as being offered feedback on demand about individual clients and groups of clients. The data collected at referral allows prioritising of referrals based on scores on the outcome measures, risk items and comments given by clients. The database has also been used for research purposes and has attracted the attention of international researchers with whom we now collaborate on a regular basis (see, for example, Stiles, Leach, Barkham, Lucock, Iveson, Shapiro, Iveson & Hardy, 2003; Lutz, Leach, Barkham, Lucock, Stiles, Evans, Noble & Iveson, in press).

The background to the setting up of the routine collection of such data and the use of the database for research is discussed in more detail in Lucock, Leach & Iveson (1999). Our use of the outcome measures to help improve “evidence based reflective practice” is more fully described in Lucock, Leach, Iveson, Lynch, Horsefield & Hall (2003).

Outcome Measures

The choice of appropriate routine outcome measures is an important issue. Measures should be valid and reliable and measure important aspects of client change. Ideally, they should also be readily understood by clinicians and inform assessment and clinical practice. It is also important to minimise the use of measures where possible to reduce the burden on clients. In this article, we review our experience of a number of outcome measures and evaluate their usefulness in routine service delivery for both psychological therapies services and more general mental health services.

It is a challenge not only to routinely measure clinical outcome, but to feed back the results to the service and individual clinicians in a meaningful way that allows them to reflect on the service provided. Therefore, in addition to describing the measures used, we will illustrate the various ways in which the outcome data is fed back into the service.

Measures that have been routinely completed by APTS clients include the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM: Evans, Connell, Barkham, Margison, McGrath, Mellor-Clark & Audin, 2002), the Beck Depression Inventory (BDI: Beck, Ward, Mendelson, Mock & Erbaugh, 1961), the Beck Anxiety Inventory (BAI: Beck, Epstein, Brown & Steer, 1988), the Dissociative Experiences Scale (DES-II and DES-Taxon: Carlson & Putnam, 1993) and the Inventory of Interpersonal Problems (IIP-32: Barkham, Hardy, & Startup, 1996). Partly to cut down the number of measures sent to clients and partly as a result of the prohibitive cost of using copyrighted measures, we have recently stopped sending clients the BDI and the BAI. At referral we use only the CORE-OM. The CORE-OM and IIP-32 are then used at the four other stages, assessment, beginning of therapy, discharge and 6 month follow up. We have also introduced our own short Screener questionnaire at assessment. This is at the pilot stage, and includes items detecting issues, such as eating disorders and substance misuse, not captured by the other measures we have used. The screener also includes risk items. The DES-II has recently been replaced in the service by the shorter DES-Taxon, a subset of eight items that discriminates better than the full scale and that is more acceptable to clients. This is used at assessment only.

The APTS service

Clients referred to the service are put on a waiting list for assessment. Assessment is carried out by experienced therapists, who recommend what, if any, further therapy might be required. The clients are then put on a waiting list for therapy, which includes individual or group therapy of various sorts. Once they start therapy, they will usually stay with the same therapist until they are discharged. Clients are sent questionnaires, including a subset of the outcome measures, on up to five occasions: at referral, before assessment, before therapy, at discharge, and at six months following discharge. If the period between referral and assessment is less than six weeks, the client is not sent a set of measures at assessment, and, similarly, if the period between assessment and therapy is less than six weeks, the client is not sent a pre-therapy set of measures. Clients are told that the measures will be used for routine clinical purposes to assess their progress and that they may also be used for research purposes. They can opt not to complete the measures at all without it affecting the service provided and they can opt for any measures they complete not to be used for research purposes. Any use of the measures by research or other staff not directly involved in the service provision is done in a totally anonymous way and the research database does not include any client identifiable information. From 2002 the data has been inputted directly onto the Trust's Clinical Information System (CIS). The data is then passed on to the service in Excel files which are converted into SPSS files for analysis. Information on number of sessions, type of therapy and types of problems are recorded at discharge.

In addition to the outcome measures, the set of questionnaires includes space for client comments. The three sets sent out before therapy allow clients to add any information about their needs that they feel might be helpful to the service and the two sets after discharge allow them to comment on the quality of the service they received. The pre-therapy comments, particularly those completed at referral, can provide information that the client has not been able or willing to disclose to the referrer. These are taken into account in prioritising referrals. The comments after therapy are fed back routinely to clinicians.

The APTS Research Database

Table 1 shows numbers of clients who have completed the various measures since 1997. For example, of the 5563 clients who have completed at least one measure on one occasion, 4535 have completed the CORE-OM at referral, while 715 have completed it at discharge. The smaller numbers completing the CORE-OM and other measures on later occasions reflect both service and client issues. Because clients were not asked to complete later measures before therapy if the period following earlier completion was less than six weeks, the numbers in the Assessment and Before therapy rows are usually smaller, except for the DES-II, which was given out only at assessment. The dramatic drop in numbers of questionnaires completed after therapy and at follow-up is a result of a number of factors. First, some of the clients in the database will not have started or completed therapy, so will only have completed some of the measures before therapy began. Second, some clients will have dropped out of therapy. Third, clients often chose not to complete the questionnaires at discharge and follow up. Such huge attrition in completion of measures is typical of most psychological therapies services, where clients having come through the service may not wish to continue involvement for many different reasons. Fourth, clinicians complete a discharge form for each client, which allows them to ask for particular clients not to be sent outcome forms if it is deemed to be clinically detrimental for the client.

Table 1. Numbers of APTS clients completing outcome measures at five stages (total n = 5563)

Stage	CORE-OM	BDI	BAI	IIP-32	DES-II	DES-Taxon	APTS Screener
1. Referral	4535	3978	1460	2555	10	-	143
2. Assessment	2046	1934	684	1913	505	64	2
3. Before therapy	923	867	351	883	2	1	-
4. Discharge	715	575	222	600	-	-	-
5. Six month follow-up	493	393	99	408	-	-	-
Pre-therapy	5228	4701	1797	3980	513	65	145
Pre-therapy & Discharge	478	397	173	397	-	-	-

The bottom two rows of Table 1 show the numbers of clients completing any of the pre-therapy measures and the numbers completing both a pre-therapy measure and a discharge measure. These are useful for tracking progress of individual clients.

The Outcome Measures and Feedback of the Data

At the request of clinicians, we provide information on the measures and the significance of scores. We provide brief background to the measure, a summary of how we have used the measure, any relevant cut-offs distinguishing levels of severity that can be used in routine clinical practice, and an indication of how the measure relates to other measures.

CORE-OM

The CORE outcome measure (CORE-OM) was developed recently in the UK (Evans et al, 2002) as part of a routine assessment system to assess clinically relevant emotional problems. It has been used predominantly in primary and secondary care settings as a generic measure to supplement more specific measures of functioning in particular areas. It is short (34 items on two sides of A4) and completed by clients to assess their feelings over the last week using a rating scale from 0 ("not at all") to 4 ("most of the time"). It produces an overall score between 0 and 4 (the average of the 34 items). It has four subscales, well-being, problems, functioning and risk. The most useful subscale is the risk subscale, which is unusual in having two items on risk to others ("I have been physically violent to others", "I have threatened or intimidated another person") as well as four items on risk to self ("I made plans to end my life", "I have thought of hurting myself", "I have thought it would be better if I were dead", "I have hurt myself physically or taken dangerous risks with my health"). We have not found the other sub-scales clinically useful.

