

Service user and carer participation in old age psychiatry

Susan Mary Benbow

A thesis submitted in partial fulfilment of the requirements of
Staffordshire University for the award of the degree of Doctor of
Philosophy Based upon Published Work.

August 2010

Contents

	Page
List of Tables	3
List of Figures	4
Abstract	5
Introduction	6
Aims	6
Objectives	6
The policy context	6
The personal and service context	16
The research programme	19
Involving users and carers as recipients of services/ care	24
Power	32
Involving users and carers as subjects of consultation	36
Between users or carers and professionals	37
In service management	40
In service planning	41
Involving users and carers as agents of control	51
In service planning	51
In developing and delivering education	52
Narrative means to therapeutic (and learning) ends	59
Learning about learning	61
Discussion	63
Conclusions	82
References	84
Appendix of publications	109

List of Tables

Table	Page
1. Potential benefits of user involvement and public involvement, modified from Coulter (nd)	15
2. A matrix of user and carer involvement modified from Tait & Lester (2005) and Peck et al. (2002)	23
3. Potential benefits and drawbacks of copying letters to users and/ or their carers	27
4. Examples of some aspects of two opposing models of working with users and carers in social care (from SCIE, 2004)	33
5. Themes identified in Consumer Group and ensuing actions, taken from Ong, Benbow, Black et al (2007) and Benbow, Ong, Black et al, (2009)	43
6. Practical outcomes across the matrix of user and carer involvement	48
7. The positive and negative effects of users and carers as teachers (modified from Wykurz & Kelly, 2002 with major modifications in bold: points taken from Benbow & Boyce (2008) in bold/italics)	54
8. Shier's model with our modifications to make it applicable to an adult context (from Shier, 2001 and Shier, 2006)	70
9. A modified matrix of user and carer involvement (with examples).	74
10. Benefits of user and carer participation in aspects of old age psychiatry divided into the categories identified in Hickey & Kipping (1998).	76
11. Constraints on/ drawbacks of user and carer participation in old age psychiatry divided into the categories identified in Hickey and Kipping (1998)	78
12. Examples of research questions	80

List of Figures

Figure	Page
1. Arnstein's ladder of citizen participation modified from Hostick (1998)	11
2. A representation of the recursive relationship between research and practice	22
3. Participation continuum (modified from Hickey & Kipping, 1998)	64
4. User and carer involvement modified from Glasby (2007)	66
5. Conceptual framework for participation from Restall & Strutt (2008)	68
6. Treseder's model applied to users and carers in healthcare from Fajerman & Treseder (1997)	71

Abstract

This thesis describes thirteen published works which constitute an evolving programme of research into service user and carer participation in old age psychiatry. They share the common objective of extending knowledge and understanding of methodologies, benefits and challenges of service user and carer participation in old age psychiatry services.

The publications contribute to knowledge in three areas. The copying of letters to users and carers, and requests for their feedback on the practice, was described as part of routine practice in old age psychiatry: this research addresses the area of 'users and carers as recipients of communication'. 'Users and carers as subjects of consultation' is addressed by several publications: an evaluation of users' experience of electro-convulsive therapy and later development of a method of integrating feedback from users into practice; a similar method was applied regionally in service improvement in order to access users' and carers' views and use them to identify areas for improvement work, and nationally by a professional organisation to inform and develop its work programme. The third area of contribution is that of 'users and carers as agents in control' and this is addressed in an initiative in higher education where users and carers were agents of control in designing, delivering and evaluating an MSc module on user and carer experience.

The contribution of the publications is related to four overall objectives: ways in which users and carers participate in old age psychiatry services; the benefits and drawbacks of user and carer participation in old age psychiatry services; ways of conceptualising user and carer participation in old age psychiatry; and finally, potential areas for future research in user and carer participation in old age psychiatry.

Introduction

Aims

To investigate user and carer participation in old age psychiatry.

Objectives

1. to consider ways in which users and carers participate in old age psychiatry services.
2. to consider the benefits and drawbacks of user and carer participation in old age psychiatry services.
3. to consider ways of conceptualising user and carer participation in old age psychiatry.
4. to consider potential areas for future research into user and carer participation in old age psychiatry.

The policy context

To understand how service users and carers currently participate in old age psychiatry it is useful to consider the historical and political context.

Before the National Health Service, healthcare in England consisted of a combination of private and public services. Private services included the voluntary hospitals which traditionally provided free care and had developed largely from charitable foundations. Public services were run by local government and had

grown out of the Poor Law system. Care was generally fragmented with limited access and wide variations geographically. The National Insurance Act (1911) predated the NHS and introduced sickness benefits funded by contributions from government, employers and employees, but this did not solve the systemic problems. Honigsbaum (1990) stresses the important role of the friendly societies which were formed by working men from the nineteenth century onwards and which provided sickness benefits to members, generally offering a capitation fee to the doctors involved. He argues that the medical profession, in supporting the creation of the NHS, chose state control in preference to control by the societies but this illustrates the inherent difficulty of the conflict between state and health service user and the core issue of user participation in health care. (For an account of the evolution of healthcare in Britain see Baggott, 2004).

The creation of the NHS by the National Health Service Act (1946) introduced the principle of healthcare for all, based on need, free at the point of delivery to England and Wales. Honigsbaum (1990) notes that no organised group spoke on behalf of patients in the lead up to the NHS but that the interests of doctors and patients coincided. Aneurin Bevan sent a message to the medical profession in the British Medical Journal (Bevan, 1948) and referred to freeing the 'doctor-patient relationship' from the money factor: participation here referred to the participation of doctors. He also writes that his job (as Minister of Health) is to provide resources and then:

“to leave you alone as professional men and women to use your skill and judgement without hindrance.” (Bevan, 1948)

This asserts the centrality of the relationship between healthcare professional and user, but is unlikely to be an acceptable model for politicians or public in the twenty-first century. Benign, and hopefully, well-intentioned paternalism (Coulter,

1999) continued to be the approach in the health service for several decades.

Ham & Alberti (2002) describe the NHS as established on the basis of an implicit compact between the government (which determined the NHS budget and guaranteed care for all), the medical profession (with responsibility for care standards and delivery) and the public (paying taxes to fund healthcare).

In 1991 the Patients Charter was introduced and later revised in 1995. It set out some fundamental rights for service users. It states that it is helping the NHS to 'listen to and act on people's views and needs'. Much of it remains aspirational today eg the statement that:

*"You can **expect** the NHS to respect your privacy, dignity and religious and cultural beliefs at all times and in all places."* (Department of Health, 1999a)

would fit with the current emphasis on dignity in care (Cass, Robbins & Richardson, 2006; Centre for Public Scrutiny, 2009).

The NHS Plan (Department of Health, 2000) was promoted as shifting the balance of power in health services towards the service user:

"For the first time patients will have a real say in the NHS. They will have new powers and more influence over the way the NHS works ...".

(Department of Health, 2000, p. 12)

The Plan aimed to increase the involvement of service users and the public in all aspects of health care. Some specific actions were set out, including: letters about an individual patient's care will be copied to the patient; patient advocates and advisers will be set up in every hospital; patients' surveys and forums will help services become more patient-centred. It grew from previous work which had highlighted three partnership areas: with patients and carers in connection with their own care; with patients and carers more generally in health and social care;

and with the public as citizens who have a stake in health and social care (Department of Health, 1999b), and followed the publication of a National Carers' Strategy (Department of Health, 1999c).

Since the NHS Plan, the rhetoric of health and social care policy documents has continued to stress greater choice, greater influence in services at all levels and more individualised care for users of services (Department of Health, 2005a; Department of Health, 2005b), along with stronger public involvement (Department of Health 2002a; Department of Health, 2006a) and increasing recognition of the important role of carers (HM Government, 2008). The language used is interesting in that it concentrates on giving people more choice, putting people 'in control', services being 'patient-led' and emphasising partnership and collaboration with patients, carers and members of the public (Department of Health, 2006b).

Terminology is, however, inconsistent. The House of Commons Health Committee (2007) used the term 'patient and public involvement' (but then described the term as a 'nebulous and ill-defined concept'). For clarity, this document will use the following terms:

- service user or user for people who are or have been patients or clients or consumers of health or social care or are using/ have used services (there is debate about the preferred term (Simmons et al, 2010; Salmon, 2010);
- carer for the family members/ family carers/ friends or neighbours supporting users; and
- participation to describe the involvement of users and carers in services in various ways – this is taken from Arnstein's ladder of citizen participation (described in Hostick, 1998: see Figure 1) and is a form of what can be

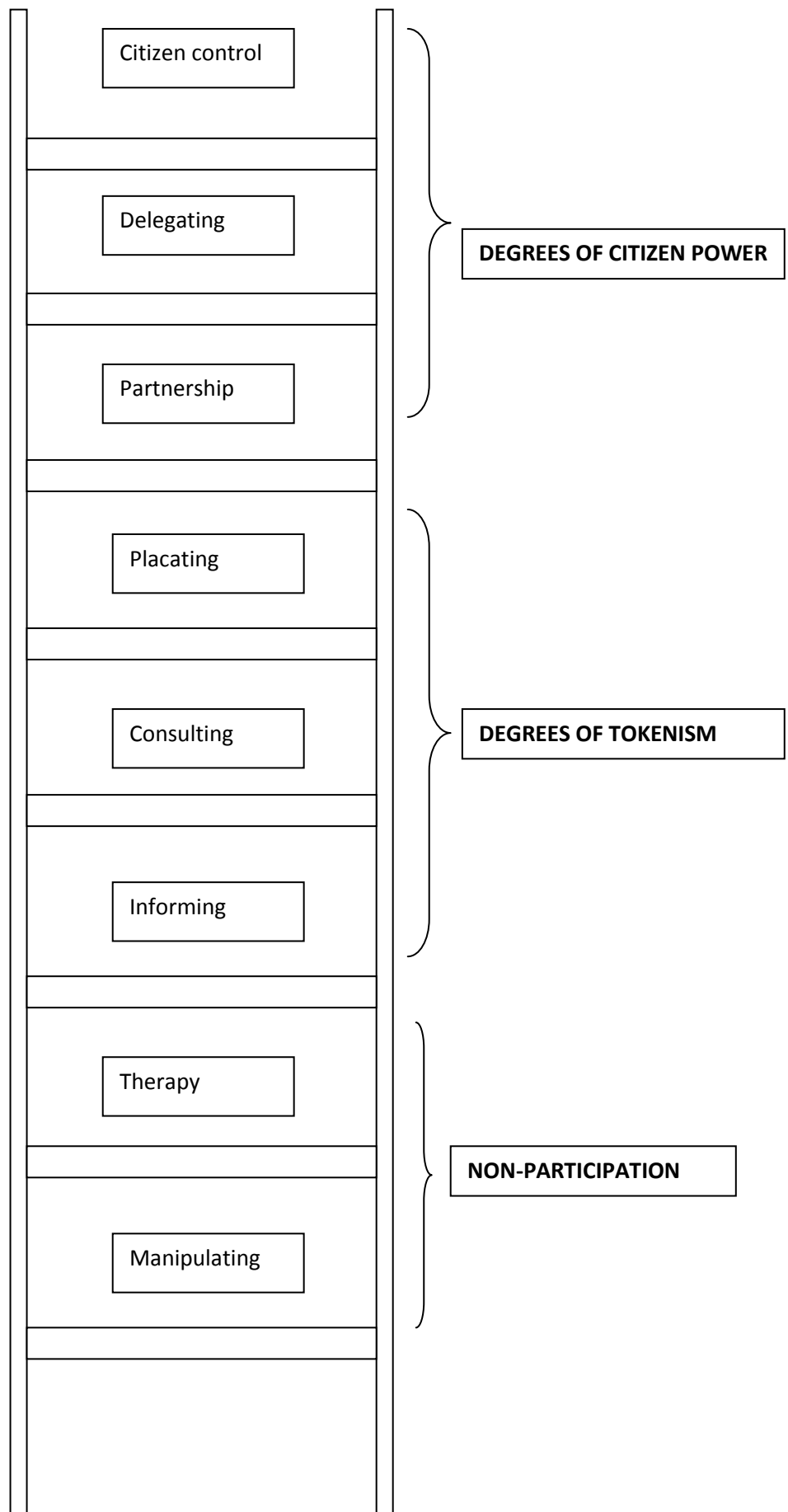
described as public participation¹ (National Council for Voluntary Organisations, 2009).

Despite the good intentions repeatedly expressed in policy documents, structures have been unstable. From the inception of the NHS, lay representatives brought a voice to hospital authorities and boards. Community Health Councils (CHCs), established in 1974 in England and Wales, introduced a framework for patient and public involvement. The CHCs had a representative role but also monitored local health services, helped with complaints and informed people about services. Their abolition was heralded by the NHS Plan and in 2002 Patient Advice and Liaison Services (PALS) were established in England in all Primary Care Trusts and NHS Trusts. (Department of Health, 2002b).

“PALS will provide a focal point to enable the organisation to learn from patients’ experiences of using services. The PALS will provide feedback on common themes and concerns which patients, their carers and families bring to (their) attention and be a catalyst for improvements and change.” (Department of Health, 2002b, p. 7)

¹ Public participation involves organisational engagement, and contrasts with individual participation (one’s everyday choices) and social participation (collective activities).

Figure 1: Arnstein's ladder of citizen participation modified from Hostick (1998)



They were followed in 2003 by the establishment of the Commission for Patient and Public Involvement in Health (CPPIH), the Independent Complaints Advocacy Service (ICAS) and Patient and Public Involvement (PPI) Forums: the latter were then replaced by Local Involvement Networks (LiNs) in 2007 alongside the abolition of the CPPIH (for a summary of milestones in PPI see Andersson, Titterton and Wilson, nd): LiNs were billed as creating:

“a strengthened system of user involvement and will promote public accountability in health and social care ...” and ‘a new duty (will be) placed on commissioners to respond to what patients and the public have said.’

(Department of Health, 2006c, p. 7)

The talk of partnership continues: in 2009 The Department of Health published the NHS Constitution which stresses partnership, and sets out rights and responsibilities for patients and for staff, stating that it aims to:

“bind together the communities and people it serves – patients and public – and the staff who work for it.” (Department of Health, 2009a, p. 2)

Ham & Alberti (2002) argued that the implicit compact between government, healthcare professions and public has been undermined and broken down in response to changes over recent years and that a new one needed to be agreed. They saw trust and good communication between all parties as fundamental to this process. The participation of users and carers in health and social care therefore carries far-reaching implications.

With regard to older people’s mental health (OPMH) the National Service Framework for Older People (Department of Health, 2001) emphasised person-centred care (Standard 2) and the issue of choice, and the National Service Framework Mental Health (Department of Health, 1999d) included a Standard on

carer support. This was taken further in Everybody's Business (Department of Health/ Care Services Improvement Partnership, 2005) which described involvement of users and carers in services as 'central to quality improvement' and argued that it should be embedded in the way staff and organisations operate. The National Dementia Strategy (Department of Health, 2009b) identifies 'engaging with public and patients' as one of the World Class Commissioning competencies which fits with many of the Strategy's objectives, describing people with dementia and their carers as being fully engaged in the design and delivery of services. The competency requires commissioners to:

“proactively seek and build continuous and meaningful engagement with the public and patients, to shape services and improve health ...”.

(Department of Health, 2007, p. 4)

Thus it is clear that user and carer participation is regarded as a policy imperative, and a range of policy documents state that this participation carries a number of benefits, including the following:

Shaping services

Improving health outcomes

Ensuring quality

Coulter (nd) distinguishes between the potential benefits of user involvement and public involvement (Table 1). A number of documents also reinforce an assumption that, as stakeholders in services, users and carers have a right to influence how those services are provided. Putting People First (HM Government, 2007) states that:

“real change will only be achieved through the participation of users and carers at every stage.” (HM Government, 2007, p. 1)

Given the clarity of policy on the issue, it is interesting that user and carer participation is not embedded within the health and social care systems. Soffe, Read & Frude (2004) surveyed the attitudes of clinical psychologists (in adult mental health services) to user involvement and noted a discrepancy between policy and practice, suggesting that ways of understanding this include the assumption that 'staff know best' and also that:

“staffs’ (sic) sense of disempowerment within the system (may render) them unable to hear users’ voices until their own voices (are) heard ...”. (Soffe, Read & Frude, 2004, p. 591).

They also note that user involvement may be threatening to staff, may impact on professional autonomy, and could potentially reduce the future role for staff groups in mental health services. Similarly Lakeman (2008) lists a number of practical issues relevant to carer involvement.

**Table 1: Potential benefits of user involvement and public involvement,
modified from Coulter (nd)**

User involvement	Public involvement
To ensure appropriate treatment, management and care	To improve service design and delivery
To improve health outcomes	To determine commissioning priorities
To reduce risk factors, prevent ill-health and promote health	To manage demand
To improve safety	To meet expectations
To reduce complaints and litigation	To strengthen accountability

The House of Commons Health Committee (2007) cautioned that:

“Structures and procedures ... will have little effect if the health service is not prepared to listen and make changes as a result of what they learn.”

(House of Commons Health Committee, 2007, p. 5)

If learning from, and working with, service users and carers are seen solely as policy drivers, it is unlikely that user and carer participation will become embedded in future health and social care practice. Rose et al (2002) articulate this bluntly:

“There is a danger that government demands for agencies to demonstrate user involvement may mean that user activities become a formal procedure to be ticked off, rather than an embedded and powerful organisational practice.” (Rose et al, 2002, p. 16-17)

Cynics might wonder whether government emphasis on user and carer involvement is just a means of shifting blame and the onus for change away from health structures and onto the users of services or merely a populist ploy.

The personal and service context

Campbell (1996) dates the upsurge in the user movement to the mid 1980s and cites the pace of change in mental health services as creating uncertainties and hence opportunities for new ideas, alongside the growth in self-help, the anti-psychiatry movement and the influence of user movements in other countries.

Crossley (1999) cites similar factors in its development, dating the birth to the early 1970s, and registering the strong involvement of non-users in the initiation of the movement, perhaps related to their position of power. Campbell (1996) notes the need to increase participation amongst groups which experience multiple exclusions, referring specifically to black and minority ethnic groups (but older

adults may be equally or even more invisible and excluded). Wallcraft, Read & Sweeney (2003) surveyed the service user movement in the early 21st century and found that the user movement did not represent or include all mental health service users. In its questions relating to equality, their questionnaire omitted issues relating to older age, asking only about minority ethnic groups, women's issues, and lesbian, gay and bisexual issues. Although one responding organisation referred to older people as a community of interest, overall older adults were conspicuous by their absence from the user movement.

Old age psychiatry (also called geriatric psychiatry, psychogeriatrics, psychiatry of the elderly, and older people's mental health) is a relatively young speciality which concerns mental health services across the range of mental health problems in later life. It has developed over the past 40 years, with specialty status being achieved in 1989 (Pitt et al, 2006). Thus the specialty has been developing over the period when the user movement has itself been developing. Our chapter in the 4th Edition of Principles & Practice of Geriatric Medicine (Benbow & Jolley, 2006) describes how services are organised and provided, and stresses that we should aim for services which we ourselves would be happy to use. Users of old age psychiatry services may be disadvantaged by several factors including: co-morbid physical illness, sensory impairments, multiple medication use, frailty associated with advanced age, social circumstances, co-morbid cognitive impairment along with other mental illness, limited finances, and the assumptions people make about advanced age and cognitive impairment. These factors are relevant to the relative absence of older users within the user movement. Carers are more visible and carer support was described in our chapter as 'a fundamental component of all aspects of service provision' (Benbow & Jolley, 2006). Ageism continues to be an issue, now unfortunately being used to argue that specialist services are

inherently ageist, an argument which obscures the ageism involved in denying the specialist needs of older adults (Benbow, 2005; Benbow, 2006).

Families are active in the care of many older people with mental health problems: One of our early papers on this topic, to which all the members of the family clinic team contributed (Benbow et al, 1990), argued the importance of the family and family approaches in causation, maintenance, assessment and treatment of mental health problems in later life. The role of the family in the care of children is clear, but for older adults the case has had to be made (perhaps another example of ageist assumptions). My personal awareness of the role of families and work with families dates from the early 1980s and led to training in systemic therapy and work in a family clinic, which was described, evaluated and published in another co-authored publication (Benbow et al, 1993). That paper quotes Roper-Hall (1992) who wrote about seeing families at referral in order to co-create alternative ways of understanding the situation. Family therapy theories and practice have continued to evolve over time from ideas about 'doing to' (and maybe even 'fixing' families) (as described in the models of therapy in one of our later family therapy papers (Benbow & Marriott, 1997, p. 139)) through developments in reflecting teams² with an expectation of openness and shifting the balance of power between therapists and families (Benbow & Marriott, 1997, p. 142) to the more recent emphasis on what has been called collaborative therapy. Anderson (2007a) described collaborative therapy as a philosophical stance or way of being:

"The therapist wants to learn and understand the client from the client's perspective and preferences. The therapist wants to learn the client's lived

² Reflecting teams have been described by Andersen (1992). The technique involves discussions between therapist and team taking place openly in front of the family rather than behind closed doors as was usual previously.

experience and the meanings and understandings associated with it.”

(Anderson, 2007a, p. 47)

These three publications, which resulted from involvement in a family therapy team in Manchester (Benbow et al, 1990; Benbow et al, 1993; Benbow & Marriott, 1997), establish how family therapy can include people with dementia and their families, how ideas from family therapy offer new perspectives and different ways of talking with users and their families and describe some theoretical concepts of systemic therapy, including feedback and circularity, the use of reflecting teams, openness and a change in the balance of power between professionals, users and families. These theoretical constructs underpin subsequent work and have shaped the later research.

The research programme

The research programme has evolved (and continues to evolve) in sympathy with family therapy concepts and in particular the ideas of Harlene Anderson described above. It encompasses several initiatives relating to both user and carer involvement at different levels. Most of the papers on which this thesis is based are co-authored. This reflects my belief that bringing together and exchanging a range of differing ideas and perspectives leads to creativity, dialogue and the evolution of ideas (see p. 37) (Inger & Inger, 1990). It relates to the ideas of double description, which originated in the work of Bateson (1972), described by Jones (1993) as follows:

“obtaining more than one view of an event would enable us to achieve the cognitive or emotional equivalent of binocular vision, thus gaining, in a

metaphorical sense, perspective on our observations and experiences.”

(Jones, 1993, p. 31)

I wrote about this issue in a paper on my leadership role as National Institute in Mental Health England Fellow in Ageing and Mental Health from 2003 to 2006 (Benbow, 2007) where I stated that:

“The achievements of the fellowship were all shared achievements.

Perhaps the key skills required were in networking widely, communication, and, not simply influencing opinion, but co-constructing opinion and co-constructing with others an agreed plan of action. A critical factor was probably to develop a collaborative leadership model ... “. (Benbow, 2007, p. 34)

This understanding also fits with my developing ideas that participation in itself is valueless – the user inevitably participates (in a narrow sense) in any encounter with a health or social care professional, but what is important is the collaboration, the mutual exchange of views and the construction of an outcome which has been influenced by all participants in the interchange.

The research programme also demonstrates a recursive relationship between research and practice. Boyer (1996) wrote about:

“clinical practice as a form of scholarship.” (Boyer, 1996, p. 1)

He elaborated on this to say that in writing about the scholarship of application he means:

“moving from theory to practice and from practice back to theory.” (ibid, p. 4)

Many of the publications on which this work is based illustrate this relationship, in that investigation leads to findings which influence practice and then feed back into

theoretical understandings and lead on to further research. This relationship is represented diagrammatically in Figure 2.

The structure of this thesis draws on Peck et al (2002), who combined what they described as 'conceptions' of user involvement (as recipients, subjects of consultation, and agents in control) with four levels of interaction to form a matrix (see Table 2 – modified from Tait & Lester (2005) and Peck et al (2002)). A fifth level of interaction has been added to the matrix (in developing and delivering education), and minor changes made to make explicit that the same matrix is applicable to both user and carer participation.

Each of the conceptions of user and carer involvement is addressed in turn and related to the research programme.

Figure 2: A representation of the recursive relationship between research and practice

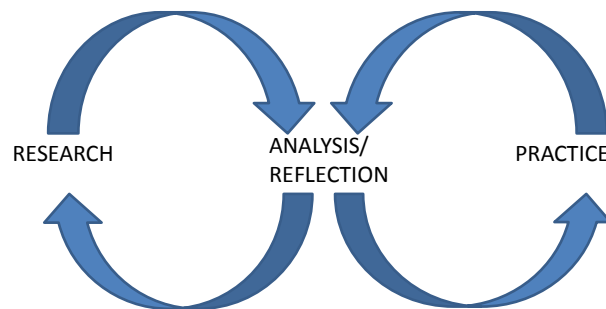


Table 2: A matrix of user and carer involvement modified from Tait & Lester (2005) and Peck et al. (2002)

Level of interaction	Conceptions of user and carer involvement		
	As recipients of service/ care	As subjects of consultation	As agents in control
Between service users/ carers	Eg Newsletters	Eg Advocacy	Eg The Hearing Voices Network (http://www.hearing-voices.org/)
Between users or carers and professionals	Eg Receiving care plans	Eg Agreeing care plans	Eg Direct payments
	Copying letters to patients		
		Patients views on ECT	
		Subjective experience of ECT	
In service management	Eg Receiving information	Eg User or carer surveys	Eg User-run crisis houses
		Patients and carers journeys through services	
In service planning	Eg Community care plans	Eg Stakeholder conferences	
		Carers narratives	
		Consumer group	
In developing and delivering education	Eg Case histories	Eg Council of elders (Katz, Conant, Inui et al, 2000)	Eg User and carer led courses
			'In our Shoes'

Involving users and carers as recipients of services/ care

In 2009 the British Medical Association (BMA) issued guidance for consultants on best practice for copying letters to patients (BMA, 2009). This document states that copying letters to users is 'beneficial on the whole' and that one potential benefit is to maximise the person's understanding of their illness. In a section on potential pitfalls it suggests that it may be inadvisable to copy letters to people with significant cognitive impairment/ dementia, and that there might be safeguarding issues which could place a child at risk when information is copied to parents.

There is no doubt that most service users are positive about their experience of receiving copy letters (Lloyd, 2004; Nandhra et al, 2004; Marzanski, Musunuri & Coupe, 2005; Treloar & Adamis, 2005; Mason & Rice, 2008). The position of carers in respect of the practice of copying letters is less clear. Dale et al (2004) reported that older adults wanted to share information with their carers: 54% of old age psychiatry out-patient users said that they would like their carer to receive a copy of the letter about their care. Carers in the same study overwhelmingly wanted to receive a copy letter (95%). Mason & Rice (2008) also looked at copying letters in an old age psychiatry service in a community mental health team context: they write that the decision to send the letter to the user or carer was based on discussion with the doctor "and common sense". If the user had established significant cognitive impairment they were asked for consent to send the letter to their carer, and if cognitive decline was advanced the letter was offered to the carer. The response to letters was positive: they were regarded as useful and clear. They note that all the respondents spoke English as their first language. Treloar & Adamis (2005) also investigated the practice of copying letters to users and carers in an old age psychiatry out-patient context. They found improved knowledge of medical recommendations amongst user and carers

together with better knowledge of who to contact. They commented on confidentiality: ‘concerns about confidentiality did not arise.’ In old age psychiatry services where users and carers are seen together letters will hold no surprises for either party.

Clark et al (2008) describe two older people’s mental health projects which involved copying letters. In terms of the matrix of user and carer involvement (Table 2) sending letters about their care to users or (with the user’s permission) to their carers is a way of involving users and/ or carers as recipients of care. If users or carers are asked to feedback about the experience, they become involved as subjects of consultation. However for consultation to have meaning, it needs to feed back into and influence services.

The Clark et al (2008) paper describes the practice of copying letters to patients as:

“offering transparency and confirming respect for equality in the relationship between patient and clinician.” (Clark et al, 2008, p. 31)

Table 3 lists potential benefits of the practice – taken from the Department of Health Good practice guidelines (Department of Health, 2003) - and evidence for the suggested benefits. The benefits are written from the viewpoint of the professional. The Clark et al paper moves further towards considering the benefits of copying letters from the perspective of service users and their families. The column in Table 3 headed ‘conclusions’, whilst supporting the Department of Health listed benefits of the practice, attempts to refocus on them from a user/ family perspective. The short quotation from page 37 of the paper in Table 3 on page 28 is important: users or carers who receive copy letters, know when they receive their copy that the professionals have received theirs and can then actively

pursue any actions or outcomes which should follow. The practice can therefore move a health/social care encounter towards partnership with users and carers.

