

**Mental Health in Old Age Bulletin
Issue 6**

Editorial Board: Alistair Burns, David Challis,
Judith Dennis and Jane Hughes

Contributors: Susan Benbow, Roger Bullock,
Alistair Burns, Judith Dennis and John Keady

Layout by: Sue Martin

Discussion Paper M121
March 2004

PERSONAL SOCIAL SERVICES RESEARCH UNIT

The University of Manchester

Dover Street Building
University of Manchester
Oxford Road
Manchester M13 9PL
Tel: 0161 275 5250

The University of Kent at Canterbury

Cornwallis Building
University of Kent at Canterbury
Canterbury
Kent CT2 7NF
Tel: 01227 823963/823862

London School of Economics

London School of Economics
Houghton Street
London
WC2A 2AE
Tel: 020 7955 6238

MENTAL HEALTH IN OLD AGE BULLETIN ISSUE 6

Editorial

Workload: Team Players v Crusading Consultants 3

Article

Younger-onset dementia: Some challenges and dilemmas 5

Current Key Issues

Gender cognitive decline and risk of AD in older persons 9

Mild cognitive deterioration and subcortical features..... 9

Book Review

Diagnosis and management of dementia 10

Website Review 11

Your Problem Answered..... 11

EDITORIAL

Workload: Team Players v Crusading Consultants

Old age psychiatrists work long hours with little opportunity for leisure, family life, research and personal study (Benbow *et al.*, 1993; Jolley & Benbow, 1997). Almost half do extra work at home on every weekday except Friday, and about a third do so on Saturdays and Sundays (Jolley & Benbow, 1997). The majority of stresses identified by old age psychiatrists relate to work overload or to organisational structure and climate (Benbow & Jolley, 1997). Increasingly they work in a setting of repeated organisational reorganisations and tight budgetary constraints (Sainsbury Centre for Mental Health, 2003), where older people's mental health services are the Cinderella of cinderellas, falling between the Older People's and Mental Health NSFs. It is not surprising then that levels of emotional exhaustion are high (Benbow & Jolley, 2002), psychiatrists are retiring earlier (Kendell & Pearce, 1997), there is concern about work patterns in psychiatry as a whole (Pajak *et al.*, 2003), and recruitment is inadequate to maintain consultant numbers (Storer, 1997).

What can be done?

The edge of chaos may be challenging and uncomfortable, but it is a creative place to be, and the role of the consultant is evolving. Workload cannot be divorced from working pattern. General psychiatry and primary care have been ahead of us in looking at new ways of working: there are STAR workers, graduate workers, gateway workers (Department of Health, 2003a), assertive outreach teams, crisis resolution teams, early intervention teams and probably others unknown to me. There are initiatives in training physicians assistants and developing GPs with a Special Interest (Department of Health, 2003b). The danger is that the patient and their family are lost in a web of tangled teams seeing workers of unknown aetiology. But there is a message here for us in older adults' mental health. The days of the lone consultant crusader are gone: we are not alone. Team working does not weaken us, it strengthens us and (more importantly) strengthens our patients, but it brings with it a need to coordinate and to concentrate expertise where it is most needed.

Old age psychiatry has shown a talent in the past to take initiatives from other spheres and to reframe them for our client group. Multiple separate teams introduce artificial boundaries. It may be better still to identify the necessary functions and to modify the core older adults community mental health team to provide them. As part of an expanded truly multidisciplinary team, providing home treatment and assertive outreach, the old age psychiatrist could concentrate on complex diagnostic and treatment issues. With dependable, properly resourced IT support, systems can be set up to ensure that people don't slip through the net and that their care is regularly reviewed and tailored to their individual changing needs (Johnson, Benbow & Baldwin, 1999).

Fantasy or reality?

At the moment this sounds like a fantasy. My own service falls far short of the vision outlined above, but with investment of time, money and people it would not be difficult to achieve radical change and move our services into the 21st century.

References

Benbow, S.M. & Jolley, D.J. (1997) Old age psychiatrists: what do they find stressful? *International Journal of Geriatric Psychiatry* 12, pp.879-882.

