

Mental Health in Old Age Bulletin Issue 12

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

Contributors: Alistair Burns, Jane Byrne, Judith Dennis, Chris Hallewell, Cees Hertogh, and Kevin Hope

Layout by: Sue Martin

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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

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EDITORIAL

Reshaping mental health services for older people

Modernise! Innovate! Integrate! Wherever one looks in health and social care, there are injunctions to change, to move on, to develop a culture of "continuous improvement".

In reality most professionals are working very hard, doing as good a job as they can, and are tired of initiatives, targets and projects. The reflective and insightful among them know that the systems in which they work are too complex and bureaucratic and that the needs of patients and carers are often lost within this complexity. To reshape Mental Health Services effectively the voice of these reflective professionals and of users and carers needs to be heard. We have (sometimes) person-centred care: we need person-centred change.

Having said that, it is important to use central initiatives and directives. Most are sensible if adapted for local use and some bring money with them.

There are four steps to reshaping services. They interact and are iterative, not a simple sequence.

- 1. Find out what happens now.
- 2. Work out what should be happening.
- 3. Decide what can be achieved.
- 4. Make it happen.

These seem obvious, but if done properly allow real change to occur.

Number 1 means not how many beds or doctors or day hospital places, but what happens to patients and carers as they travel along the journey of their dementia, depression or other illness. Detailed maps of what has happened to real people take time to create, but lead to useful insights. These maps are reality based, so they are locally relevant. They are about what patients and carers need and want: for example, evidence based interventions and person-centred processes, not about what services offer. It is what you do, not where you do it or who does it, that determines effectiveness.

The second step is similarly challenging. This is where the prescription for service delivery in the NSF is useful, but does not replace the need to develop a local vision. But how to engage all players? The complexity and variety of needs and wants of our patients mean that the Old Age Psychiatry Service can only be effective within a working system of care. General Practice, Acute Trust, Mental Health Trust, Social Services, Voluntary Sector, Nursing Home and Residential Sector are all responding to different pressures and have widely varying cultures. All need to be involved and their developments co-ordinated if Mental Health Services are to be effectively reshaped.

The third factor introduces pragmatism. How much money? What disinvestment is possible? What are local managerial and clinical capacities? What are the local

priorities? Who is there to work with? Who will be responsible for the different parts of treatment and care and how will they be co-ordinated?

The fourth factor can be seen as a grand process of strategy implementation and indeed there may be complex estate schemes to organise. As important, though, is identifying small improvements in keeping with the devised plan. Each vacancy needs to be seen as an opportunity, do we need a direct replacement for that post, or would the money be better spent on something else? Achieving the competencies, including attitudes that staff in all sectors need to deliver the personalised treatment and care plans of a modern Old Age Psychiatry Service, is the biggest single task in reshaping services. You can devise the most NSF-compliant service model but if the skills to deliver it are not there the result will be failure and demoralisation. Similarly, you can write the world's best protocols with Primary Care or whoever, but producing a glossy protocol is not implementation.

So reshaping Mental Health Services is complex and difficult. It needs vision, leadership, time, persistence and then endlessly more of these same qualities. It can only be successful if these qualities are shared by a team of empowered individuals.

So what's stopping us?

Chris Hallawell Consultant in Old Age Psychiatry Penrith Hospital

ARTICLE

Advanced interdisciplinary education in dementia

September 2003 saw the first cohort of students entering on to a postgraduate programme in dementia care at the University of Manchester and in so doing realised a strategic vision which had been set in process some four years previously. At that time the Regional Health Authority had responded to calls from practitioners and managers for a response to the relative educational under-investment in the dementia care workforce by inviting tenders to provide a multidisciplinary postgraduate programme.

Working in collaboration with the Bradford Dementia Group at Bradford University and the University of Northumbria, Manchester was successful in being awarded a contract by the Workforce Development Confederations that assumed workforce planning role from the disbanded Regional Health Authority.