Table 3 also sets out as drawbacks the factors which the Department of Health (2003) lists under the heading of when letters should not be copied. Two additional factors have been added to this list: letters may be written differently as a result of the practice of copying them to users, and the practice will involve some extra cost to services. Evidence for the drawbacks is set out in the Table and conclusions are drawn in the final column.

Table 3: Potential benefits and drawbacks of copying letters to users and/ or their carers

Potential benefits of copying letters to service users from Department of Health (2003)		Evidence for this statement	Conclusions with reference to the contribution of Clark et al (2008)
More trust between service users and professionals	Increased openness leads to greater trust between professionals and service users.		Increased openness <i>should lead</i> to greater trust between professionals and service users.
Better informed service users	Service users and carers have a better understanding of the condition and how they can help themselves.	O'Driscoll, Koch and Paschalides (2003) found that letters helped patients understand their diagnosis and treatment. Nandhra et al (2004) reported that patients said receiving letters helped them "gain perspective" on their condition. O'Driscoll et al (2003) reported that users found that letters helped them understand their diagnosis and treatment.	Service users and carers have a better understanding of <i>the professionals' views about or assessment of the</i> condition and how they can help themselves.

Better decisions	Service users are more informed and better able to make decisions about treatment options.	Treloar and Adamis (2005) found that users who received letters had a better knowledge of their care plan and who to contact.	Copying letters “ <i>establishes a culture of openness, inclusiveness and partnership between professionals and families, and improves the appropriateness of service responses.</i> ” (Clark et al, 2008, p. 37).
Better compliance	Service users who understand the reasons for taking medication or treatment are more likely to follow advice.		Professionals who discuss matters fully and communicate openly with service users will give better advice and it is likely that compliance with it will be greater.
More accurate records	Errors can be spotted and corrected by the service user.	O’Driscoll et al (2003) and Mason and Rice (2008) reported some errors in letters which were corrected by patients.	Errors can be spotted and corrected by the service user.
Better consultations	Professionals confirm that patients understand what is said during the consultation. Patients are better prepared and less anxious.		Where professionals understand the requirement to communicate openly with service users they are likely to make more effort to do so which should lead to more satisfactory consultations from everyone’s perspective.
Health promotion	The letters can be used to reinforce advice on self-care and life styles.		Letters could be used to set out the views of service users and carers about the illness.

Clearer letters between professionals	Letters written between professionals are clear and understandable to both professional and lay people.		Letters which are clear to users are likely to be clear to the professionals who receive them.
Ensuring all aspects of care plan progressed as planned (Mason and Rice, 2008).			<i>“It enables patients and carers to play an active part in interpreting findings and making and evaluating plans for care and treatment.”</i> (Clark et al, 2008, p. 37)
When letters should not be copied from Department of Health, 2003 - drawbacks		Evidence for this drawback	
Where the user does not want a copy	People may have problems with privacy at home, may be in situations of domestic violence, may not accept the diagnosis or may feel they criticise the professional by asking for a letter.	Most studies in this area have found that a minority of users do not want a copy letter (Dale et al, 2004; Marzanski, Musunuri & Coupe, 2005; Mason & Rice, 2008).	Sending a letter to a person's home could in theory lead to a breach of confidentiality, increase the risk of domestic violence or elder abuse, or compromise the relationship between the person and the professional.
Where the clinician feels that it may cause harm to the user or for other reasons	Sometimes “health professionals are anxious to protect patients” (page 7); concern about reactions to bad news, sensitive areas such as child protection and mental health.	Some psychiatrists express concerns over patients' distress (Murray et al, 2003; Nandhra et al, 2004). Some users express concerns about possible distress (Marzanski, Musunuri & Coupe, 2005). Information was found to be omitted from almost one quarter of letters in	A letter could cause distress or put a person at risk in some way eg if it is seen by a person for whom it is not intended.

		<p>Nandhra et al's (2004) work.</p> <p>Mason and Rice (2008) reported that one service user was distressed by the letter.</p> <p>Some authors have expressed concern about the potential effect on the therapeutic relationship (eg Lloyd, 2004; Tahir, Bisson & Wilcox, 2005).</p>	
Where the letter includes information about a third party who has not given consent	This could lead to a potential breach of confidentiality and there may be additional concern that harm might result either to the user or the third party.	<p>Third party information was removed from one letter in Mason & Rice's (2008) study.</p> <p>Two instances of omitting third party information were reported by Murray et al (2003).</p>	Letters between professionals may include third party information with possible consequences if this information is revealed. In addition users may share letters with other family members/ carers thus further disseminating information.
Where special safeguards (eg) for confidentiality may be needed.	Sexually Transmitted Diseases clinics are given as an example.	Some users express concerns about confidentiality (Marzanski, Musunuri & Coupe, 2005).	<p>Older people living in care homes may be at risk of compromised confidentiality.</p> <p>People with impaired capacity may need special consideration.</p>

<i>The letters themselves change as a result of the practice</i>		<p>Psychiatrists omitted information from letters (Murray et al, 2003; Nandhra et al, 2004)</p> <p>Psychiatrists alter their usual letter writing practice (Nandhra et al, 2004).</p>	Changes to letters could be regarded as a positive or a negative outcome of the practice.
<i>Increase in workload (and costs) for the NHS</i>		<p>Small increase in secretarial workload was reported by Nandhra et al (2004). This has been a concern in other areas of medicine (eg rheumatology; Payne & Jobanputra, 2006; Nixon & Courtney, 2005). Pilgrim & Waldron (1998) drew attention to the economic constraints on participation and this is relevant even with a simple intervention. Young-Min et al (2004) commented on the need for large print letters and audiotapes as an alternative for some users.</p> <p>Jelley, van Zwanenberg & Walker (2002) highlighted the potential difficulties for those with educational disabilities and inadequate reading skills in English.</p>	<p>There are additional costs involved in copying letters to users. As yet there is no study of the cost-effectiveness of the practice.</p> <p>Translation into black and minority ethnic (BME) languages is helpful but is not regarded as essential (Clark et al, 2008).</p>

Power

The reflecting team (Andersen, 1992) is a way of sharing the ideas of therapists with families. Before it was introduced, families often met with therapists and were 'observed' by a team from behind a one-way screen. When the team came out from behind the screen and talked together about their ideas with the family listening, they became a reflecting team. This, then, was a move away from paternalism and secrecy towards openness and collaboration. It also involved a change in the power balance between families and the professionals working with them.

The Social Care Institute for Excellence (SCIE) (Carr, 2004) considered whether user participation had made a difference to social care services. The report noted a lack of research on both the impact and outcome of user participation, and commented on the importance of power issues in relation to user participation. The historical attitude towards people using social services, which saw them as passive recipients of care, was regarded as placing professional staff in a 'paternalistic' position as decision-makers. The report highlighted two differing models and a number of relevant issues which are set out in Table 4.

Table 4: Examples of some aspects of two opposing models of working with users and carers in social care (from SCIE, 2004)

	Paternalism model	Partnership (or collaborative) model
Practical aspects	Administrative systems which support institutions eg clinics organised around the convenience of staff members.	Negotiation of administrative and other arrangements with recognition and accommodation of the needs and wishes of users and carers.
	Embedded power differentials organised around the convenience of staff.	The organisation negotiates arrangements with recognition that staff, user and carer needs are all important.
	Use of expert language which excludes users and carers from discussions.	Attention to language to ensure that users and carers are able to actively contribute to discussions.
Organisational aspects	Lack of organisational expertise in engaging users	Organisation actively engaged with users and carers at a number of levels and open to trying different ways of doing so.
	Set of professional values	Users' and carers' values, choices and priorities are recognised and valued.
Beliefs	Assumptions about (and privileging of) expert knowledge.	Recognition of and valuing of user and carer expertise and ways to ensure that it is appropriately acknowledged and influences any ensuing actions.

In systemic therapy it has been argued that power stems from the use of expert language and its imposition on the client's experience (Anderson & Goolishian, 1990). This criticism may be equally applicable to encounters in health and social care. In systemic therapy over the past twenty years or so there has been a move away from power and control (Hoffman, 1993a) towards an emphasis on collaboration (Anderson, 2007a) and dialogue (Anderson, 2007b). Alongside this is debate about 'not-knowing' and 'client-as-expert' (Anderson, 2005). The concepts of 'not-knowing' and 'client-as-expert' involve respect and dignity for the service user and their family, a recognition that they hold expertise regarding their own/ their family member's illness and/ or circumstances, and a humble acceptance of the fact that the therapist or health professional doesn't necessarily know best. These concepts are not threats to the knowledge, expertise and skill of the therapist (or health/ social care professional): instead they make the expertise of the professional available in partnership with the knowledge and experience of user and carer. They provide foundations for a more balanced collaborative relationship between therapist (or health/ social care professional) and the users and carers they encounter.

A simple intervention (in this case copying letters to service users and/ or carers) may be symbolic and more powerful than might have been anticipated. It involves a move away from expert language and secrecy. When the people receiving letters are empowered to use the letters to actively take a lead in their own (or their relative's) care and also consulted about their experience so that learning is used to inform the development of individual care and of the service itself, the balance of power shifts further. This leaves the BMA (2009) guidance for consultants looking rather patronising in its assessment of the practice of copying

letters, particularly as Clark et al's (2008) initiative included people with cognitive impairment, dementia and other mental health problems of later life. Thus 'copying letters to patients' can shift the balance of power in the relationship between professional and the users and carers they are working with. To classify this initiative as a way of involving users and carers as recipients of services/ care is to make an assumption that the initiative involves information flow in one direction: when information flows in both directions and change may ensue from the interchange, the level of participation shifts further up the ladder in Figure 1.

Involving users and carers as subjects of consultation

Consultation is the act or process of consulting and one definition of 'to consult' is 'to exchange views'. Exchanging views in itself could be a sterile exercise; the purpose of consultation is to influence and ideally to improve decision-making.

Restall & Strutt (2008) referred to this bluntly, in writing:

“participation activities which consisted solely of information exchange were, at best, a waste of time and, at worst, exploitation. People did not want to participate for the sake of legitimizing what health planners had already decided, but rather to make a real impact on decisions that improve services.” (Restall & Strutt, 2008, p. 236)

Crawford et al (2002) point out, from the perspective of users' participation in planning/ developing health care, that participation is intended to legitimise the decisions of administrators and managers rather than to devolve power. SCIE (Carr, 2004, p. 18) calls this a 'technology of legitimation' which aims only to support the predetermined organisation position/ plan, rather than to look for ways to improve and develop plans/ proposals:

“exercises to approve of service planning and policy proposals, rather than enabling service users to be key players or partners in their formulation”
(Carr, 2004, p. 17).

It is relevant to consider what we mean by consultation, since Peck et al (2002) described the second conception of user involvement as involvement as 'subjects of consultation'.

Between users or carers and professionals

Involving service users and/or carers as subjects of consultation is not uncommon and one of my early publications (Benbow, 1988) is an example with respect to users who were receiving treatment with electro-convulsive therapy. They were asked for their views on, fears and worries about, and experience of ECT: this included information about the side-effects they experienced during treatment. The conclusions of the study focussed on the need to review consent procedures and the way users and their families are informed about the treatment. Through these mechanisms the findings were used to inform and develop practice.

In a later publication, written with a colleague (Benbow & Crentsil, 2004), we report on a consultation with people receiving treatment with ECT specifically with regard to side-effects during treatment (using the same recording form employed in the earlier study) and whether they rated themselves as showing a response to treatment. This paper makes it clear that information given by users was fed back into, and influenced, practice. The discussion states that the forms were returned to clinic staff in order that action could be taken to alleviate side-effects where possible. The paper suggests additional ways in which the information could influence practice; by facilitating changes to treatment techniques and procedures during a course of treatment; the findings could be used to inform discussion with people who are considering having ECT (and their families); and feedback could be used in planning clinic policies and procedures. Thus we go a step further than the 1998 paper, and it represents a small step towards ECT being more of a partnership between clinic staff and those using their services, and towards building ways of incorporating the experience of treatment into the ongoing routine administration of treatment and operation of the clinic. Both papers illustrate a consultatory approach. A proper and effective relationship between professional

and user inevitably involves consultation, but with improving practice this has evolved and reflection reveals more subtleties in what may be encompassed within the category of 'consultation'.

The change in emphasis between 1998 and 2004 papers parallels the development in family therapy of ideas about reflexivity, which Hoffman (1993b) describes as folding back upon itself, indicating a:

“mutually influenced process as opposed to one that is hierarchical and unidirectional.” (Hoffman, 1993b, p. 127)

Lax (1992) uses the term co-construction to describe how the story a person tells in therapy is told in conjunction with a therapist and is therefore:

“neither the client’s nor the therapist’s story, but a co-construction of the two.” (Lax, 1992, p. 73)

These concepts encapsulate the idea of circular relationships, of bidirectional influences and the way in which the process between therapist and family is mutually influenced and mutually influencing. Dallos & Draper (2010) describe family therapy as

“a collaborative process, involving a co-construction of new ways of seeing problems ... (which) requires a sociological awareness of issues of power ... Added to this the therapist is expected to be aware of ... potentially oppressive assumptions and practices inherent in their privileged position of power and status...”. (Dallos & Draper, 2010, p. 97)

This is a sobering thought when applied to ECT practice, which involves powerful treatment given to people who are often very vulnerable and ill: images which arouse extreme responses. Nevertheless by modifying ECT clinic procedure in response to user consultation the operation of the clinic itself becomes more of a

co-construction between staff and service users and gives users power and influence despite their vulnerability.

Although these two papers (Benbow, 1988; Benbow & Crentsil, 2004) apply to ECT, an exploration of notions about the consultation process is widely applicable: one way to look at the design of a treatment plan involving mental health staff and a user (and perhaps also their family) might be as a co-construction, where all contribute in partnership. Consultation, which aims to influence and develop a decision or plan, can also be seen in these terms. This means that the relationship between those involved is critical to developing the outcome. Cecchin (1992) wrote (about therapy) that:

“what we discovered depended on the ‘discoverer’ ...”. (Cecchin, 1992, p. 89)

Examined from this perspective, it is not surprising that interviewers who have been users elicit more negative satisfaction scores in evaluating mental health services (Simpson & House, 2002). Rose et al (2003) found that the methods used to elicit users' views influence their reports of benefit, noting that user-led studies reported lower rates of benefit with respect to ECT than professional-led studies. It is tempting to regard one approach as 'right' and the other as 'wrong' rather than to regard them both as different, and as both contributing to 'binocular vision' (see p. 18).

Users particularly might argue that, if matters are not unidirectional, the impact of true participation will be shown by evidence that consulting users and carers influences outcomes. The thrust of and changes with this ECT work show, at least in a small way, how this can be developed and they have been woven into the development of our group's thinking about this area.

In service management

We have also described how users and carers can work with health and/or social care professionals to map their journey (in this case with a dementia) and review their experiences of care with a view to improving and developing services in an account of some of the work of the West Midlands Older People's Mental Health Collaborative (Doherty et al, 2009). We describe two carers' journeys and some of the learning which was derived from mapping them, and how this led to action points for the organisation concerned. We note that this process:

“may even have wider benefits in altering the relationship between users, carers and those professionals working with them ...” (Doherty et al, 2009, p. 510)

and may bring about:

“changes in culture for the individuals and services involved.” (ibid, p. 501)

This is another example of sharing power in collaboration, of deriving mutual benefit from the exercise, and of co-creating new ideas in conversation.

Turner et al (2000) described students listening to, and learning from, the family carer's story in a palliative care setting. They note that meeting the carer had, what they described as, a profound impact on the students. They argue that the experience will stay with the students and may have a lasting impact on their practice. Andrews (2007) writes about honouring elders through conversations about their lives, expressing the belief that conversations:

“would have meaning and therapeutic value for the elders.” (Andrews, 2007, p. 152)

This offers another perspective on conversations with users about their illness journeys.

The staff members who were involved in our dementia journey mapping were working both in management and care (Doherty et al, 2008). This allowed the project to influence relationships between individual users, carers and a range of staff members within the organisation involved. At the same time practical benefits were developed with the potential to change practice at the level of families using the service and at the level of organisational policies, procedures and plans. It would have been helpful to get feedback from the users/ carers whose journeys were mapped about how they perceived the exercise and its effects, both on their journeys and on their relationships with professionals and organisations involved, and this is an action point for our future work.

In service planning

My election to the Chairmanship of the Faculty of Old Age Psychiatry in 2002 for a four year term presented an opportunity to develop the relationship between users, carers and old age psychiatrists nationally, and to set up a way in which all could work together on matters of mutual interest. With a group of colleagues, I have described some of the work which grew out of this national working group of users and carers (called the Consumer Group at their request) in two publications. The group acted as a forum for collecting and reflecting on written narratives produced by those carers of people with dementia who chose to do so (Benbow et al, 2009). The narratives were subjected to a qualitative thematic analysis and the analysis was presented to the user/ carer forum for discussion and consideration of how the themes could be addressed in the work of the group. This methodology, we felt, constituted 'consultation' between the professionals and carers involved, and actions were developed in partnership, which moved the initiative further up Arnstein's ladder (see Figure 1). Table 5 sets out the identified themes from the

narratives paper and from a related paper written by the same group (Ong et al, 2007), together with the ensuing actions. It is evident that, although the Consumer Group was established in response to a professional initiative and with professional interests in mind, it led on to actions which were co-created by the interaction between Consumer Group members:

“(the) users and carers ... at times were challenging, refreshingly politically incorrect and unafraid to raise any issue that concerned them ...” and *“the group was valuable in ways that had not been anticipated.”* (Ong et al, 2007, p. 48)

Furthermore:

“the group did not want to work to the faculty’s agenda, and instead saw this as their opportunity to get the faculty to take the actions they think are needed.” (ibid, p. 48)

Table 5: Themes identified in Consumer Group and ensuing actions, taken from Ong, Benbow, Black et al (2007) and Benbow, Ong, Black et al, (2009)

Carers themes	Actions arising from Group
Difficulties in obtaining a diagnosis	One day conference organised with primary care.
Bridging private and public worlds	Involvement of carers in the Consumer Group.
Stressors associated with caring for a person with dementia	Involvement of carers in the Consumer Group.
Difficulties with services offered by social services	Raised awareness amongst professionals attending the group, and in the Faculty generally.
Emotions experienced by carers	<p>Addressed by the exercise of producing and sharing the narratives.</p> <p>Feeding the themes into the work of the Consumer Group and of the organisations involved (the Faculty of Old Age Psychiatry, the Alzheimer's Society and Age Concern).</p> <p>Writing a paper in order to make the learning more widely available to others.</p>
Other themes	Example of actions arising from Group
Commenting on Faculty and College documents and	Eg when the Faculty considered updating their report on ethnic elders, the Consumer

proposals	<p>Group organised a meeting to which elders from minority ethnic communities were invited through one of the organisations involved in the Group. This led on to joint working on a document later published as a report (Shah, Adelman and Ong, 2009).</p> <p>Eg the Group collaborated on a Faculty document on copying letters to patients (Faculty of the Psychiatry of Old Age, 2004a).</p>
Discussing and planning work proposed by Faculty	<p>eg one member of the Consumer Group becoming involved in work on transitions between working age adult and older adult services and others became involved in a one day meeting which contributed to the work. The end result was a document called Links not Boundaries which I edited on behalf of a working group (Royal College of Psychiatrists, 2009).</p>
<p>Responding to issues raised by users and carers at the Group.</p> <p>Note: Users and carers could add anything they wished to the agenda and raise non-agenda items at the meeting for discussion and debate.</p>	<p>Eg members of the Consumer Group raised concerns about the interface between primary care and old age psychiatry. This linked with the carer theme of delay in diagnosis and led on to a joint seminar looking at the issue.</p>

Sharing frustrations and concerns.	eg the Consumer Group debated the issue of using anti-psychotic drugs to treat people with dementia and the discussions contributed to the Faculty advice produced on the use of atypical antipsychotics (Faculty of the Psychiatry of Old Age, 2004b; Barker & Benbow, 2004).
Forum to discuss future strategy of all those involved in the Group.	Future strategy was discussed at the Group, allowing all three organisations to contribute, alongside individual users and carers.

Table 6 sets out the practical outcomes from each of these areas of work across the matrix of user and carer involvement, demonstrating that actions which carried the potential to change relationships and working practice resulted in each case.

In its links with ideas from systemic therapy, the Consumer Group illustrates teaching and learning as collaborative and relational practices (McNamee, 2007). The members (users, carers and professionals) all learned from each other and taught one another. That learning was carried into the work of all the organisations involved. The work of the Group also touched on what Hoffman (2007) describes as ‘witness’³ which she says bypasses the hierarchy implicit in most social interaction. A striking experience was a workshop run by Consumer Group members at the Faculty of Old Age Psychiatry residential conference when a latecomer asked one of the presenters where she worked, only to learn that she was a service user with vascular dementia. This gave an appreciation of the benefits of a radical challenge to the usual power structures, and has influenced (and is still influencing) later and ongoing work of our group.

The Consumer Group work then did not simply involve users and carers as subjects of consultation (although it was intended to fulfil that role). It allowed users and carers to exert more control and start to influence the agenda and strategy of the organisation they are working with, to the benefit of all concerned. It involved what Rober (2005) describes as receptivity and reflection on behalf of all concerned. He goes on to write that:

³ London & Tarragona (2007, p. 256) distinguish ‘aboutness’ from ‘witness’ noting that traditional training stresses knowing *about* people but that *knowing with* refers to “a joint exploration between client and therapist in order to understand together the clients’ experiences, meanings, and possible solutions to their dilemmas.”

“understanding becomes an active, creative process in which the meanings of the client make contact with the meanings of the therapist. In this process, new meanings emerge that are different from the original meanings of the client.” (Rober, 2005, p. 481)

This joint endeavour subverts the expected power structure and the Consumer Group is a process model which is potentially applicable to other settings. Whilst it fails to establish Arnsteins ‘citizen power’, this sort of initiative certainly establishes a strong and creative citizen influence, and moves this debate on to the third of Peck et al’s (2002) conceptions: users and carers as agents of control.

Table 6: Practical outcomes across the matrix of user and carer involvement

Level of interaction	As subjects of consultation		
	ECT practice in Benbow (2004) Practical outcomes	Doherty et al (2009) Practical outcomes	Benbow, Ong, Black et al (2009) and Ong, Benbow, Black et al (2007) Practical outcomes
Between service users/ carers	Not directly addressed.	<ul style="list-style-type: none"> The experience was seen as valuable to users and carers in helping them share and make sense of their experiences (some evidence for this in Greenhalgh and Hurwitz (1999)). 	<ul style="list-style-type: none"> Highlighting to Group members that the needs of carers and users are not always the same and that members needed to be aware of this (documented in meeting minutes 19/2/2006).
Between users or carers and professionals	<ul style="list-style-type: none"> future recipients of treatment to be asked to rate the presence/ severity of possible side-effects before as well as during treatment. actions taken to alleviate side-effects to be recorded (but numbers of treatment changes not reported in paper). 	<ul style="list-style-type: none"> information available to users and carers to be reviewed along with how and when it is made available to them. Lack of information on Direct payments and Power of Attorney was highlighted and need for staff training in this area (Bleakley (2005) noted the role of stories as tools in educating health and social care staff). 	<ul style="list-style-type: none"> Users and carers were full members of the group and could raise issues for discussion or have them included on the agenda thus challenging the usual power balance.

In service management	<ul style="list-style-type: none"> • routine feedback from users to influence clinic policies and procedures. 	<ul style="list-style-type: none"> • to identify a key worker for each service user and their family. • to raise with managers the issue of recruiting and employing BME workers. • Both above points fit with Blickem & Priyadharshini's (2007) concepts of journeys/stories as a means to analyse services in order to improve and develop them. 	<ul style="list-style-type: none"> • Commenting on/ and being involved in the production of Faculty and College documents and proposals eg Links not Boundaries (Royal College of Psychiatrists, 2009). • Raising issues relevant to management which they considered the Faculty should address eg interface with primary care.
In service planning	<ul style="list-style-type: none"> • other clinics recommended to record subjective side-effects and follow up longer term side-effects and outcomes. 	<ul style="list-style-type: none"> • to raise with managers the issue of the non-existence of night services and the need identified for them. • to investigate options for transport to day care which was not flexible enough • need to look at how to meet cultural needs of BME families. • Above three points fit with the use of stories as essential feedback for service providers and commissioners (Scottish Government, 2009) 	<ul style="list-style-type: none"> • Commenting on/ and being involved in the production of Faculty and College documents and proposals eg Links not Boundaries (Royal College of Psychiatrists, 2009). • Raising issues relevant to planning which they considered the Faculty should address eg work on services for ethnic elders.

In developing and delivering education	Not addressed	<ul style="list-style-type: none"> • need for staff training related to specific areas of information highlighted by carers. 	<ul style="list-style-type: none"> • Eg one day conference organised with primary care in October 2005. • Members of the Consumer Group ran a workshop at a Faculty residential conference. • Members of the Group or their contacts spoke at various Faculty workshops/ seminars eg in May 2006 speakers from Users in Partnership and Carers in Partnership spoke at a one day seminar (see Royal College of Psychiatrists (2009) p. 18). • Faculty events were advertised to the Group and they were invited to attend should they so wish.
--	---------------	---	--

Involving users and carers as agents of control

The third 'conception' of user and carer involvement is as agents of control (in Peck et al's (2002) terminology). It is apparent from the preceding discussions of users and carers as recipients of care and as subjects of consultation that these three 'conceptions' are not separate and discrete. Instead their boundaries merge so that they form a spectrum of participation. Consultation may be about 'ticking boxes' at times, but at its best it carries the underlying assumption that actions will result from that consultation. This introduces the possibility of the people running the consultation sharing power with those they consult, so that the outcome is not necessarily that intended by either group but instead a co-construction which grows out of the dialogue between the two. The outcome then becomes, not the outcome of one party imposed on another, but a different outcome to which both groups are signed up. This fits well with theories of systemic therapy.

In service planning

The Consumer Group initiative (Ong et al, 2007; Benbow et al, 2009) crossed the boundary from consultation to control by giving the users and carers involved the space to influence the focus and activity of the professionals they were working with. This could be classified as users and carers as agents of control in service planning, using Peck et al's (2002) terminology. This was not what was originally intended by the initiative, but it can be argued that all concerned gained as a result.

The work described in Benbow, Taylor & Morgan (2008), which was taken further in Benbow & Boyce (2008), also moves from users and carers being treated as subjects

of consultation to becoming involved as agents of control (see Table 2). Furthermore it involves work in developing and delivering education rather than in service provision, management or planning.

In developing and delivering education

Education offers an opportunity to influence the health and social care system by influencing those working within it. Tew, Gell & Foster (2004) describe how the involvement of users and carers in education at all levels is essential if health and social care professionals are to develop partnership working with the people using their services. They listed a series of areas for involvement: direct delivery of learning and teaching, course / module planning, programme management, recruitment and selection of students, practice learning, student assessment, course evaluation and as course participants

The involvement of users and carers in non-passive roles in the education of health and social care professionals is a relatively recent development. Previously, users may have been involved as 'teaching aids' (Repper & Breeze, 2007), for example in the bedside teaching of medical students. Wykurz & Kelly (2002) reviewed the involvement of users in medical education, describing their active (as opposed to passive) involvement as new. Forrest et al (2000) describe drawing on users' views to influence design of a pre-registration nursing curriculum. Ikkos (2003) describes users as teachers of interview skills, teaching doctors to understand the 'point of view' of 'patients' with mental illnesses. Livingston & Cooper (2004) went further: they described users and carers as active educators in professional training, arguing that their different perspective gives them a unique role in teaching. Recently Lloyd,

Carson & Bleakley (2007) produced a toolkit and reported a project to investigate the needs of service users involved in planning and delivering mental health services and education. Anderson, Ford & Thorpe (2008) have described involving people with communication needs in developing and delivering education.

Table 7 sets out positive and negative effects of users and carers as teachers.

Wykurz & Kelly (2002) acknowledge that they found the emphasis to be on the value (rather than potential negatives) of users as teachers and state that this might be due to publication bias. Other writers allude to possible negative effects (for example see Walters et al, 2003). It is likely that the mechanism by which users and carers are involved is important in ensuring a positive experience for all involved.