Benbow, S.M. & Jolley, D.J. (2002) Burnout and Stress amongst Old Age Psychiatrists. *International Journal of Geriatric Psychiatry* 17, pp.710-714.

Benbow, S.M., Jolley, D.J. & Leonard, I.J. (1993) All work? A day in the life of geriatric psychiatrists. *International Journal of Geriatric Psychiatry* 8, pp.1019-1022.

Department of Health (2003a) *Fast-forwarding primary care mental health graduate primary care mental health workers: best practice guidance*. London, Department of Health.

Available at: <http://www.nimhe.org.uk/downloads/fastforwardguidancejan03.pdf>

Department of Health (2003b) *Practitioners with special interests: bringing services closer to patients*. London, Department of Health.

Johnson, M., Benbow, S.M. & Baldwin, R.C. (1999) An electronic patient record system and geriatric psychiatry: considerations and implications. *Ageing and Mental Health* 3, pp.257-263.

Jolley, D.J. & Benbow, S.M. (1997) The everyday work of geriatric psychiatrists. *International Journal of Geriatric Psychiatry* 12, pp.109-113.

Kendell, R.E. & Pearce, A. (1997) Consultant psychiatrists who retired prematurely in 1995 and 1996. *Psychiatric Bulletin* 21, pp.741-745.

Pajak, S., Mears, A., Kendall, T. *et al* (2003) Workload and working patterns in consultant psychiatrists: an investigation into occupational pressures and burdens. (College Research Unit, Royal College of Psychiatrists Project Report), London, Royal College of Psychiatrists, 2003.

Available at: <http://www.rcpsych.ac.uk/cru/hsrp/workloadreport.pdf>

Sainsbury Centre for Mental Health (2003) *Money for Mental Health: a review of public spending on mental health care* (Briefing no 22).

Available at: www.scmh.org.uk

Storer, D. (1997) Prematurely retiring consultant psychiatrists. *Psychiatric Bulletin*, 21, pp.737-738.

Susan Benbow

Chair, Faculty of Old Age Psychiatry

ARTICLE

Younger-onset dementia: Some challenges and dilemmas

In contemporary society dementia is socially, culturally and professionally constructed as an older person's disease. And although the formal definition of dementia has changed over time, its correlation with the ageing process has not. Yet, as both clinical contact and the literature reveals, people under the age of 65 years are also diagnosed with this condition. Indeed, a number of researchers and commentators have proposed unique social challenges and issues that younger people with dementia and/or their families encounter. These include:

- Workforce/retirement/financial issues (Walton, 1999);
- Managing changing relationships within the family (Cox & Keady, 1999);
- Concerns about genetic transmission, from both the family and younger person him/herself (Woods, 1999);
- A more rapid loss of awareness for the person with dementia and descent into its 'moderate' and 'severe' stages (Tindall & Manthorpe, 1997);
- The person having more energy/being more physical active (Freyne, *et al.*, 1995);
- Feelings of extreme social isolation in living with the condition (Williams, Keady & Nolan., 1995); and the
- Premature death of the younger person (Newens, Forster and Kay, 1993).

Although Alzheimer's disease (AD) is recognised as being the most common cause of younger-onset dementia, it accounts for only 35% of all presenting conditions (Harvey, 1998), or around 35 cases of AD per 100,000 of the population aged 64 or under. As Harvey (1998) suggests in his informative report, projected to the United Kingdom population, this equates to around 5,500 people aged 64 or under with AD.

The Alzheimer's Society (2001) currently estimate that there are 18,500 younger people with dementia living in the UK and suggest that this population is more likely to experience atypical dementias, such as HIV-related dementia, alcohol-related dementia, frontotemporal dementia, primary progressive aphasia and progressive visuospatial dysfunction. Accordingly, memory loss may not be the initial presenting problem and other symptoms may be prevalent, such as behaviour and personality changes and language disturbances, and high levels of psychiatric morbidity expressed through delusions and hallucinations. With such a complex clinical picture in mind, Harvey (1998) suggests that service planners should aim for between 150-200 younger people with dementia per 600,000 of the population. Moreover, the low density of cases in a given population can cause difficulty for service planners in rural communities/areas when economics and value for money – measured and expressed through service contacts – are brought into the equation. The Report also provided comparative information about the financial costs of care for younger people with dementia. Here, costs of care in the community amounted to £1,561 per annum compared to £20,924 per annum for residential care. This is a significant

difference in resource allocation and one that is not reflected in the statutory benefits available to individuals or family carers of younger people with dementia.

