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MENTAL HEALTH IN OLD AGE BULLETIN
ISSUE 7

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EDITORIAL

Recognition of dementia in primary care

Recognition of dementia in primary care is as important as it is problematic. Recent estimates suggest that while primary care practitioners recognise half to two thirds of those with moderate and severe dementia respectively, they know only about a third of those in the early stages. Early recognition has the potential to prevent the development of excess disability by addressing co-existing health and mental health conditions. In addition, early recognition allows for the introduction of services and supports to ensure the maintenance of optimal psychological and social lives. Arguably recognition of dementia has most to offer those in the early stages of the condition yet it is precisely this group of people who are least likely to be detected. The reasons for this paradoxical situation are complex and inter-related.

Some have to do with the condition itself:

- the contested nature of the condition with some arguing that it is not the result of an underlying disease process but rather an accelerated form of ageing;
- the difficulty of distinguishing the condition from changes associated with normal ageing and depression;

Some have to do with the stigma associated with dementia:

- an awareness that a diagnosis of dementia has a social and personal cost to that individual and their family;
- reluctance to assign an older person a label which, rather than opening up opportunities for care and support, may close them off;
- a recognition that a diagnosis of dementia often results in older people with mental health problems experiencing triple jeopardy; that is discrimination based on their age, mental health problem and dementia;
- Primary care, as is common in health care, may hold ageist views about what can be expected in old age and the appropriateness of directing resources to this age group;

Some have to with the reluctance to break bad news:

- while research suggests that most people would want to know this diagnosis, evidence suggests a reluctance on the part of professionals to share the diagnosis;
- some of this reluctance can be likened to the situation with cancer 20 years ago, that is a concern with the emotional effects of telling people they have a terminal condition about which nothing medical can be done;
- a lack of awareness of the usefulness to people with dementia and their families of knowing what is causing changes to their abilities and behaviour;
- a lack of awareness that people with dementia and their families are, like other people living with chronic conditions, active agents who strive to cope with, and adjust to, living with this condition;

- some argue that the person will not be capable of understanding the implications of the diagnosis, while others that the implications of the diagnosis will be so severe as to challenge the person's emotional well-being;

Some have to do with the lack of support for primary care in the diagnosis and ongoing support of people with dementia

- In some areas there are insufficient specialist secondary services (such as old age psychiatry and memory clinics) to support diagnosis;
- Some primary care practices may fear they lack adequate financial resources to support people with dementia;
- Most primary care services are generally better prepared for, and supported to, care for acute conditions rather than chronic conditions;

Some have to do with a lack of awareness of effective services and supports:

- a lack of awareness of supports, services and Societies which exist to help people with dementia and their families adjust to, and live quality lives with, the condition;
- a lack of information about anti-dementia drugs or a view that their limited efficacy does not outweigh the personal and social cost of the neuro-psychiatric label;

Several strategies have been developed to improve the recognition of dementia in primary care. As difficulties with recognition and diagnosis of dementia in its early stages are caused by a variety of factors, a variety of approaches to improving recognition are required. Not all of these target primary care professionals directly. These include:

- Guidelines for the primary care management of dementia published in the British Medical Journal in 1998;
- Educational efforts for primary care practitioners including practice-based workshops, the development of a CD-ROM (downloadable from www.alzheimers.org.uk) and Decision Support Software;
- Consumer education and activation (useful examples in the UK include Alzheimer Scotland Action on Dementia and in the US the Alzheimer's Association Los Angeles);
- NICE endorsement of anti-dementia drugs for people with Alzheimer's disease;
- Structured partnerships between medical, social and voluntary services (see for example www.nccconline.org/about/alzheimers.htm);
- Public education campaigns to remove stigma and ensure that people understand that while little can be done to arrest the neurological disease, much can be done to maximise psychological and social well-being;

With a full appreciation of the variety of factors affecting the recognition of dementia in primary care, the Department of Health's 2001 National Service Framework providing clear policy guidance on the need for early diagnosis and intervention, and the variety of strategies developing to support primary care professionals in recognising dementia, the future looks brighter for the early recognition of dementia in primary care.

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ARTICLE

Palliative care in dementia

'Life is pleasant. Death is peaceful. It's the transition that's troublesome.' - Isaac Asimov

Is dementia a "terminal illness"?