Table 7: The possible positive and negative effects of users and carers as teachers (modified from Wykurz & Kelly, 2002 with major modifications in bold: points taken from Benbow & Boyce (2008) in bold/italics)

	For students	For users and carers	For trainers
Positive effects	<ul style="list-style-type: none"> • Enables access to users and carers personal knowledge and experience of condition and services • Helps deepen understanding/ empathy • Provides constructive feedback • Reduces anxiety • Increases confidence • Influences attitudes and behaviour • Improves acquisition of skills • Increases respect for users and carers • Places learning in context • Increases their knowledge • Provides new insights • Improves their understanding of users and carers • “Students remember what they hear from patients.” (Farrell, 	<ul style="list-style-type: none"> • Uses their experience of their condition and services positively • Uses their knowledge and experience • Acknowledges their expertise • Is empowering • May help future users/ carers • Increases their knowledge/ insight/ understanding • Improves their understanding of health/ social care professionals • Reduces anxiety • Increases confidence and self-esteem • allows people to learn more about themselves (Livingstone & Cooper, 2004) • provides a sense of personal satisfaction (Livingstone & 	<ul style="list-style-type: none"> • Provides additional teaching resources • Improves quality of teaching • Offers alternative teaching opportunities • Develops mutual understanding • Enlists new advocates • Provides value for money • Gives a more balanced understanding of the relationship between users and carers and those working with them (Walters et al, 2003) • May increase the motivation and enthusiasm of students and trainers (Walters et al, 2003) • Teaching has a greater focus on users (Stringer et al, 2008)

	<p>Towle & Godolphin, 2006, p. 5)</p> <ul style="list-style-type: none"> • <i>“Give(s) students the opportunity to have new and different conversations with the people they work with.” (Benbow & Boyce, 2008, p. 12)</i> • <i>students should: “have re-evaluated the relationship between health and social care professionals and the users and carers they work with.” (Benbow & Boyce, 2008, p. 12)</i> • <i>“a course which had the capacity to change the attitudes of professional practitioners.” (Hughes, 2008)</i> 	<p>Cooper, 2004)</p> <ul style="list-style-type: none"> • <i>may enable them to earn money (Livingstone & Cooper, 2004)</i> • <i>May influence their relationship with health/ social care staff (Hutchings, 1999)</i> • <i>“it was a privilege to think that my own experience and reflection might in some small way enable others to benefit.” (Hughes, 2008).</i> • <i>“The teaching is, and was, a two way thing; I myself learnt things about myself and the system.” (Morgan, 2008)</i> 	<ul style="list-style-type: none"> • <i>“To facilitate, and sometimes empower, people that use services is a humbling experience ...”. (Benbow & Boyce, 2008, p. 13)</i>
--	---	--	---

Possible negative effects	<ul style="list-style-type: none"> • Blurring of the boundary between user/ carer and staff • Anxiety provoking • Sense of obligation to user or carer • Unrealistic expectations of practice (Masters et al, 2002) • High emotional demands of user (and maybe carer) involvement (Masters et al, 2002) 	<ul style="list-style-type: none"> • Blurring of the boundary between user/ carer and staff • Anxiety provoking • Potentially intrusive • High emotional demands of involvement (Masters et al, 2002) • <i>“Feeling under pressure to perform ...”. (Benbow & Boyce, 2008, p. 11)</i> 	<ul style="list-style-type: none"> • Blurring of the boundary between user/ carer and staff • Anxiety provoking • Considerable demands in time and energy (Masters et al, 2002) • <i>Demands on trainers: “the preparation involved is considerable.” (Benbow & Boyce, 2008, p. 10) and trainers need to “be prepared to improvise and be highly flexible.” (ibid, p. 12)</i>
---------------------------	---	--	---

A range of models has been described for involving users and/ or carers as teachers; one to one conversations (Elliott et al, 2005); long term following of a person living with a dementia (Skog et al, 2000); working with service user (or carer) groups (Humphreys, 2005); involvement in developing, delivering and evaluating education (Barnes, Carpenter & Bailey, 2000); workshop based teaching (Waterson & Morris, 2005); a 'facilitated dialogue' (Scheyett & Diehl, 2004).

We described the involvement of users and carers in teaching on an MSc module for health and social care professionals (Benbow, Taylor & Morgan, 2008). Our stated aim was to give the students a different perspective of assessment and care planning. As with the Consumer Group initiative, this innovation had consequences beyond those expected. The student ratings and feedback were overwhelmingly positive. A point of note, which illustrates a change in the balance of power, is that one of the co-authors of this paper is a service user who contributed to the development of the work and also by writing about her experiences. The paper concludes:

"We have also recently been awarded a grant from the Higher Education Academy to develop a module designed and run by users and carers for future inclusion on the MSc course, which will give the opportunity to try out some of the ideas arising from the experiences we describe here." (Benbow, Taylor & Morgan, 2008, p. 16)

The quotation above refers to the mini-project described in our report to the funding organisation, the Higher Education Academy (Benbow & Boyce, 2008). A dedicated module was planned and designed in partnership with users and carers using focus

groups, and a recruitment workshop was held at which Morgan (co-author of the 2008 paper and an honorary lecturer at the University) spoke about her experience of teaching.

The design of the module drew on several strands of work. Firstly, Wenger's ideas about communities of practice and his writings about learning underpinned the approach of the module:

“Learning is a matter of engagement ...” and “Learning transforms our identities: it transforms our ability to participate in the world by changing all at once who we are, our practices and our communities ...”. (Wenger, 1998, p. 227)

Secondly, Katz et al's (2000) work on a Council of Elders suggested one feature built into the module design: we required students to carry out interviews with users and families (with their consent) on specified topics between some of the sessions and then to present their learning from the interviews to the group (including both students and teachers). Thirdly, McNamee's writing about the importance of relationships and 'teaching as conversation' (McNamee, 2007) led to the design of the teaching as conversations with users and carers. In addition, by including interviews with users and carers, and feedback from them, throughout the module, the teaching team aimed to give students the opportunity to experience new and different conversations with the people they were working with.

In keeping with the shift in emphasis, Benbow & Boyce (2008) includes forewords written by a user (Morgan, 2008, p. 3) and a carer (Hughes, 2008, p. 4). The project

involved users and carers in the direct delivery of learning and teaching, in module planning, in student assessment and course evaluation, and the authors write:

“Involving users and carers at all levels of education sends a powerful message to the professionals they train about the value and importance of hearing and attending to the voices of those using their services.” (Benbow & Boyce, 2008, p. 6)

Narrative means to therapeutic (and learning) ends

White & Epston (1990) described the power of stories:

“In striving to make sense of life, persons face the task of arranging their experiences of events in sequences across time in such a way as to arrive at a coherent account of themselves and the world around them.” (White & Epston, 1990, p. 10) *“these stories are constitutive – shaping lives and relationships ...”*. (ibid, p.12)

In addition Greenhalgh & Hurwitz (1998) describe narrations as:

“the forward movement of description of actions and events making possible the backward action of self reflection and self understanding.” (Greenhalgh & Hurwitz, 1998, p. 4)

and go on to argue that, in education, narratives are memorable, built on experience and initiate reflection. That reflection is initiated in all parties, ie in respect of the ‘In our Shoes’ project, the students reflected and learned from the conversations with users and carers, the user and carer teachers reflected and learned from their experience of teaching (see the quote from Morgan (2008) in Table 5) and the

conversations they took part in, and the trainers/ facilitators also reflected and learned from their involvement.

Anderson (2007b) describes the storytelling process in systemic therapy as complex, actively involving the listener in both hearing and speaking. Andrews (2007) stresses the specific importance of this process for older adults who can:

“rejoin or “re-member” themselves into the meanings of their life and life itself through a process of telling their stories to people they respect, who in turn, reflect on what they say.” (Andrews, 2007, p. 151)

This fits with McNamee’s (2007) concept of teaching as a relational practice, a collaborative conversation. One of the concerns expressed about involving users and/or carers in teaching is that those people who have the confidence and motivation to teach may not be representative of the majority of users and carers: Repper & Breeze (2007) reported that some mental health lecturers had expressed this view. Whilst this may be true in some settings, if we understand people’s stories as conceptualised here, then this concern is largely irrelevant: learning will still grow out of the relationships established and the conversations that take place, whether or not people’s experiences are regarded as ‘typical’. Similarly we wrote:

“The teaching team came to the view that the individual material brought by users and carers, whilst clearly important and influential, is only part of the learning experience and the process of the sessions is equally powerful, ie learning from users and carers, having the opportunity to talk, question and debate with them in an educational environment.” (Benbow & Boyce, 2008, p.

13)

We can also apply the ideas of reflexivity (discussed earlier, p. 37) to teaching and the way that the process between user/ carer teachers, facilitators, and students involves mutual (multi-directional) influence. Cole & Knowles (2001) describe this (in relation this time to life history research) as:

“the notion of mutuality in purpose, process and result ...” (Cole & Knowles, 2001, p. 28)

and use the term ‘conversation-in-relation’.

The ‘In our Shoes’ project *shared* power between educators, practitioners, students, users and carers, and all parties *collaborated* in the design, delivery and assessment of the module. The project involved a shift in power dynamics, but giving power to user/ carer teachers did not involve the facilitators in sacrificing their own roles and authority as some have feared (Felton & Stickley, 2004). To describe this as an initiative illustrating users and carers as agents of control (the top rung of Arnstein’s ladder of participation, see Figure 1) is potentially misleading: collaboration or partnership might be a more useful concept here. The project evolved from the interaction between users, carers, educational staff, practitioners and the third sector. The acknowledgements (Benbow & Boyce, 2008, p. 18) credit the Phoenix Centre, the Alzheimer’s Society and Approach, a third sector organisation led by Boyce who co-authored the report.

Learning about learning

The experience of 'In our Shoes' led the team to read about and reflect on learning and older people. This grew out of conversations with Morgan who wrote in our first paper on teaching:

"in a way I thought I was useless. By the way the students listened and the questions they asked it gave me the feeling that maybe I had contributed into making them think outside the box, help them understand how and why the system needs to change." (Benbow, Taylor & Morgan, 2008, p. 15)

and who has since gone on (with support from the team) to publish about her experiences (Morgan, 2009; Morgan, 2010). Understanding her perspective and reflecting on these ideas led to the guest editorial on older people, mental health and learning published in *International Psychogeriatrics* (Benbow, 2009), which argues that opportunities for learning should be considered as part of mental health promotion in all older people, those with and without mental health problems. The evolution of these ideas of our team, illustrated across the works described here, is epitomised in this recent publication.

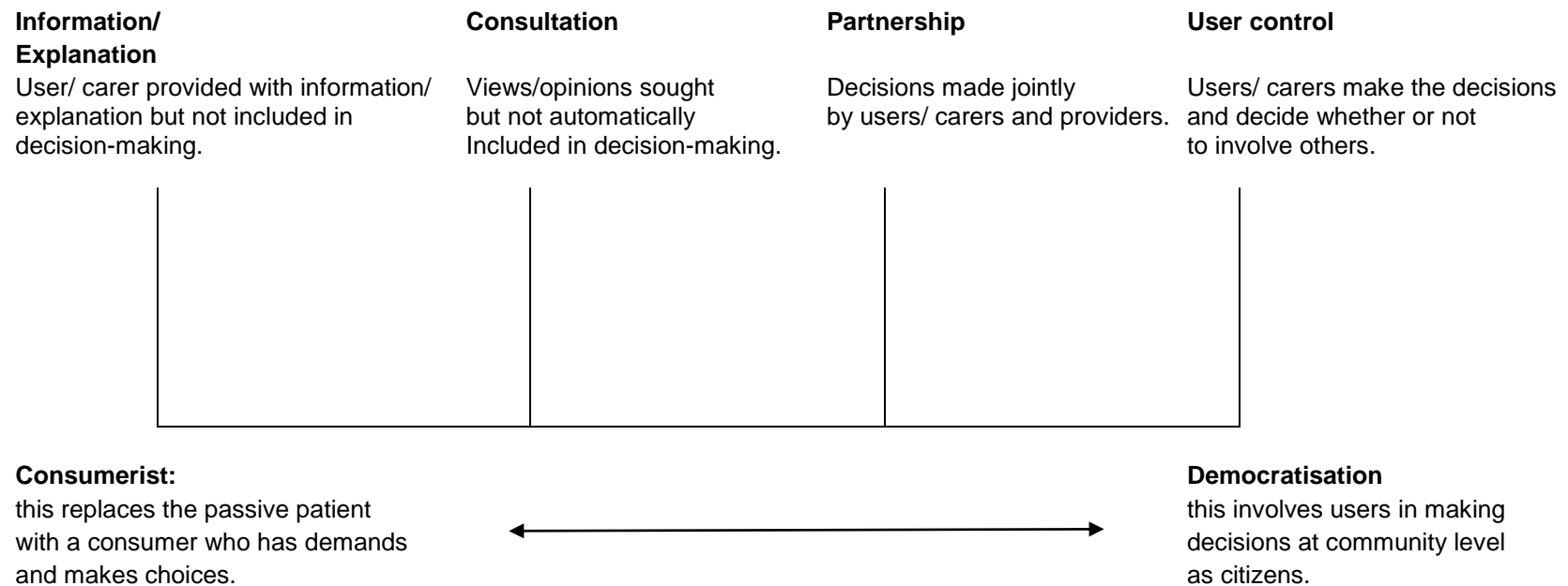
Discussion

This thesis set out four objectives: these are to consider:

1. ways of conceptualising user and carer participation in old age psychiatry,
2. ways in which users and carers participate in old age psychiatry services,
3. the benefits and drawbacks of user and carer participation in old age psychiatry services, and
4. potential areas for future research in user and carer participation in old age psychiatry.

Hickey & Kipping (1998) put forward three main rationales for involving users and carers: the desire to provide a service responsive to their wishes, users and carers have a right to be involved in decision making which will affect them, and being involved in decision-making is potentially of therapeutic benefit for people with mental health problems. They described consumerist and democratization approaches to participation (see Figure 3). How user and carer participation is conceptualised will influence understanding of the ways of involving them, and the possible benefits and drawbacks in doing so. Their notion of the potential therapeutic benefit of participation could be regarded as patronising, and it may be more appropriate to turn this round and regard not being involved as potentially detrimental.

Figure 3: Participation continuum (modified from Hickey & Kipping, 1998)

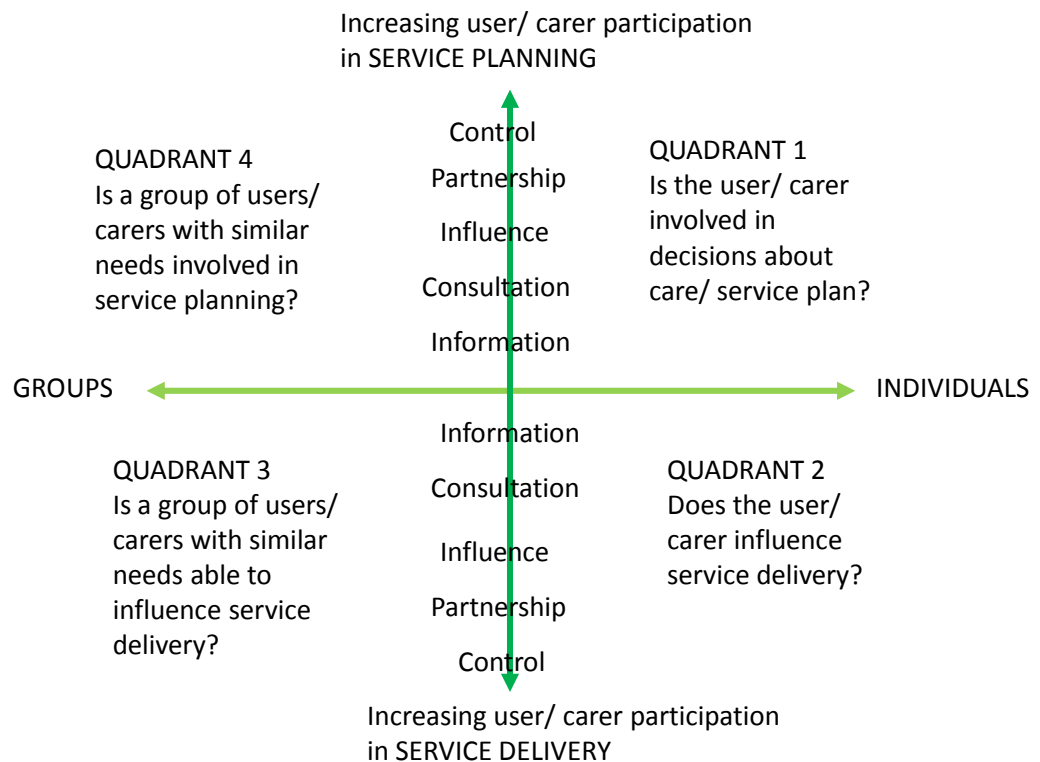


1. Ways of conceptualising user and carer participation in old age psychiatry

We have described and discussed some of the ways in which users and carers participate in old age psychiatry services in the context of the matrix of user and carer involvement set out in Table 2, modified from Tait & Lester (2005) and Peck et al (2002), with reference to the contributions made by our group and our publications and in the context of theories from systemic therapy. The matrix distinguishes levels of interaction, allowing distinctions to be drawn between participation in interactions between users or carers and professionals, in service management, in service planning and in the provision of education. It also distinguishes three ‘conceptions’ of involvement, as recipients of services, as subjects of consultation and as agents of control. Whilst I have found this classification helpful, it obscures the amorphous boundaries between the three ‘conceptions’, and carries with it an assumption of hierarchy, ie that ‘agents of control’ is the pinnacle of participation.

Arnstein’s ladder of citizen participation (Figure 1) offers a framework which describes participation on an axis from non-participation (users and carers as passive recipients of treatment/ education) to citizen control (citizen power). Using this model the aim would be user/ carer control – it imposes a hierarchy of participation with a rigid dichotomy: either users have power or professionals have power. Similarly Hickey & Kipping (1998) saw participation as a continuum (Figure 3) from information/ explanation to user control, passing through partnership. Glasby (2007) cites the work of Hoggett (1992) in setting out a model which includes the issue of whether participation is enacted as an individual or through collective action (Figure 4): again the aim is control.

Figure 4: User and carer involvement modified from Glasby (2007)



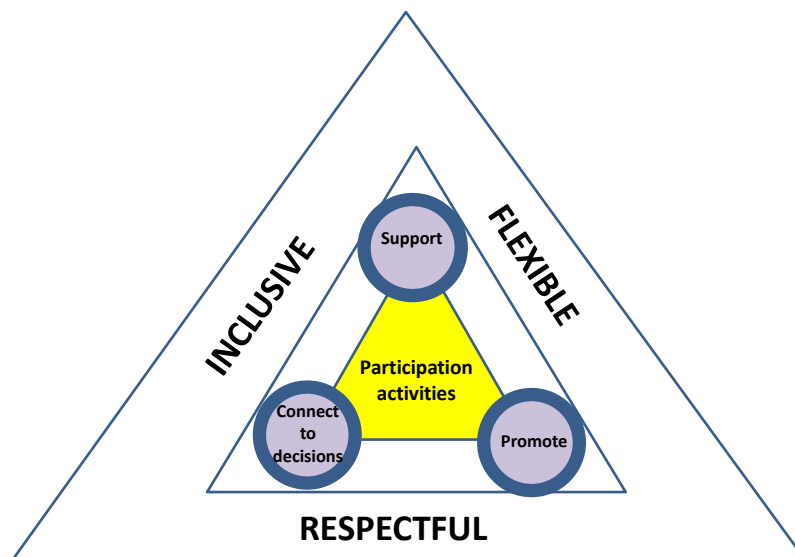
My main criticism of these models is that they fail to take account of the expertise of health and social care staff and the importance of the interaction between users, carers and health and social care practitioners. How then are we to take account of the expertise brought to decision-making by health and social care staff? Tritter & McCallum (2006) commented on the emphasis on power in participation, stating that it ignores the existence of different forms of knowledge and expertise. They argued that, to reflect the diverse ways that users participate, Arnstein's ladder would need to have multiple ladders, some with more rungs than others, and with bridges between the ladders, resulting in a scaffold structure.

Perhaps we could envisage participation as a balance between user/ carer control/ power and health care professional control/ power. The balance in the early days of the NHS was for professionals to control decision-making. There has been a shift towards user and carer control, but, if we take seriously the need for flexibility, inclusiveness and respect in participation activities (as described by Restall & Strutt (2008) in their 'conceptual framework' for participation set out in Figure 5), then genuine partnership/ collaboration becomes the pinnacle of participation, valuing and respecting the contribution made by all parties to the decision. Tritter & McCallum (2006) describe this as:

“not a hierarchy of knowledge ... but rather a complementarity between forms of knowing ...”. (Tritter & McCallum, 2006, p. 164)

Restall & Strutt's (2008) model was developed from an analysis of focus groups and interviews with users, which highlighted factors that participants believed facilitated participation. They identified a need to 'connect to decisions', which can be understood as a requirement that decisions should be co-constructed ie influenced by all parties.

Figure 5: Conceptual framework for participation from Restall & Strutt (2008)



Additionally I would advocate that we learn from work on participation and interesting models of participation in children's services (Wright et al, 2006) which can be extrapolated with modifications to adult settings and which avoid the hierarchical approach. Young children are often excluded from consultations or decision-making by parents and health/ social care practitioners making decisions on their behalf (Wright et al, 2006): there are interesting parallels with old age psychiatry where adult children/ relatives and practitioners may disempower and exclude older adults and make decisions for them. Shier (2001 and 2006) devised a model with five levels of participation and three stages of commitment. My modification of this to make it applicable to an older adult context is set out in Table 8. At each level of participation an opening may occur (first stage of commitment) and an opportunity might allow this to operate (second stage of commitment). At the third stage of commitment it becomes an obligation, ie it is incorporated within the organisation as agreed policy/ procedure. This is designed as a planning/ assessment tool and to use it one starts at the bottom (indicated in Table 8 by Start Here). It is not a hierarchy where higher is necessarily better, instead Shier argues that different levels are appropriate to different situations.. Similarly Treseder (Fajerman & Treseder, 1997) incorporated the idea of child and adult initiated participation into a circular model, used in younger people's settings: these are described as five degrees of participation which are regarded as five different but equally good practice options applicable to different situations. I have modified this for application to users' and carers' participation in old age psychiatry (see Figure 6).

Table 8: Shier's model with our modifications to make it applicable to an adult context (from Shier, 2001 and Shier, 2006)







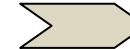








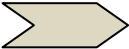
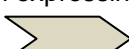
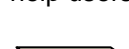


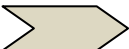
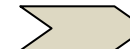
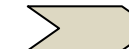

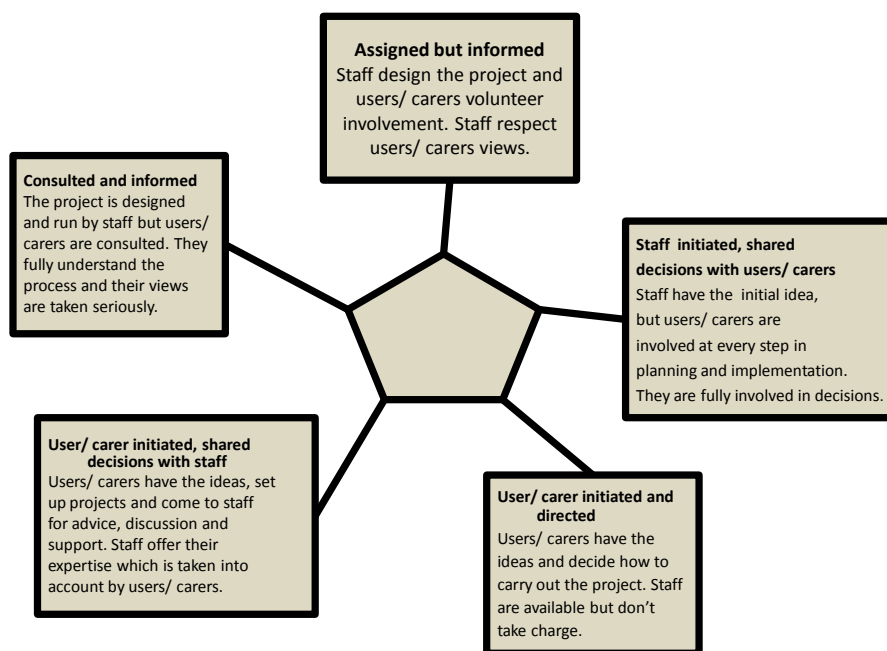
		Levels of commitment	
Levels of participation	Openings	Opportunities	Obligations
5. Users/ carers share power and responsibility for decision-making 	Are workers/ organisation ready to share power with users/ carers? 	Is there a procedure to enable users/ carers to share power and responsibility for decisions? 	Is it a policy requirement that users/ carers share power and responsibility for decisions? 
			
4. Users/ carers are involved in decision-making processes 	Are workers/ organisation ready to let users/ carers join in decision-making processes? 	Is there a procedure to enable users/ carers to join in decision-making processes? 	Is it a policy requirement that users/ carers must be involved in decision-making processes? 
			
3. Users'/ carers' views are taken into account 	Is the worker/ organisation ready to take users'/ carers' views into account? 	Does the decision-making process enable the worker/ organisation to take users'/ carers' views into account? 	Is it a policy requirement that users'/ carers' views must be given due weight in decision-making? 
			
2. Users/ carers are supported to express their views 	Is the worker/ organisation ready to support users/ carers in expressing their views? 	Does the worker/ organisation have a range of processes to help users/ carers express their views? 	Is it a policy requirement that users/ carers must be supported in expressing their views? 
			
1. Users/ carers are listened to Start here 	Is the worker/ organisation ready to listen to users/ carers? 	Does the worker/ organisation work in a way that enables listening? 	Is it a policy requirement to listen to users/ carers? 

Figure 6: Treseder's model applied to users and carers in healthcare from Fajerman & Treseder (1997)



Thus, in reflecting on the ways in which our publications have contributed to what we know about user and carer participation in old age psychiatry services, I have concluded that participation is better understood as a spectrum. Users' and carers' voices can be heard in a variety of ways, but in order to participate in service delivery, management, planning, and improvement, together with workforce education and training, what users and carers say must carry the potential to influence and change, and the aim of participation is better conceptualised as partnership/ collaboration rather than control/ power. Partnership implies similar status, shared power and some equality of influence over agenda, implementation and outcomes: this is in line with Rutter et al's (2004) findings that users were more concerned with influence, sharing and outcomes.

In my view, having reflected on a number of models of participation, key questions when assessing the process of user and/ or carer participation include the following:

- How are users able to influence the decision making/ planning process?
- How are carers able to influence the decision making/ planning process?
- How are health and social care professionals able to influence the decision making/ planning process?
- Is the process flexible enough to enable all parties to participate as far as they are able?
- Are all parties to the decision/ plan respected for what they bring to the decision making/ planning process?
- How are the outcomes of the process influenced by those involved?
- How are the outcomes of the process evaluated?

2. Ways in which users and carers participate in old age psychiatry services

Table 9 is a modification of Table 2 and endeavours to incorporate some of the discussion above in a modified matrix of user and carer involvement, where the aim is partnership/ collaboration between users and carers and professionals. The main difficulty with this modified matrix is that it still implies a hierarchy. Fajerman & Treseder (1997) argued that their five degrees of participation (Figure 6) should be regarded as different but equal, and that differing situations will necessitate differing approaches to participation. A circular model would have much to commend it in avoiding the imposition of hierarchy, and would resonate with systemic theory. Collaboration in systemic work has been described as a “learning state of mind” (Fernandez, Cortez & Tarragona, 2007, p. 142) and:

“When the conversations and reflections were successful, therapists and clients alike developed new ideas that expanded their understanding of the present and of what might come in the future.” (Fernandez, Cortez & Tarragona, 2007, p. 142-3)


Table 9: A modified matrix of user and carer involvement (with examples).

Items in bold and italics highlight the main changes we have made to the original matrix of Tait & Lester (2005) and Peck et al. (2002).

Note:

(1) that instead of 'agents in control' we have reframed the aim of participation as the category 'as respected partners'

(2) that the original matrix did not include education but we see this as an important sphere of influence.