The programme was developed against a backdrop of significant demographic trends and changes in funding, provision and organisation of care for people with dementia. These changes suggested an increased need for multidisciplinary and multi-agency services that need to be accessible, flexible and inclusive and driven by the needs of the clients and carers. The programme is designed to provide high quality practice based education required by those who are involved in the development and delivery of such services. It aims to equip them with advanced knowledge and skills to promote the well-being and personhood of people with

dementia and their carers and promote the dissemination of evidence-based practice as well as contribute to developments in service provision.

Three exit points are available, namely PG Certificate, PG Diploma and MSc. The course, being supported by the NHS has a number of funded places covering course and tuition fees to postgraduate diploma level for NHS staff working in the North West of England. There may also be funding available for staff working in non-NHS organisations and social care within the region. Twenty one staff registered for the first year of the programme and comprised of nurses, occupational therapists and social workers working across primary and secondary care.

There have been a number of exciting developments in course development designed to address the practice based focus of the course. Supervision arrangements have progressed around a model identified at a regional event in April 2003. Senior clinical colleagues have been recruited to act as practice supervisors within the University setting working with smaller, focused groups of students engaged in skills acquisition. A student portfolio of practice based outcomes has been developed which has proven to be a highly influential and welcome factor in the course with exposure to a peer review mechanism proving both challenging and validating.

It is recognised that support in the practice setting is a necessary component of the programme. Indeed it is essential if application of learnt concepts is to be meaningful and make a difference not only to individual practitioners but at an organisational level. To this end, students and employing organisations have been invited to collaboratively identify an 'Implementation Mentor' to support each student. This person works in the same organisation as the student, has organisational authority within that organisation but is not necessarily the line manager of the student. Their specific role includes conducting regular meetings to facilitate ongoing practice teaching and experience in order to ensure students have opportunities to develop appropriate practice skills. In line with the practice development ethos of the programme mentors play a significant part in helping the student to think about how to align the theoretical concepts being learnt and the practice skills being developed with their own organisational strategy. Mentors have responded by questionnaire about the perceived impact of the course on participants with responses referring to increased confidence, enthusiasm, and conviction and networking in general. Notably, the development of transferable skills and the application of evidence based practice were cited.

Protected time has been secured from a number of clinical colleagues both in terms of practice supervision and in the ongoing development and implementation of the curriculum. This is a welcome and important contribution to the programme. We are looking to further strengthen and broaden relationships with clinical and research environments with forthcoming research seminars in collaboration with the Research and Education Department at South Manchester being an example.

At the end of the first year much satisfaction can be gained from the performance of students particularly in terms of practice development. However, significant challenges lay ahead not least those of capacity building and recruitment. In as much, the programme needs to be promoted to those at an executive level across

health and social care as a viable option for movement towards the strategic imperatives outlined in the NSF for Older People and the NHS Plan. Emphasizing the importance of longer term investment in the workforce becomes a futile activity in the absence of any evidence of impact. It is gratifying then that, for the dementia programme this evidence is beginning to emerge early in the process.

The other arm of the equation is identifying those individuals who can best utilise the opportunities available and make a contribution to dementia care environments. In this respect, significant activity is taking place across the region in promoting access to the programme within the context of personal development plans. A potentially limiting factor though, is the end product of many years relative under investment in the dementia care workforce and a perceived lack of preparedness to study at postgraduate level. As a consequence consideration has been given to widening the entry gate for admission to the programme. Apart from the traditional criteria there is an option which asks potential recruits for other evidence of previous study assessed on the basis of equivalence to good honours degree knowledge and skills. The framework for higher education qualifications in England, Wales and Northern Ireland published by the Quality Assurance Agency for Higher Education (2000) (www.gaa.ac.uk) provides a range of descriptors. These allow an opportunity for staff working in dementia care environments to make the case for admission to the programme located around evidence of broader outcomes particularly in practice. In this respect the goal of enhancing accessibility to the course yet maintaining high academic standards is achieved.

There is then much to be proud of in terms of dementia care and Manchester's contribution. The next generation of workers will have at their helm increasingly knowledgeable and skilled practitioners who will act as pioneers. The challenge is to facilitate developmental pathways for future leaders that take into account the broad spectrum of care provision and care providers. The fact that we have secured on element of this in Manchester is an exciting and not inconsiderable achievement that needs to be proclaimed loudly and proudly.