The CORE-OM can be freely copied on a copy-left basis (i.e., don't change it and don't use it for profit). In addition, two shorter forms (19 items on one side of A4) are available and have been used in the APTS for assessing client progress session-by-session.

Table 2 shows the scores grouped into three ranges for the CORE-OM and its risk sub-scale, based on UK national data and local Wakefield data, which have fed into national norms (see Barkham et al, 2001). Clients scoring in the minimal range are defined to be below the clinical cut-off. Separate cut-offs are used for male and female clients. The table also shows the proportions of APTS clients scoring in the various ranges at referral, so that 84% of referrals (male or female) score above the clinical cut-off, with 28% of female referrals and 26% of male referrals scoring in the severe range. This allows us to conclude that APTS, like other psychological therapies services, is receiving referrals from clients with serious problems, not just the "worried well". The table also shows that well over half the clients referred score above the clinical cut-off for risk.

Table 2. Clinical cut-offs for the CORE-OM and proportions of APTS clients scoring in the various ranges at referral

Measure	Clinical Cut-offs		Percentage of Clients		
	Female	Male		Female	Male
CORE-OM *(n = 4543)*	2.50-4.00	2.50-4.00	severe	28%	26%
	1.29-2.49	1.19-2.49	moderate	56%	58%
	0.00-1.28	0.00-1.18	minimal	16%	16%
Risk sub-scale *(n = 3727)*	0.31-4.00	0.43-4.00	clinical range	59%	54%
	0.00-0.30	0.00-0.42	non-clinical	41%	46%

Fig 1. CORE-OM scores at referral 1997-2003

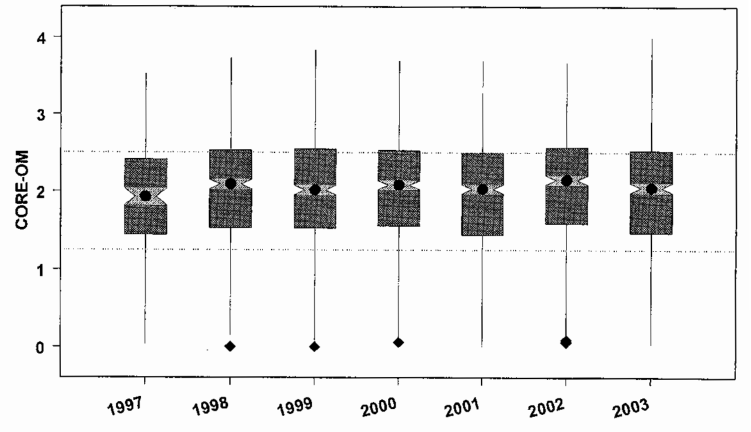


Figure 1 shows the same data in box-plot form, reported separately for each year. Each box-plot gives a summary of the CORE-OM scores for clients referred in each year. The black dots in the middle of the boxes are the average scores (medians) for each year, the boxes include the middle 50% of the data, and the whiskers include the highest and lowest 25% of the scores, with unusually large or small scores (outliers) shown as diamonds at the top or bottom of the plot. The clinical cut-off of 1.25 (the average of the male and female cut-offs) and the severe cut-off of 2.50 are shown as dotted lines. This allows us to see immediately that in each year well over 75% of referrals (the box and the upper whiskers enclosing 75% of the scores) score above the clinical cut-off. The notches in the boxes are 90% confidence intervals for the median scores, which allow a rough statistical comparison of year on year data. If the notches do not overlap when comparing two years, there is a reliable difference in average scores for the two years. With no overlaps apparent and the box-plots having very similar shapes, it is clear that there has been no variation in severity of referrals in the period 1997-2003. Although the box-plots do not allow totally accurate estimates of proportions above the cut-offs (the actual percentage given in Table 2 across all years is 84%), they do allow a quick visual comparison to be made.

Figure 2 shows box-plots of the CORE-OM scores at the five therapy stages. This shows little variation in scores before therapy starts, with over 75% of clients scoring above the clinical cut-off at referral, before assessment and before therapy and little difference between the medians. The actual percentages above the clinical cut-off at these three points are 84%, 80% and 78%, respectively. After therapy, the percentages above the clinical cut-off drop to 38% at discharge and 44% at six-months follow-up, and the figure shows reliable differences between the two post-therapy sets of scores and the three pre-therapy sets.

These plots do not track individual clients. To check on individual client progress, the so-called Jacobson plot in Figure 3 contains a dot for each of the 478 clients who have completed a CORE-OM at some point before therapy and at discharge (Jacobson & Truax, 1991). Dots appearing below the main diagonal show clients whose scores have decreased after therapy, showing some improvement. However, by the nature

Fig 2. Box-plots of CORE-OM scores at the five stages for 5563 clients

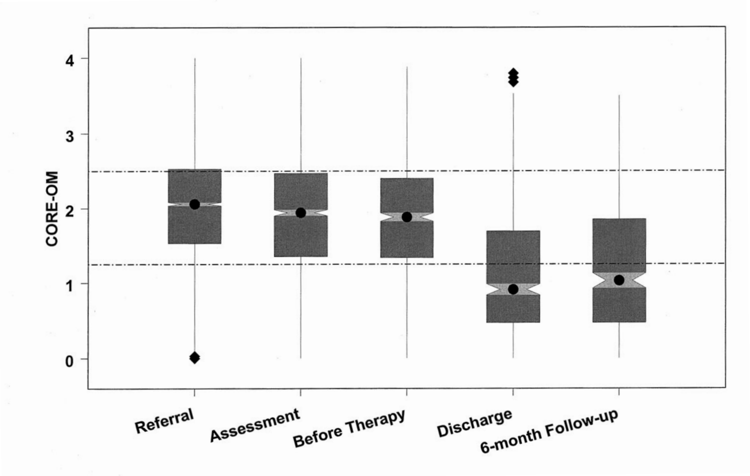
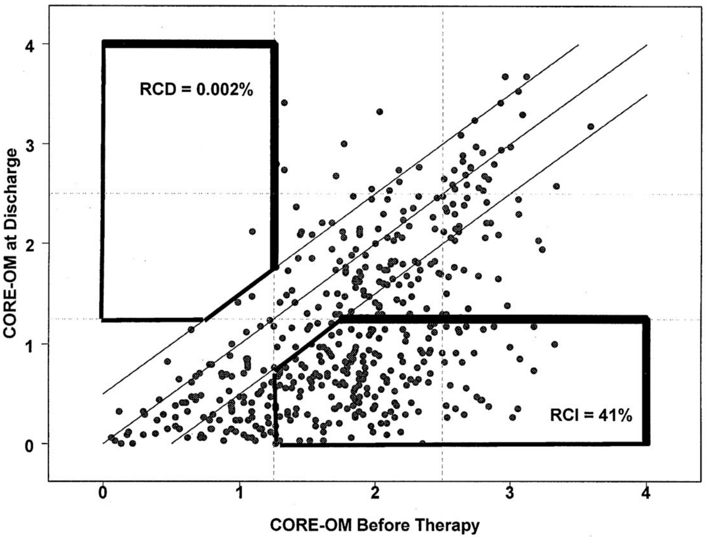


Fig 3. Jacobson plot of CORE-OM scores before therapy and at discharge for 478 clients



of all measures, some fluctuation in scores completed by the same clients on two occasions would be expected by chance, so the tram-lines on either side of the main diagonal correct for this by taking into account the reliability of the measure. Taking this into account for the CORE-OM, any client showing more than a 0.5 difference in before and after scores has a statistically reliable difference between the scores. 286 dots (60%) are below the lower tram-line, so 60% of clients show reliable improvement on the CORE-OM following therapy. 19 clients (4%) have dots above the upper tram-line, so these show reliable deterioration.