Dementia is a malignant and ultimately fatal neurodegenerative process, yet is not viewed as a "terminal" disease. In one survey, only half of carers of dementia patients questioned said they thought the patient was likely to die compared to three quarters of those caring for a cancer patient. In women, dementia carries a relative risk of death greater than that of carcinoma of the gastrointestinal tract. Despite this epidemiological evidence, this view is also found amongst health professionals. Dementia is only recorded on a third of death certificates, despite the fact that bronchopneumonia, the commonest cause of death in these patients, is often a direct result of the dementia. This is equivalent to a situation where a patient has died from bronchopneumonia, secondary to carcinoma of the lung, but malignancy is omitted from the death certificate. This rarely occurs because most doctors conceptualise carcinoma as a terminal illness (1)

The effect of cognitive impairment on mortality

Cognitive impairment alone significantly increases mortality in the elderly. The mortality risk ratio of mild/moderate dementia is twice that of neoplastic disease (2). A third of patients with moderate Alzheimer's disease (MMSE scores of 19-23), aged between 75 and 84 years, will die within a year. Hospital admission of a person with dementia for acute medical illness is a critical event. In a recent American study, half of patients with severe dementia admitted with hip fracture or pneumonia died within 6 months (3).

The role of palliative care in dementia

Avoidance of iatrogenic suffering is fundamental to the provision of good quality medical care, yet studies have shown that dementia patients are often subject to painful and unnecessary investigations in the terminal phase of their illness (3). This contrasts with the palliative care model where management of pain is of primary importance. Despite this use of unnecessary investigations, health care workers persistently underestimate levels of pain experienced by the elderly and patients with dementia. Achieving adequate pain control is rare; one study of patients with fractured neck of femur found that cognitively impaired patients were prescribed a third as much analgesia as cognitively intact controls (4). The Regional Study of Care of the Dying found that significantly more dementia patients experienced pain in the last 6 months of life compared to those with cancer (75% vs. 60%) (5). It may be difficult to detect pain in dementia patients who are unable to express their needs and hospital staff may have underlying beliefs that analgesia will precipitate a delirium. The mismanagement of pain causes difficulties in caring for these patients in the setting of the general hospital, increasing behavioural problems such as agitation, aggression and resistance to care. Acute hospital admission is detrimental to pain management as the carers who know the patient best are often not present. When formalised pain assessment scales are used in dementia patients the use of analgesics increases significantly, indicating previously unmet needs.

It has been argued that medical care based on cure and maximal prolongation of life is inappropriate for patients with advanced dementia and that a palliative care model should be adopted. Attempts to prolong the life of a patient with dementia using antibiotics, intravenous fluids and tube feeding are ineffective. Specific approaches adopted from palliative care such as interventions for agitation, constipation and pain improve quality of care, decrease the number of unnecessary investigations and may lead to cost savings.

Barriers to the adoption of a palliative care approach in dementia

There are a number of reasons why palliative care approaches to end-stage dementia have not been adopted. There is a very limited evidence base for the provision of palliative care services in dementia; a systematic review found only one randomised controlled trial. Little is known about the experience of dementia patients and their carers in the last stages of life in the UK health service. The few studies available have been carried out in the United States where the legal framework differs to that of the UK, for example, tube feeding of end stage dementia patients is standard clinical procedure in some US states, despite robust evidence that this is not beneficial.

One of the main barriers identified by a number of authors and by the National Hospice Council is that there are no validated prognostic indicators for patients with end-stage dementia who are suffering from acute physical illness. Clinicians are deterred from treating advanced dementia as a terminal illness because of this perceived prognostic uncertainty. If the terminal stage of dementia can be more clearly identified we may encourage a change in clinical practice and in the attitude of professionals and carers and increase the availability of palliative care to dementia patients.

Public policy and debate

Numbers of elderly people are increasing in the United Kingdom and the incidence of dementia from all causes increases with age. Currently approximately 600,000 people in the UK have dementia but it is estimated that by 2026 there will be 840,000 rising to 1.2 million by 2050. It is likely that more elderly patients will be admitted to the acute general hospital setting and up to a third of these patients will have some form of cognitive impairment. Increasing numbers will be subject to poor quality end-of-life care compared to those with cancer. This will lead to the inappropriate use of resources and dementia patients may be wrongly perceived to be “blocking” acute medical beds.