Kevin Hope

Programme Director, MSc in Dementia Care University of Manchester email: kevin.hope@manchester.ac.uk

CURRENT KEY ISSUES

Intracranial volume in mild cognitive impairment, Alzheimer's disease and vascular dementia: evidence for brain reserve?

Wolf, H. *et al.* (2004) Intracranial volume in mild cognitive impairment, Alzheimer's disease and vascular dementia: evidence for brain reserve? *Int J Geriatr Psychiatry*. Oct;19(10):995-1107.

The objective of the study was to examine the reserve effects of brain volume in geriatric outpatients with mild cognitive impairment, Alzheimer's disease and vascular dementia. Analysis of the total intracranial volume (ICV) served as an estimate of the maximum attained brain volume in life. One hundred and eighty one

subjects with a mean age of 60 who were consecutive referrals to a geriatric outpatient department (n = 96) and the age-matched healthy controls (n = 85). T1-weighted MRI scans were assessed using a stereological method to measure ICV and brain volume, and hippocampal atrophy was assessed using a visual rating scale. ICV was significantly smaller in patients with Alzheimer's disease and vascular dementia than in controls, but the effect size was small. After adjusting for age and gender, having an ICV in the smallest quartile significantly increased the risk of cognitive impairment (either mild cognitive impairment or dementia). In patients with dementia, but not in MCI, severity of cognitive impairment and ICV were moderately correlated. The effect of ICV and cognition was not related to hippocampal atrophy. The findings are compatible with the volume reserve effects that modify the clinical expression of symptoms in both Alzheimer's disease and vascular dementia and may have implications for the design of neuroimaging studies that use ICV for normalization procedures.

An open trial of venlafaxine for the treatment of late-life atypical depression.

Roose, S.P. et al. (2004) An open trial of venlafaxine for the treatment of late-life atypical depression. Int J Geriatr Psychiatry. Oct;19(10): 989.

The objectives of the study was to assess treatment in the atypical subtype of older patients with major depressive disorder, which is characterised by mood reactivity, significant weight gain or increase in appetite, hypersomnia, leaden paralysis, and a long-standing pattern of interpersonal rejection sensitivity. The study reports the characteristics of patients and treatment results of an eight-week open-label trial of venlafaxine in a sample of older depressed patients these symptoms. Patients received fixed dose of up to 300mg a day of venlafaxine for eight weeks. Seventeen patients were examined, the mean age of whom was 65.6 years, and three- quarters were female. Fifty-three per cent of patients presented with late-onset atypical depression after the age of 50. Fifteen of the 17 patients completed the eight-week treatment trial. The mean score on the Hamilton Rating Scale for Depression (24item version) decreased from 22.2 to 11.8, and the mean total for the atypical items decreased from 6.2 to 2.8, both results being highly statistically significant. Remission was defined as a final Hamilton score of less than or equal to 10, and a 50% reduction in baseline Hamilton score and on an intention to treat basis, the remission rate was 65%, 73% in the completers.

The conclusions of the study were that in this sample of late-life patients with atypical depression, venlafaxine was reasonably effective and well tolerated. However, the effectiveness had to be considered in the light of the fact that it was an open trial of antidepressant medication, and questions remain about the similarity of these symptoms in older people as compared to younger people.

Potential treatment effects of donepezil not detected in Alzheimer's disease clinical trials: a physician survey

Rockwood, K., Black, S.E. Robillard, A., Lussier, I. (2004) Potential treatment effects of donepezil not detected in Alzheimer's disease clinical trials: a physician survey. *Int J Geriatr Psychiatry*. Oct;19(10):954-960.

The objectives of the study were to identify and categorise clinically recognisable positive effects of donepezil in the treatment of Alzheimer's disease on the basis that standard psychometric tools are used in clinical trials and these trials sometimes do not capture clinically demonstrable effects. A list of potential effects was developed using a clinical trials database and the experience of an expert panel, and these were incorporated into a questionnaire which, after being tested on a focus group, were used in a postal survey of physicians. Data were classified into various domains and reviewed by a second panel. Items that were most rated as being improved were related to frontal systems function, including attentional capacity and initiative. Behavioral symptoms which were among the highest rated items were apathy, mood, and agitation, and the top two other items were social interactions and involvement in domestic activities. Of the top ten symptomatic treatment effects, only four appeared to be readily identified by current standard measures. The conclusions of the study were that physicians recognize several treatment outcomes as important, but these are not well captured by current standard measures. New methods to capture such effects are important.