The lower box in Figure 3 encloses dots for which the pre-therapy scores were above the clinical cut-off and the discharge scores are below the cut-off, as well as being statistically different (i.e., below the lower tram-line). 194 clients (41%) are represented here and these are clients who are deemed to have shown reliable and clinical improvement following therapy. The upper box encloses any dots for which the pre-therapy scores were below the clinical cut-off and the discharge scores are above the cut-off, so these would indicate clients who have shown reliable and clinical deterioration. Only one client (0.002%) is shown here. The Jacobson plots allow us to feed back results for individual clients to clinicians as well as give a picture of the overall quality of the service. Clients figuring above the upper tramline and, in particular, in the upper box, would be of particular note.

These three figures are routinely produced for all outcome measures. They show effectively the same picture of the service, so will not be repeated when considering later measures.

The CORE-OM correlates quite highly with the BAI (r = 0.61), the IIP-32 (r = 0.62) and the DES-II (r = 0.55 with the DES-II total score and r = 0.49 with the DES-Taxon) and very highly with the BDI-I (r = 0.85).

The high correlation with the BDI makes it possible to translate between the two with a high degree of accuracy using either the tables provided by Leach, Lucock, Barkham, Noble & Iveson (submitted) or the following equations:

For female clients:

$$\text{BDI-I} = (2.403 \times \text{CORE} + 2.117)^{1.667} \quad (1f)$$

$$\text{CORE} = 0.309 \times \text{BDI-I}^{0.60} - 0.152 \quad (2f)$$

For male clients:

$$\text{BDI-I} = (2.289 \times \text{CORE} + 2.068)^{1.667} \quad (1m)$$

$$\text{CORE} = 0.319 \times \text{BDI-I}^{0.60} - 0.142 \quad (2m)$$

The first equation in each pair allows a BDI-I score to be predicted from a client's CORE-OM score, while the second allows a CORE-OM score to be predicted from a BDI-I score. If there is interest in translating between the CORE-OM and the more recent version of the BDI, the manual for the BDI-II (Beck, Steer & Brown, 1996) contains a table for translating between the BDI-I and the BDI-II, which can be used together with equations 1 and 2 or the tables in Leach et al (submitted).

Beck Depression Inventory (BDI-I)

The BDI is a widely used specific measure of depression. It asks clients to rate their feelings over the past week on 21 items, using a four-point rating scale from 0 to 3, with the four points spelled out separately for each item. The clinical norms are based on US data, but it has been widely used in the UK for many years. The version we have used is the original version, now known as the BDI-I. A later version, the BDI-II, is available (Beck et al, 1996), but is not yet so widely used. The main score used is the overall score, from 0 to 63, the sum of the 21 item scores. We have also found two individual items (2 and 9) useful in assessing risk to self. Item 2 asks about feelings of hopelessness and item 9 focuses on suicide ideation. We have traditionally used high scores on these items to prioritise referrals.

The BDI is copyrighted and costs over £1 per copy. Because of the large numbers of referrals and the need to send copies at five stages and repeat copies to clients who do not return them, the cost has become prohibitive to the service, so we have stopped using the BDI on a regular basis. The possibility of predicting the BDI score from the CORE-OM score has helped clinicians who have traditionally relied on the BDI to assess severity of depression and clinical change.

The clinical cut-offs for the BDI are shown in Table 3, with the percentages of APTS clients scoring in the various ranges. 75% of clients referred score in the moderate or severe clinical depression ranges. This figure includes people not referred specifically for help with depression and again points to the service being referred clients with serious problems, not the "worried well".

Beck Anxiety Inventory (BAI)

The BAI is a specific measure of anxiety completed by clients and, like the BDI, is widely used, with norms based on US data, but sufficient experience of its use abroad for these norms to apply also to the UK. Clients are asked to assess their feelings over the past week on 21 items, using a rating scale of 0 ("not at all") to 3 ("severely"). A single score is reported, the sum of the 21 item scores, ranging from 0 to 63.

It is copyrighted, so may not be copied. It also costs over £1 per copy and again the prohibitive cost of using it for 1200 referrals a year at five stages has meant that we stopped using it on a regular basis about two years ago.

The clinical cut-offs and proportions of clients scoring in the various ranges at referral are shown in Table 3. 63% of clients referred, for whatever reason, score within the

Table 3. Clinical cut-offs for the BDI-I, BAI and DES-II and proportions of APTS clients scoring in the various ranges at referral (BDI & BAI) or assessment (DES-II)

Measure	Clinical Cut-offs		Percentage of Clients
Beck Depression Inventory (BDI) *(n = 3978)*	30-63	Severe	36%
	17-29	Moderate	39%
	10-16	Mild	16%
	0- 9	Minimal	9%
Beck Anxiety Inventory (BAI) *(n = 1460)*	26-63	Severe	35%
	16-25	Moderate	28%
	8-15	Mild	23%
	0-7	Minimal	13%
Dissociative Experiences Scale *(n = 513)*			
DES II	30-100	clinical range	15%
	0-29	non-clinical	85%
DES Taxon	20-100	clinical range	16%
	0-19	non-clinical	84%

"moderate" or "severe" anxiety ranges. A large proportion of clients referred score within the clinical ranges for both depression and anxiety, with the correlation between the BDI-I and the BAI being high (r = 0.60). Such co-morbidity is typical of NHS psychological therapies services.

Dissociative Experiences Scale

The Dissociative Experiences Scale assesses level of dissociative experience by asking clients to state what percentage of time they have particular experiences. We began using the full DES-II at assessment at the request of clinicians in one of the sites who were seeing increasing numbers of clients who experience serious dissociation. Dissociation is a significant factor in assessing suitability for therapy and type of psychological therapy indicated. On the full scale of 28 items, some of the experiences are common to most people some of the time, such as not remembering what has happened for part of a trip by car or bus. Others, such as finding yourself in a place and having no idea how you have got there, are rarely experienced by people without severe dissociative problems. The full scale (DES-II) gives a score from 0 to 100, the average of the scores for the 28 items. The DES-Taxon consists of eight rarer experiences. It therefore discriminates better between those who dissociate and those who do not. Again scores are averaged to give a score between 0 and 100. The clinical cut-off for the full DES-II is 30 and for the DES-Taxon it is 20. We used the full version initially because of concerns that using just the eight DES-Taxon items might worry clients. However, our experience so far is that those clients who do dissociate are quite prepared to fill in a shorter form based on the DES-Taxon items, and those who do not are happy to tick no to all the questions. For this reason, we have discontinued using the full version and now rely on just the eight-item DES-Taxon scale. Clients now complete this across the service at the assessment stage only.