Standard two of the National Service Framework for older people supports the use of better quality end-of-life care for the elderly noting that: “many older people and their carers have also found that palliative care services have not been available to them”. To date palliative care services have been concentrated on those with cancer; fewer than 2% of patients under the care of a hospice have a diagnosis of a neurological illness. The National Hospice Council Report “Reaching out: Specialist Palliative Care for Adults with Non-Malignant Diseases” concluded that palliative care services should be available on the basis of patient and family need, not diagnosis.

The Alzheimer’s Society carer network has identified care standards in terminal care as one of its top 10 research priorities and the society has released a position statement on this: *“The palliative care needs of people with dementia have received little attention to date. The Society believes that it is inappropriate for a person with advanced dementia to be given artificial hydration and nutrition for the sole purpose of prolonging life. Treatment should be given to maximise the quality of life and comfort of a person with dementia”.*

Debate about end of life care for patients with dementia is now being conducted in the press (see Alzheimer’s Society news letters, November and December 2003). In September 2003 the Radio 4 broadcaster John Humphrys wrote a humane and considered article for *The Times* newspaper describing the death of his father from dementia. *“…when he collapsed, he was taken into hospital and hovered on the brink of death. But he was treated as though he’d had an awful accident and everything had to be done to save him. You cannot tell a doctor to let your father die. Or so I thought. The drips and the care did their work and he recovered-after a fashion…As his wise consultant said, a generation ago he would have been allowed to die without enduring so much indignity and suffering. Increasingly we keep people alive because we can. We need to regain the sense that death is not something we should apologise for”.*

The article prompted a massive response; Humphrys said that never, in 45 years of journalism had he had such a reaction to his writing. The ensuing debate covered issues including euthanasia, advanced directives, living wills and the “double effect” (where morphine given as pain relief in the final stages of life also hastens death by causing depression of respiration). A consistent theme of the correspondence in *The Times* and the Alzheimer’s Society newsletter was that patients and carers should be able to make individual choices about the end of life care they receive whether this involves full medical intervention or euthanasia. It is important that we, as professionals, help patients and carers to understand that “palliative care” does not mean that all treatment is withdrawn. It is not an “easy option”; good palliative requires the skills of a multidisciplinary team, may be more expensive and time consuming than carrying on with “treatment as normal”, and ultimately gives people choices about how they wish to control their own “transition” from life to death.

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CURRENT KEY ISSUES

A randomised placebo-controlled trial in cognitive impairment in Parkinson’s disease

Leroi I. *et al*. (2004*)* A randomised placebo-controlled trial in cognitive impairment in Parkinson’s disease. *International Journal of Geriatric Psychiatry,* 19, pp.1-8**.**

The objective of the study was to evaluate the efficacy and safety of donepezil in patients with Parkinson’s disease who had cognitive impairment. A randomised double-blind placebo controlled study involved nine patients who took placebo and seven who received donepezil for an average of fifteen weeks. The primary outcome measures were from a detailed neuropsychological battery which included assessments of global cognitive status as well as memory, attention, psychomotor speed, visuo-spatial and executive function. Psychiatric symptoms and activities of daily living were secondary outcome measures. The emergence of motor signs and assessment of adverse effects were taken as indicators of safety.

Patients on active drug showed a specific and significant improvement on the memory subscale of the Dementia Rating Scale, and there was also a trend towards improvement of a measure of psychomotor speed and agitation. Adverse effects included the premature withdrawal of four patients on active medication, including two for peripheral cholinergic effects and one for Parkinsonian features. The conclusion was that donepezil has a beneficial effect on memory and may improve other cognitive problems in people with Parkinson's disease, but the tolerability suggests that careful monitoring is needed in this group of patients particularly as the dosage increases.

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Right hemisphere and cephalopathy in elderly subjects with schizophrenia : evidence from neuropsychological and brain imaging studies

Gabrovska Johnson V. *et al*. (2003*)* Right hemisphere and cephalopathy in elderly subjects with schizophrenia: evidence from neuropsychological and brain imaging studies: A randomised placebo-controlled trial in cognitive impairment in Parkinson's disease . *Psychopharmacology* 169 pp.367-375

It is known that cognitive impairment is a recognised feature of schizophrenia and that a proportion of elderly patients suffering from schizophrenia develop a dementia which is not of a recognised form such as Alzheimer's disease. It has been documented that progression of cognitive deficits occurs in older people in institutions, although there is some debate as to whether this occurs in people in the community. The exact pattern of the cognitive deficits in this group has not been clearly defined, although there is some evidence that it differs from that in Alzheimer's disease. The purpose of this study was to characterise the neuropsychological deficits in elderly patients with schizophrenia and to compare them with those in Alzheimer's disease and to establish, using MRI scans, the presence of any underlying structural brain abnormality.