In a typical GP surgery, therefore, reaching a diagnosis of dementia in middle age is a rare event and the diagnosis is often reached when all other possibilities have been exhausted. Such a fact may also help to explain why people with the early signs of younger-onset dementia can remain undiagnosed in primary care for some considerable time with Walton (1999), for instance, suggesting that this can also be due to the general practitioners' unwillingness to consider it as a diagnostic option. Whilst this observation may paint a rather pessimistic picture of the situation facing younger people with dementia and their families it is important to highlight the positive contribution that such men and women have made, and are continuing to make, to the field of dementia care. Notably, some of the earliest autobiographical texts on the experience of dementia were written by younger people (see for example: Davis, 1989) and Alzheimer himself conducted his groundbreaking research into the life (and premature death) of Auguste D, a 51 year-old woman admitted to the Frankfurt am Main insane asylum in Marktbreit, Germany in 1901 (for a more complete discussion see: Maurer, Volk and Gerbaldo, 1997). Younger people with dementia are also continuing to push the boundaries of advocacy work (Boden, 2002), and highlight their struggle to society as a whole. Slowly but surely it is society, not just the individual, that is being actively challenged to respond and positively adapt to the experience of dementia.

As an expression of this momentum, within the UK, and propelled by the changes in community care legislation and the person-centred movement, the needs of younger people with dementia are now written into policy documentation. For example, Standard 7 (Mental Health in Older People) of the *National Service Framework for Older People* (Department of Health, 2001) demands that the National Health Service and councils responsible for social service provision should:

Review current arrangements in primary care and elsewhere for the management of dementia in younger people, and agree and implement a local protocol across primary care and specialist services, including social care (p. 106).

Whilst it is disappointing that the needs of younger people with dementia are tied up within an older person's strategy, their inclusion nevertheless signals the UK government's intent to focus attention on this key group of people.

Whilst such a focus is encouraging, there have, to date, been few studies that are based on an in-depth exploration of the younger person's subjective experience and fewer still that also include the family's perspective. With the advent of therapeutic medication regimens, an early diagnosis of younger-onset dementia can bring with it (notionally at least) person-centred treatment and appropriate support. Staff skills can also be utilised to assess the person and their experience through their biography and life course; ideally through a dedicated care pathway. Within such a framework it is also important to care for the staff involved in working with younger people with dementia, and their families, as this work can be very stressful and demand that staff confront their own beliefs about what it is to have 'a dementia'. Being with someone of the same age, or younger than oneself who has the condition,

is a sobering and self-challenging experience and one where supervision should be a mainstay of clinical work.

In 1995 the Alzheimer's Society surveyed their branches in England, Wales and Northern Ireland about services available to younger people with dementia and their families in their area. Sixty-eight (about one third) of the questionnaires were returned to make it the only (reasonably) large-scale national survey currently available that addresses this specific population. Chief amongst the findings was that:

- Most younger people with dementia receive services which have been designed primarily with the needs of the older person in mind;
- Less than one quarter (22%) of the branches were aware of genetic counselling services being available for families of the younger person with dementia;
- Only 13% of local Alzheimer's Society branches said specialist day care or respite care services for younger people with dementia were available in their area, and only 15% said specialist home help services were provided; and
- 94% of the Society's branches said specialist residential care for the younger person with dementia was not available in their area.

Nearly ten years on it is vital that we continue to address each of these points and grapple with the complex issues that they raise. Younger people with dementia are finding a voice and it is vital that we don't simply listen to it, but, more importantly, actively learn from it and include the younger person's needs and wants within a reconfiguration of services, service provision and research attention.