Table 3 shows that 15% of APTS clients score above the clinical cut-off for the full DES-II, while 16% score above the cut-off for the DES-Taxon. Figure 4 is a box plot of the distribution of DES-Taxon scores, which shows most clients scoring well below the clinical cut-off of 20.

The DES-II and its Taxon subscale is not copyrighted, so may be used freely in the NHS and other setting

Inventory of Interpersonal Problems (IIP-32)

The IIP-32 is a short form developed in the UK (Barkham et al., 1996) of the much longer 127 item IIP scale originated in the US (Horowitz, Rosenberg, Baer, Ureno, & Villasenor, 1988). Two major theoretical approaches underpin common uses of the IIP. The first is the factor analytic approach embedded in the development of the short version, which posits eight factors underlying personal problems. These eight factors are the eight separate subscales of the IIP-32, which have been grouped into four bipolar factors by Barkham, Hardy & Startup (1994). The four bipolar factors were identified as problems relating to competition (hard to be assertive vs. too aggressive), socialising (hard to be sociable vs. too open), nurturance (hard to be supportive vs. too caring), and independence (hard to be involved vs. too dependent). The second theoretical approach is based on Leary's (1957) interpersonal circle and results in a more complex circumplex scale (see, for example, Alden, Wiggins & Pincus, 1990). Our use of the IIP has followed the factor analytic model. We started using it in the service at the request of clinicians following psychodynamic psychotherapy treatment models, who wanted a measure that would tap interpersonal problems.

The IIP-32 has 32 items on two sides of A4. 19 items are phrased "It is hard for me to …" (e.g., "join in groups", "be assertive with another person"), while the remaining items are phrased "too much", such as "I fight with other people too much" and "I open up to people too much". Each item is rated by the client on a five-point scale from "not at all"(0) to "extremely" (4). An overall score is obtained as the average of all 32 item scores, giving a score from 0 to 4. In addition, eight sub-scale scores are derived to reflect difficulties in the four bipolar factors. No normative data are available, so Table 4 gives the highest scoring percentiles of APTS clients at referral, which will allow high scorers to be noted. For example, only 5% of clients score 2.62 or above on the full scale, but 25% of clients score 2 or above.

Fig 4. Box plot of scores on the Dissociative Experiences Scale (DES-Taxon) for 512 clients at assessment. The dotted line indicates the clinical cut-off

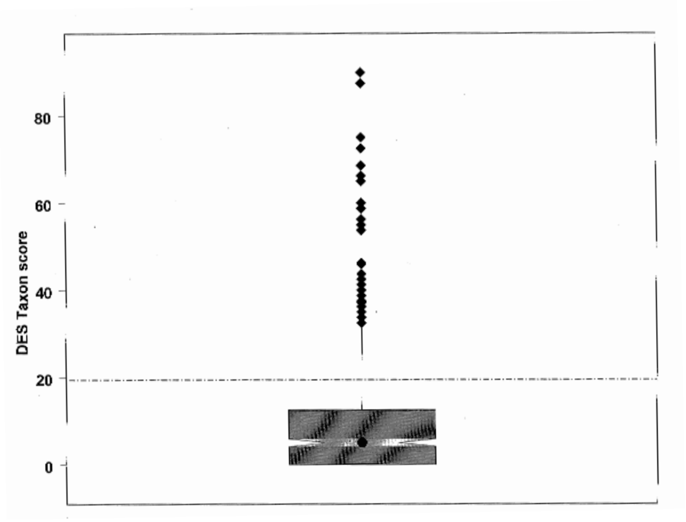


Table 4. Percentages of clients scoring in various ranges for the Inventory of Interpersonal Problems (IIP-32)

Measure	Percentage of Clients
IIP Total Score	5% score 2.62 or above
(n = 2555)	10% score 2.40 or above
	25% score 2.00 or above
IIP Subscales	
1. Hard to be Sociable	5% score 4.00
	10% score 3.50 or above
	25% score 2.75 or above
2. Hard to be Assertive	5% score 3.75 or above
	10% score 3.25 or above
	25% score 2.75 or above
3. Too Aggressive	5% score 3.75 or above
	10% score 3.25 or above
	25% score 2.50 or above
4. Too Open	5% score 3.25 or above
	10% score 2.75 or above
	25% score 2.00 or above
5. Too Caring	5% score 3.50 or above
	10% score 3.00 or above
	25% score 2.50 or above
6. Hard to be Supportive	5% score 3.00 or above
	10% score 2.75 or above
	25% score 1.75 or above
7. Hard to be Involved	5% score 3.75 or above
	0% score 3.25 or above
	25% score 2.25 or above
8. Too Dependent	5% score 3.25 or above
	10% score 3.00 or above
	25% score 2.25 or above

The IIP-32 is not copyrighted, so can be freely used in NHS settings. It correlates reasonably well with the CORE-OM (r = 0.62) and the BDI-I (r = 0.63), and moderately with the BAI (r = 0.43) and the DES-II (r = 0.48).

Discussion

We have described five measures used routinely to evaluate our psychological therapies service. Some measures, such as the CORE-OM, are used at all stages, whilst others, such as the DES-Taxon are used only at assessment. In selecting the measures we have taken into account the need for reliable and valid measures of change and the views of therapists that have led to the introduction of the IIP-32 and the DES-Taxon. We have also taken into account cost which has led us to use the CORE-OM as the main outcome measure, and abandon use of the BDI and BAI. The CORE-OM is a general measure of psychological problems whilst the BDI, BAI, DES and IIP measure more specific problems and aspects of functioning. It could be argued that the CORE-OM is therefore the best measure for the routine service evaluation and the other more specific measures could be used for more specific purposes. For example the BAI may be appropriate to evaluate anxiety management groups.

We now only use the CORE-OM at the referral stage because of concerns about asking clients to complete too many questionnaires at a time when they are not in direct contact with clinicians. It is possible clients may become distressed when completing questionnaires that raise issues for them and this can be addressed when the client has access to a therapist. The abandonment of the BDI and the use of the CORE-OM as the main outcome measure are further supported by our ability to reliably convert CORE-OM scores to BDI scores.

In order to inform assessment and reflective practice clinicians must feel part of the process and find the information understandable, interesting and helpful. There is a danger it is seen as merely an administrative exercise, an add-on to an already difficult role with little relevance to the service and clients needs. They require feedback in a form that is readily understood and information on the nature of the measures and the meaning of scores. Regarding reflective practice, when the outcome data has been fed back to clinicians, a number of further questions become apparent. For example, in Figure 3, one wonders about the characteristics of clients who significantly improve or significantly deteriorate and reasons for this change. If they deteriorate, is it due to the therapy or outside factors? When we look at the number of sessions provided, the question often raised is why are some clients seen for longer-term therapy and how is the decision made? Why do some clients opt out of the service? This has led to further off- shoot projects examining some of these questions. The use of measures to enhance assessment and evaluate clinical outcome should therefore be seen as part of a wider process of reflective practice.