Alistair Burns

Professor of Old Age Psychiatry Wythenshawe Hospital MANCHESTER email: a.burns@manchester.ac.uk

BOOK REVIEW

Dependence and autonomy in old age. An ethical framework for long-term care

George J. Agich. *Dependence and autonomy in old age. An ethical framework for long-term care.* Cambridge (UK): Cambridge University Press, 2003. 207 pages. ISBN 0-521009200

Dependence and autonomy in old age (2003) is the only slightly revised re-edition of the author's earlier study Autonomy and long-term care published in 1993. The fact that this work needed no thorough reworking already demonstrates its durable actuality.

The author's aim is rather ambitious: he wants to develop an ethical framework for long term care inspired on the value of autonomy. Seemingly this is an almost impossible endeavour, since the standard concept of autonomy in bioethics stresses the values of independence, negative freedom, non-interference and rational free choice and thus can only paradoxically be connected with the practice and ethics of long term care. But it is a very valuable endeavour, not only with regard to the recipients of long term care – that is: the dependent elderly – but also to their

caregivers. The general predominance of autonomy in mainstream medical ethics has resulted in a situation in which the appeal to this principle virtually trumps all other moral concerns. Thus autonomy has become more an obsession than a moral principle, leaving caregivers in long term care with the permanent feeling that - although they are doing their best – they are still not doing the right thing in terms of ethics and moral responsibility. For instance: they are in a way constantly violating the principle of non-interference so highly esteemed in current medical ethics.

Agich sets out to develop a practical alternative to this dominant liberal view of autonomy. In doing so he wants to conserve what is valuable in the liberal view and upholds that it is possible to criticize this concept without throwing out the baby with the bath water. Valuable in the liberal concept are the right to information, privacy, freedom of choice and the right of elders to live up to their own vision of the good life. In ethical terms these are rights to be left alone, and this is also where the perils of liberal theory come in, because such rights can work out in - what has been termed by Applebaum in a psychiatric context - a "right to rot." According to Agich the deficiencies of the liberal view of autonomy have to do with the fact that it is based on an extrapolation of political concepts that are valuable in the public realm where people interact as equal citizens beyond its proper domain to the ethical realm and to (care) relationships characterized by asymmetry, vulnerability and dependency. Secondly this concept is deficient because of the abstract and unrealistic view of persons as independent and self-sufficient centres of decision-making that it supports. Autonomy can only be a significant concept for thinking about the ethics of long term care if it is grounded in the concrete social world of every day life. Therefore a phenomenological approach is needed, whereas Agich's study also draws on ethnographic studies of long term practices. He points to the specific interdependency of human life and places autonomy in a developmental perspective. This perspective is not restricted to childhood development, socialisation and education, but is characteristic of human life as a whole. People, through their interdependent, social and historical nature, are constantly developing themselves, not in the sense of a process directed toward some abstract ideal or end state, but as an integrative process of accommodating oneself to new circumstances and adapting those circumstances to one's unique structure of meaning. This process of identification with changing circumstances forms the basis of actual autonomy: "to be autonomous is to be a particular agent individualizing one self in particular circumstances through effortful striving in the shared social world." Such striving is also evident in the chronically ill and dependent elderly, even in people with dementia: they too are involved in interpretative efforts to make sense of their fractured world and to hold on to a sense of self and identity. Caregivers can do much to support their feelings of dignity and enhance their identity and autonomy through respectful communication, through assisting and facilitating them in telling the stories of their life and through developing a caregiving relationship in which care is not simply taken over, but also returned. Agich specifically calls attention to how several mundane features of the long term care setting, related to time, space, communication and affectivity in the caring relation can be adopted meaningfully to foster the autonomy of the dependent elder despite the onslaught of impairment. Thus, this very thoughtful and stimulating book helps to rethink the everyday ethics of long term care. It offers no normative solution to ethical conflicts, nor does it provide the reader with any prescriptive advice, but these are not the objectives of the author: he is confident that they who do the actual care work are better equipped

to devise solutions to problems and improve the quality of care than someone trained in bioethics and philosophy. Nonetheless his book offers a moral vocabulary that has the potential to counterbalance the dominant but unilateral approach of right based ethics.