Spheres of influence	Increasing user and carer participation 		
	As recipients of service/ care	As subjects of consultation	<i>As respected partners</i>
Between service users/ carers	Newsletters	Advocacy	User and carer groups/ organisations
Between users or carers and professionals	Receiving care plans	Agreeing care plans	<i>Co-constructing care plans</i>
In service evaluation and management	Receiving information	User or carer surveys	Users and carers as <i>partners</i> in service management
In service planning	Community care plans	Stakeholder conferences	<i>Co-constructing service improvements</i>
<i>In developing and delivering education</i>	Case histories/ Testimonies	Models such as the Council of elders (Katz, Conant, Inui et al, 2000)	<i>Users and carers as teachers, curriculum designers, evaluators etc</i>

3. The benefits and drawbacks of user and carer participation in old age psychiatry services

Table 10 sets out possible benefits of user and carer participation and Table 11 possible drawbacks/ constraints. Both Tables use headings taken from Hickey and Kipping (1998) in order to separate both benefits and drawbacks into those relating to each of four areas: user/ carer issues, professional culture, organisational culture and the wider society. This separation opens up the possibility that what may constitute a benefit in one area may at the same time constitute a drawback in another, eg changes to organisational culture may be regarded negatively by professionals but positively by users and carers (or vice versa). This highlights the complexity of research into participation.

Hickey and Kipping (1998) argue that it is important to be realistic and to identify constraints in order to consider possible ways of overcoming them or, if they cannot be overcome, to avoid developing unrealistic expectations. However, the current literature focuses more on benefits and on processes of participation rather than outcomes. The lack of literature on constraints and drawbacks may reflect publication bias and adds further weight to the need to develop research on user and carer participation in old age psychiatry.

Table 10: Benefits of user and carer participation in aspects of old age psychiatry divided into the categories identified in Hickey & Kipping (1998).

Note: this represents a distillation of the literature with inclusion of my interpretation of benefits which can reasonably be extrapolated from it.

User/ carer issues	Professional culture	Organisational culture	Wider society
<ul style="list-style-type: none"> • Promotion of further user/ carer involvement initiatives (Doel et al, 2007). • It uses their condition/ knowledge/ experience positively (Wykurz & Kelly, 2002). • Empowers users/ carers (Wykurz & Kelly, 2002) • Presents an opportunity to help future users/ carers (Wykurz and Kelly, 2002). • Increases their knowledge/ gives new insights (Wykurz and Kelly, 2002). • Improves their understanding of professionals/ organisations (Wykurz and Kelly, 2002). • May lead to services more attuned to the needs of users/ carers (Stringer et al, 2008). • May improve treatment 	<ul style="list-style-type: none"> • Increased experience of user/ carer involvement initiatives. • Increases their knowledge/ gives new insights (Wykurz & Kelly, 2002). • Improves their understanding of users/ carers perspectives and experiences (Ikkos, 2003; Repper & Breeze, 2007; Wykurz & Kelly, 2002). • May improve treatment compliance/ health outcomes/ quality of life (Stringer et al, 2008; Crawford et 	<ul style="list-style-type: none"> • Embedding of user/ carer involvement initiatives in organisational culture. • Improves organisational understanding of users/ carers perspectives and experiences. • Changes to service priorities may result (Doel et al, 2007). • Changes to management systems may result (Doel et al, 2007). • Services may be more accessible (Crawford et al, 2002). • Service may be more responsive to the needs of older adult users and carers (cf children: Wright et al, 2006). • Services may be more 	<ul style="list-style-type: none"> • Beneficial effect on attitudes towards mental illness and those with mental ill-health. • Improved service provision, planning and improvement. • Improved education/ training of professionals in health and social care. • Participation embodies a sound democratic principle (Rutter et al, 2004). • Challenges presumptions about the needs of older adults users and carers (cf children: Wright et al, 2006).

<p>compliance/ health outcomes/ quality of life (Stringer et al, 2008; Crawford et al, 2002; Walker & Dewar, 2001).</p> <ul style="list-style-type: none"> • May increase user/ carer satisfaction (Stringer et al, 2008). • May lead to a safer environment for users/ carers (Stringer et al, 2008). • May improve self confidence and self-esteem (Stringer et al, 2008). • Enjoyment (cf children: Wright et al, 2006). • Opportunity to develop social networks (cf children: Wright et al, 2006). • Spencer et al (2000) suggest that users might feel more 'enabled' after involvement in teaching ie better able to cope with their condition. 	<p>al, 2002)</p> <ul style="list-style-type: none"> • May lead to a safer environment for staff (Stringer et al, 2008). • May improve job satisfaction. 	<p>acceptable (Crawford et al, 2002).</p> <ul style="list-style-type: none"> • May benefit the organisation by improving health outcomes (Stringer et al, 2008; Crawford et al, 2002). • Users/ carers may be more satisfied with services (Doel et al, 2007). • May lead to safer environment which benefits the organisation by reducing risks. • May impact on staff turnover, sickness rates etc. • Changes to organisational attitudes/ culture (Crawford et al, 2002). 	
--	---	---	--

Table 11: Constraints on/ drawbacks of user and carer participation in old age psychiatry divided into the categories identified in Hickey and Kipping (1998)

Note: this represents a distillation of the literature with inclusion of my interpretation of benefits which can reasonably be extrapolated from it.

User/ carer issues	Professional culture	Organisational culture	Wider society
<ul style="list-style-type: none"> • Impact of user mental health/ carer stress on decision-making ability. • Impact of participation on user/ carer mental health (Simpson & House, 2003). • Users/ carers may decide not to take part in decision-making. • Users/ carers regarded as not representative (Crawford et al, 2003; Simpson & House, 2003; Repper & Breeze, 2007; Benbow, Taylor & Morgan, 2008). • Remuneration – effect on benefits (Haeney et al, 2007). • Dissatisfaction with what is offered (Rutter et al, 2004). • Users/ carers desire for independence (Rutter et al, 2004). 	<ul style="list-style-type: none"> • Lack of recognition of the ability of users to contribute. • Use of language which excludes users/ carers (Lammers & Happell, 2003). • User decision-making seen to undermine/ threaten staff/ 'professional autonomy' (Soffe, Read & Frude, 2004). • Increased involvement of users may decrease the role of staff (Soffe, Read & Frude, 2004). • Disempowerment of front-line staff (Soffe, Read & Frude, 2004). 	<ul style="list-style-type: none"> • 'Tokenism' - lack of/ limited commitment to participation (Crawford et al, 2003; Rutter et al, 2004; Simpson & House, 2003). • Lack of resources to support participation (Crawford et al, 2003; Pilgrim & Waldron, 1998). • Lines of accountability preclude active decision-making. • Uncertainty about how to achieve participation (Rutter et al, 2004). • Conflicting management priorities (Rutter et al, 2004). • A strategy to legitimise unpalatable change eg rationing (Rutter et al, 2004). 	<ul style="list-style-type: none"> • Attitudes towards mental illness and those with mental ill-health. • Societal methods of control eg supervision registers, Mental Health legislation etc. • Participation may be a strategy to legitimise unpalatable change eg rationing (Rutter et al, 2004).

4. Potential areas for future research in user and carer participation in old age psychiatry

The process of user and carer participation is often well described in the literature but, since it is seldom linked to outcomes, in future work it will be important to include clear measurable outcomes. SCIE (Doel et al, 2007) flagged up the need to establish the impact of user and carer participation and considered what resources and tools might be needed. In addition, the process of participation needs to attend to the need to include groups which are traditionally regarded as 'harder to reach' within the 'hard to reach' group of older adults eg black and minority ethnic elders (Butt & O'Neil, 2004) and older people with a learning disability. Table 12 sets out my views on key priorities for future research, focussing on the outcomes of participation.

A fundamental question remains. If research were to show conclusively that there are no benefits to user and carer participation (or even detrimental effects), would this evidence be sufficient to convince professionals and organisations that they should exclude users and carers from decision-making, or would the political, moral and ethical arguments in favour of participation outweigh the evidence? This question highlights the complexity of the issue and the need to consider participation in its broader societal context. It does not undermine the need for further research, but instead supports a research focus on what outcomes (for users/ carers, professionals, organisations and services) relate to different forms of participation and in what circumstances, for both users and carers.

Table 12: Examples of research questions

User/ carer issues	Professional culture	Organisational culture	Wider society
<ul style="list-style-type: none"> • Is there a change in users' treatment compliance when they feel more able to influence the services they receive? • Is there a change in users' health outcomes when they feel more able to influence the services they receive? • Do carers experience less or more stress when they feel more able to influence the services they and their relative receive? • Are users and carers more or less likely to be satisfied with services when they feel more able to influence them? • Are 'harder to reach' groups of users and 	<ul style="list-style-type: none"> • Are staff members who routinely involve users and carers in their care different in their empathy/ understanding or in other ways? • After involvement in user and carer participation projects, are staff members more or less likely to involve them in other ways? • Are staff members who involve users and carers more likely to be satisfied in their jobs/ less likely to suffer from burnout and stress (or is the reverse true)? • Are staff members disempowered or empowered by involvement in 	<ul style="list-style-type: none"> • Do organisations which involve users and carers in one organisational area then involve them in others? • Does user and carer participation influence staff turnover, sickness levels etc? • Are there fewer complaints about staff members who support user and carer participation (or is the reverse true perhaps because of increased expectations or increased willingness to complain)? • What changes in organisations follow from increased user and carer participation? 	<ul style="list-style-type: none"> • Do staff attitudes become more or less positive towards user and carer participation after involvement in participation projects? • When users and carers are seen to participate, what effect does that have on public perceptions of mental illness ... • ... and on perceptions of the organisations involving them? • When users and carers are involved in research what changes to research prioritisation and funding prioritisation can be measured? • When users and carers are involved in education/ training what changes to

<p>carers equally involved in participation initiatives?</p> <ul style="list-style-type: none"> • What modifications to participation initiatives facilitate the involvement and influence of 'harder to reach' groups of users and carers? • Does the process of participation affect the self-esteem of users and/ or carers involved? • What measurable changes take place in service provision following the involvement of users and carers (this could be related to different levels of user and carer influence)? 	<p>participation projects?</p> <ul style="list-style-type: none"> • When users and carers are involved in the education/ training of professional staff what changes in staff members' practice and attitudes can be measured? 		<p>education priorities, curriculum content or design can be identified?</p>
--	---	--	--

Conclusions

I have found that systemic therapy offers a useful theoretical base for considering participation in old age psychiatry: in particular, ideas about 'client-as-expert', co-construction, collaboration, learning as a relational practice and 'witness'.

There are a number of different models of user and carer participation, but the idea that the pinnacle/ aim of participation should be user/ carer control is flawed and based on a hierarchical prejudice (Cecchin, Lane & Ray (1994) describe prejudice as any pre-existing thought that contributes to one's view, perceptions and actions). I conclude that models which involve mutual respect, partnership and collaboration have much to commend them and that we can learn from models used in other contexts eg young people's services.

To assess the impact of participation requires evidence that involving users and carers influences outcomes. The emphasis in future research on user and carer participation in old age psychiatry should therefore be on measurable outcomes or the link between process and outcomes rather than on process per se. This applies to participation in education and research as well as in aspects of service delivery and planning. For example it would be possible for a group of students to ask the users and carers they work with to rate them using a 360° appraisal tool and then to repeat the rating after an educational intervention or training course in order to investigate a specific hypothesis (for example investigating changes in staff members' practice or attitudes).

It is important to establish whether positive outcomes from user/ carer teaching translate into the workplace and change practice, and to establish how the participation of users and carers in service delivery and planning changes services, organisations and those involved in providing and planning them.

Morgan (2008) wrote passionately about her involvement in teaching and her words sum up my conclusions about the whole issue of user and carer participation in old age psychiatry:

*“People say “why bother, nothing will change”, but it can and will. We have to believe that, working together, users, carers, and professionals teaching one another, surely, surely **will** make a difference.”* (Morgan, 2008)

We need to work together with users and carers to get the evidence to demonstrate that what she says is right.

References

Andersen, T. (1992). Reflections on reflecting with families. In S. McNamee & K.J. Gergen, eds. *Therapy as social construction*. London: Sage Publications. Ch. 4, pp 54-68.

Anderson, E.S., Ford, J.S. & Thorpe, L.N. (2008). *Listening to users and carers who have limited communication capacity or skills. Report to the HEA*. Available at:

<http://www.health.heacademy.ac.uk/publications/miniproject/2008anderson.pdf>

[Accessed 2 August 2010].

Anderson, H. (2005). Myths about “not-knowing”. *Family Process*. 44 p. 497-504.

Anderson, H. (2007a). The heart and spirit of collaborative therapy: the philosophical stance- “a way of being” in relationship and conversation. In H. Anderson & D. Gehart, eds. *Collaborative therapy Relationships and conversations that make a difference*. London: Routledge. Ch. 4, pp. 43-59.

Anderson (2007b). Dialogue: people creating meaning with each other and finding ways to go on. In H. Anderson & D. Gehart, eds. *Collaborative therapy Relationships and conversations that make a difference*. London: Routledge. Ch. 3, pp. 33-41.

Anderson, H. & Goolishian, H. (1990). Beyond cybernetics: comments on Atkinson and Heath’s further thoughts on second order family therapy. *Family Process*. 29 p.157-163.

Andersson, E., Tritter, J. & Wilson, R. (eds.) (nd). *Healthy democracy the future of involvement in health and social care*. London: Involve and NHS National Centre for Involvement. Available at: <http://www.involve.org.uk/assets/Uploads/Healthy-Democracy.pdf> [Accessed 2 August 2010].

Andrews, J. (2007). Honoring elders through conversations about their lives. In H. Anderson & D. Gehart, eds. *Collaborative therapy Relationships and conversations that make a difference*. London: Routledge. Ch. 10, pp. 149-166.

Baggott, R. (2004). *Health and health care in Britain*. 3rd ed. Basingstoke: Palgrave MacMillan.

Barker, A. & Benbow, S.M. (2004). Atypical antipsychotics in dementia care. Future management options. *Pulse*. 64 (17) p. 46-47.

Barnes, D., Carpenter, J. & Bailey, D. (2000). Partnerships with service users in interprofessional education for community mental health: a case study. *Journal of Interprofessional Care*. 14 (2) p. 189-200.

Bateson, G. (1972). *Steps to an ecology of mind*. New York: Ballantine Books.

Benbow, S.M. (1988). Patients' views on electroconvulsive therapy on completion of a course of treatment. *Convulsive Therapy*. 4 p. 146-152.

Benbow, S.M. (2005). One -ism too many. *Old Age Psychiatrist*. 38 p. 3.

Benbow, S.M. (2006). Age inclusivity and specialism. *NIMHE Mental Health Promotion Newsletter*. April p. 8-9.

Benbow, S.M. (2007). Reflections on leadership role as Fellow in Ageing & Mental Health with the National Institute of Mental Health England 2003-2006. *International Journal of Leadership in Public Services*. 3 p. 26-36.

Benbow, S.M. (2009). Older people, mental health and learning. *International Psychogeriatrics*. 21 (5) p. 799-804..

Benbow, S.M. & Boyce, W. (2008). *In our shoes: a user and carer led teaching module*.

Higher Education Academy Mini-Project report. Available at:

<http://www.health.heacademy.ac.uk/publications/miniproject/benbow.pdf>

[Accessed 2 August 2010].

Benbow, S.M. & Crentsil, J. (2004). Subjective experience of ECT. *Psychiatric Bulletin*. 28 p. 289-291.

Benbow, S.M., Egan, D., Marriott, A., Tregay, K., Walsh, S., Wells, J., Wood, J. (1990). Using the family life cycle in later life families. *Journal of Family Therapy*. 12 p. 321-340.

Benbow, S.M. & Jolley, D. (2006). Organisation of services in geriatric psychiatry. In J. Pathy, A. Sinclair & J. Morley, eds. *Principles & Practice of Geriatric Medicine*. 4th ed. Wiley, Chichester: Wiley. Ch. 99, pp. 1163-1171.

Benbow, S.M. & Marriott, A. (1997). Family therapy with elderly people. *Advances in Psychiatric Treatment*. 3 p. 138-145.

Benbow, S.M., Marriott, A., Morley, M. & Walsh, S. (1993). Family therapy and dementia: review and clinical experience. *International Journal of Geriatric Psychiatry*. 8 p. 717-725.

Benbow, S.M., Ong, Y.L., Black, S. & Garner, J. (2009). Narratives in a user and carers' group: meanings and impact. *International Psychogeriatrics*. 21 p. 33-39.

Benbow, S.M., Taylor, L. & Morgan, K. (2008). Multiple perspectives: Involving users and carers in educating health and social care professionals. *Quality in Ageing*. 9 (2) p. 12-17.

Bevan, A. (1948). A message to the medical profession from the Minister of Health. *British Medical Journal*. 2 (4565) p. 1.

Bleakley, A. (2005). Stories as data, data as stories: making sense of narrative inquiry in clinical education. *Medical Education*. 39 (5) p. 534-540.

Blickem, C. & Priyadharshini, E. (2007). Patient narratives: the potential for "patient-centred" interprofessional learning? *Journal of Interprofessional Care*. 21 (6) p. 619-632.

BMA (2009). *Defining best practice for copying letters to patients. Guidance for consultant doctors*. London: BMA. Available at:

http://www.bma.org.uk/images/consultantscopyingletterstopatients_tcm41-190155.doc [Accessed 2 August 2010].

Boyer, E.L. (1996). Clinical practice as scholarship. *Holistic Nursing Practice*. 10 (3) p. 1-6.

Butt, J. & O'Neil, A. (2004). *'Let's move on'. Black and minority ethnic older people's views on research findings*. York: Joseph Rowntree Foundation. Available at: <http://www.jrf.org.uk/sites/files/jrf/185935176x.pdf> [Accessed 2 August 2010].

Campbell, P. (1996). The history of the user movement in the United Kingdom. In T. Heller et al., eds. *Mental Health Matters*. Basingstoke: Palgrave MacMillan. Ch. 25, pp. 218-225.

Carr, S. (2004). *Has service user participation made a difference to social care services?* SCIE Position paper 3. London: SCIE. Available at: <http://www.scie.org.uk/publications/positionpapers/pp03.asp> [Accessed 7 December 2010].

Cass, E., Robbins, D. & Richardson, A. (2006). Dignity in care. SCIE Adults' Services Practice Guide 9. London: SCIE.

Cecchin, G. (1992). Constructing therapeutic possibilities. In S. McNamee & K.J. Gergen, eds. *Therapy as social construction*. London: Sage Publications. Ch. 6 pp. 86-95.

Cecchin, G., Lane, G. & Ray, W.A. (1994). *The cybernetics of prejudices in the practice of psychotherapy*. London: Karnac Books.

Centre for Public Scrutiny (2009). Walk a mile in my shoes. Scrutiny of dignity and respect for individuals in health and social care services: a guide. London: Centre for Public Scrutiny. Available at:

http://www.dignityincare.org.uk/library/Resources/Dignity/OtherOrganisation/Walk_a_mile_in_my_shoes.pdf [Accessed 7 December 2010].

Clark, M., Benbow, S.M., Moreland, N., Scott, V. & Jolley, D. (2008). Copying letters to older people in mental health services – policy with unfulfilled potential. *Quality in Ageing*. 9 (3) p. 31-38.

Cole, A.L. & Knowles, J.G. (2001). Principles guiding life history researching. In *Lives in context. The art of life history research*. Oxford: AltaMira Press. Ch. 2 pp. 25-44.

Coulter, A. (1999). Paternalism or partnership? *British Medical Journal*. 319 p. 719-720.

Coulter, A. (nd). Patient engagement: why is it important? In E. Andersson, J. Tritter & R. Wilson, eds. *Healthy democracy the future of involvement in health and social care*. London: Involve and NHS National Centre for Involvement. Pp. 27-35. Available at: <http://www.involve.org.uk/assets/Uploads/Healthy-Democracy.pdf> [Accessed 2 August 2010].

Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N. & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *British Medical Journal*. 325 (7375) p. 1263.

Crawford, M.J., Aldridge, T., Bhui, K., Rutter, D., Manley, C., Weaver, T., Tyrer, P. & Fulop, N. (2003). User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers. *Acta Psychiatrica Scandinavica*. 107 p. 410-414.

Crossley, N. (1999). Fish, field, habitus and madness: the first wave mental health users movement in Great Britain. *British Journal of Sociology*. 50 (4) p. 647-670.

Dale, J., Tadros, G., Adams, S. & Deshpande, N. (2004). Do patients really want copies of their GP letters? A questionnaire survey of older adults and their carers. *Psychiatric Bulletin*. 28 p. 199-200.

Dallos, R. & Draper, R. (2010). An introduction to family therapy. Systemic theory and practice. 3rd Edition. Maidenhead: Open University Press.

Department of Health (1999a). *The Patient's Charter for England*. Available at: <http://www.pfc.org.uk/node/633> [Accessed 2 August 2010].

Department of Health (1999b). *Patient and public involvement in the new NHS*. Leeds: NHS

Executive. Available at:

http://www.dh.gov.uk/en/PublicationsAndStatistics/LettersAndCirculars/HealthServiceCirculars/DH_4004176 [Accessed 2 August 2010].

Department of Health (1999c). *Caring about carers: a national strategy for carers*.

London: Department of Health. Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006522 [Accessed 2 August 2010].

Department of Health (1999d). *National service framework for mental health:*

modern standards and service models. London: Department of Health. Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009598 [Accessed 2 August 2010].

Department of Health (2000). *The NHS Plan: A plan for investment. A plan for reform*.

London: Department of Health. Download at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002960 [Accessed 2 August 2010].

Department of Health (2001). *National Service Framework for Older People*.

London: Department of Health. Available at:

http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_4003066 [Accessed 2 August 2010].

Department of Health (2002a). *Shifting the Balance of Power: The Next Steps*.

London: The

Stationery Office. Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008424 [Accessed 2 August 2010].

Department of Health (2002b). *Supporting the implementation of patient advice and liaison services. A resource pack*. Available at:

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4015493 [Accessed 2 August 2010].

Department of Health (2003). *Copying letters to patients: good practice guidelines*. Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007561 [Accessed 2 August 2010].

Department of Health (2005a). *Creating a patient-led NHS: delivering the NHS improvement plan*. London: Department of Health. Available at:

http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4106506 [Accessed 2 August 2010].

Department of Health (2005b). *Independence, well-being and choice: our vision for the future of social care for adults in England*. London: Department of Health.

Available at:

http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4106477 [Accessed 2 August 2010].

Department of Health (2006a). *A stronger local voice: A framework for creating a stronger local voice in the development of health and social care services*. London:

Department of Health. Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4137040 [Accessed 2 August 2010].

Department of Health (2006b). *Our health, our care, our say: a new direction for community services*. London: Department of Health. Available at:

<http://www.dh.gov.uk/en/Healthcare/Ourhealthourcareoursay/index.htm> [Accessed 2 August 2010].

Department of Health (2006c). *A stronger local voice: a framework for creating a stronger local voice in the development of health and social care services. A document for information and comment*. London: Department of Health. Available at:

http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4137041.pdf [Accessed 2 August 2010].

Department of Health (2007). *World class commissioning: competencies*.

Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080958 [Accessed 2 August 2010].

Department of Health (2009a). *The NHS Constitution*. Available at:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093442.pdf [Accessed 2 August 2010].

Department of Health (2009b). *Living well with dementia: A National Dementia Strategy*. Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058 [Accessed 2 August 2010].

Department of Health/ Care Services Improvement Partnership (2005).

Everybody's Business. Integrated mental health services for older adults: a service development guide. Available at:

<http://www.mentalhealthequalities.org.uk/our-work/older-life/everybodys-business/> [Accessed 2 August 2010].

Doel, M., Carroll, C., Chambers, E., Cooke, J., Hollows, A., Laurie, L., Maskrey, L. & Nancarrow, S. (2007). *Participation: finding out what difference it makes*.

Stakeholder Participation Guide 20. London: SCIE. Available at:

<http://www.scie.org.uk/publications/guides/guide20/files/guide20.pdf> [Accessed 2 August 2010].

Doherty, D., Benbow, S.M., Craig, J. & Smith, C. (2009). Patients' and carers' journeys through older people's mental health services: powerful tools for learning. *Dementia*. 8 (4) p. 501-513.

Elliott, T., Frazer, T., Garrard, D., Hiskinbotham, J., Horton, V., Mann, J., Soper, S., Turner, J., Turner, M. & Whiteford, A. (2005). Practice Learning and Assessment on BSc (Hons) Social Work: 'Service User Conversations'. *Social Work Education*. 24 (4) p. 451-466.

Faculty of the Psychiatry of Old Age (2004a). Copying clinical letters to patients. Guidelines for Old Age Psychiatrists. Available at:
<http://www.rcpsych.ac.uk/pdf/guidelinesCopyingPatients.pdf> [Accessed 2 August 2010].

Faculty of the Psychiatry of Old Age (2004b). *Atypical antipsychotics and BPSD. Prescribing update for Old Age Psychiatrists*. Available at:
<http://www.rcpsych.ac.uk/pdf/Atypicalguidance.pdf> [Accessed 2 August 2010].

Fajerman, L. & Treseder, P. (1997). *Empowering children and young people. Promoting involvement in decision-making*. London: Save the Children.

Farrell, C., Towle, A. & Godolphin, W. (2006). *Where's the Patient's Voice in Health Professional Education?* Vancouver, Canada: University of British Columbia, Division of Health Care Communication. Available at:
<http://www.chd.ubc.ca/dhcc/sites/default/files/documents/PtsVoiceReportbook.pdf>
 [Accessed 2 August 2010].

Felton, A. & Stickley, T. (2004). Pedagogy, power and service user involvement. *Journal of Psychiatric and Mental Health Nursing*. 11 p. 89-98.

Fernandez, E., Cortez, A. & Tarragona, M. (2007). You make the path as you walk: working collaboratively with people with eating disorders. In H. Anderson & D. Gehart, eds. *Collaborative therapy Relationships and conversations that make a difference*. London: Routledge. Ch. 9, pp. 129-147.

Forrest, S., Risk, I., Masters, H. & Brown, N. (2000). Mental health service user involvement in nurse education: exploring the issues. *Journal of Psychiatric and Mental Health Nursing*. 7 p. 51-57.

Glasby, J. (2007). User involvement and citizenship. In *Understanding health and social care*. Bristol: Policy Press. Ch. 7, pp. 129-148.

Greenhalgh, T. & Hurwitz, B. (1998). Why study narrative? In T. Greenhalgh & B. Hurwitz, eds. *Narrative based medicine. Dialogue and discourse in clinical practice*. London: BMJ Books. Ch. 1, pp. 3-16.

Greenhalgh, T. & Hurwitz, B. (1999). Why study narrative? *British Medical Journal*. 318 p. 48-51.

Ham, C. & Alberti, K.G.M.M. (2002). The medical profession, the public, and the government. *British Medical Journal*. 324 p. 838-42.

Hickey, G. & Kipping, C. (1998). Exploring the concept of user involvement in mental health through a participation continuum. *Journal of Clinical Nursing*. 7 p. 83-88.

HM Government (2007). *Putting people first. A shared vision and commitment to the transformation of adult social care*. Available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118 [Accessed 2 August 2010].

- HM Government (2008). *Carers at the heart of 21st-century families and communities*. London: Department of Health. Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_085338.pdf [Accessed 2 August 2010].
- Hoffman, L. (1993a). The case against power and control. In *Exchanging voices. A collaborative approach to family therapy*. London: Karnac Books. Ch. 1, pp. 5-55.
- Hoffman, L. (1993b). A reflexive stance. In *Exchanging voices. A collaborative approach to family therapy*. London: Karnac Books. Ch. 5, pp. 111-133.
- Hoffman, L. (2007). The art of “withness”: a new bright edge. In H. Anderson & D. Gehart, eds. *Collaborative therapy Relationships and conversations that make a difference*. London: Routledge. Ch. 5, pp 63-79.
- Honigsbaum, F. (1990). The evolution of the NHS. *British Medical Journal*. 301 p. 694-699.
- Hostick, T. (1998). Developing user involvement in mental health services. *Journal of Psychiatric and Mental Health Nursing*. 5 p. 439-444.
- House of Commons Health Committee (2007). *Patient and public involvement in the NHS: Third report of sessions 2006-7 Vol 1*. London: HMSO. Available at: <http://www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/278i.pdf> [Accessed 2 August 2010].

Hughes, G. (2008). Foreword. In S.M. Benbow & W. Boyce. *In our shoes: a user and carer led teaching module*. Higher Education Academy Mini-Project report. P.

4. Available at:

<http://www.health.heacademy.ac.uk/publications/miniproject/benbow.pdf>

[Accessed 2 August 2010].

Humphreys, C. (2005). Service user involvement in social work education: a case example. *Social Work Education*. 24 (7) p. 797-803.

Hutchings, D. (1999). Partnership in education: An example of client and educator collaboration. *Journal of Continuing Education in Nursing*. 30 (3) p. 128-131.

Ikkos, G. (2003). Engaging patients as teachers of clinical interview skills. *Psychiatric Bulletin*. 27 p. 312-315.