The use of the measures described in this paper therefore has a number of aims in addition to service evaluation. They provide information on clinical outcome for the service as a whole, they provide information to inform the initial assessment, including risk and suitability for different forms of therapy, and they are fed back to clinicians to enhance reflective practice.

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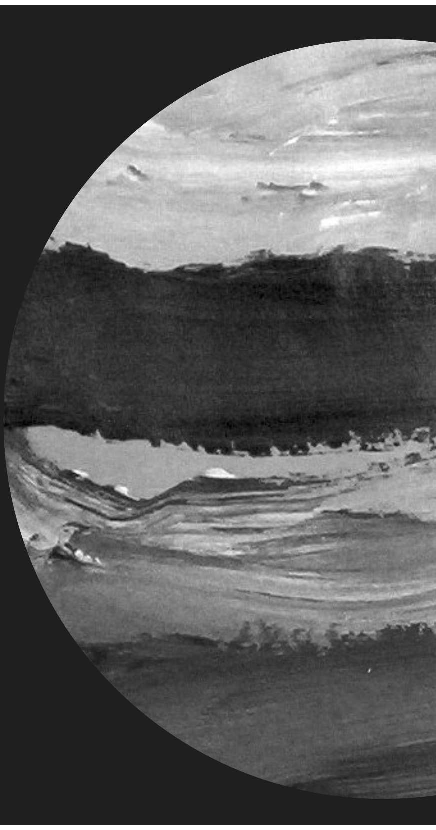
Surviving dementia as a carer

Anne Haughie



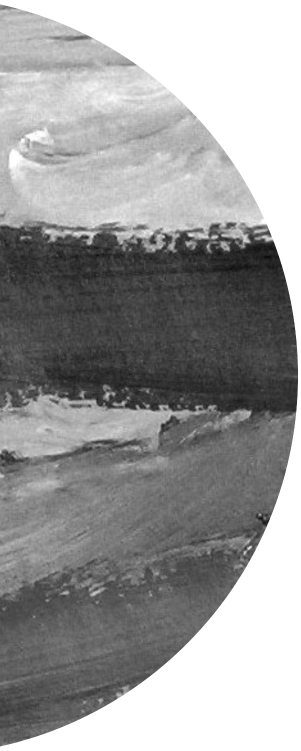
Surviving Dementia as a carer

Anne Haughie

Abstract

This article highlights the issues and problems that carers must face when looking after someone with a dementia related illness. Many carers become seriously depressed, isolated or even marginalised and the demands of the caring role can cause many physical, mental and emotional health problems that if not addressed can lead to complete mental breakdown and ultimately 'burnout'. The key to surviving as a carer is in developing an understanding of the nature of dementia, together with a realistic attitude to the never ending workload and then to adopt effective coping strategies. This involves accessing and accepting help from many sources; these include cognitive behaviour therapy, complementary practitioners, joining a support group, maximising income and developing a healthy lifestyle. A number of practical suggestions are made that will help a carer maintain physical and mental well-being; some simple tried and tested pleasurable activities are also recommended. The ultimate key to survival is maintaining a sense of humour. Although written primarily for carers, this article will also be of interest to health-care professionals involved in dementia care. A comprehensive list of relevant addresses and telephone numbers is included.

Key Words: Dementia, Carers, Carer Support



Dementia affects people from all walks of life. Carers, usually partners or close family members, have diverse backgrounds with varied life experiences. Mostly, we are thrust into the role without any prior qualifications, training or preparation for dealing with what lies ahead.

Such is the nature of dementia that often, in its early stages, nobody but the carer knows there is a problem. A forgotten word, a half-finished sentence, a faraway look, or a flash of fear in frightened eyes. Now you see it, now you don't. Initially, the shift in personality is almost imperceptible. Himself or herself, only more so. Odd behaviour rationalised: A, B, C, or D — Accuse! Bluster! Confabulate! Deny! As the condition progresses, you are faced with situations that would tax the Wisdom of Solomon and are challenged by behaviour that would try the patience of even the most saintly of Saints. There are episodes of forgetfulness or confusion when things are lost or hidden. Keys, watches and wallets are favourites, although knickers and underpants also turn up in the most unlikely of places. Ice cream is stored in the microwave and cornflakes in the freezer. Items disappear into a shopping bag without being paid for. Scissors, socks and even shovels are purchased every shopping trip to then sit forgotten at the back of the broom cupboard or garden shed. Finances are muddled. Bills unpaid or paid twice over. Clothing is worn inside out, back to front, six at a time and, sometimes, not at all. Personal hygiene is neglected. Who needs a bath or shower if you had one four weeks ago? Unsavoury, unappetising and unspeakable habits develop. Why use the loo if you can pee in a cup? Rituals and obsessive or compulsive behaviour dictate that peas must be eaten standing up but definitely not before you've knocked three times on the ceiling!

Intransigence, temper tantrums, aggressive or violent behaviour alternate with panic attacks, acute anxiety and childlike dependency. Can't cook! Won't cook! Shan't! So there! Leave me alone! Don't you dare leave me! Please don't leave me! The same interminable questions are asked again and again. Where did I lose my marbles? Who is the Prime Minister anyway? Does anybody care! Fact and fantasy become interwoven. Insight flies out the window. Lucidity is interspersed with episodes of paranoia. The postman and the window cleaner are plotting to run off with Grandma's silver candlesticks. There may even be delusional thoughts when you are accused of all manner of indiscretions. Oh would that you had the energy or the time but you are expected to be there when you are needed and, what is more to the point, even when you are not!

As the demands placed on you become more and more unreasonable, you discover that being the carer of someone with a dementia is rather like competing in the 'high jump' — sooner or later, no matter how good you are or how hard you try, you just cannot jump any higher. Unlike the athlete, carers do not land elated to a round of applause; we land depressed, defeated and demoralised.

When we are in a caring role, it is essential to remember that there is a limit to our energy, good nature, patience and tolerance. Otherwise we will end up feeling like Ixion, the figure in Greek mythology who was bound to a wheel that revolved endlessly round the heavens. We will certainly be unable to fulfil our role effectively if we become chronically over tired or ill through stress. If we fail to heed the warning signs that we are becoming overstressed, we begin to dread each day and our role as a carer eventually becomes an impossible burden. We therefore need to learn how to manage our reactions to stress in order to help us go on caring.

Stress is a normal part of life. It is the way we react to changes and different situations. Like changes, stress can be positive or negative. Positive stress helps us channel our energies to perform well. Without positive stress we would never achieve anything worthwhile. But even positive stress needs to be balanced with time off for relaxation in order to build up reserves of physical and emotional energy. If stress is constant, we experience negative stress and we become increasingly distressed. Negative stress can cause many ailments, ranging from tension headaches or high blood pressure to complete mental breakdown.

'Burnout' is a state of physical, emotional and mental exhaustion caused by long term involvement in situations that are emotionally demanding. It is a very real potential health problem facing a carer who lives permanently in an emotionally charged environment and who feels under constant pressure to be unselfish and understanding. Whilst it is quite normal to feel tired and bad-tempered at times or to experience bouts of weepiness or edginess when the going gets rough, 'burnout' is when we feel so chronically ground down that we feel we can no longer cope. 'Burnout' is often accompanied by a growing feeling of isolation or lack of control. We may experience feelings of utter hopelessness, hostility to the person we are caring for, resentment of other family members or friends and complete disillusionment with the doctors and health-care professionals with whom we come into contact. We fall into a miasmic pit from which we can find no escape. It is often impossible to recover our original motivation once we have reached this stage.