Twenty-eight elderly patients with schizophrenia who had had an onset of illness before the age of forty-five were examined – twelve scored in the dementia range and were compared with sixteen equally impaired patients with early Alzheimer's disease. Thirteen of the patients with schizophrenia consented to a brain MRI scan, and the results were compared to those of thirty age-matched controls.

The main results were that the schizophrenia group was more impaired in visuo-spatial tasks than the Alzheimer's group but less impaired on verbal tasks, despite similar overall cognitive impairment. The MRI scans revealed right-sided enlargement of the ventral CSF spaces in the schizophrenia patients particularly in the posterior third, and this correlated with their impaired performance on visuo-spatial tasks. The overall conclusion was that right hemisphere impairment underlies the specific profile of cognitive impairment in elderly patients with schizophrenia.

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BOOK REVIEW

Handbook of Neuropsychology

Boller, F. and Cappa, S. (eds) (2001) *Handbook of Neuropsychology* 2nd Edition Volume 6 Aging and Dementia. Elsevier ISBN 0 444 50377 3 Pp 482

The sixth volume of the *Handbook of Neuropsychology* comprises a collection of papers detailing current research in experimental and clinical aspects of the neuropsychology of ageing and dementia written by leading researchers in the field predominantly from the USA, France and Italy.

Each paper, forming one chapter of the volume, contains clearly presented, detailed discussions of specific topics in ageing and dementia citing a wealth of recent international research in each area. The book opens with papers discussing cognitive and neurobiological changes in animals and the potential for advancement of research into human Alzheimer's Disease. The following chapters discuss the effects of normal ageing, Alzheimer's disease and related disorders on attention, language, spatial abilities, olfaction and motor function. In chapter four Balota & Faust examine the role of attention in Dementia of Alzheimer's type, arguing that impairment of attentional systems reaches beyond the traditional attentional paradigms playing an important role in deficits of language and memory. Chapter six gives an excellent account of current research into memory systems and subsystems in normal ageing, Alzheimer's Disease, Huntington's Disease and Parkinson's Disease.

The book contains a thorough discussion of dementia syndromes concentrating on epidemiology, neuropathology, neurochemistry and treatment strategies for the most prevalent forms of dementia with particular emphasis on Alzheimer's disease. In chapter 13 Pippenger & Cummings consider the efficacy of cholinesterase inhibitors, anti-oxidants, anti-inflammatory drugs and estrogen replacement therapy in the treatment of dementia. However, the use of non-pharmacological treatments such as Bright Light Therapy and psycho-social interventions are not discussed.

A detailed presentation of clinical features, therapy, neuropsychology, neuropathology, neurobiology and genetics of frontotemporal lobar degeneration and Lewy Body dementia is given in Chapter 14. This is followed by an examination of cognitive impairment in Parkinson's disease, Huntington's disease and HIV infection. Chapter 18 discusses brain imaging in normal ageing and dementia, this chapter considers structural and functional imaging with particular focus on cognitive activation and studies of neurotransmitter function. Chapter 19 addresses the debate regarding the influence of education level on the diagnosis and assessment of dementia, a review of the current literature fails to reach a firm conclusion. The final chapter considers the evaluation of severe dementia with an informative review of appropriate clinical rating scales for use with this population.

Whilst comprehensive and informative this book is not an introductory text as it requires the reader to have at least a basic understanding of the neuropsychology of memory and neurodegenerative diseases. The *Handbook of Neuropsychology* is intended as a reference for clinicians including neurologists, psychologists and psychiatrists, and researchers in the field, although a large proportion of the content of this volume appears tailored towards the latter.

Aging and Dementia is a valuable resource for clinicians and researchers, it is an excellent source of current research and debate in neuropsychology. A particular strength of this volume is the detailed account of the more often neglected forms of dementia seen in Parkinson's disease, Huntington's disease and HIV infection, frontotemporal lobar degeneration and Lewy Body dementia in addition to comprehensive discussion of the more common forms of dementia.