Finally, there are some shared common experiences among people of any age diagnosed with dementia, which include: multiple losses related to social roles, autonomy, and respect; and the impact on self-hood and self-esteem. However, people diagnosed with younger-onset dementia appear to have added additional stressors because of their age and stage in the family life cycle. These added stressors have more of an overwhelming impact upon the whole family system. In addition, families and younger people with dementia will construct their own meaning from events and from one another's situation. As such, services will need to be flexible and person-centred and work within a framework that is understandable to all parties concerned. A difficult but necessary task, and one that is obligatory if a more person-centred and inclusive service is to emerge.

References

Alzheimer's Society (2001). *Younger people with dementia: a guide to service development and provision*. London, Alzheimer's Society.

Alzheimer's Society (1995). *Services for Younger People with Dementia. Report by the Alzheimer's Disease Society*. London, Alzheimer's Society.

Boden, C. (2002). A person-centred approach to counselling, psychotherapy and rehabilitation of people diagnosed with dementia in the early stages. *Dementia: The International Journal of Social Research and Practice*, 1(2), pp.141-156.

Cox, S., & Keady, J. (1999). *Younger people with dementia: Planning, practice and development*. London, Jessica Kingsley Publishers.

Davis, R. (1989). *My Journey into Alzheimer's Disease*. Amersham-on-the-Hill, Buckinghamshire: Scripture Press.

Department of Health. (2001). *National Service Framework for Older People: Modern Standards and Service Models*. London, Department of Health.

Freyne, A., Kidd, N., Coen, R., & Lawlor, B.A. (1995). Burden in carers of dementia patients: Higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry* 14, pp.784-788.

Harvey, R. (1998). *Young onset dementia: epidemiology, clinical symptoms, family burden, support and outcome*. London, Dementia Research Group. Imperial College School of Medicine.

Available at: www.dementia.ion.ucl.ac.uk

Maurer, K., Volk, S. and Gerbaldo, H. (1997). Auguste D. and Alzheimer's disease. *The Lancet* 349, pp.1546.

Newens, A.J., Forster, D.P., Kay, D.W.K., Kirkup, D.W.K., Bates, D. & Edwardson, J. (1993). Clinically diagnosed pre-senile dementia of the Alzheimer's type in the Northern Health Region: ascertainment, prevalence, incidence and survival. *Psychological Medicine* 23, 631-644.

Tindall, L., & Manthorpe, J. (1997). Early onset dementia: A case of ill-timing? *Journal of Mental Health* 6, pp.237-249.

Walton, J. (1999). Young-onset dementia. In: Adams, T. and Clarke, C. Eds., *Dementia care: Developing partnerships in practice*. London, Bailliere Tindall Publishing. Pp.57-279.

Williams, O., Keady, J., & Nolan, M. (1995). Younger-onset Alzheimer's disease: Learning from the experience of one spouse carer. *Journal of Clinical Nursing* 4, pp.31-36.

Woods, B. (1999). Psychological interventions. In Cox, S. and Keady, J. Eds. *Younger people with dementia: Planning, practice and development*. London: Jessica Kingsley. pp.245-260.

John Keady

Professor of Health, Community and Education Studies
Northumbria University
email: john.keady@unn.ac.uk

CURRENT KEY ISSUES

Gender cognitive decline and risk of AD in older persons

Barnes L. *et al.* (2003) Gender cognitive decline and risk of AD in older persons. *Neurology* 60, pp.1777-1781.

While cross-sectional studies have shown gender differences in cognitive function and risk of Alzheimer's disease in older people, mixed results have emerged from longitudinal studies which compare change in cognitive function over time. Five hundred and seventy-seven older women and 271 older men who had completed an average of 5.8 annual evaluations with a follow-up of 95% in survivors were recruited from the Religious Orders Study, whose aim is to carry out a longitudinal clinical and pathological study of ageing and Alzheimer's disease in older Catholics, nuns, priests and brothers. Generally, men and women declined in all abilities assessed during follow-up period, but there was no difference in the mean rate of change for either gender when age, educational and initial level of cognitive function were controlled for. There was no difference in the risk of incident Alzheimer's disease between men and women, nor did possession of apolipoprotein E4 make any difference. Duration of use of oestrogen was related to rate of decline, as well as the presence of visuo-spatial abilities in women, but the overall conclusion was that the patterns of cognitive decline and incidence of Alzheimer's disease are similar in older men and women.