The first strategy for preventing 'burnout' is to be aware of it as a potential problem. If we understand that we are at risk and can learn to recognise the early warning signs of stress, we can take action to protect ourselves before we start to burn out. As a carer, we spend much of our life attending to the needs of someone who is dependent on us for their every need. But what about our own needs? Paying attention to our own needs isn't selfish and doesn't mean that we don't care. Instead, this will provide our mind and body with the essential maintenance and nourishment that will allow us to go on caring. Like a privet hedge that needs to be cut back regularly if it is not to get out of hand, a carer's commitments to the demands placed on him or her need regular pruning in order to prevent overload. The key is knowing where the critical point is and stepping back before we step beyond it.

Every day we will encounter things that drain us with little opportunity to be nourished. If we are more drained than nourished, it is inevitable that our inner reserves will eventually run dry. If we are constantly giving out, we also need to have as much coming back in. When managing our personal finances, we all know that income must match or, even better, exceed expenditure but we rarely think to apply this strategy to managing our emotional energy. We need to examine the various aspects of our life that drain us and then weigh these up against those aspects that give us what we need in order to thrive. How does the balance look? A bit grim?

Sometimes it is the expectations we have of ourselves that can put us under most pressure creating intense psychological strain. Can we really expect ourselves to be Superman or Superwoman all the time? It is natural to aspire to high standards and ideals but it is extremely wearing when we cannot achieve them all. How many of those 'must do's' and 'should do's' are realistically achievable by one person with limited energy stocks? When it becomes impossible to juggle all the demands something has to go. This may involve accepting that we can often achieve more by doing less. It is essential to prioritise and to ask ourselves what would be the consequences if we don't achieve everything we expect of ourselves. Will the person we are caring for really come to any harm if we say 'No!' or 'I need a break!' once in a while? Even dementia sufferers cannot have their own way all of the time. Will it really be such a catastrophe if we leave the dusting for another day or don't iron the sheets until tomorrow or even don't iron them at all? Remember — spiders need homes and laundry baskets are not meant to be empty — they are designed to have laundry in them!

Many carers become seriously depressed and feel isolated or even marginalised when they are alone day after day with the person they are caring for. Letting off steam to a sympathetic ear from time to time can help enormously. Talk to your Community Psychiatric Nurse or Social Worker about how you feel. Part of his or her role is to provide carers with emotional support. Find out if there is an Admiral Nurse in your area; these nurses specialise in dementia care and understand the problems facing carers. The Alzheimer's Society has a national helpline staffed during office hours by people who are experienced in all aspects of dementia and who can also put you in touch with support groups and other organisations that you may find helpful. Of course, as we all know, crises (unlike health-care professionals) don't keep office hours or take holidays! If you feel alone or desperate, need to hear a friendly voice or you just want to cry in the middle of the night, the Samaritans are always there, whatever the hour, whatever the reason. Talking to other carers and hearing about their experiences can be very therapeutic — there are telephone networks as well as support groups. While nobody can ever walk a mile in your shoes, we've all trudged up a few steep hills and through some pretty inhospitable terrain.

No-one can be in complete control of all of life's stresses all of the time but we can learn how to manage these more effectively. If we recognise the situations that cause us to feel stressed and we are aware of our reactions to these, we can begin to develop ways to deal with the problems. We may need help to do this and accepting this can be very painful. While most of us don't feel embarrassed about asking for help or technical support when our car won't start or our computer programme crashes or the washing machine goes berserk and floods the kitchen, we all find it harder to ask for help when we think we may risk exposing an area of our own weakness or vulnerability. We often perceive our difficulties in coping as a carer as personal failure or lack of personal qualities rather than as in the nature of the impossibility of dementia.

Developing a positive attitude to the problems we experience as a carer is an important skill in managing stress. Cognitive behaviour therapy (CBT) can help us to understand the role that our mind plays in how we feel and how we respond to what is happening to us and the person we are caring for. Sometimes we are too close to the problems and become overwhelmed by their enormity or we get bogged down by going over the same ground again and again. It is easy to become involved in infuriating and emotionally draining circular arguments with the person we are caring for. A cognitive behaviour therapist can help us to look at things from a different perspective and to think more flexibly. It may not be possible to change our overall situation but we can be helped to handle that situation and the way we react to it more positively. For example, we can learn how to respond to challenging behaviour. If we think about the behaviour patterns that most wind us up or grind us down, we can decide whether realistically we can change them. Often we can't. We all accept that we cannot change the weather. We may grumble about it but we know there is nothing we can do other than adapt to its vagaries or leave the country. Dealing with dementia is really no different. Once we understand this, we can start to learn new coping strategies. With help we can also come to terms with our anger and frustration and overcome depression, low self-esteem and negative thoughts. Feeling good about ourselves and being confident helps us to develop assertiveness and negotiation skills and a 'won't be made to feel guilty', 'won't be bullied', 'won't be ground down' approach to the challenges of being a carer.

Financial worries add greatly to stress and there are several benefits and allowances to which carers are entitled that will help improve your financial situation. Tackling the complicated forms and paperwork can be very daunting but if you contact the Benefits Agency (Social Security) arrangements can be made for an adviser to visit you at home and help you fill in the forms or talk you through them over the phone. If you or the person you are caring for has become muddled or behind with tax affairs, it is tempting to ignore the tax demands and bury your head in the sand, which just makes everything more scary and difficult to face. In these circumstances, the Inland Revenue will give you a sympathetic hearing (trust me!) together with practical advice. Arrangements can usually be made for penalties to be deferred or even waived and for you to be given extra time or help to complete the tax return. You may also find it reassuring to discuss your financial affairs with an Independent Financial Adviser (IFA) who can assist with budget planning and help you to maximise your income and any savings or investments you have. A solicitor will advise on legal matters such as setting up an Enduring Power of Attorney so that you can sign documents and take important decisions with regard to property and financial affairs on behalf of the person you are caring for. Your local Citizens Advice Bureau can advise on finding an IFA and a suitably experienced solicitor.

For many carers becoming 'home manager' is often a completely new role that dumps previously unfamiliar challenges on us. After years of being able to rely on someone else to deal with those niggling little jobs such as putting up shelves and curtain rails, replace leaking tap washers, move heavy furniture around the home, climb up stepladders to change light bulbs or go rummaging around in the loft for the Christmas tree, or assemble flat-packed furniture with a screw driver that has a mind of its own (Omigod!) suddenly we have to cope alone. It is often these trivial but essential tasks that become the last straw to break the camel's back at a time when we have so many additional stresses to cope with. A telephone call to your local office of Age Concern will put you in touch with their 'Handy Person Service'. There is no charge for their help; you just pay for the cost of any materials required.