Inger, I.B. & Inger, J. (1990). *Co-constructing therapeutic conversations. A consultation of restraint*. Hampshire: DC Publishing.

Jelley, D., van Zwanenberg, T. & Walker, C. (2002). Copying letters to patients. Concerns of clinicians and patients need to be addressed first. *British Medical Journal*. 325 p. 1359.

Jones, E. (1993). Working in teams. In *Family systems therapy. Developments in the Milan-systemic therapies*. Chichester: Wiley. Ch. 2, pp. 30-54.

Katz, A.M., Conant, L., Inui, T.S., Baron, D. & Bor, D. (2000). A council of elders: creating a multivoiced dialogue in a community of care. *Social Science and Medicine*. 50 p. 851-860.

Lakeman, R. (2008). Family and carer participation in mental health care: perspectives of consumers and carers in hospital and home care settings. *Journal of Psychiatric and Mental Health Nursing*. 15 p. 203-211.

Lammers, J. & Happell, B. (2003). Consumer participation in mental health services: looking from a consumer perspective. *Journal of Psychiatric and Mental Health Nursing*, 10 p. 385-392.

Lax, W.D. (1992) Postmodern thinking in a clinical practice. In S. McNamee & K.J. Gergen, eds. *Therapy as social construction*. London: Sage Publications. Ch. 5 pp. 69-85.

Livingston, G. & Cooper, C. (2004). User and carer involvement in mental health training. *Advances in Psychiatric Treatment*. 10 p. 85-92.

Lloyd, G. (2004). Medical Records: copying letters to patients. *Psychiatric Bulletin*. 28 p. 57-59.

Lloyd, M., Carson, A. & Bleakley, C. (2007). Exploring the needs of service users involved in planning and delivering mental health services and education. Report to the HEA. Available at:

http://www.health.heacademy.ac.uk/projects/miniprojects/mlloyd_reportsummary

[Accessed 2 August 2010].

London, S. & Tarragona, M. (2007). Collaborative therapy and supervision in a psychiatric hospital. In H. Anderson & D. Gehart, eds. *Collaborative therapy Relationships and conversations that make a difference*. London: Routledge. Ch. 16, pp. 251-267.

Marzanski, M., Misunuri, P. & Coupe, T. (2005). Copying letters to patients: a study of patients' views. *Psychiatric Bulletin*. 29 p. 56-58.

Mason, J. & Rice, D. (2008). Does a business-like letter written for a general practitioner meet the standards for patients? *Psychiatric Bulletin*. 32 p. 259-262.

Masters, H., Forrest, S., Harley, A., Hunter, M., Borwn, N. & Risk, I. (2002). Involving mental health service users and carers in curriculum development: moving beyond 'classroom' involvement. *Journal of Psychiatric and Mental Health Nursing* 9 p. 309-316.

McNamee, S. (2007) Relational practices in education: teaching as conversation. In H. Anderson & D. Gehart, eds. *Collaborative therapy Relationships and conversations that make a difference*. London: Routledge. Ch. 19, pp. 313-335.

Morgan, K. (2008) Foreword. In S.M. Benbow & W. Boyce. *In our shoes: a user and carer led teaching module*. Higher Education Academy Mini-Project report. P. 3. Available at:

<http://www.health.heacademy.ac.uk/publications/miniproject/benbow.pdf>

[Accessed 2 August 2010].

Morgan, K. (2009). Risks of living with Alzheimer's disease: a personal view.

Journal of Adult Protection. 11 (3) p. 26-29

Morgan, K. (2010). Dignity in dementia: a personal view. *Dementia*, in press.

Murray, G., Nandhra, H., Hymas, N. & Hunt, N. (2003). Copying letters to patients.

British Medical Journal. 326 p. 449.

Nandhra, H., Murray, G., Hymas, N. & Hunt, N. (2004). Medical records: Doctors' and patients' experiences of copying letters to patients. *Psychiatric Bulletin*. 28 p.

40-42.

National Council for Voluntary Organisations (2009). Understanding participation:

A literature review. Available at:

<http://pathwaysthroughparticipation.org.uk/wp-content/uploads/2009/09/Pathways-literature-review-final-version.pdf> [Accessed 9 August 2010].

Nixon, J. & Courtney, P. (2005). Copying clinic letters to patients. *Rheumatology*.

44 p. 255-256.

O'Driscoll, B.R., Koch, J. & Paschalides, C. (2003). Copying letters to patients.

Most patients want copies of letters from outpatient clinics and find them useful .

British Medical Journal. 327 p. 451.

Ong, Y.L., Benbow, S.M., Black, S. & Garner, J. (2007). A Consumer Group:

Reflections on experience of involving users and carers in the work of the Faculty of Old Age Psychiatry. *Quality in Ageing*. 8 p. 45-49.

Payne, G. & Jobanputra, P. (2006) Copying correspondence to patients.

Rheumatology. 45 p. 493-494.

Peck, E., Gulliver, P. & Towel, D. (2002). Information, consultation or control: user involvement in mental health services in England at the turn of the century. *Journal of Mental Health*. 11 (4) p. 441-451.

Pilgrim, D. & Waldron, L. (1998). User involvement in mental health service development: How far can it go? *Journal of Mental Health*. 7 p. 95-104.

Pitt, B., Arie, T., Benbow, S.M. & Garner, J. (2006). The history of old age psychiatry in the UK. *IPA Bulletin*. 23 (2) p. 8-10.

Repper, J. & Breeze, J. (2007). User and carer involvement in the training and education of health professionals: a review of the literature. *International Journal of Nursing Studies*. 44 p. 511-519.

Restall, G. & Strutt, C. (2008). Participation in planning and evaluating mental health services: building capacity. *Psychiatric Rehabilitation Journal*. 31 p. 234-238.

Rober, P. (2005). The therapist's self in dialogical family therapy: some ideas about not-knowing and the therapist's inner conversation. *Family Process*. 44 p. 477-495.

Roper-Hall, A. (1992). Better late than never? Family therapy with older adults. *Clinical Psychology Forum*, p. 14-17.

Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P. & Wykes, T. (2002). *User and carer involvement in change management in a mental health context: Review of the literature*. Report to the National Coordinating Centre for NHS Delivery and Organisation R&D (NCCSDO). London: NCCSDO (revised 2003). Available at: <http://www.sdo.nihr.ac.uk/files/project/17-final-report.pdf> [Accessed 2 August 2010].

Rose, D., Wykes, T., Leese, M., Bindman, J. & Fleischmann, P. (2003). Patients' perspectives on electroconvulsive therapy: systematic review. *British Medical Journal*. 326 p. 1363.

Royal College of Psychiatrists (2009). *Links not boundaries: service transitions for people growing older with enduring or relapsing mental illness*. London: Royal College of Psychiatrists. Available at: <http://www.rcpsych.ac.uk/files/pdfversion/CR153.pdf> [Accessed 2 August 2010].

Rutter, D. et al. (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science and Medicine*. 58 p. 1973-1984.

Salmon, T. (2010). What's in a name? Patient, survivor, client. *The Psychiatrist*. 34 (4) p. 164.

Scheyett, A. & Diehl, M.J. (2004). Walking our talk in social work education: partnering with consumers of mental health services. *Social Work Education*. 23 (4) p. 435-450.

Scottish Government (2009). *Mental health collaborative programme toolkit*. Edinburgh: the Scottish Government. Available at: <http://www.scotland.gov.uk/Resource/Doc/261001/0077874.pdf> [Accessed 2 August 2010].

SCIE (2006). *Practice guide: the participation of adult service users, including older people, in developing social care*. Practice Guide 11. SCIE. Available at: http://icn.csip.org.uk/library/Practice_guide_Adult_social_care_participation_SCI_E.pdf [Accessed 2 August 2010].

Shah, A., Adelman, S. & Ong, Y.L. (2009). *Psychiatric services for black and minority ethnic older people*. College Report 156. London: Royal College of Psychiatrists. Available at: <http://www.rcpsych.ac.uk/files/pdfversion/CR156.pdf> [Accessed 2 August 2010].

Shier, H. (2001). Pathways to participation: openings, opportunities and obligations. *Children and Society*. 15 p. 107-111.

Shier, H. (2006). Pathways to participation revisited. *Middle Schooling Review (New Zealand)*. [Online] 2 p. 14-19. Available at: http://www.harryshier.110mb.com/docs/Shier-Pathways_to_Participation_Revisited_NZ2006.pdf [Accessed 2 August 2010].

Simmons, P., Hawley, C.J., Gale, T.M. & Sivakumaran, T. (2010). Service user, patient, client, user or survivor: describing recipients of mental health services. *The Psychiatrist*. 34 p. 20-23.

Simpson, E.L. & House, A.O. (2002). Involving users in the delivery and evaluation of mental health services: systematic review. *British Medical Journal*. 325 p. 1265.

Simpson, E.L. & House, A.O. (2003). User and carer involvement in mental health services: from rhetoric to science. *British Journal of Psychiatry*, 183 p. 89-91.

Skog, M., Grafstrom, M., Negussie, B. & Winblad, B. (2000). The patient as 'teacher': learning in the care of elderly persons with dementia. *Nurse Education Today*. 20 p. 288-297.

Soffe, J., Read, J. & Frude, N. (2004). A survey of clinical psychologists' views regarding service user involvement in mental health services. *Journal of Mental Health*. 13 (6) p. 583-592.

Spencer, J., Blackmore, D., Heard, S., McCorie, P., McHaffie, D., Scherpbier, A., Gupta, T.S., Singh, K. & Southgate, L. (2000). Patient-oriented learning: a review of the role of the patient in the education of medical students. *Medical Education*. 34 p. 851-857.

Stringer, B., Van Meijel, B., De Vree, W. & Van Der Bijl, J. (2008). User involvement in mental health care: the role of nurses. A literature review. *Journal of Psychiatric and Mental Health Nursing*. 15 p. 678-683.

Tahir, T.A., Bisson, J.I. & Wilcox, J. (2005). Copying clinic letters to psychiatric patients. *Psychiatric Bulletin*. 29 p. 327-329.

Tait, L. & Lester, H. (2005). Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment*. 11 p. 168-175.

Tew, J., Gell, C. & Foster, S. (2004). *Learning from experience. Involving service users and carers in mental health education and training*. Available at: http://www.positive-options.com/news/downloads/HEA_and_NIMHE_-_Learning_from_experience_-_2004.pdf [Accessed 2 August 2010].

Treloar, A. & Adamis, D. (2005). Sharing letters with patients and their carers: problems and outcomes in elderly and dementia care. *Psychiatric Bulletin*. 29 p. 330-333.

Tritter, J.Q. & McCallum, A. (2006). The snakes and ladders of user involvement: moving beyond Arnstein. *Health Policy*. 76 p. 156-168.

Turner, P., Sheldon, F., Coles, C., Mountford, B., Hillier, R., Radway, P. & Wee, B. (2000). Listening to and learning from the family carer's story: an innovative approach in interprofessional education. *Journal of Interprofessional Care*. 14 (4) p. 387-395.

Walker, E. & Dewar, B.J. (2001). How do we facilitate carers' involvement in decision making? *Journal of Advanced Nursing*. 34 p. 329-337.

Wallcraft, J., Read, J. & Sweeney, A. (2003). *On our own terms. Users and survivors of mental health services working together for support and change*. London: Sainsbury Centre for Mental Health.

Walters, K., Buszewicz, M., Russell, J. & Humphrey, C. (2003). Teaching as therapy: cross sectional and qualitative evaluation of patients' experiences of undergraduate psychiatry teaching in the community. *British Medical Journal*. 326 p. 740-745.

Waterson, J. & Morris, K. (2005), Training in 'social' work: exploring issues of involving users in teaching on social work degree programmes. *Social Work Education*. 24 (6) p. 653-675.

Wenger, E. (1998). *Communities of practice. Learning, meaning and identity*. Cambridge: Cambridge University Press.

White, M. & Epston, D. (1990). *Narrative means to therapeutic ends*. New York: WW Norton & Co.

Wright, P., Turner, C., Clay, D. & Mills, H. (2006). *The participation of children and young people in developing social care*. SCIE Guide 11. Available at: <http://www.scie.org.uk/publications/guides/guide11/index.asp> [Accessed 2 August 2010].

Wykurz, G. & Kelly, D. (2002). Developing the role of patients as teachers: literature review. *British Medical Journal*. 325 p. 818-821.

Young-Min, S.A., Hamilton, J., Heycock, C. & Kelly, C. (2004). Copying clinic letters to patients will place additional demands on both secondary and primary care: a hospital outpatient questionnaire. *Rheumatology*. 43 p. 1306-1307.

Appendix:

The 13 publications on which this thesis is based in date order.

Publication 1.

Benbow, S.M. (1988). Patients' views on electroconvulsive therapy on completion of a course of treatment. *Convulsive Therapy*. 4 p. 146-152.

Convulsive Therapy
4(2):146-152 © 1988 Raven Press, Ltd., New York

Patients' Views on Electroconvulsive Therapy on Completion of a Course of Treatment

S. M. Benbow, M.B., Ch.B., M.Sc., M.R.C. Psych.

York House, Manchester Royal Infirmary, Manchester, England

Summary: Patients' attitudes towards electroconvulsive therapy (ECT) on their completion of a course of treatment were studied using a semi-structured questionnaire. Twenty-six patients were seen before the junior doctors were trained in ECT administration and 28 patients afterwards. Most patients' attitudes were favourable, although very few fully understood the treatment. Training the junior doctors had no effect on patients' attitudes, but was associated with a shorter mean course length. ECT was acceptable to most patients who received it.

Key Words: Electroconvulsive therapy—Attitudes to treatment—Side effects—Informed consent.

Although the use of electroconvulsive therapy (ECT) has declined over the past 10 years in the United Kingdom (Lambourn and Barrington, 1986), it is still widely used to treat patients with major depressive illnesses and is sometimes regarded as the first-choice treatment in severe deluded or suicidal melancholic syndromes (Ottosson, 1985). ECT has, however, attracted adverse publicity. This has led to regulation of its use in North America (Winslade et al., 1984; Greenblatt, 1984). Actual rates of ECT in some provinces of Canada are now below expected rates, suggesting that patients who might benefit from ECT are not receiving it (Smith and Richman, 1984).

In the United Kingdom, ECT is still available to depressed patients despite publicity for the view that "ECT should soon find a place in medical museums" (Annesley, 1983). Investigations of the attitudes of patients and/or the lay population to ECT have been comparatively recent (Kalayam and Steinhart, 1981) and have been reviewed by Freeman and Cheshire (1986). Concern about the portrayal of ECT by the media and its effect on the attitudes of patients and the general public led to our study of patients' views about their experience of ECT. A

criticism of previous retrospective studies has been the elapsed time between the course of ECT and the assessment (Freeman and Kendell, 1980; Hughes et al., 1981). It was decided, therefore, to interview consecutive patients who had been treated with ECT at the completion of their course, shortly before their discharge from hospital. The study was conducted at the same time as an investigation of the effect of training on the administration of ECT by junior hospital doctors, to test whether improvement in techniques of administration is associated with more favourable recipients' attitudes towards ECT (Benbow, 1986).

METHOD

Patients who completed a course of ECT between August 10, 1982, and December 1, 1982, at the University Hospital of South Manchester were included in the study. They were interviewed shortly before discharge from the hospital, and their attitudes to ECT were assessed according to the method described by Freeman and Kendell (1980). They were first given a semi-structured interview based on a questionnaire, which asked about their views and experience of ECT together with factual details of treatments received, including side-effects and previous symptoms. They were then given an attitude questionnaire with responses of "agree," "disagree," or "don't know" to statements about ECT. (Copies of the schedules are available from the author.) Details of the ECT course were obtained from the case-notes and checked against the patients' information. Throughout the article, percentages are based on the number of patients who replied to particular questions (a minimum of 52), not on the total sample size.

RESULTS

During the study, 59 patients completed a course of ECT, but five were not seen before discharge from hospital. Interviews were conducted with 54 patients (92%). There were 18 men (31%) and 41 women (69%); 24 (41%) were >60 years old.

Details of the Course

Thirty-three patients (63%) knew how many ECT treatments they had received; the rest did not know or gave an incorrect number of treatments (always fewer than had actually been given). The length of course ranged from 3 to 15 with a mean of 8.7 treatments. Forty-four patients (85%) knew how often per week they had received ECT. Twenty-four patients (46%) did not know why they had been treated. One patient claimed to have requested it and another claimed it was to treat physical symptoms. Four patients (8%) said that tablets had not helped or that the ECT was better than tablets; and five other patients (10%) said that ECT was quicker than drugs. Seven patients (14%) thought treatment was for "nerves" and eight patients (15%) for "depression." Two patients recalled that they had recovered with ECT previously.

When asked about symptoms before treatment, 26 patients (50%) reported depression or suicidal ideas, six (12%) reported confusion or poor memory, four (8%) anxiety, and three (6%) physical symptoms. Hallucinatory phenomena or delusions were the main complaints for seven patients (14%), and six (12%) could

not recall their symptoms prior to treatment. Twelve (23%) believed that treatment had been stopped because they were better. Thirteen (25%) said they had been told that they had had enough treatment or that they had finished the course. Four patients had asked the doctor to stop, one said treatment was stopped because of side-effects, and another one in order to try tablets. Twenty-one patients (40%) said they did not know why the treatment had been stopped.

Response to Statements about ECT

Patients' responses to statements about ECT are presented in Table 1, and their ratings of fears and worries about ECT are summarised in Table 2. The questions are taken from Freeman and Kendell (1980).

Experience of the Treatment

Thirty-two patients (62%) recalled nothing pleasant about treatment, while 20 patients (39%) recalled as pleasant the experience of going to sleep (9), the cup of

TABLE 1. *Response to statements about ECT*

Statement	Agree	Disagree	Don't know
1. I was so upset by the treatment, I'd be reluctant to have it again.	14	75	12
2. If necessary I'd readily have the treatment again.	71	20	10
3. More explanation should be given to patients about the treatment.	59	29	12
4. ECT is a frightening treatment to have.	29	63	8
5. My memory now is better than it ever has been.	10	75	16
6. My memory has not returned to normal after ECT.	37	43	20
7. ECT is helpful but the side-effects are severe.	16	69	16
8. ECT has no effect on memory at all.	20	65	16
9. ECT causes permanent changes in memory.	24	33	43
10. ECT is a very good treatment.	61	16	24
11. ECT is dangerous and it should not be used.	0	69	31
12. ECT is given to too many people	4	35	61
13. ECT is often given to people who do not need it.	14	22	65
14. ECT is a helpful and useful treatment.	73	4	24
15. ECT works for a short while but the effects do not last.	24	20	57
16. ECT gets you better more quickly than medicine	57	14	29

All numbers are percentages.

PATIENTS' VIEWS ON ECT

149

TABLE 2. *Patients' fears and worries about ECT*

Worry or fear	Not at all	A little	A lot
1. About being made unconscious	63	24	14
2. About losing control of bladder	94	4	2
3. About embarrassing things happening while unconscious	82	18	0
4. That electricity was used in treatment	65	24	12
5. About having a fit or a turn	84	14	2
6. Of possible brain damage as a result of treatment	69	22	10
7. None	31		

All numbers are percentages.

tea afterwards (7), the staff in the ECT department (5), and the experience of waking up again after treatment (1).

Thirty-two patients (62%) recalled nothing unpleasant about the treatment, while 20 patients (39%) reported one or more unpleasant features. After-effects (7), waiting before treatment (5), the injection (5), the experience of going under the anaesthetic (3), the experience of waking afterwards (2), and the thirst prior to treatment (1) were the most frequent reports (Table 3).

Twenty-three patients (44%) could not recall any side-effects (Table 4). Of the 29 (56%) who recalled side-effects, 17 complained of headaches, ten of memory problems, six of dizziness or light-headedness, two of nausea and/or vomiting, two of tiredness and/or malaise, and one of confusion.

Benefit of Treatment

Thirty-eight patients (73%) said that ECT had helped them. Of these, nine said that they were well, seven no longer were anxious, five no longer were depressed, four were relieved of psychotic thoughts, three could think more clearly, and two had improved appetites.

Forty-four patients (85%) said that they were prepared to have ECT again. Of the eight (15%) who would not agree to ECT again, three had not liked the treatment, one had never wanted it, one felt it had not worked, and one each refused because of the waiting and the side-effects. Forty patients (77%) said that they would recommend ECT to a friend who had been advised by a psychiatrist

TABLE 3. *Patients' experience of different parts of treatment*

Aspect of treatment	Pleasant	Neutral	Unpleasant
1. Premedication	4	96	0
2. Waiting for treatment	2	49	49
3. ECT staff	82	12	6
4. Anaesthetic injection	18	45	37
5. Falling asleep	41	47	12
6. Waking up	18	55	27
7. The recovery period	12	51	37

All numbers are percentages.

TABLE 4. *Patients' assessment of side-effects*

Symptom	Symptom reported	Reported to prompt	Rated severe	Rated mild/mod.
1. Memory impairment	20	61	20	41
2. Headache	31	69	16	53
3. Confusion	6	43	10	33
4. Dizziness	7	43	4	29
5. Vomiting	2	2	0	2
6. Other ^a	17	6	0	6
7. None	31	12		

All numbers are percentages.

^a Feeling "muzzy," "fuzzy," ill, or "rough."

to have the treatment. While every patient had signed consent forms agreeing to have ECT and stating that the treatment had been explained to them, ten patients (19%) could not remember having given consent to ECT or thought that they had not done so. Seventeen patients (33%) felt that they could not have refused to have ECT. Fifteen patients (29%) were not happy with the way that they had been asked to give consent or could not remember having been asked at all.

Understanding of the Treatment

Only six (12%) patients had a full understanding of the procedures involved in ECT, thirteen (25%) a partial understanding, and 33 (64%) no idea or only described the anaesthesia as the treatment. Twenty-nine patients (56%) did not know why ECT is given, and 39 (75%) had no idea how it might work. One person said that the fit was the effective part of the treatment. Other theories were it "shocks you to normal," "shakes your brain," "makes you forget," "snaps you out of it," "interrupts your thoughts," "affects the sub-conscious," "affects the brain cells," and "changes brain chemicals."

Training of Junior Doctors in ECT Administration: Effect on Patients' Attitudes

Twenty-six patients completed a course of ECT before junior doctors were formally trained in ECT technique, and 28 patients completed a course subsequently. No differences were found in attitudes towards treatment between these groups, despite a marked improvement in the doctors' technique as reported previously (Benbow, 1986). However, the mean ECT course length was 9.4 for patients treated by the pre-training group and 8.0 for those treated by the post-training group. This difference is statistically significant at the 5% level ($t = 1.97$; $p = 0.025$).

DISCUSSION

This study finds ECT an acceptable treatment for the majority of patients, as previously reported by Baxter et al. (1986b), Freeman and Kendell (1980), Hughes et al. (1981), and Gomez (1975), and as memorably described by Gray (1983). Most patients would be prepared to have ECT again and would recommend the

treatment to a friend. Three-quarters of patients said that the treatment had helped them. The findings reported here are remarkably similar to those of Freeman and Kendell (1980). Clearly, however, patients in the U.K. have little understanding of what the treatment involves, despite procedures for informed consent. Although the questions in the Baxter et al. (1986b) study are not directly comparable, it seems likely that American patients are much more knowledgeable about ECT. Only a minority of patients in our study were able to describe the treatment adequately. Do our patients want to know more about ECT? Are we justified in forcing knowledge on people who may not want it? Are anxious psychiatrists reluctant to impart knowledge to patients fearing that it might militate against successfully obtaining consent? Does a greater understanding of ECT increase or decrease the likelihood of the patient consenting to the treatment? Bird (1979) reported that patients who were aware of publicity about ECT had a greater knowledge of the procedure, but no increase in their fear of it. Media coverage of ECT was not shown to have an adverse effect on patients' attitudes, a finding not sustained by O'Shea (1986) in a questionnaire-based survey of a lay population.

Improvement in junior doctors' technique of ECT administration was not related to an improvement in patients' attitudes towards treatment, but was associated with a shorter mean course length. This finding suggests that the training of those who administer ECT may be important in the patients' response to ECT and merits further investigation.

Almost one-third of our patients expressed dissatisfaction with the way that they had been asked to give their consent. Normal practice in South Manchester was for the prescribing psychiatrist to give a verbal explanation only. Baxter et al. (1986a) have used a videotape to inform patients about ECT during the process of seeking consent, but patients who saw it were less sure that they had adequate information on which to decide whether to accept treatment than those who did not see it. Although one feels intuitively that a fuller understanding of ECT should alleviate a patient's anxiety, this has not yet been demonstrated. The optimum method of seeking consent is not known. Almost one-third of our patients reported that they could not have refused ECT (compare with 23%, Freeman and Kendell, 1980).

If ECT is to remain a treatment option for patients with severe or unresponsive depressive illnesses, it is important that the procedures of informing the patient, seeking consent, and carrying out the treatment itself are well designed, professionally executed, and continually reappraised and improved. The issue of consent is a contentious one, but nevertheless must not be avoided. If our own patients can receive ECT and still remain ignorant about it, then we cannot expect the general public to be better informed. Although this study highlights the acceptability of ECT to the consumer, it also finds ignorance by the consumer of the details of the experience. Perhaps, those who prescribe ECT should review consent procedures and the way in which patients and their relatives are informed about the treatment.

We are not aware of standards for the assessment of competency to consent to or refuse treatment. In each consent procedure, we must consider that "autonomy and freedom may be meaningless legal phrases to some patients who are engulfed

by symptoms of severe mental illness" (Hoffman, 1985). We have a duty to make effective treatments available to patients, and we should not deprive them because of proscriptive legal requirements for consent to treatment that belittle the trust between the patient and his or her medical advisor.

REFERENCES

- Annesley, P. ECT should soon find a place in medical museums. *Hospital Doctor*, 21 July 1983.
- Baxter, L. R., Roy-Byrne, P., Liston, E. H. and Fairbanks, L. Informing patients about electroconvulsive therapy: effects of a videotape presentation. *Convulsive Ther.* 2:25-29, 1986a.
- Baxter, L. R., Roy-Byrne, P., Liston, E. H. and Fairbanks, L. The experience of electroconvulsive therapy in the 1980s: a prospective study of the knowledge, opinions and experience of California electroconvulsive therapy patients in the Berkeley years. *Convulsive Ther.* 2:179-189, 1986b.
- Benbow, S. M. Effect of training on administration of electroconvulsive therapy by junior doctors. *Convulsive Ther.* 2:19-24, 1986.
- Bird, J. M. Effects of the media on attitudes to electric convulsion therapy. *Br. Med. J.* 2:526-527, 1979.
- Freeman, C. P. L. and Cheshire, K. E. Attitude studies on electroconvulsive therapy. *Convulsive Ther.* 2:31-42, 1986.
- Freeman, C. P. L. and Kendell, R. E. ECT: I. Patients' experiences and attitudes. *Br. J. Psychiatry* 137:8-16, 1980.
- Gomez, J. Subjective side-effects of ECT. *Br. J. Psychiatry* 127:609-611, 1975.
- Gray, E. G. Severe depression: a patient's thoughts. *Br. J. Psychiatry* 143:319-322, 1983.
- Greenblatt, M. ECT: please, no more regulations! *Am. J. Psychiatry* 141:1409-1410, 1984.
- Hoffman, B. F. The impact of new ethics and laws on electroconvulsive therapy. *Can. Med. Assoc. J.* 132:1366-1368, 1985.
- Hughes, J., Barraclough, B. M. and Reeve, W. Are patients shocked by ECT? *J. R. Soc. Med.* 74:283-285, 1981.
- Kalayam, B. and Steinhart, M. J. A survey of attitudes on the use of electroconvulsive therapy. *Hosp. Community Psychiatry* 32:185-188, 1981.
- Lambourn, J. and Barrington, P. C. Electroconvulsive therapy in a sample British population in 1982. *Convulsive Ther.* 2:169-177, 1986.
- O'Shea, B. ECT and the media. *Bull. R. Coll. Psychiatr.* 10:84, 1986.
- Ottosson, J.-O. Use and misuse of electroconvulsive treatment. *Biol. Psychiatry* 20:933-946, 1985.
- Smith, W. E. and Richman, A. Electroconvulsive therapy: a Canadian perspective. *Can. J. Psychiatry* 29:693-699, 1984.
- Winslade, W. J., Liston, E. H., Ross, J. W. and Weber, K. D. Medical, judicial and statutory regulation of ECT in the United States. *Am. J. Psychiatry* 141:1349-1355, 1984.

Publication 2.

Benbow, S.M. Egan, D., Marriott, A., Tregay, K., Walsh, S., Wells, J. & Wood, J. (1990). Using the family life cycle in later life families. *Journal of Family Therapy*. 12 p. 321-340.