Cees Hertogh

Vivium Naaderheem email: c.hertogh.vivium.n1

WEBSITE REVIEW

Sexuality and Dementia

"There are three main issues surrounding sexuality and dementia, namely change in sexual interest, altered sexual behaviours and sexual dysfunction. These can result in misery for patients and carers. Professionals of all disciplines need to be alert to these problems and offer support and help when necessary." Warner, J. (2000) Sexuality and dementia. In: O'Brien, J., Ames, D. & Burns, A. (eds) Dementia 2nd ed. London: Arnold, p.271.

A Medline search using terms 'Dementia' AND 'Sexuality' returned a mere 7 hits for an unrestricted time span. While this might indicate a lack of scholarly research into the topic there is nevertheless widespread awareness of the sexual needs of dementia patients; numerous books on dementia contain some reference to it and many have a chapter devoted to the subject.

Here we present an overview of material available on the Web.

A rare resource aimed particularly at the medical community on this topic is on the site of the American Psychological Association. They support an 'Office on Aging' which is described as 'a coordination point for APA activities pertaining to aging' and serves as an information and referral source on ageing issues. They published a useful Aging and Human Sexuality Resource Guide, available www.apa.org/pi/aging/sexuality.html. Although this was compiled in 1999, there may be some helpful items for anyone investigating the subject. In particular there are two articles about the sexuality of dementia sufferers. The resource guide lists books and book chapters as well as videos on the topic and organisations which are concerned with the subject. It gives a link to the website of the Society for the Scientific Study of Sexuality www.ssc.wisc.edu/ssss.

Alzheimer's Australia NSW produced an annotated resource list on intimacy and sexuality issues in dementia in 2002. This includes a section specifically for health professionals dealing with dementia patients. This may be found at http://www.alzheimers.org.au/upload/rl_Intimacy%20and%20sexuality%20issues%20in%20dementia.pdf.

For those with an interest in the residential care setting there are two articles available as pdf files for downloading from the web. One examines the types and prevalence of sexual expression by people with dementia in residential care and staff's responses to such expression. It was written by Carole Archibald (whose PhD

on the sexuality of dementia patients was completed in 2002) and published in Health and Social Care in the Community in 1998 and is obtainable from: http://www.blackwell-synergy.com/links/doi/10.1046/j.1365-2524.1998.00104.x/pdf.

There is also a 25 page document (source not stated) probably originating from a group of residential homes in Canada entitled Intimacy, sexuality and sexual behaviour in dementia: how to develop practice guidelines and policy for long term care facilities. This may be interesting in itself but additionally has a useful set of references at the end. You can download this from http://www.fhs.mcmaster.ca/mcah/cgec/toolkit.pdf.

The Alzheimer's Society's general Reading List for Dementia Care Workers refers to two books and a video on the subject. They are to be found on pp. 23-24 at http://www.blackwell-synergy.com/links/doi/10.1046/j.1365-2524.1998.00104.x/pdf.

At the popular level, the following overseas publications may be of interest to spouses of people with dementia.

Alzheimer's New Zealand have produced a factsheet giving help and advice for partners of people with dementia. This is located at http://www.alzheimers.org.nz/fact14.html.

The USA based Family Caregiver Alliance makes available its factsheet on Coping with Changes in your Intimate Relationship as a printable version on http://www.blackwell-synergy.com/links/doi/10.1046/j.1365-2524.1998.00104.x/pdf.

Of interest also may be the day course for carers called A Person-centred Approach to People with Dementia in Caring Environments which covers issues of sexuality. This is run by the Dementia Services Development Centre at the University of Stirling. For further information contact them at http://www.dementia.stir.ac.uk.

Judith Dennis

Library and Information Officer North West Dementia Centre / PSSRU email: judith.dennis@manchester.ac.uk