Physically fit and healthy people are better able to handle stress than those who are not. A healthy lifestyle includes following a balanced diet with limited intake of caffeine, salt and fatty foods, cutting back on the cigarettes and down on the alcohol (oh dear!) watching our weight and introducing some moderate daily exercise such as a brisk walk or a swim. Establishing a regular sleep pattern is also very important. There are many relaxation techniques that can help; these include breathing exercises, muscular relaxation, visualisation, meditation or quiet contemplation.

A referral by your GP to a homeopathic practitioner, aromatherapist or other complementary practitioner may also be helpful; these professionals have excellent listening skills and can advise on the many natural remedies that can help with stress related problems. Some of these treatments are available free to carers through the NHS. Your doctor or practice nurse will know what is available. Many local authorities run low cost, physical activity and leisure schemes (PALS) at local sports and recreation centres that introduce people to a wide range of carefully graded exercise and activities that aid physical and mental well-being. Again speak to your doctor or practice nurse or contact your local Leisure and Recreation Services via your Town Hall for further information.

The Carers Gateway (Kirklees) is an organisation that is funded by Social Services and the local authority and runs an extensive programme of activities and training for carers in Kirklees, together with social and respite breaks in an informal setting. Transport and care cover are available. Many branches of the Alzheimer's Society also provide training for carers. The Dementia Relief Trust (the organisation that trains Admiral Nurses) and the National Association for Providers of Activities for Older People (NAPA) both hold workshops and training events which informal carers as well as professionals are welcome to attend. Carers UK and The Princess Royal Trust for Carers are two more useful organisations to contact.

Don't forget about your spiritual needs; these can be met in a variety of ways, not necessarily religious; a vase of beautiful flowers, a work of art or classical music can all work wonders for your spiritual well-being — try listening to Ludovico Einaudi's piano music on his album 'I Giorni'. Even if you are unable or do not wish to attend a place of worship or feel you cannot pray or do not believe in the power of prayer yourself, you may appreciate a pastoral visit or find the knowledge that others are thinking about you and praying for you to be of great comfort.

One very important matter you may have felt too embarrassed to bring up with anyone — and doctors often hesitate to probe — is your sexual needs. If you have previously enjoyed an active and fulfilling sex life with a spouse or partner and are deprived of this as his or her dementia progresses, this can have a devastating effect on your emotional wellbeing. Or if you have had sexual or relationship problems for a long time but you previously had an interesting job or social life that compensated for this, you may experience feelings of resentment, frustration, loneliness or great unhappiness as these outlets are denied you in the need to be a full-time carer. If you simply try to ignore your sexual needs or attempt to repress them, your inner turmoil will inevitably come back to haunt you in your dreams; this can cause sleep disturbances, physical symptoms or even severe depression. Talking your feelings through with your doctor, priest, therapist, counsellor or trusted friend can help you come to terms with the problems and explore ways to meet your needs. You may wish to contact Relate; its counsellors are experienced in supporting people through all kinds of emotional conflicts; they are entirely non-judgemental and anything you discuss with them is completely confidential and will never be disclosed to anyone.

Physical and emotional well being will improve if you learn to enjoy what little free time you have and stop feeling obliged to cram every minute of your day with work and chores. A pleasurable activity can help you to relax and unwind and to be effective, this does not even need to take you away from home or the person you are caring for. Put on headphones, turn on some relaxing music and drift off into a world of sun, sand, sea and sangria. Make a reminiscence or memory box by collecting together favourite photographs and objects that bring back memories of happy events in your life.

A pet can be a wonderful companion but, if pet ownership is not practical or possible for your circumstances, a national charity called Pets as Therapy (PAT) has local volunteers who will visit individuals or groups regularly with a dog, cat or even a rabbit specially chosen for its friendly nature and 'cuddle-ability'. Many people derive a great deal of pleasure from attracting wild birds into their garden. The acrobatic antics of a couple of blue tits hanging upside down from a peanut feeder are delightful to watch. A group of starlings or sparrows squabbling over some food scraps or elbowing each other out the way so they can take a bath in a shallow bowl are hilarious. A robin or a blackbird will soon have you trained to appear at the same time every day with some grated cheese or a few raisins or sultanas. If you dig up a couple of juicy worms, the robin may even become bold enough to take them from your hand. Lack of a garden isn't a problem; there is a vast range of feeders that can be attached to a window or window ledge. You can even buy worms in tubs! Magazines, catalogues and feeding guides that are available free of charge from the Royal Society for the Protection of Birds (RSPB) and many seed companies can open up a whole new world of never ending entertainment through your letter box and living room window. Get out to the local park and feed the ducks — they will never fail to cheer you up as they dip and dive 'up tails all' or come waddling to greet you, especially when they have their ducklings in tow. And of course, you will also meet people of all ages who will enjoy a chat.

At the end of the day, a critical factor in hanging on to your stress levels depends on hanging on to your sense of humour. Laughter remains the best medicine of all and is the cure for many ills. After all, it is quite normal and perfectly reasonable to feel like murdering someone who is difficult and demanding — it only becomes unreasonable if you actually go ahead and do it!

Acknowledgements

I should like to thank members of North Kirklees Alzheimer's Society for their friendship and for sharing their experiences, laughter and tears with me. My thanks to all the charities and agencies mentioned for practical assistance and support in my role as a carer. I wish to express my great appreciation of the work and kindness of everyone involved in Older People's Services at the Priestley Unit, Dewsbury and District Hospital, especially Dr Nisreen Booya, Consultant Psychiatrist, and Phil Stewart, Cognitive Behaviour Therapist, for their longstanding and continuing support.

Useful addresses and telephone numbers

Carer support, information and training

Alzheimer's Society
Gordon House
10, Greencoat Place
London
SW1P 1PH
National helpline: 0845 300 0336
Website: www.alzheimers.org.uk

North Kirklees Alzheimer's Branch Office: 01924 444074
North Kirklees Support Groups: Roy Isherwood, 01274 870154

Carer's Gateway (Kirklees)
6/8 St Peter's Street
Huddersfield
HD1 1DH
Tel: 01484 226050
email: carers.gateway@kirkleesmc.gov.uk

The Dementia Relief Trust
6 Camden High Street
London
NW1 OJH
Tel: 020 7874 7210
Website: www.fordementia.org.uk

Carers UK
20-25 Glasshouse Yard
London
EC1A 4JT
Information line: 0808 808 7777
Website: www.carersonline.org.uk

Princess Royal Trust for Carers
142 Minories
London
EC3N 1LB
Tel: 020 7480 7788
Website: www.carers.org

National Association for Providers of Activities for Older People (NAPA)
Contact: Tessa Perrin
12 Walter Way
Silver End
Withan
Essex
CM8 3RJ
Tel: 01376 585225

Age Concern
Astral House
1268 London Road
London, SW16 4ER
National Information Line: 0800 00 9966
North Kirklees Office: 01274 871328
Website: www.ace.org.uk

Emotional support

Samaritans
The Upper Mill
Kingston Road
Ewell
Surrey, KT17 2AF
National helpline: 08457 90 90 90
Website: www.samaritans.org

Relationship problems

Relate
Herbert Gray College
Little Church Street
Rugby
CV21 3AP
National helpline: 08451 304 010
Website: www.relate.org.uk