Journal of Family Therapy (1990) **12**: 321-340

Using the family life cycle with later life families

Susan Benbow, David Egan, Alison Marriott, Kath Tregay, Stuart Walsh, Jude Wells and Jane Wood*

The development of a family clinic for later life families within an Old Age Psychiatry service is briefly described. An extended life cycle model has been found useful in understanding and working with such families and is also described, together with two cases which illustrate the practical application of the model.

Introduction

The family context

Those who work with the elderly mentally ill cannot avoid involvement with their families and find that adequate assessment of a patient is often impossible without involving members of their social and family network (Hemsi, 1982). Brice Pitt (1982) writes that 'far and away the most important agency supporting the psychogeriatric patient at home is the family'. As well as the importance of the family in assessment and support, family changes are often implicated in the initial referral of an elderly person for help. Ratna and Davis (1984) collected details on 142 consecutive referrals to a community oriented psychogeriatric service and found that bereavement, departure of or illness in a carer, retirement or family conflict precipitated 60% of referrals.

It would therefore seem that family approaches which recognize the potential role of the family in the cause, maintenance, assessment and treatment of the problems of the elderly will be valuable in old age psychiatry. There are however aspects of treatment in later life families which differ from those in families earlier in their life cycles. Later life families are often, for example, involved with a carer network for which a network-oriented approach may be particularly helpful (see Pottle,

Accepted version received August 1990.

* Family Therapy Team for the Elderly, Central Manchester Health Authority, Manchester Royal Infirmary, Manchester, U.K.

321

322 *S. Benbow et al.*

1984). In contrast this paper focuses more on the later life family in itself and on how an understanding of family life cycle issues may be helpful.

Evolution of the family clinic

The Old Age Psychiatry service in Central Manchester is based at York House, Manchester Royal Infirmary, in a psycho-geriatric assessment unit which opened in 1984 when the first consultant took up post. From the beginning, the service has been community-orientated and staff of all disciplines have come into close contact over long periods with the families of those elderly people in the district who are seen as mentally ill. Increasingly, staff were aware that many problems could only be understood within a family context. Difficulties often arose when significant members of the family were not seen or perhaps when the family and professional staff had differing views on the referred patient's best interests or again when there was a perceived conflict between the interests of the referred patient and those of their family. There were also families where more than one member had psychiatric problems and it was impossible to attempt to treat one member in isolation from the rest of their family. Such awareness within the staff group gradually led to the formation of a core group of eight staff (one doctor, two social workers, two psychologists and three nurses) who eventually committed one session each week to a family clinic now known as the Central Manchester Old Age Psychiatry family clinic. [see Marriott and Pickles (1987) for a more detailed description of its development].

Two lecturers in social work with experience of family therapy in general psychiatry agreed to guide and supervise the team who met with one or both of them monthly, either to see a family or to talk about problems and progress.

The clinic procedure

Two team members interview the family, whilst the rest act as a back-up team, behind a one-way screen. If the family agree, the interview is videotaped. A nominated supervisor in the back-up team decides when and how to intervene using a telephone link and another nominated member takes notes. The family and therapists meet for about 45 minutes and reconvene for about 10 minutes to conclude the session, following a short consultation break.

An understanding of the family life cycle has been crucial to the development of the work.

The family life cycle

One model of the life cycle divides family development into six stages: five cover the period from single adult to launching children and one final stage is regarded as spanning the period from retirement until the death of both spouses (Carter and McGoldrick, 1989). Clearly this is unbalanced, in that the final stage could cover as many years as the first five stages. The implication is that in later life a family stops developing. This is not in accordance with our experience. Family development and maturation continue in the setting of a series of life cycle events which have to be accommodated. Indeed, some of the most difficult adjustments may have to be made in later life, and problems can occur here, as they can occur earlier (Barnhill and Longo, 1978).

The post-retirement or ageing family has been represented as a brief terminal offshoot of the cycle (Turnbull, 1989). The post-retirement period has in fact lengthened over recent years as people have survived longer when earlier stages concerned with child-rearing have concurrently become shorter (Glick, 1977). In late life the family may have to accommodate the retirement of the first partner and then of the second. It may also have to adjust to illness and disability in its elders. Their role as grand-parents will develop and may be important in the changes facing their adult children. They may become great-grand-parents, with implications also for the generations between. Support of younger generations is often under-emphasized by observers, but may be considerable. Loss of status and respect may result from a society's negative view of ageing. This may push the elderly towards their families, perhaps seeking a valuable role, or, sometimes, families themselves may share society's negative stereotypes of late life. Loss of the peer group occurs at this stage of life with a period of accumulating bereavements. When the first partner dies the residual partner may suffer additional social restrictions (since activities which were open to couples may be closed to the widowed) which may in turn put further pressure on family relationships. Thus this period can be eventful and demanding of considerable change and adjustment (Walsh, 1989).

Blenkner (1965) extended the stages of development to incorporate a phase of 'filial maturity', defined as the mature adult's capacity to be depended upon by the parent, and regards this not as role reversal but as fulfilment of the filial role. Part of later family development may involve adult children adjusting to the parent's need to depend on them and the elderly parent accepting their own need to depend on, and accept help from, their adult children. Attachment theory can be

324 *S. Benbow et al.*

usefully applied to later life issues here. Adult children may respond to a decline in their ageing parents by adopting caregiving behaviours, even before actual help is needed. Filial anxiety (when contemplating the possibility of having to provide help to ageing parents) may also lead to adult children feeling stressed although they are providing little or no practical help at this stage. Strain and negative feelings can be related more to perceived parental dependency rather than the amount of practical help given (Cicirelli, 1983).

Cross generational interplay of life cycle problems and change

Some therapists have recognized the continuing adaptive capacity of the elderly (Brody, 1974) and their ability to grow and change (Spark and Brody, 1970). Intergenerational work has been used to try to help 'every member regardless of age or phase in life' (Spark, 1974), but usually the approach is from the viewpoint of trying to help with an identified patient presenting early in the family life cycle. Older family members themselves are thought to seek help only rarely and are regarded as unlikely to present to family therapists (Carter and McGoldrick, 1989).

When one generation faces an important life cycle transition, another generation in the same family may also be confronted by their own transition point. Walsh (1989) describes how 'lack of complementarity or fit' can occur when the developmental needs of two generations are incompatible. It may be possible in therapy to allow the transitional development of one generation to assist the adjustment of another. The second case history presented here illustrates this.

The cross generational aspect is often important in work with the elderly, since the therapist commonly belongs to a younger generation. This can have advantages and disadvantages (Simon, 1989) but clearly cannot be avoided in work with later life families.

Integration of family therapy and the old age psychiatry service

Multi-disciplinary staff teams in old age psychiatry work with later life families in their everyday work, but the use of more formal family therapies with such families has attracted little attention. Work with two families will be described which illustrates the practical application of life cycle theory in old age psychiatry. The two cases also illustrate how family therapy can take place alongside other therapeutic activities: the

first patient was an in-patient or attended the day hospital throughout most of the work. Her therapists saw her as part of their everyday work in these other settings. One disadvantage of this method of working is that contact with the therapists continues outside the family sessions and cannot be rigorously controlled. However, sometimes this may give opportunities for therapists to reinforce certain messages, and, if communication between the family therapy team and the rest of the old age psychiatry team is good, other members of the team may do likewise. Thus messages can be reinforced in a number of different ways, which may in some circumstances be an advantage of this way of working.

Another potential disadvantage is that a therapist may arrange to review a patient outside formal family clinic meetings and find that other family members have attended expecting a full family session. This happened during work with the second family, but the therapist continued the therapeutic line that had been agreed in the previous session, and the unscheduled family meeting proved to be advantageous.

It is important to ensure that conflicting messages are not given by staff who are not directly involved in the therapy sessions, since this could undermine therapy. Communication within the old age psychiatry service could constitute a problem. In practice this has not been insurmountable and has been dealt with by inviting non core group members to observe sessions with the back-up team in order to ensure that they understand and work with the therapy. Thus while in the first case, the patient was an in-patient, a ward nurse always attended sessions and liaised with the ward staff, thereby ensuring a coherent approach. Another benefit of this way of working is that it allows new ideas to be shared with staff who may not otherwise have this opportunity.

The first case also illustrates the initial use of traditional psychiatric procedures followed by a family approach. We have used this sequence successfully with some families, but with others have employed family and psychiatric approaches simultaneously. Occasionally we have offered a family assessment from first referral, but these families have been difficult to engage either in therapy or in the service generally. Many people referred to our service present with a mixture of physical, psychological and family problems from the outset, but in the majority we feel that simple treatment of the illness presented will enable the family to resolve their problems and move on. A small proportion have increasing difficulties as treatment of the referred patient is attempted, or with time the family aspect becomes more prominent. These are the families who have often been convened in the family clinic. Undoubtedly, by this stage, the family are often engaged with members

326 S. Benbow et al.

of the psychiatric service and it is easier to convene a family meeting. Also any medical problems will have been clarified and will not dominate discussions. It may be that elderly people are more readily engaged by an offer of traditional treatment initially. Perhaps the elderly need more 'orientation' to talking therapies than younger people. Alternatively, their expectations may reflect those of the referring agents, who may not yet expect family therapy as a first-line offer. It is also possible that we have our own misconceptions regarding what the elderly and their families will accept. Whichever reason one favours, the time allowed by moving from a traditional to a family approach may enable staff to gradually re-orientate the family, so they are able to accept an appointment in the family clinic later.

Case 1: The E. family

Referral

Emma E., a single woman of 74, was first referred to the Old Age Psychiatry service on 10 September 1985 when her family doctor requested a domiciliary visit. He described her as a quiet lady, always physically fit, who had gradually become 'more confused' over the previous three weeks with 'paranoid ideas' about people trying to break into the house. At first he thought she had suffered a small stroke, but this was not confirmed. He had started her on a major tranquillizer because of agitation in the evenings. Her sister and brother-in-law were described as very concerned and trying to care for her.

Initial assessment

Emma was visited at home where she lived with her sister and brother-in-law, and was seen with her sister Jane. Both described a change in her following a series of robberies over the previous Christmas period. She had become afraid that the house would be robbed and complained of noises in the back yard at night which she feared were caused by people trying to break into the house. Sometimes she could hear people talking outside, but could not decipher their exact words. Over the two or three weeks prior to referral she had become increasingly anxious about being left in the house on her own, and had started to follow her sister everywhere.

She had no past psychiatric history. She was one of five sisters (Figure

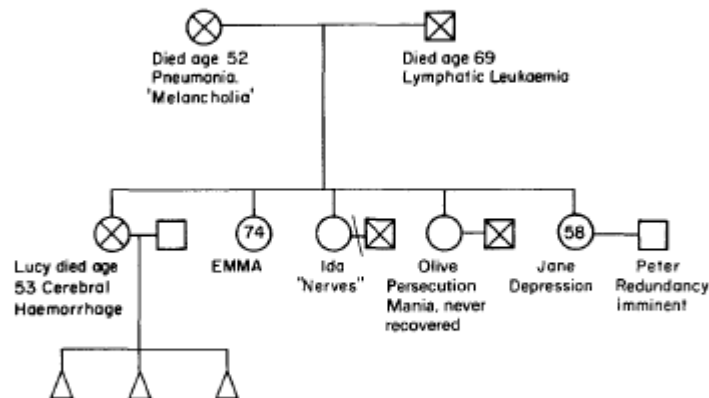


Figure 1

1) and had worked as a clerk in a mail order firm until retiring at 64. She had lived with Jane, her youngest sister, for 31 years and had never married. She had at one time been a singer and dancer in concert halls. Her mother was said to have had 'melancholia': Jane had been treated with ECT for depression in the past and another sister, Olive, had received psychiatric treatment for 'persecution mania'.

On mental state examination at that time, Emma was found to be anxious, agitated and depressed with biological symptoms of depressive illness and nocturnal auditory hallucinations. Treatment was started in the community with anti-depressant tablets.

Psychiatric treatment

Subsequent home visits suggested that Emma was starting to respond to the medication. However, in mid-December the GP phoned to report a deterioration in the 'confusion' and Emma was admitted to the assessment ward on 12 December 1985. She was thought to be showing signs of anti-depressant toxicity, and, when the dose was decreased, appeared to be well on the ward, with no evidence of residual depression or psychotic symptoms. After successful home leave she was discharged home on 10 January 1986.

She remained well at home for three days and then became low in mood with ideas of hopelessness, guilt and worthlessness plus biological symptoms of depression. She walked to a reservoir near her home

328 S. Benbow et al.

intending to drown herself, but was seen by a neighbour, escorted back home and readmitted to hospital on 21 January 1986.

A short course of ECT was stopped when she became elated, talkative and noisy with grand plans for her future. Her mood then stabilized on lithium and anti-depressant tablets. After two successful weekends at home she was discharged on 25 April 1986, apparently well, to attend the day hospital from home. From early May her symptoms gradually reappeared and she was readmitted, depressed, suicidal and psychotic on 13 June 1986. She had several transient ischaemic attacks on the ward and was started on aspirin as prophylaxis, but her mood gradually improved and there was little to support a diagnosis of depression after one month as an in-patient. The most obvious feature of Emma's illness by now was that she could be very well on the ward for prolonged periods but would rapidly relapse following discharge home despite continuing maintenance treatments. Jane and her husband Peter were invited by letter to a formal family assessment on 15 July 1986.

Family therapy assessment and hypotheses

The first meeting on 15 July 1986 addressed three main issues: why did Emma not stay well; what was the family's view of the problem when Emma was at home; what was it like for Jane and Peter when Emma was ill? Careful tracking elicited additional information about the family's history and linked recent events with those in the past. Emma was seen by Jane as becoming 'awkward' as she got older, and this threatened the family homeostasis and could not be tolerated.

Emma had clearly been enmeshed with Jane, and Peter had been peripheral. Jane had functioned as parent and Emma as child, but the latter was now growing up and making a bid to be more independent e.g. by buying her own piano. This had unbalanced the system, in conjunction with Peter's impending redundancy which would throw him together with the women, threatening their close relationship and testing his marriage. Could Emma's 'growing up' be viewed as necessary to allow space for Peter and Jane to become a married couple when Peter effectively retired from work? Jane was felt to be vulnerable in contrast with Emma's strength and clear ability to influence the behaviour of both Jane and Peter. A family approach offered a way forward for the family. All three family members were facing important life cycle transitions.

Attempting to leave

A second meeting on 6 October 1986 planned to look at what happened during a period when Emma was home on leave from hospital. Before the session the team agreed to endeavour to get the family to make decisions about periods of leave, rather than professionals prescribing leave which was then unsuccessful. Initially Emma indicated that she felt the leave had been successful, but complained of feeling sick, and her subsequent non-verbal behaviour dominated the meeting. Soon she had to leave the room to be sick in the toilet. Jane talked about her worries during the leave, but particularly the possibility of Emma having a relapse: could she face this? When the family members were each asked what they wanted to do next, Peter asked for discharge that day (speaking for Jane), Jane said that she would not say ('I'm used to a doctor telling me . . . I won't tell you') and Emma said that she wanted to stay in hospital for a few more days, explaining that she felt happier with people around her. Jane broke down at this point but said that she was upset because she could not cope if Emma were to become ill again, and could not take the responsibility. Jane summed up her feeling as 'I want her home, but I want her home well' (but if the change in Emma was seen as due to her ageing, would she ever be really well again?). Jane's distress, however, could be related to Emma's bid to remain in hospital, independent from her family.

By the end of the session Emma was slumped in her chair, looking ill and taking no part in the proceedings: inevitably she remained in hospital.

In retrospect Emma was clearly in control of the session and of decisions stemming from it. Her behaviour was adolescent and could be understood as a bid for freedom or a rebellion against her 'parent' (Jane).

The third session on 20 October 1986 followed a long weekend at home. Jane was clearly very angry as she came up to the interview room, and exploded with anger at the video recording set-up although it was identical to the previous meetings. Emma said that she had no objection to the set-up and Jane stormed out. Peter explained that Jane was angry and disappointed with herself because the leave had been unsuccessful. Emma had heard voices and Jane and she had not spoken for 36 hours before coming to the session. After only a brief conversation the family were sent out together to discuss how to proceed. After a break, Emma returned alone to the interview room, and said 'I'll have to go back to hospital.' Thus, once more, Emma distanced herself from her parental sister. At this point the team started to take therapeutic control.

330 *S. Benbow et al.*

Overnight stays were banned, a critical and long overdue measure which allowed other issues to be addressed.

The therapists visited Jane and Peter at home for a fourth session on 17 November 1986, and attempted to reconvene a full family session. Jane initially did not want any recording equipment or back-up team, but related her upset to Emma's hearing voices and refusing to share her feelings with Jane.

Later, Peter and Jane agreed to attend and a fifth session was held on 21 November 1986. The plan was to take therapeutic control, to attempt to understand why hospital was different from home, to avoid the family having to make decisions, to agree beforehand that no-one would leave the session, and to focus on sadness and other feelings.

The family agreed not to leave the session prematurely, although Jane was initially reluctant. A clear description of what happened at night when Emma heard voices was at last obtained, and Jane went on to talk about how it reminded her of her mother's death when she was young. She also described how she felt a responsibility to carry on looking after Emma, who was the only sister to remain single. The backup team gave one therapist the task of joining with Jane and 'confirming' her (Minuchin and Fishman, 1981). Jane responded positively to comments reinforcing how difficult all this must be for her and how sad and upset she must feel. The session concluded with Peter and Jane being given the task of working out how Peter could help Jane when she was sad and worried about Emma.

All the team felt that this was a turning point in therapy. The task was to help Jane and Peter to adjust to more time together and to allow Emma some freedom, away from her controlling parent (Jane).

At the sixth family session on 9 December 1986 the three family members interacted more. Jane was very engaged with one therapist, and the attempts to join with her seemed to have produced change. The voices were successfully linked with worry. Discussion on possible new ways of coping was constructive and a coping strategy was planned for the Christmas break since the family all wanted to be together at Christmas. They were told to expect the voices to occur and were able to contemplate this and how they might each cope.

The team hypothesized that Peter was disengaged from his wife's feelings and that Emma was needed by Jane to fill this gap. However, had Jane been covertly seeking care from Emma under the guise of mothering her? This might explain Emma's obvious enjoyment of her freedom and Jane's distress at the prospect of losing her. Emma's attempt to grow up might be related to Peter's impending redundancy which would allow

him to replace Emma, and perhaps give space for Emma to grow up at last.

Letting go

The seventh meeting on 16 January 1987 followed the Christmas break. The coping strategies had failed and all agreed that the leave had been unsuccessful. Discussion moved on to other alternatives: perhaps Emma could not return home because she was too worried without professional staff to look after her and perhaps Jane could not continue to take responsibility for her because of the stress this placed on her. Peter would need his wife more now that he was redundant. After the break the therapists said that we would list Emma for a place in an Elderly Person's Home. Jane accepted this, but expressed doubts about whether she could cope with it.

Our plan now was to support Jane and Peter in allowing Emma to move into an EPH and to look at potential problems for each of them over the transition period and how these could be dealt with; also to ensure that Jane and Peter were still able to have a role in Emma's life within an EPH.

At the next session on 13 February 1987 Jane and Peter were seen as a couple. Jane was initially angry about Emma visiting her by bus on a foggy day, but relaxed as the session progressed. She denied any part in the decision that Emma should go into a Home: 'It's what Emma wants . . . I don't have to like it and I don't.' She perceived Emma as well at the time but saw it as only temporary. It was apparent that Jane had difficulty in drawing a line between being concerned for Emma and actively interfering in her life. Similarly Emma appeared to put pressure on Jane to become involved, thereby reinforcing her behaviour.

Jane was encouraged to see a continuing role for herself, communicating with staff. Her belief that Emma would relapse was accepted and it was predicted that this was likely to occur on admission to an EPH.

On 13 March 1987 the couple were seen again. By now Jane appeared to be distancing herself from Emma. She acknowledged her upset about losing Emma to a Home, but was trying to find new activities with other family members. Peter seemed more withdrawn and anxious: he revealed for the first time a nine-year history of depression treated with anti-depressants. His feelings and difficulties were acknowledged and normalized in view of his recent redundancy and worries about Emma and Jane.

This was felt to be a positive session as both moved towards letting

332 S. Benbow et al.

Emma go, accepting the upset of the loss and restructuring their own lives together.

Growing up

A tenth meeting soon afterwards on 30 March 1987 was held to inform the family that Emma had been offered a place at an EPH. Jane was upset and cried when told. Peter held her hand supportively. His feelings were also acknowledged, and their future roles were anticipated. Both were given positive feedback about caring for each other and sharing their feelings. It was agreed to meet again when Emma had decided whether to accept the place. Emma was discharged to the Home on 10 April 1987.

Jane and Peter were seen again on 7 May 1987. Peter was feeling better, but Jane was down and having difficulty with sleep. Much of the session concentrated on what they were doing at home and how they felt. Both spoke more readily and openly about this. Again they were given a positive message about how well they were both coping at a difficult time and encouraged to continue the quest for interests of their own. It was agreed to meet at the EPH review when Emma would decide whether she wanted to remain permanently at the Home.

The last family meeting took place on 16 June 1987 at the Home with Emma present. She had settled into the Home well and wanted to stay. She was obviously enjoying life, had made new friends, was going out on the bus to town and only visiting Jane for one day each week. Jane had accepted this but expressed her sadness about it. Peter was supportive towards his wife and optimistic for the future. Jane and Peter were offered a final session, but said that they felt able to cope and would contact one of the therapists if necessary.

Peter and Jane were contacted by telephone later that autumn and were doing well. They had experienced worries over another sister's mental state and had used their knowledge of the system to seek help appropriately. They had both accepted that Peter would not return to work and had effectively retired. Both had found new interests. Emma continued to enjoy her independence and, although she has intermittently heard voices since, she has not needed psychotropic medication and has continued to enjoy life.

Case 2: The T. family

Referral

Patricia T. was first referred to the Old Age Psychiatry service in November 1985 by a geriatrician who saw her with multiple physical complaints but no significant illness to account for them. He identified her as being depressed and was concerned that she might take an overdose.

Initial assessment

Patricia was seen at home on 8 November 1985. She described herself as always having been a depressive. Her husband had died just over 3 years before of lung cancer and, following this, she had moved to live in a flat which she hated. She related the worsened depression sometimes to her husband's death and sometimes to the move.

She had suffered a 'breakdown' at the age of 20 and had been treated with ECT at 40 for a puerperal illness. For years she had taken amphetamines to keep herself going at work, where she worked long hours as a waitress, travelling around to keep in a job. Her mother had played an important role in bringing up her two daughters, Patricia (now Mrs F.) and Sue. She described her father and brother as 'depressive'. Figure 2 presents the family tree.

On examination at this time she was depressed and felt that she would be better off dead, but said that her responsibilities towards her grandchildren stopped her from taking an overdose. She could see no future for herself and complained that she was afraid of being alone, describing physical symptoms of anxiety when alone, particularly at night. For many months one or more of her younger daughter's three children had been staying the night at her flat to avoid Patricia's having to sleep there alone.

At this stage Patricia was offered a period of assessment as an in-patient or day-patient, but refused both. She wanted tablets, but had been prescribed numerous drugs in the past with no apparent response. A letter was sent to inform the GP of what was advised and no further appointment was made.

In September 1987 Patricia was re-referred at her own request by her GP with complaints of depression, bowel and urinary disturbance, weight loss, poor appetite and fear of being alone at night.

She was seen in the out-patient clinic with her older daughter,

334 S. Benbow et al.

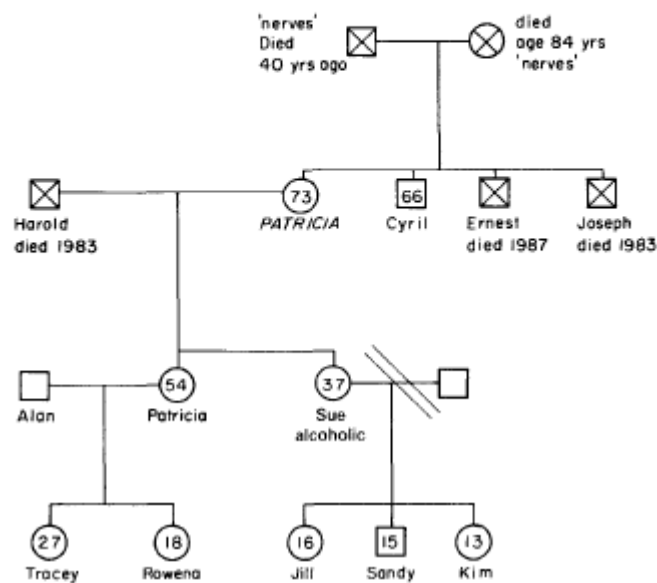


Figure 2

Patricia F., and presented an identical history and mental state to that seen in 1985. She accepted an offer of assessment as a day hospital patient.

Assessment in the day hospital revealed no evidence of sustained mood disorder, although she and her older daughter (the main carer) continued to complain bitterly about the problems at home. A family assessment was therefore offered.

Family therapy

Patricia, both daughters, Mr F (son-in-law) and Sue's three children had been invited to the first meeting on 8 January 1988 but only Patricia and her older daughter attended. Issues addressed were:

1. What role did Patricia fulfil with regard to her grandchildren? It was felt that Patricia was parenting them since Sue was described as a divorced alcoholic, absorbed with her own problems. The children

were known to be truanting and Patricia was worried that they might get into trouble.

2. What was the relationship between mother and daughters? Mrs F appeared to be parenting her mother and spending time with her at the expense of her own family. Patricia always expressed love, concern and worry about her other daughter Sue, who unlike her sister, appeared to do little or nothing to help her mother.

Hypothesis

Patricia and her daughter Mrs F were thought to be enmeshed, with Mr F having a more peripheral position. However, to an extent he regulated the distance between mother and daughter by objecting if his mother-in-law spent too much time at their house. Mrs F felt torn between her husband and mother, and if she spent less time with her mother worried about her even more. It was in her interest, as well as her mother's to encourage Sue's children to spend time with their grandmother and she had even given them money to go by taxi to their grandmother's house late at night. Patricia's illness also benefited Sue who had her children cared for while she attended to her own needs. The grandchildren were allowed to spend time at Patricia's house when they truanted from school, which was comfortable for them and gave Patricia the company she sought. Thus it was difficult to see how Patricia could lose her symptoms, since everyone in the family gained by them. Why, however, was she presenting now?

It was planned to offer Patricia admission to hospital and then to aim for an early meeting with all the family since admission should increase motivation to change. This intervention took Patricia's symptoms seriously, but also reinforced the boundaries between the generations.

The day after her admission to hospital Patricia took her own discharge on 14 January 1988.

Can Patricia move towards old age?

A further attempt was made to convene the whole family on 29 January 1988 to look at what happened during admission and why it failed. Once more only Patricia and Mrs F attended. The question of why Patricia was presenting now was answered early in this meeting, when she complained that 'my grandchildren are going out and leaving me'. This tied in with the worsening of her symptoms. In their early teens, the children now wanted to go out to parties and discos, rather than

336 *S. Benbow et al.*

spending the evening with grandmother. The family had paid for taxis from discos to ensure that Patricia was not left alone all night, but the children were rebelling at this and Mrs F rightly pointed out that the status quo could not continue indefinitely.

It was accepted by all that Patricia could not live alone, and indeed she had never done so, making it unlikely that she would feel able to in the future. Various options were considered:

1. Patricia could move to live with Sue but Mrs F pointed out that they had never got on well and could not live together. Sue had never offered to have her mother and Patricia felt that the house was too small.
2. Patricia could move to live with Mrs F but her husband would not tolerate this and both women knew this. Even visits by Patricia precipitated resentment from the son-in-law. Nevertheless, it seemed that this was Patricia's preferred option.
3. A companion could be sought for Patricia but as Patricia said, 'Who would live with me when I'm like this?' Mrs F also pointed out that this would be expensive.
4. Patricia could move to a private home. This seemed to be Mrs F's preferred option, despite the cost, but required Patricia to see herself as elderly and in need of care.
5. Nothing might change, and the grandchildren would continue to stay with Patricia at night. Both women said they accepted that this could not continue for much longer.

The team supported Mrs F in not taking her mother in (because of other responsibilities) and Patricia in not wanting to live alone (because of loneliness and anxieties about being alone). Mother and daughter agreed to look at other options and to discuss them with the absent family members.