Alistair Burns

Professor of Old Age Psychiatry

University of Manchester

email: a.burns@manchester.ac.uk

Mild cognitive deterioration and subcortical features: prevalence of clinical characteristics and association with cardiovascular risk factors in community dwelling older persons (the InCHIANTI study)

Geroldi C. *et al.* (2003) Mild cognitive deterioration and subcortical features: prevalence of clinical characteristics and association with cardiovascular risk factors in community dwelling older persons (the InCHIANTI study). *Journal of the American Geriatric Society* 51, pp.1064-1071.

The objectives of this study were to identify people with cognitive impairment and Parkinsonian features and to investigate the vascular correlates of this condition. The Chianti geographic region in Tuscany, Italy was chosen, and 556 subjects aged between 70 and 90 with a Mini-Mental State Examination of greater than 3 out of 30 were examined. Low cognitive performance was defined as age and education adjusted Mini-Mental State Examination score below the 50 of percentile for the population, and subcortical features were defined as plastic rigidity on neurological examination, gait disturbance (small step gait or Parkinsonian gait) and dysexecutive features. Two-hundred and forty three subjects had high cognitive performance, 166 had low cognitive performance without subcortical features, and 75 had low cognitive performance with subcortical features. Vascular risk factors were hypertension, atrial fibrillation or pathological findings on an ECG, low serum high-density lipoprotein or

high low-density lipoprotein cholesterol, diabetes, obesity, and heavy smoking. Three main vascular risk factors were associated with a higher prevalence of low cognitive performance with subcortical features – hypertension, atrial fibrillation or other ECG changes, and low high density lipoprotein cholesterol. It was suggested that gait disturbance and nonamnesic cognitive symptoms might be the consequence of subcortical vascular damage.

Alistair Burns

Professor of Old Age Psychiatry

University of Manchester

email: a.burns@manchester.ac.uk

BOOK REVIEW

Diagnosis and management of dementia

Gordon Wilcock, Romola Bucks & Kenneth Rockwood (1999) *Diagnosis and management of dementia* Oxford, OUP. ISBN 0192628224; Price £42.50

This is a comprehensive and well put together text that is subtitled “a manual for memory disorder teams”. This immediately assuages the fears of those who do not want to set up clinics in their beloved community services and then dashes their hopes by opening with “Establishing and organising a clinic”. However after taking the reader through the physical processes of setting up a clinic, the book has contributions from many early exponents of the field and cleverly weaves together the components that make up what is needed to make a holistic assessment of someone with a cognitive disorder. This includes a significant contribution from the various therapies that are often not available to new services. It also makes clear the contributions that each specialty can make, including the equal importance of medical and psychiatric examination. Too often, memory services are being set up simply by manipulating existing resources. The book makes it apparent that this is a specialised field needing dedicated sessional time and good multidisciplinary interaction to produce the best results.

The book is still surprisingly up to date given its 1999 publishing date. This is an achievement on behalf of the authors, but it is sad that apart from the introduction of memantine as a new symptomatic treatment, and perhaps a few differences in the way vascular cognitive impairment is classified and viewed there have been few major advances for the next edition.

If it has a weakness, the book covers assessment and diagnosis of mild to moderate dementia well, but may not go in to care management issues and the primary care perspective enough – though I can understand why. This is probably where the various countries differ most in their provision of services and to list different models would have interrupted the flow of the piece. However, care management, even in mild dementia, is an area that is evolving rapidly and may need longer sections, with perhaps social work input, in future editions if the manual is to be comprehensive. But currently it is probably the most multidisciplinary friendly of the reasonable length tomes that cover this field and a valuable resource for all memory disorder teams, whatever their level of development (we actually have two copies).

Conflict of interest: I promise I am not just saying this because all the authors are friends of mine.

Roger Bullock

Consultant in Old Age Psychiatry
Avon & Wiltshire Mental Health Care Partnership NHS Trust
email: info@Kingshill-research.org

WEBSITE REVIEW

Zetoc

Zetoc is the name given to the British Library electronic table of contents database. Since its launch in September 2000 it has proved a valuable tool for many who want to keep up-to-date with what's going on in their field, a related field or for finding out what their contemporaries/rivals are up to in the publishing world.