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WEBSITE REVIEW

Free journals on the web (1)

The following titles are available freely on the web (in full-text where indicated):

Geriatrics and Aging

The home page of the full electronic version of the journal *Geriatrics and Aging*, published by Ribosome Communications, Inc. Aimed at physicians involved in the treatment and care of elderly patients, the journal publishes articles which cover key issues and current trends in geriatric medicine and research. Current and back issues are available in full-text from this site and all articles are searchable by article, title, author, name, key words, departments, volume and number and publishing date.

http://www.geriatricsandaging.com/

ECT on-line

This resource is part of the 'Psychiatry On Line' series, and is written by Carl S. Littlejohns MB, ChB, MRCPsych. This site has a British bias and provides an introduction to the therapy as well as advice on ECT documentation, ECT papers published in the medical literature, ECT on the internet and repetitive transcranial magnetic stimulation. Most of the material on this site will be of interest to professionals concerned with ECT and alternative methods of treatment, however there are also online patient information leaflets covering ECT which will be of interest to a wider audience. This resource is published on the web by Priory Lodge Education, a UK-based publisher of Internet medical journals.

http://www.priory.co.uk/psych/ectol.htm

Psychiatry on-line

A peer reviewed online journal of psychiatry, appearing monthly. Contains articles, opinion, letter and reports. An archive of peer reviewed articles is being maintained. A page of links to psychiatry resources worldwide is available, although no description of the resources included is given. Published by Priory Lodge Education Ltd.

http://www.priory.co.uk/psych.htm

Table of contents and abstracts only

The International Journal of Geriatric Psychiatry publishes articles relating to ‘the causes and treatment and care of all forms of mental disorder which affect the elderly’, and includes topics such as epidemiology of mental disorders in old age, clinical aetiological studies, post-mortem pathological and neurochemical research, treatment trials, and evaluative studies of geriatric psychiatry services. The journal is aimed at psychiatrists, psychologists, neurobiological researchers, social scientists and other working in the therapeutic professions. The tables of contents and abstracts can be accessed online for free from 1996 onwards. The full-text of articles are also available from 1996 onwards to personal and institutional subscribers. The journal is made available on the web by Wiley InterScience.

http://www3.interscience.wiley.com

Clinical Geriatrics

Clinical Geriatrics is a peer-reviewed medical journal that focuses on both the clinical and practical issues related to the treatment and management of the older patient. The journal is committed to publishing details, up-to-date information for clinicians who diagnose and treat the elderly. It provides continuing medical education for its clinician readership. Clinical review articles prepared by experts in the field discuss a wide range of medical conditions. These discussions are designed to educate clinicians about the often significant clinical differences found in older patients, and to help them to diagnose accurately and treat them.

http://www.mmhc.com/cg/

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YOUR PROBLEM ANSWERED

"Dear Jane,
I am a practising old age psychiatrist trying to wrestle with the practicalities of the single point of access with referrals to social services. I would be very grateful for any information on the background to this policy and any practical help you can be in guiding me through the maelstrom of documentation in this field.
Alistair"

Two important changes relating to the way in which referrals for social care are processed were introduced in April 2003. It is important that colleagues in the NHS are aware of these. I will endeavour to briefly summarise the background to these, summarise their scope and note how these changed practice might impact on the work of old age psychiatrists. At the outset it is important to note that these changes apply irrespective of whether referrals for social care are made to colleagues working within a social services department or a care trust.

Fair Access to Care Services Guidance

For some time central government has been concerned to promote greater consistency in the way individual need for social care is assessed. Guidance has been issued which aims to ensure there is consistency in the way that every person's needs are assessed with fair and transparent procedures followed in every case. This process is based on the objective of promoting the maximum independence for service users and included greater standardisation of risk assessment and the requirement for the regular review of circumstances.

For old age psychiatrists this more standardised approach to the assessment of need for social care for vulnerable older people is likely to require:

- the provision of the same range of information for each person routinely referred for social care;
- the provision of more information to assist in the determination of eligibility for assistance.

In return, old age psychiatrists should in the process of time expect patients with similar needs and circumstances to receive similar care outcomes although not exactly the same range of services.

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