On 10 February 1988 Patricia moved into a rest home on a trial basis. In late April there was a request for a domiciliary visit and Patricia was seen alone at her flat on 22 April 1988. At the Home she had eaten well, gained weight and felt happier, fitter and less anxious. She said that she had not fitted in there and was too well to live in a Home, so she had returned to live alone in the flat. Immediately she regretted this move, was afraid to remain on her own and symptoms had rapidly returned. She presented with a mixture of anxiety and depressive symptoms but no evidence of a sustained biological depressive illness, and her complaints were clearly closely linked with her social circumstances.

She was offered day hospital attendance and a further family meeting, which she accepted but said 'They won't come.'

On 6 May 1988 Patricia and Mrs F attended a meeting unaccompanied by other family members. The plan was to look at what led Patricia to leave the Home, drawing on a hypothesis that Patricia's being ill allowed her to keep the grandchildren with her, preventing them from getting into trouble when truanting and providing supervision which was not given by their alcoholic mother. If Patricia recovered, who would care for their grandchildren? They were, however, now adolescent and were starting to go out and have boyfriends so Patricia had become more ill to maintain the system. Taking on the parenting role prevented Patricia from having to face life alone as a widow in sheltered housing where all her neighbours would be elderly.

A paradoxical approach

It became clear early in the session that the same alternatives were available as before. It was also clear that Patricia saw herself as too ill to live alone but too fit for a rest home which linked with her difficulty in seeing herself as elderly. The team's difficulty was that other members of the family had again failed to attend, thus blocking access to important parts of the system. During the break it was decided to try a paradoxical approach. It was suggested that Patricia would get worse in order to stop the grandchildren from growing up and away from her and that it did not seem that she could stop fulfilling this role and risk losing them by going into a private home. Patricia responded by saying that she didn't really want the children round, the only problem was being frightened. We offered another meeting in July.

Meanwhile Patricia stopped attending the day hospital. The family cancelled the next family meeting because Mrs F was moving. We wrote and offered to meet the family at Patricia's flat, but only Patricia was there at the appointed time. The grandchildren were still staying with Patricia at night, apart from two nights each week when she stayed at Mrs F's house. She said she had liked day care but was unable to attend after an argument with a nurse. We agreed that the team social worker would look at benefit problems with her, at her own request, and would arrange a day centre visit, to see whether she could attend there.

The social worker attempted twice to see Patricia by appointment, but she was out on both occasions. The doctor member of the team called subsequently to review Patricia medically at her flat, having informed her of the appointment by telephone (in view of the social worker's

338 S. Benbow et al.

difficulties in getting to see her). On arrival she was greeted by Patricia and taken upstairs to meet Patricia's brother (Cyril), Mrs F and the older two of Sue's children (Jill and Sandy).

The critical transition

For some time, different members of the family talked about their worries regarding Patricia, and described the difficulties for the grandchildren in having to stay with her. In response to questions, Jill told her grandmother that she, her brother and sister could not carry on doing this for much longer. She was about to leave school and start a job and had started to go out with boyfriends. Despite her worries for Patricia, she could not carry on. Patricia insisted she did not want to go and live with Mrs F, but non-verbally indicated that this was exactly what she did want. Mrs F said that her husband had already found Patricia's presence in the house two nights each week too much and that her younger daughter was thinking of leaving home to get away from the trouble between her father and grandmother. Mrs F and Cyril agreed that they were concerned that Patricia was unable to eat, losing weight and would fade away if she remained in the flat. The therapist could only shake her head sadly, agree how awful it all was and how the family had no alternative but to watch Patricia deteriorate since there was nowhere else she could go and no-one who could stay with her. The therapy team was helpless.

Shortly afterwards Patricia moved into the rest home where she had previously stayed briefly and gave up her flat. She increased in weight, brightened in mood, slept better and started to help staff with more disabled residents. She continued to visit her family and they visited her regularly.

Therapy involved re-establishing the generational boundaries and acknowledging the life cycle changes (for Patricia, adjustment to ageing and seeing herself as part of a peer group of old people; for the grandchildren, development of increasing independence as they moved towards life on their own). The critical transition was the developing independence of the grandchildren, which forced Patricia to confront her own ageing and her need to be with others, thereby moving her on as the grandchildren progressed towards their separation from the family. Identifying the critical life cycle transition, and using it to help other members of the family to move on simultaneously, was an important part of therapy.

Conclusions

It is important in work with the elderly to take into account the family context. This facilitates understanding amongst all members of a family, and makes the professionals' tasks easier. A family approach is not contra-indicated by co-existing physical and psychiatric illness in the referred patient, as was shown in the first family case study. Indeed, in later life, physical symptoms are often an available, acceptable and useful route to extra care, as illustrated by Patricia.

The family life cycle presents a useful way of describing and understanding families in later life, since changes continue throughout old age and demand ongoing adaptation and maturation. Chronological age may not be an indicator of the family's life cycle stage, as illustrated by the E family who, despite being chronologically at retirement, were developmentally dealing with the separation of their growing child (Emma) and the issue of whether they could launch her into the world on her own. Life cycle issues of different generations in one family may overlap but as one generation moves through a transition, they can help another generation to negotiate their own changes, which can help to overcome 'stuckness' in the family generally.

A family therapy approach can add a new dimension to an Old Age Psychiatry service, where it can be integrated with the range of interventions more commonly used in late life. Emma's case demonstrated this: a conventional psychiatric approach led to a cycle of readmissions, whereas a systemic contextual approach allowed change for Emma and the other members of her family to take place. Without such an approach would the cycle of discharge, relapse and readmission have continued? Would the only conventional solution have been long-stay in-patient psychiatric care? This raises the question of what happens to families with problems like this in the absence of systemic understanding and treatment. Family therapy has a great deal to offer to later life families and, having recognized this, it is important to ensure that all who might benefit from such an approach have access to it.

Acknowledgement

We would like to acknowledge the contribution of Mary Varley who has nurtured the germinating seeds of systemic thinking and helped us grow, and to thank former members of the family therapy team who have now moved on but whose work and ideas have since borne fruit, especially Ann Quinn.

340 S. Benbow et al.

References

- BARNHILL, L. R. and LONGO, D. (1978) Fixation and regression in the family life cycle. *Family Process*, **17**: 469–478.
- BLENKER, M. (1965) Social work and family relationships in later life with some thoughts on filial maturity. In: E. Shanas and G. F. Streib (Eds), *Social Structure and the Family*. Englewood Cliffs N.J., Prentice-Hall Inc.
- BRODY, E. M. (1974). Aging and family personality: a developmental view. *Family Process*, **13**: 23–37.
- CARTER, B. and MCGOLDRICK, M. (1989) Overview. The changing family life cycle: a framework for family therapy. In: B. Carter and M. McGoldrick (Eds), *The Family Life Cycle. A Framework for Family Therapy*. Boston. Allyn and Bacon.
- CICIRELLI, V. G. (1983) Adult children and their elderly parents. In: T. H. Brubaker (Ed), *Family Relationships In Later Life*. Beverly Hills. Sage Publications.
- GLICK, P. (1977) Updating the life cycle of the family. *Journal of Marriage and the Family*, **39**: 5–13.
- HEMSI, L. (1982) Psychogeriatric care in the community. In: R. Levy and F. Post (Eds), *The Psychiatry of Late Life*. Oxford. Blackwell Scientific Publications.
- MARRIOTT, A. and PICKLES, A. (1987) A family clinic for the elderly in central Manchester. *PSIGE*, **24**: (Oct.): 12–14.
- MINUCHIN, S. and FISHMAN, H. C. (1981) Joining. In: *Family Therapy Techniques*. London. Harvard University Press.
- PITT, B. (1982) In: *Psychogeriatrics An Introduction to the Psychiatry of Old Age*, 2nd Edition. Edinburgh. Churchill Livingstone.
- POTTLE, S. (1984) Developing a network-orientated service for elderly people and their carers. In: A. Treacher and J. Carpenter (Eds), *Using Family Therapy*. Oxford. Blackwell.
- RATNA, L. and DAVIS, J. (1984) Family Therapy with the elderly mentally ill. Some strategies and techniques. *British Journal of Psychiatry*, **145**: 311–15.
- SIMON, R. M. (1989) Family Life cycle issues in the therapy system. In: B. Carter and M. McGoldrick (Eds), *The Changing Family Life Cycle. A Framework For Family Therapy*. New York, Gardner Press.
- SPARK, G. M. (1974) Grandparents and intergenerational family therapy. *Family Process*, **13**: 225–237.
- SPARK, G. M. and BRODY, E. M. (1970) The aged are family members. *Family Process*, **9**: 195–210.
- TERKELSEN, K. G. (1980) Towards a theory of the family life cycle. In: E. A. Carter and M. McGoldrick (Eds), *The Family Life Cycle: A Framework For Family Therapy*. New York. Gardner Press.
- TURNBULL, G. J. (1989) Violence, families and society. *Psychiatry in Practice*, **8**: 10–13.
- WALSH, F. (1989) The family in later life. In: B. Carter and M. McGoldrick (Eds), *The Changing Family Life Cycle. A Framework For Family Therapy*. Boston. Allyn and Bacon.

NOTE: This publication is copyright The Association of Family Therapy and Systemic Practice and published by Wiley: it is reproduced here with permission (Licence number 2487020807844).

Publication 3.

Benbow, S.M., Marriott, A., Morley, M. & Walsh, S. (1993). Family therapy and dementia: review and clinical experience. *International Journal of Geriatric Psychiatry*. 8 p. 717-725.

INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY, VOL. 8: 717-725 (1993)

FAMILY THERAPY AND DEMENTIA: REVIEW AND CLINICAL EXPERIENCE

S. M. BENBOW, A. MARRIOTT, M. MORLEY AND S. WALSH

Family Therapy Team, York House Family Clinic, York House, Manchester Royal Infirmary, Oxford Road, Manchester, M13 9BX, UK

SUMMARY

Family therapy techniques have, until recently, had little impact on the development of old age psychiatry and the services provided. The literature on family therapy in relation to people with dementia and their families is reviewed and illustrated with results from a study of families coping with dementia who attended the York House Family Clinic. Similar therapeutic techniques were used with families coping with dementia as with those coping with other mental illnesses in later life, but some differences were found in the areas of discussion during sessions. Families coping with dementia were seen for fewer sessions, but more family members were present per session and sons and daughters-in-law were more likely to attend. The literature and various hypotheses which might explain these differences are presented and discussed. Further work in this area is needed, but our findings suggest that family therapy can be useful in work with dementia sufferers and their families, and can be offered within an old age psychiatry service.

KEY WORDS—Family therapy, dementia, geriatric psychiatry.

Dementia is a major health problem and accounts for a large proportion of referrals to old age psychiatry services. Ratna and Davis (1984) studied 142 consecutive referrals to a psychogeriatric service and reported a diagnosis of dementia in 47% of referred patients. They found that departure or illness of the carer constituted one of the largest groups of referrals and noted that, although the focus has often been on the patient, the resources and abilities of the carer can be more important in determining outcome. In concluding, they argued in favour of a family-centred approach to the care of the elderly mentally ill. Family therapy has, however, not been a prominent component of old age psychiatry services in the past.

THE ELDERLY IN FAMILY THERAPY

Older people have been seen as an adjunct to the treatment of younger families (Spark and Brody, 1970), rather than as a group of people who might

themselves benefit from this form of treatment. There has been a widespread belief that older adults are not psychologically minded (Hughston *et al.*, 1989). Flori (1989) found age to be negatively correlated with the likelihood of taking part in family therapy. There is, however, growing evidence of increasing interest in the use of family therapy in late life (Richardson *et al.*, in press). Anderson (1988) described old people as 'ill-defined figures populating the upper fringes of genograms constructed to illuminate the problems of younger generations'. This view has not been unchallenged, as others have argued that changes in the older adult's functional capacity threaten the stability of the family (Greene, 1989). Thus chronic illness of any sort (or even old age itself with its associated changes) will have a ripple effect through the extended family. Montalvo and Thompson (1988) describe the care of an elderly man suffering from dementia, which demonstrates the importance of family work in a geriatric medical context. Perhaps the use of family therapy understanding and techniques could be as relevant to work in geriatric medical settings as to geriatric psychiatry.

Address for correspondence: Dr S. M. Benbow, Consultant Psychiatrist (Old Age Psychiatry), York House, Manchester Royal Infirmary, Oxford Road, Manchester, M13 9BX, UK.

0885-6230/93/090717-09\$09.50
© 1993 by John Wiley & Sons, Ltd.

Received 17 August 1992
Accepted 23 January 1993

DEMENTIA AND FAMILY THERAPY

Jeffery (1987) pointed out that 'the battlefield of dementia is probably the major issue that distinguishes family work with the elderly from family work with younger age groups'. Is it appropriate to consider the use of family therapy in families struggling to cope with a demented member?

Jeffery (1987) drew attention to the possible advantages and disadvantages of involving the elderly person with dementia in family meetings, and highlighted the problems which it brings for both families and therapists. Only if the old person is present can the therapists observe and intervene during the session in family interactions involving the elderly person directly. Inviting the old person communicates important messages to the family: that this is a problem for the whole family, and that the identified patient has legitimate needs and views. Some might argue that the identified patient has a right to be present. Alternatively, family and therapists may anticipate problems within the session if a cognitively impaired old person is to be included, although Jones and Flickinger (1986) point out that even severely organically impaired people may have periods of greater emotional and cognitive clarity. Is there a risk of a catastrophic reaction or intense distress for the old person? Does the family risk becoming 'pathologized' by this approach? Will family members be reluctant to openly acknowledge and discuss the 'dementia' (a terminal illness) with the elderly person present? It may be difficult for staff with limited family experience to deal with these issues.

Experience at York House Family Clinic

A retrospective case note study has been carried out of the first 33 consecutive families seen in the York House Family Clinic between 1985 and December 31, 1990. Of the identified patients, 16 were diagnosed as suffering from a dementing illness, and 11 of these were diagnosed clinically as having multiinfarct dementia and five as having Alzheimer's disease (group D). Seventeen received other diagnoses (group O). These two groups, and the family interventions used in the clinic with them, were compared using the detailed records of each session. Sociodemographic details, information on referral to the clinic, attendance at sessions, discharge and follow-up information were obtained from the case notes. Two team members identified areas of discussion and family therapy

techniques used. (See Appendix for definitions of terms used in the study. Copies of the family questionnaire can be obtained from the authors.) The team discussed each family and rated outcome retrospectively in each of three areas: for the family, identified patient and ongoing contact with the old age psychiatry service. Statistical analyses were carried out using Unistat. Some of the findings from the study will be used to illustrate this review. Statistics need to be interpreted with caution because of the small numbers involved.

Table 1. Characteristics of the patients and their families divided into demented and non-demented groups with percentages in brackets

	Dementia (N = 16)	Other (N = 17)
<i>Sex of identified patient (IP)</i>		
Male	8 (50)	2 (12)
Female	8 (50)	15 (88)
<i>Age of IP</i>		
Mean	78.4	73.9
Range	66-93	67-81
<i>Marital Status of IP</i>		
Married	7 (44)	7 (41)
Single	1 (6)	2 (12)
Widowed	8 (50)	8 (47)
<i>Living Status of Patient</i>		
Alone	4 (25)	5 (29)
Sheltered	1 (6)	1 (6)
Elderly persons' home	0 (0)	0 (0)
Private home	0 (0)	0 (0)
Long-stay hospital bed	0 (0)	0 (0)
Own home with family	9 (56)	9 (53)
Family home with family	2 (13)	2 (12)
<i>Status of IP when first seen</i>		
Inpatient	5 (31)	5 (29)
Outpatient	7 (44)	6 (35)
Day patient (psychiatric day hospital)	0 (0)	5 (29)
Day patient (psychogeriatric day hospital)	4 (25)	1 (6)
<i>Method of discharge from the clinic</i>		
Planned	12 (75)	7 (41)
Failed to attend	3 (19)	2 (12)
Other	0 (0)	2 (12)
Ongoing at 31.12.90	1 (6)	6 (35)

Table 1 presents some characteristics of our patients and their families. Although group D were

older, this was not a statistically significant difference (chi-square = 5.39, $df = 5$, $p = 0.37$), but they were more likely to be male (chi-square = 4.04, $df = 1$, $p = 0.044$). Marital status did not differ between the two groups, nor did the patient's living circumstances at the time of first invitation to the clinic. Status of the identified patient when first seen was similar in the two groups.

The finding that more families in group O continued to attend the clinic after 31.12.90 is likely to be related to the greater number of sessions for which they attended.

Comments

Some of the differences between the groups are not unexpected: group D were older, but the prevalence of dementia increases with age (Jorm, 1990). The difference in sex distribution between the two study groups is likely to be related to the excess of people with multi-infarct dementias in group D. This illness presents with a fluctuating picture which causes particular difficulties for families and which may account for the over-representation of multi-infarct over Alzheimer dementia in group D as a whole. Another potential stress for families may be shown in the details of living situation, where a surprisingly high proportion of referred people live in their own home with other family members. Gilleard *et al.* (1992) studied the attitudes of district nurses, GPs, hospital doctors and social workers towards family therapy for older adults, and found that carer stress was given as one of the three main reasons for referring an older person to family therapy.

TASKS OF FAMILY THERAPY WITH FAMILIES COPING WITH DEMENTIA

The family conference has been seen simply as a strategy for deciding how to share responsibility among members of families caring for a demented member, and offering a forum for getting together all those involved (Schmall and Pratt, 1989). It could be regarded as a resource for the whole family (Sholevar and Perkel, 1990). It offers but one way of addressing family issues.

Grunebaum and Friedman (1988) have described five tasks in building collaborative relationships between families and mental health professionals:

ensuring that the family has the opportunity to be heard, imparting information, helping the family deal with feelings related to the identified patient's illness, identifying family coping patterns and helping family members face conflicts between their own needs and those of the identified patient. The first two may often be readily addressed without the need for formal family therapy. The last three may be of particular value in family work with dementia sufferers and their carers. Chase and Holmes (1990) viewed the roles of family therapy differently and suggested three: as a primary agent of change, as a preliminary to the acceptance of treatment, and as an adjuvant to the use of other treatments. If we try to apply these models to dementia, then treatment will need to be interpreted broadly, to incorporate social and psychological management, rather than narrowly as meaning just physical treatments. It is likely that any role for family therapy in families coping with dementia as a primary agent of change will be limited, and Chase and Holmes' latter two areas are more likely to be appropriate. A problem-focused approach may be suitable, as described by Sholevar and Perkel (1990).

York House Family Clinic

Areas of discussion during the family meetings are listed in Table 2. They are ranked in descending order taking the group as a whole. Chi-squared tests were performed on the data using 2×2 contingency tables divided according to group (D or O) and whether the topic featured in discussion; significant p -values are indicated. The referred person's forgetfulness and the referred person's behaviour were more likely to be discussed with group D families. These differences are likely to relate to the particular symptoms exhibited in dementing illnesses. Change in time spent together by family members featured more often with group O families. Although housing problems, marital problems and retirement featured more in meetings with families in group O, these did not reach statistical significance.

Table 3 presents the number of sessions carried out with the whole group and with each subgroup. It shows that group D were seen for fewer sessions (mean 1.6) than group O (mean 3.2) but this difference was not statistically significant. Table 4 presents the number of family members present at each family session, and demonstrates that more members were present at group D than group O sessions.

Table 2. Areas of discussion in the two groups of families during family meetings with percentages in brackets

	Dementia (N = 16)	Other (N = 17)	Total (N = 33)
Referred person's physical health	8 (50)	11 (65)	19
Decision about change of residence	8 (50)	9 (53)	17
Other family members' mental health	6 (31)	9 (53)	15
Bereavement	6 (31)	7 (41)	13
Other family members' physical health	7 (44)	6 (35)	13
Referred person's forgetfulness	10 (63)	1 (6)	11**
Referred person's behaviour	8 (50)	2 (12)	10*
Seeking medical solutions	3 (19)	6 (35)	9
Recent change in time spent together	1 (6)	8 (47)	9*
Difficulty controlling anger/temper	5 (31)	4 (24)	9
Financial problems	2 (13)	6 (35)	8
Leaving home	4 (25)	3 (18)	7
Marital problems (other family member)	2 (13)	5 (29)	7
Recurring patterns across generations	2 (13)	4 (24)	6
Housing problems	1 (6)	5 (29)	6
Social status differences	4 (25)	2 (12)	6
Problems associated with work or unemployment	2 (13)	4 (24)	6
Marital problem (IP + spouse)	1 (6)	4 (24)	5
Alcohol problems	2 (13)	3 (18)	5
Retirement	0 (0)	5 (29)	5
Suicidal ideation	2 (13)	2 (12)	4
Family secret	1 (6)	2 (12)	3
Longstanding family rift	1 (6)	1 (6)	2
Unemployment of family member	0 (0)	2 (12)	2
Referred person's sensory deficit	2 (13)	0 (0)	2
Drugs problem	1 (6)	0 (0)	1

* $0.05 > p > 0.02$.** $p = 0.002$.

Table 3. Numbers of sessions carried out with groups D and O

	Group D	Group O	Total (Group D+O)
No. of sessions	26	54	80
No. of patients	16	17	33
Mean number of sessions	1.6	3.2	2.4

Comments

It is not surprising that the referred person's forgetfulness and behaviour were more often discussed in group D, given the diagnosis of dementia. It is possibly more surprising that there were so few other differences, and that both groups had much in common. Change in time spent together by family members might have been expected to figure prominently in both groups in the light of Ratna and Davis's study (1984). Some of the five tasks

Table 4. Numbers of family members present at each family meeting

No. of family members present	Group D	Group O	Total (D+O)
2	1	26	27
3	9	17	26
4	8	5	13
5	1	4	5
6	5	1	6
7	1	1	2
8	1	0	1
Total	111	156	267
No of sessions	26	54	80
Mean family members	4.3	2.8	3.3

identified by Grunebaum and Friedman (1988) may be appropriately addressed in the context of these

discussion areas, particularly helping the family deal with feelings related to the person's illness (especially behaviour changes and forgetfulness) and helping family members to face conflicts between their own needs and those of the identified patient.

Goldstein (1990) has examined the role of family therapy and mutual support groups for carers, and found that certain topics are more likely to come up in one setting or the other. In family therapy elder neglect, abuse and exploitation are more likely to be discussed. Unfortunately, information on abuse was not specifically sought in our review, although we are aware that it is an issue for a number of families we see and further research on this area is planned.

Families with dementia more often attend once only to resolve a crisis, frequently the crisis of whether the demented member should move to alternative accommodation or not. The fact that more family members attended group D meetings may imply that demented people have large families, or that their family members are more likely to attend (perhaps they may have changed their lifestyles to accommodate the old person's dementia, eg by giving up work), or that their families are more likely to become/remain involved, or that the crisis draws the family together. Another factor here is that group O families were more likely to attend for a series of sessions and sometimes particular family members attended together by agreement to address issues in their relationship, in the absence of other family members.

In broad terms, this crisis use (for families coping with dementia) may fit into Chase and Holmes' (1990) category of family therapy as a preliminary to the acceptance of 'treatment' (in its widest sense). Families coping with illnesses other than dementia are seen more often, which may reflect the use of family therapy as an adjunct to the use of other treatments and also as the primary agent of change. This finding is an important one to reflect upon, since it may show our own perception of how to help these families rather than theirs. Perhaps the families of people with dementia should be offered a follow-up appointment when the crisis has been resolved, to allow consideration then of whether any further sessions would be helpful.

Greene (1989) has already observed that families of demented people tend to remain in therapy for relatively short periods. She sees therapy as mobilizing the family system on behalf of its members and facilitating more positive interdependence.

GENDER AND CAREGIVING IN FAMILIES WITH DEMENTED RELATIVES

York House Family Clinic

The 111 family members who attended group D (and 156 in group O) sessions were classified according to their relationship to the referred person. The spread of relationships is shown in Table 5. Sons and daughters-in-law were more likely to attend group D meetings compared with group O meetings. Sisters and brothers-in-law were more likely to attend group O meetings than group D.

Table 5. Relationship of family members attending family meetings to referred patient

Relationship	Group D	Group O	P
Sons	27	12	0.0003
Daughters	21	25	0.65
Spouses	13	18	0.88
Son-in-law	4	4	0.90
Daughter-in-law	18	3	0.0001
Sister	0	11	0.01
Brother	0	3	0.38
Brother-in-law	0	11	0.01
Stepdaughter/stepson	1	1	0.63
Granddaughter/son	1	8	0.12
Niece/n. husband	0	6	0.09
Boyfriend	0	2	0.63
Identified patient	26	52	0.11
Total attendances	111	156	

Comments

The different profiles of members attending in the two groups is difficult to interpret. The finding that sons were more likely to attend group D meetings may be related to the finding that men tend to specialize more in the 'managerial' aspects of care (Collins, 1992), and group D meetings were more often used to make 'management' decisions. Horowitz (1985) pointed out that sons who care expect active support from their wives, so the numbers of daughters-in-law attending meetings is perhaps unsurprising. Women who care may not have the same expectations of their partners, so the disparity between daughters and sons-in-law

attending group O meetings may be similarly unremarkable.

INSTITUTIONALIZATION

The move to institutional care is a stress for families which can be approached using family therapy (Rodway *et al.*, 1987). Solomon (1982) sees four possible crises or stages: the decision to enter, admission, the move to a more intensive level of care, and dying in institutional care. She perceives a need for institutions to enter into 'partnership' with families.

POSSIBLE MODELS OF FAMILY THERAPY

Pottle (1984) described a domiciliary psychogeriatric team which used brief problem-focused interventions designed to encourage the family network to mobilize its own resources. Their model involved convening as many members of an old person's supportive network as possible, with particular importance attached to involving the person who wants change to take place. With its emphasis on positive reframing and affirming the value of family and neighbour support, this model is readily applicable to families coping with dementia. The use of a family therapy clinic within an old age psychiatry service has been described elsewhere (Marriott and Pickles, 1987; Benbow *et al.*, 1990). In Central Manchester the clinic has now been operating for over 6 years and the approach has evolved over time, but is broadly systemic. Hughston *et al.* (1989) have argued that successful treatment of adults will need to be systemic, i.e. 'to take into account the context of the older adult as an organized whole with parts or subsystems continuously interconnected in a mutually regulatory, patterned relationship ... (in order) to formulate a systemic and comprehensive treatment plan'.

A focus on problems has been seen as appropriate in families caring for someone with a dementia (Sholevar and Perkel, 1990). Bonjean and Spector (1988) describe strategic therapy as a useful problem-solving framework, which they regard as more compatible with the outlook of elderly people than more traditional approaches in that it is short-term and defines specific realistic goals. They describe work with a couple where the husband had been diagnosed as suffering from Alzheimer's disease.

This solution-focused systemic strategic family therapy may be flexible enough to allow the needs of all family members to be heard and considered, and also takes into account the developmental and relationship context (Bonjean, 1989). Bonjean (1989) describes how the focus is initially on the older adult but later shifts to take in the whole family, and how its members adapt to the dependence, deterioration and loss of a progressive dementing illness while protecting individual family members' development. She sees the dilemmas of care as reawakening old family conflicts.

Roper-Hall (1992) argues the case for systemic family therapy and feels that seeing the family together when referral is organized about illness and/or dependency can provide a context with the potential for 'co-creating alternative ways of understanding the situation'. She illustrates her views with an account of an elderly woman with memory difficulties following stroke, but they would apply equally to a family coping with a progressive dementia.

In reviewing the use of the clinic, some of the questions we wanted to start to address were: is the clinic used for families coping with dementia in a similar way to its use for other later life families, and are there any particular areas of dementia care where family therapy might be of particular value?

York House Family Clinic

All families attending this clinic included a member over 65 years of age who had been referred to the old age psychiatry service with a problem perceived by the referrer as psychiatric. They had been identified by a member of the old age psychiatry staff as having a family problem, referred to the clinic and the referral accepted as appropriate for assessment or treatment in the clinic. At present we do not have defined selection criteria, but the process of review and evaluation of our work, which continues, aims to attempt to tease out possible criteria and to start to address outcome by examining family satisfaction with the clinic.