The database lists the contents of around 20,000 current journal titles and something in the region of 16,000 conference proceedings are added to it each year. Users can choose to search the journal articles database or the conference proceedings one or you can search both simultaneously. Search results may be downloaded and emailed to the address of your choice; alternatively there are filters which enable you to download them into bibliographic software such as EndNote.

A major feature of the service is the facility it offers to set up a **Zetoc Alert**. An Athens password is required to take advantage of this. **Zetoc Alert** is a current awareness service which forwards to you by email references to journal articles you indicate (by a prearranged profile) will be of interest to you. There are two ways of going about this. You can select specific journal titles and references of all the articles in the most recent issue will be emailed to you each time a new one is published. Alternatively you can opt to receive references to articles which have keywords of your choice in the title – or you can do both.

Search **Zetoc** or set up your own **Zetoc Alert** on <http://zetoc.mimas.ac.uk>

Judith Dennis

Library and Information Officer
PSSRU, University of Manchester
email: judith.dennis@manchester.ac.uk

YOUR PROBLEM ANSWERED

I am studying for an MSc in Applied Psychology. I need to do a literature review on psycho-social aspects of caring for people over the age of 65. I would be most grateful for advice.

A literature review needs to be both comprehensive as far as *types of information sources* is concerned as well as fairly specific as regards *subject matter*. It will need to encompass the history and development of thinking and practice in the area as

well as including all relevant current references, so it will be necessary to look for books, reports, conference proceedings as well as journal articles.

First, **choose your sources**. If you belong to the generation which has grown up accustomed to the search engine, your first reaction will be, no doubt, to turn to Google and in this way you will quickly retrieve a vast amount of information; but how you will know whether it is reliable? Some of it will be but much will not. Fortunately for you there is a wealth of good additional information sources accessible from your PC which can save you the anxiety of wondering about this; searching for information from these is not as straightforward as typing in a random keyword but the results will be more satisfactory. Some of the bibliographic databases which you may need are:

ASSIA – a social sciences database comprising references to *journal articles*.

Cinahl – for *journal articles* in the nursing area.

COPAC – this is the union catalogue of all major research libraries in the UK. It is therefore a good place to start searching for *books* on your subject.

Embase – for *journal articles* on health related subjects (has a European focus).

Medline – the key source of information about *journal articles* in the field of medicine (US based).

Psycinfo – the major source of references to *journal articles* in the psychology and psychiatry fields.

Sigle – gives access to *reports* and *conference proceedings*.

Zetoc – gives access to *journal articles* and *conference proceedings*.

It will also be beneficial to have a look at the website of the National electronic Library for Mental Health <http://www.nelmh.org> as well as OMNI <http://www.omni.ac.uk>.

Next, **define your search terms**. It will be worthwhile spending time doing this as it will save you time in the end. Try constructing a mini-table of subject terms which define your topic and think of synonyms for your concepts. Something along these lines:

psychosocial	caring	elderly
interpersonal	nursing	older
environment		geriatric
attitude		aged

Constructing a table like this will help you clarify your thinking about your topic as well as helping you find the most helpful search terms in the databases you use. All databases offer free keyword searching but for a search like yours which needs to be

well-focused it is better to find a *thesaurus* term if the database offers one (though many databases automatically 'map' the terms you choose to the thesaurus) – this way you will more easily retrieve references which are relevant.

With a search that has more than one concept it is helpful to build up single concept sets to start with as this provides you with the flexibility to combine them at will subsequently. You can also apply limits (e.g. date) to these sets as required to ensure you have a manageable set of references at the end (unless you have an extremely new or narrow topic your problem is more likely to be retrieving too many references than too few).

One last tip: if you are going to be carrying out these searches over a few weeks, it will be helpful to you to **save your search strategy**. Many databases offer the facility to do this. You can then quickly re-run your searches just before you decide which ones to pursue and you'll pick up any publications which have been added to the databases since you did your original search.

Judith Dennis

Library and Information Officer
PSSRU, University of Manchester
email: judith.dennis@manchester.ac.uk