Coping strategies

British Association for Behavioural and Cognitive Psychotherapies:
Globe Centre
PO Box 9
Accrington
BB5 2GD
Tel: 01254 875 277
Website: www.babcp.org.uk

Spiritual support

Faith in Elderly People (Leeds): 01943 879320
Huddersfield Deanery Project for Older People: 01484 300094

Financial advice

Benefits Enquiry Line: 0800 882 2200
Inland Revenue: 0845 915 5996
Citizens Advice Bureau: 020 7833 2181

Physical activities and exercise

Kirklees Active Leisure: 01484 234097

Companion animals and birds

Pets As Therapy (PAT)
17 Ambrook Road
Reading
RG2 8SL
Tel: 08702 401 239
Website: www.petsastherapy.com

Royal Society for the Protection of Birds (RSPB)
The Lodge
Sandy
Bedfordshire
SG19 2DL
Tel: 01767 680551
Website: www.rspb.org.uk

University of
HUDDERSFIELD

Calderdale and Huddersfield NHS
NHS Trust

Research in Health & Social Care:

A Practical Introduction

A course designed to assist front-line clinicians and their managers to:

- access, evaluate, and apply research evidence to practice
- develop or participate in local research projects
- understand the place of research and evidence in modern health and social care.

It has been accredited by the University of Huddersfield. For the first time the course will be able to offer both Undergraduate and Masters (M) level accreditation (subject to final approval).

Programme

Five blocks of study are offered, comprising 16 sessions, divided into 5 blocks, with additional sessions and tutorial support offered for those seeking M-level accreditation.
Block 1: Preparing for a Project
Block 2: Obtaining and Evaluating Current Evidence
Block 3: Introduction to Research Methods
Block 4: Statistical Principles and Analysis of Data
Block 5: Surviving and Managing Your Project

CONTINUING PROFESSIONAL DEVELOPMENT AND ACCREDITATION.

Staff completing the whole course, and submitting a number of pieces of work for assessment, will receive academic credits. These can be counted towards a qualification in any UK higher education institute, providing it accepts that the content and outcomes of this course are relevant to the qualification sought. Study patterns can be taken to achieve accreditation at either undergraduate or post-graduate level.

Additionally the course has been granted approval for CPD purposes by the Royal College of Physicians of London (and therefore qualifies for CPD purposes by the other Royal Colleges).

The course is open to all professional qualified NHS and social care staff, and to any others who can demonstrate that they are able to benefit from it and apply their learning to their work.

Continued funding from the West Yorkshire Workforce Confederation will mean that there is no charge for this programme to subscribing agencies – West Yorkshire NHS and Social Care agencies.

Course Dates:

14th January 2005
Based at Calderdale Royal Hospital.
8 weeks duration; 1 full day session per week.

For further information, contact:
John Hiley, Course Leader and Research & Development Co-ordinator, tel. 01484 347004, or e-mail jhiley@cht.nhs.uk or visit www.rdlearning.org.uk/coursedetails.asp?ID=15083

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MSc in Learning Disabilities - Quality of Life

This part time pathway allows students to obtain a Postgraduate Certificate, a Postgraduate Diploma or the full MSc. We also welcome students who may wish to do single modules.

The pathway is run by practising health service professionals and emphasises the clinical aspects of work with people with learning disabilities. It would particularly suit people wishing to pursue a career in the NHS in such areas as nursing, clinical psychology, occupational therapy, physiotherapy, or in social work (whether case management or residential).

Bursaries are available ranging from £500 to £1000; these will be awarded at the discretion of the course team.

Part time modules offered in Learning Disabilities
- Aspects of Nursing & Therapeutic Interventions
- The Psychology of Learning Disabilities
- Psychiatry of Learning Disabilities
- Quality of Life Evaluation

Each module costs £250 (subject to change) and is worth 15 Masters level credits. The completion of the 4 core modules can result in being awarded a Postgraduate Certificate.
For further details please phone Rukhsana Ahmed (Course Secretary) on 01484 473211 or Professor Stephen Read (Pathway Leader) on 01484 473496

Mental Health and Learning Disabilities Research and Practice

Types of manuscript

Articles, Short Papers, or Reviews, are welcomed from practitioners, managers, researchers, and academics, working or involved in any aspect of mental health and learning disabilities, and service users or service user groups. All articles and papers are peer reviewed by at least 2 referees.
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Short papers and reviews - Short papers of up to 3,000 words are welcomed on issues of practice or research.
Educational and Service Developments - The 'Developments' section of the journal will provide evaluation, review or critical appraisal of a recent development in policy, practice, education and research in mental health and learning disability.

Submission of manuscripts

Contributors are asked to submit 3 copies of their paper or one copy by e-mail attachment, together with a separate sheet providing brief biographical details and details of their full postal and email address, telephone and fax numbers. Manuscripts should be submitted using A4 size paper, in double line spacing with wide margins.
Authors should submit 3 copies of their manuscript, including any tables or illustrations, to The Editor or by e mail to: a.holmes@hud.ac.uk. Authors are advised to retain a copy of their paper.

Presentation of manuscripts
Articles

Articles should be between 3,000 and 5,000 words.
Abstract - an abstract of the paper, of up to 200 words, should accompany the article together with up to 6 key words suitable for indexing, abstracting, and on-line search purposes. The abstract should provide a concise summary of the whole paper.
Author details - a brief biographical note about the author should be submitted on a separate sheet. Details should include the author's full postal and email addresses, telephone and fax numbers.
Abbreviations – all abbreviations should be preceded on the first occasion they appear, by the full name. Full stops should be used after abbreviations such as e.g., i.e., etc., and where the end of a word is cut as in p. (page), or ed., but are not necessary in acronyms such as HMSO, HMIP, UK.
Notes should be kept to a minimum and placed at the end of the article before the references. Footnotes should not be included.
Quotations – use single quotation marks for material quoted in the text. Double quotation marks can be used for quotes within quotes. Long quotations (40 words or more) should be displayed indented. Shorter quotes may be retained within the text.
Tables, figures, and diagrams should be kept to a minimum and, where included, should be submitted on separate sheets attached to the article with a short title. In the text the position of a table, figure, or diagram should be shown by typing on a separate line 'take in Table 1(Figure 1/Diagram 1)'. Tables, figures, and diagrams should be in black and white, clear and well drawn.
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References in the Reference list should conform to the following style:
Robson, C. 1997. Real World Research. Oxford, Blackwell Publishers Ltd.
Phillips, C., Palfrey, C., & Thomas, P. 1994. Evaluating Health and Social Care. London, Macmillan Press Ltd
Minto, C., & Morrow, M. 2000. Clinical supervision for nurses in a learning disability forensic service. In Mercer, D., Mason, T., McKeown, M., & McCann, G. Forensic Mental Health Care. London, Churchill Livingstone.
Faulkner, A., & Thomas, P. 2002. User-led research and evidence based medicine. British Journal of Psychiatry 180: 1 – 3.

Additional points on style to assist contributors

• It is expected that language used in articles will be non-sexist, non-racist, and non-discriminatory. • Single spaces should be used after full stops, commas, colons and semicolons, quotation marks etc. • Dates should be written in the form 1 January 2004.

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Educational and service developments

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