Techniques used with families are ranked in descending order (taking the group as a whole) and presented in Table 6. Chi-squared tests were performed using 2x2 contingency tables divided by group (D or O) and by whether or not that technique was used. No significant differences were found. The table demonstrates that a spread of techniques was used in both groups, with little evi-

Table 6. Techniques used in meetings with the two groups of families with percentages in brackets

Technique	Dementia (N = 16)	Other (N = 17)	Total (N = 33)
Positive reframe	13 (81)	16 (94)	29
Circular questioning	11 (69)	12 (71)	23
Structural techniques	9 (56)	11 (65)	20
Genogram	7 (44)	8 (47)	15
Task-setting	6 (38)	7 (41)	13
Other *	6 (38)	2 (12)	8
Therapist assigned to ally with family member	3 (19)	3 (18)	6
Transgenerational analysis	2 (13)	4 (24)	6
Paradox	2 (13)	5 (29)	5
Prescribing symptom	0 (0)	2 (12)	2
Modelling	2 (13)	0 (0)	2
Split message	0 (0)	2 (12)	2
Exploring family myths	0 (0)	1 (6)	1

* Includes information-gathering, goal-setting.

dence that particular techniques were preferentially used in one group rather than the other.

Comments

The finding that techniques used with families did not differ between the two groups suggests that similar techniques are useful for families, regardless of whether one of them has an identified dementia or another psychiatric problem. We had suspected that behavioural techniques might be more often used in group D, but this was not supported by our results. Some techniques we would regard as intrinsic to our work (eg circular questioning and positive reframing), but analysis of the written records of sessions did not reveal them to have been used in all families. This might reflect the selectivity of the observer who made the record, who must inevitably screen out some material and is likely to more often reject that which is unremarkable and regarded as intrinsic to that clinic's style.

OUTCOME AND EFFECTS OF FAMILY THERAPY

Zarit *et al.* (1987) looked at interventions with the caregivers of dementia patients, comparing family work with support groups. The model of family intervention was behavioural in orientation, based on stress management, and lasted for 7 weeks. They found lower levels of burden and psychiatric symptoms following treatment, but improvement was no greater than for families on the waiting list, who

subsequently went through the treatment programme. There was no long-term control group, but improvements were maintained at 1-year follow-up. The authors argued that a 7-week period may have been too short to demonstrate change. Their study reveals some of the difficulties in designing research to look at change in response to therapy, in using a control group and in selecting outcome measures, particularly in relation to the deteriorating condition of a person with dementia and the inevitably associated stress for family members. Gilleard *et al.* (1992) asked a group of professionals which problems would be most likely to benefit from a family therapy approach. Family conflict was most often considered suitable (46%) with carer stress second (28%). Both of these are common problems in families coping with a demented member, although the authors point out that their respondents contrasted these problems with the problems they perceived older adults as seeking help with (loneliness, depression, dementia and the need for social services).

York House Family Clinic

Outcome for each family was classed as not helped, moderately helped or considerably helped for the referred patient, family and team, by team consensus. This is a crude attempt to start to examine outcome, and the team recognize that it is unsatisfactory in a number of ways (Bloch *et al.*, 1991). Table 7 shows the team ratings, with little difference between groups D and O.

Table 7. Outcome as rated by team consensus retrospectively

	Group D (N = 15)	Group O (N = 11)
Referred patient		
Not helped	4 (27)	1 (9)
Moderately helped	6 (40)	5 (45)
Considerably helped	5 (33)	5 (45)
Family		
Not helped	1 (7)	1 (9)
Moderately helped	5 (33)	4 (36)
Considerably helped	9 (60)	6 (55)
OAP Team		
Not helped	1 (7)	0 (0)
Moderately helped	7 (47)	5 (45)
Considerably helped	7 (47)	6 (55)

Note: Seven families still attending as at 31/12/90.

CONCLUSION

Provisionally our conclusions are that review of the literature and of our work suggests that family therapy can be useful in work with families coping with dementing illnesses and can be employed within an old age psychiatry service. There are, however, practical differences involved in working with these families. Family therapy offers exciting possibilities for old age psychiatry teams, and further research on its use and implications is needed.

ACKNOWLEDGEMENTS

Our thanks to all members of the team, past and present, who have contributed to the work described in this article.

REFERENCES

- Anderson, D. (1988) The quest for a meaningful old age. *Networker*, July/Aug 17-20, 22, 72-75.
- Benbow, S. M., Egan, D., Marriott, A. et al. (1990) Using the family life cycle with later life families. *J. Fam. Ther.* 12, 321-340.
- Bloch, S., Sharpe, M. and Allman, P. (1991) The use of systemic family therapy in adult psychiatry. *Brit. J. Psychiat.* 159, 357-364.
- Bonjean, M. J. (1989) Solution focused psychotherapy with families caring for an Alzheimer's patient. *J. Psychother. Fam.* 5, 197-210.
- Bonjean, M. and Spector, R. (1988) Empowering the elderly. *Networker*, July/Aug 25-29, 76-79.
- Chase, J. and Holmes, J. (1990) A two year audit of a family therapy clinic in adult psychiatry. *J. Fam. Ther.* 12, 229-242.
- Collins, C. (1992) Carers: Gender and caring for the elderly. In *Recent Advances in Psychogeriatrics 2* (T. Arie, Ed.) Churchill Livingstone, Edinburgh, pp. 153-161.
- Flori, D. E. (1989) The prevalence of later life family concerns in the marriage and family therapy journal literature (1976-1985): A content analysis. *J. Marital Fam. Ther.* 15, 289-297.
- Gilleard, C., Lieberman, S. and Peeler, R. (1992) Family therapy for older adults: A survey of professionals' attitudes. *J. Fam. Ther.* 14, 413-422.
- Goldstein, M. Z. (1990) The role of mutual support groups and family therapy for caregivers of demented elderly. *J. Geriatr. Psychiat.* 23, 117-128.
- Greene, R. (1989) A life systems approach to understanding parent-child relationships in aging families. *J. Psychother. Fam.* 5, 57-69.
- Grunebaum, H. and Friedman, H. (1988) Building collaborative relationships with families of the mentally ill. *Hosp. Commun. Psychiat.* 39, 1183-1187.
- Horowitz, A. (1985) Sons and daughters as caregivers to older parents: Difference in role performance and consequences. *Gerontologist* 25, 612-617.
- Hughston, G. A., Christopherson, V. A. and Bonjean, M. J. (1989) Aging and family therapy: An introduction. *J. Psychother. Fam.* 5, 1-11.
- Jeffery, D. (1987) Should you involve an older person about whom there is an issue of cognitive competence in family meetings? *PSIGE* 24 (Oct.), 8-11.
- Jones, S. and Flickinger, M. A. (1986) Contextual family therapy for families with an impaired elderly member: A case study. *Clin. Gerontologist* 6, 87-97.
- Jorm, A. F. (1990) Prevalence. In *The Epidemiology of Alzheimer's Disease and Related Disorders*. Chapman & Hall, London, pp. 54-76.
- Marriott, A. and Pickles, A. (1987) A family clinic for the elderly in central Manchester. *PSIGE* 24 (Oct.), 12-14.
- Montalvo, B. and Thompson, R. F. (1988) Conflicts in the caregiving family. *Networker*, July/Aug., 31-35.
- Pottle, S. (1984) Developing a network-orientated service for elderly people and their carers. In *Using Family Therapy* (A. Treacher and J. Carpenter, Eds). Blackwell, Oxford.
- Ratna, L. and Davis, J. (1984) Family therapy with the elderly mentally ill. Some strategies and techniques. *Brit. J. Psychiat.* 145, 311-315.
- Richardson, C., Lieberman, S., Peeler, R. E. et al. (1993) Family therapy for older people: A review of the literature. *J. Fam. Ther.*, in press.
- Rodway, M. R., Elliott, J. and Salva, R. J. (1987) Intervention with families of the elderly chronically ill: An

- alternate approach. *J. Gerontol. Soc. Work* 10, 51-60.
- Roper-Hall, A. (1992) Better late than never? Family therapy with older adults. *Clin. Psychol. Forum*, 14-17.
- Schmall, V. L. and Pratt, C. C. (1989) Family caregiving and aging: Strategies for support. *J. Psychother. Fam.* 5, 71-87.
- Sholevar, G. P. and Perkel, R. (1990) Family systems intervention and physical illness. *Gen. Hosp. Psychiat.* 12, 363-372.
- Solomon, R. (1982) Serving families of the institutionalised age: The four crises. *J. Gerontol. Soc. Work* 5, 83-96.
- Spark, G. M. and Brody, E. M. (1970) The aged are family members. *Fam. Process* 9, 195-210.
- Zarit, S. H., Anthony, C. R. and Boutselis, M. (1987) Interventions with care givers of dementia patients: Comparison of two approaches. *Psychol. Aging* 2, 225-232.
6. Drama work: circle if used within the family session(s).
 7. Role play: a family member was asked to role play within the family session.
 8. Role reversal: therapist and client or two family members reverse roles and *actively* play the new role in the session.
 9. Sculpting: asking family members to adopt particular positions/postures.
 10. Empty chair: a chair is left intentionally vacant for an absent member.
 11. Positive reframe: relabelling an action, statement, thought, positively, eg 'your anger shows your concern', 'your action is protecting your mother'.
 12. Prescribing symptoms: prescribing/telling the person to continue with their symptom, eg we want you to continue being ill/not taking your tablets, etc.
 13. Paradox: an intervention which, if followed, will accomplish the opposite of what it is seemingly intended to accomplish, eg giving a message which it is intended the family member(s) will resist/do the opposite to/act in a different way to.
 14. Split message: team present a message but some/one member(s) of the team present an alternative message to the family.
 15. Structural moves: includes asking family members and/or therapists to change chairs; asking family members to speak directly to one another rather than to therapist; delineating boundaries.
 16. Task setting: (a) intrasession, eg give family a task to do during the break or in session; (b) intersession, eg give family a task to do before next session.
 17. Modelling: therapist models/demonstrates a different emotional or behavioural response to a given situation.
 18. Other(s): be over-rather than underinclusive.

APPENDIX

Notes to aid completion of family questionnaire

1. Genogram circle if there is genogram in family clinic notes.
2. Circular questioning: questions designed to elicit information to better understand the connectedness of the system, eg asking a family member what another member would have said/done.
3. Transgenerational analysis: looking at patterns/links recurring across generations.
4. Family myths: a body of beliefs that the family has about itself and its members which has some stability conferred by having been repeatedly confirmed by family consensus over the years, eg 'all people who move to hospital die', 'expressing sadness will lead to madness/loss of control', ... etc.
5. Therapist assigned to ally with family member: ie team have agreed to do this as a therapeutic plan.

NOTE: This publication is copyright John Wiley & Sons, Ltd, and is reproduced here with permission (licence number 2487030840578).

Publication 4.

Benbow, S.M. & Marriott, A. (1997). Family therapy with elderly people.

Advances in Psychiatric Treatment. 3 p. 138-145.

Family therapy with elderly people

Susan M. Benbow & Alison Marriott

Those who work with older adults will inevitably find themselves working with families. Indeed assessment of an older person is often difficult if members of their family and social network are not involved. Referrals to social and psychiatric services are often precipitated by family changes. Ratna & Davis (1984) described 142 consecutive referrals to a community old age psychiatry service and found retirement, family conflict, departure of or illness of a carer, or bereavement precipitated 60% of referrals. Thus, work with older adults will often necessitate work with families, although it may not be seen in those terms.

A history of family therapy

Family therapy began to develop in the UK and the USA in the 1950s. Theoretical models were developed in which the family was regarded as a system and contributions to the developing field came from many areas including psychoanalysis, mathematics, cybernetics and communication theory. The family as a system was conceptualised as an entity whose component parts interact and evolve together in ways which maintain the system. Instead of regarding symptoms as a problem for individuals, problems were seen as having a systemic function in maintaining or unbalancing relationship patterns involving individuals. From the shared systemic understanding various schools of family therapy developed ('structural', 'strategic' and 'systemic' models of therapy; see below).

Traditionally, family therapy has probably been used most in work settings with younger families, particularly those with young children or adolescents. There is, however, a growing interest in using

family approaches and techniques with older adults. Chronic illness of any sort can send ripples through the extended family, so family work may be as important in work with physically as with mentally ill older adults. Since family support often becomes important as people age, it could be argued that family therapy may be at least as useful in later life as in younger families.

Family systems therapy

Jones (1993) defined a system as:

a group of elements in interaction with one another over time, such that their recursive patterns of interaction form a stable context for individual and mutual functioning.

The focus is on the relationships between parts of the system rather than the individuals involved in it. The designation of what constitutes or is involved in the system is a distinction drawn by an observer and is open to other interpretations. Feedback and circularity are important ideas in considering interactions. If A tells B to do something and B does it, then this may affect A's behaviour in future: she may be more likely to tell B to do something. A's actions therefore influence B's, but B's response to A's actions also influences A's future actions. This circularity leads to ideas of positive and negative feedback in interactions between individual family members. Punctuation refers to the way in which an observer selects out particular sequences of interaction. An observer may choose a linear punctuation, such as A tells B to do something and B does it, or a circular punctuation, such as A is more likely to tell B to do something because B has always expected A to make the decisions in their relationship in the past. Circular views of interactions between

individuals can avoid both the attribution of blame and the need for assumptions about initial causes.

These ideas are as relevant to later life as to younger families, perhaps even more so since older people in families will have established patterns of interactions over long periods of time.

Models of therapy

Structural family therapy

A structural therapist joins with a family, challenges them and then offers alternative ways of behaving using verbal and non-verbal techniques. Once families have tried out alternative patterns of behaviour new relationships develop which are thought to be reinforcing.

Structural therapists are interested in sub-systems within families, and 'healthy' families are seen to be those in which boundaries between the sub-systems are effectively established. In later life boundaries between sub-systems may change; thus, if there are sub-systems of children, parents and grandparents, when the grandparents become frailer and in need of more support the boundaries may need to be renegotiated to allow for continued family functioning. Sometimes families may seek assistance if renegotiation cannot be achieved by their own efforts.

Strategic therapy

A strategic therapist aims to remove the power of the symptom in defining family relationships by changing family organisation in a stepwise fashion.

Some have argued that strategic therapy offers a useful problem-solving framework that is more compatible with work in late life since it is short-term and defines realistic goals (Bonjean & Spector, 1988). Developed societies may regard older people and older life cycle changes as 'problematic' – negative stereotypes of ageing and ageist attitudes may be common. This may fit with a strategic approach. A family may view their situation in coping with an ageing family member and that person's needs as a problem requiring a solution. A solution-focused therapy may thus offer effective intervention.

Milan systemic therapy

A systemic therapist aims to change the family's beliefs. Therapist neutrality and teamwork are often intrinsic features.

Roper-Hall (1992) argues that systemic family therapy can provide a way of "co-creating alternative ways of understanding the situation", and is particularly appropriate in later-life work, where referrals may involve illness and/or dependency. Systemic therapy tries to help a family generate their own ways of dealing with a situation and may be particularly appropriate when a family faces a situation which is unlikely to change (e.g. chronic physical or mental illness or the inevitable decline of a dementing illness). If the family members' beliefs and perceptions change, then this may influence how they cope with what is effectively the same situation.

Other family interventions

Work on expressed emotion (EE), which involves interviewing family members and measuring critical or hostile comments about the identified patient, has led to a psychoeducation model of intervention. For example, Barrowclough & Tarrier (1992) describe an intervention model for people suffering from schizophrenia and their families. This approach emphasises the importance of family interactions and family responses to the well-being of individuals with serious mental health problems in terms of relapse prevention and high EE. This approach could be considered for families with high levels of EE who are struggling with chronic or recurrent illness in older family members.

Family therapy applied to older adults and their families

The techniques/ideas selected here are a few of those core family therapy ideas which can be useful in everyday practice with older adults. They may not necessarily be the most important but can nevertheless be influential outwith the family therapy clinic.

The family life cycle

The family has a life cycle, as does an individual. One model divides family development into six stages of which five cover the period from single adulthood to launching children and one final stage is seen as spanning retirement until death of both partners (Table 1) (Carter & McGoldrick, 1989). This model is unbalanced since the final stage could, with shorter periods of child-bearing, early

Table 1 Stages of the family life cycle

Family life cycle stage	Key issues
Leaving home: single young adults	Accepting responsibility for self; independence
Joining families through partnership: the young couple	Commitment to a new family; negotiation
Families with young children	New members join the system
Families with adolescents	Flexibility of boundaries to allow growing independence; ageing of grandparents
Launching children moving on	Exits from family and renegotiation of partnership; 'empty nest'
Later life family	Shifting of generational roles

retirement and extended life expectancy, cover as many years as the first five. This imbalance could imply that the later stages of the family life cycle involve fewer developmental tasks.

However, later stages of family life involve many adjustments. One partner may retire first, followed by the second. Illness and disability of family members may occur. For older family members their roles as grandparents may involve different forms of child care and support of their own children, now themselves parents. Many people may become great-grandparents, with implications for all generations of the family. Loss of their peers may occur, and loss of the status associated with younger adulthood and paid employment. Eventually one partner dies and the surviving partner faces additional social restrictions associated with widowhood.

Later family development may involve parents accepting the need to depend on others including their children, and adult children accepting that parents may need to accept help from and to depend on them. Attachment theory can be seen as important here. Adult children may anticipate parental decline by taking on care-giving before help is actually needed, or feel stressed despite providing little or no help. Perceived parental dependency may relate to negative feelings more than the amount of practical help given.

An understanding of later life cycle issues can be vital to an understanding of the difficulties experienced by older adults referred to services. It also helps professionals to take a more holistic and comprehensive approach to care as the individual will be treated within the context of the stage of life they have reached, and the life cycle

issues which other family members are facing will also be taken into account.

Cross-generational interplay of life cycle problems

When one generation faces an important life cycle transition, another generation of the same family may be facing its own transition point. If the needs of the two generations are incompatible there is lack of 'complementarity' or 'fit'.

The family life spiral is another way of looking at this (Fig. 1). At some times in family development family members are closely involved with one another (e.g. during times of childbirth and death). At others family members are orientated more towards interests outside the family (e.g. during adolescence, the 40s and early retirement). If one generation is passing through an outward-looking phase when another seeks closeness, tensions may arise (Combrinck-Graham, 1988).

When working with older people their families may often be facing these tensions. For example, a person's expectations of retirement may not accord with their partner's or children's expectations. The older person may look forward to more time at home, more freedom to pursue interests or more boredom. Their partner may anticipate more help with their own tasks, more companionship or more closeness. Adult children may expect more help with babysitting, more visits, more time together as a family. There may be marked differences between the expectations of different generations, and in expectations of care, which may lead to conflict and/or disappointment among family members.

Genograms

The use of a genogram or family tree is an economical way of collecting, organising and storing information (Fig. 2). Although genograms may be regarded as a distinctive feature of family therapy they can be used in routine practice and can be a useful part of case notes.

Many older people who have had long-standing illnesses will have enormous case files with information buried deep within them. A genogram can be used to summarise family information and to highlight important landmarks, illnesses etc. This can also be a useful tool in general practice.

Circular questions

Circular questions aim to gather information by asking questions in terms of differences and hence

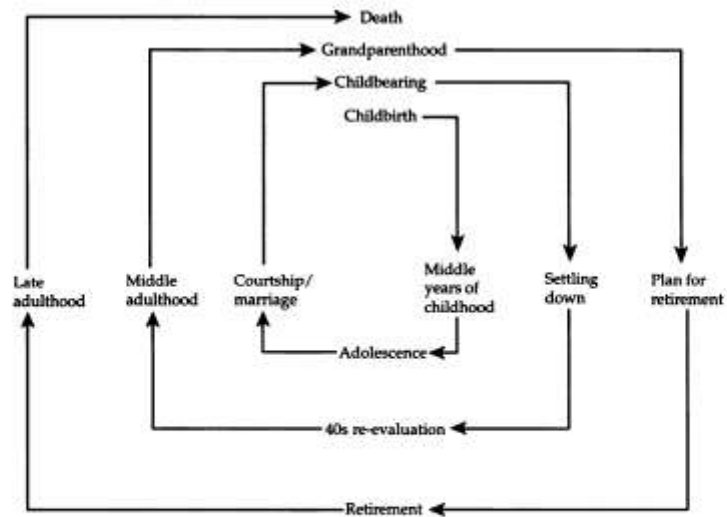


Fig. 1 Family life spiral

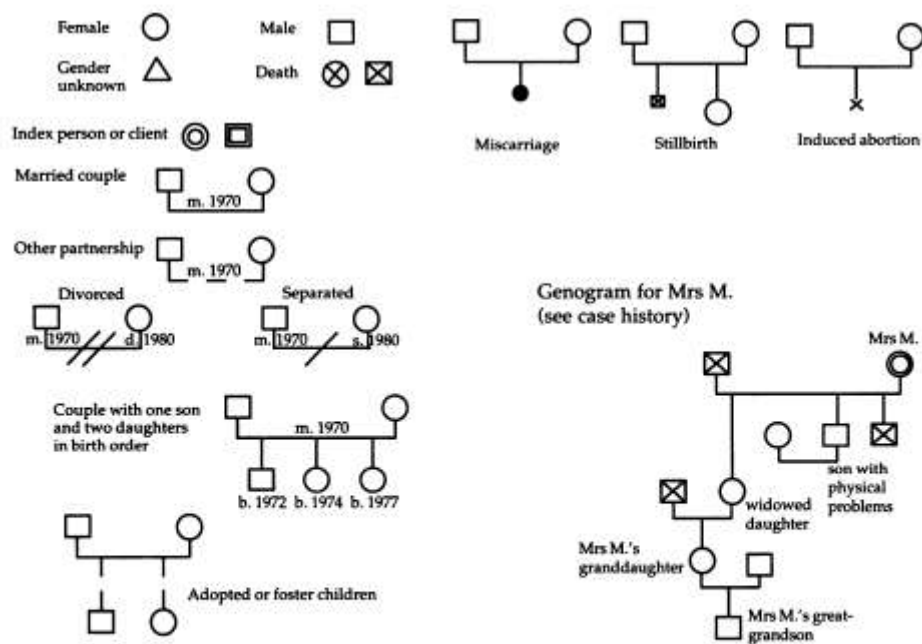


Fig. 2 Genogram symbols

Table 2 Categories of circular questions

Category	Description	Examples
Sequential	Enquire about specific behaviours in specific circumstances	When your mother says she will never go into a Home, what does your brother do?
Action	Enquires into differences indicated by behaviour	What does your mother say or do that makes you say she is confused?
Classification	Allows ranking of family responses	Who in the family most thinks that putting your mother in a Home will solve the problem?
Diachronic	Investigates changes in behaviour indicating changed relationships at two time points	Did Frank and your mother get close before or after your father died?
Hypothetical	Investigates differences in opinion regarding imagined situations	Suppose your mother decided to go into a Home, whose life would change most in the family?
Mind reading	Examines communication in a family	If your father were still alive today what would he think about your mother going into a Home?

of relationships. Table 2 summarises the six main categories of questions. In therapy the questions are linked with systemic hypotheses, but they are thought-provoking questions which can have a role in day-to-day work with families. They help professionals (and family) to understand the relationships between family members, how they perceive one another and what their expectations of services and change are. At an initial home assessment visit it can be useful to ask a referred person what they were hoping for from the assessment and what they think various important others were hoping would come from it.

Reflecting teams

Tom Andersen and coworkers developed the use of reflecting teams (Andersen, 1992). Originally this involved team members talking about their ideas regarding a family while the family and therapist listened. It can be seen as an extension of Bateson's concept of double description which Jones (1993) describes as:

obtaining more than one view of an event (which) would enable us to achieve the cognitive or emotional equivalent of binocular vision, thus gaining, in a metaphorical sense, perspective on our observations and experiences.

It carries with it an expectation of openness between family and professionals and a change in the balance of power.

This model fits too with the way many multi-disciplinary teams work by drawing on the ideas and contributions of various team members with different perspectives rather than relying solely on

the most articulate, most senior or loudest team members.

Family therapy with older adults

Formal family therapy is used with older adults and their families in a number of centres around the UK. It is used with functional psychiatric illness, with organic brain syndromes and in those with chronic physical illness.

Functional psychiatric illness

We use family therapy with families where functional illness leads to their contact with the service, often utilising family therapy alongside other therapeutic activities (Benbow *et al*, 1990).

Case history

Miss E., a single woman of 74 years old, presented with an agitated depressive illness with marked biological symptoms. She lived with her sister and brother-in-law and had retired at 64. Their mother was described as having melancholia and two sisters had had psychiatric treatment. After initial assessment at home, antidepressive drug treatment was started but Miss E. deteriorated, appeared to be 'confused' and was admitted to in-patient care. On the ward the antidepressives were cut down and she appeared well. After successful home leave she was discharged but within three days became severely depressed with ideas of guilt, hopelessness and

worthlessness. She went to a local reservoir intending to drown herself, but was taken home by a neighbour and readmitted. After a short course of ECT she was mildly elated, but stabilised and was discharged home on maintenance drug treatment. Her symptoms started to reappear within two weeks and she was readmitted depressed, suicidal and psychotic six weeks after discharge. On the ward she soon improved. A formal family meeting was arranged with Miss E., her sister and brother-in-law.

In conversation it emerged that the two sisters had always been close and in some ways her sister had always parented Miss E. Her brother-in-law's forthcoming redundancy had caused worry for all three family members and before her illness started Miss E. had become more independent (e.g. buying a piano).

Team hypotheses included the following:

- (a) Was Miss E.'s 'growing up' allowing space for her sister and brother-in-law to become a married couple?
- (b) Was Miss E.'s illness keeping her sister from worrying about her husband's redundancy and their future relationship?
- (c) Was Miss E.'s depression keeping her sister busy and well (since her sister too had a history of depression)?

All three family members were facing important transitions: what conflicts were there between their needs?

This initial meeting led on to a series of 12 meetings during which Miss E. decided to move into a residential home and eventually her sister and brother-in-law were seen several times as a couple. They appeared to become closer over time, although both found losing Miss E. difficult. Miss E. settled in to her chosen residential home quickly, made new friends, limited her visits to the family to once weekly and started to do things she had not done for years (e.g. going to town on the bus shopping). When contacted for follow-up by telephone some months after the final session, her sister and brother-in-law had found new interests and become more involved with other family members, as well as continuing weekly contact with Miss E.

Organic brain syndromes

Family therapy has been used in a number of settings with families whose members suffer from chronic illness. Dementia is one chronic illness with repercussions for the whole family. We have reviewed our experience in this area (Benbow *et al.*, 1993). We commonly involve the cognitively impaired family member in family meetings and

often see families for a small number of sessions stretched out over a fairly long time course, sometimes years, as they struggle to adjust to the dementia sufferer's decline. The issues discussed are often similar to those discussed in families coping with functional illness and we use the same approach or range of techniques in working with them. Feedback to date is generally positive, although we are still evaluating outcome. We believe that the relationship between family and psychiatric service is more collaborative overall using this approach.

Case history

Mrs M., a widow in her 90s, lived with her widowed daughter and presented with cognitive impairment and some depressive symptoms. Her daughter felt stressed and anxious caring for her mother, who was a strong-minded, independent woman, reluctant to accept help from outside the family. She had a married son with long-standing physical health problems and another son had died. Over a period of several years Mrs M., her daughter, daughter-in-law, son, granddaughter, granddaughter's husband and great-grandson in various combinations met on several occasions to negotiate together how to support Mrs M. and her daughter and to discuss how the whole family had been affected by her illness. Eventually Mrs M. moved into a residential home as her health deteriorated, but the family meetings, although separated by a number of months, appeared important in negotiating her care in the community for several years.

Family therapy within the wider psychiatric services

Our interest in family therapy has had effects throughout the old age psychiatry service.

Community service

Where the family/members of the support system have not been seen, it could be argued that assessment of the older person is incomplete. The reason for referral may be related to family changes or perceptions rather than changes in the medical/psychiatric state of the older person. Thus, community staff may be more likely to involve family/other supporters throughout their contact with older people in services which take a family therapy approach.

Sometimes community visits by individual staff members may be met by groups of family members concerned about their older relative. It is helpful

to be able to draw on family therapy training and ways of understanding which act as resources in dealing with situations like this and which may help us as professionals to consider alternative ways of dealing with difficult situations. One particularly difficult situation can be when family members are more concerned about a situation than the older person themselves is.

Day hospital

We have involved family/other supporters in review meetings in the day hospital since our involvement in family therapy. There is a balance between the need for openness and family involvement and the perceived right of the patient to confidentiality with regard to details of their illness. This can be an area of potential conflict but if we perceive our role as one of helping the whole family, rather than an individual in isolation, this can alter the openness/confidentiality balance. Being clear where we stand in relation to this will help us to address the dilemma with family members where there are particular problems.

Hospital wards

Involvement of family members throughout an admission can be very difficult and time-consuming in practice, so often one member of the old age psychiatry team will need to act as primary liaison with the family. Sometimes formal family meetings may be arranged while an older adult is on the ward. On one ward we involve family/other carers in meetings with the staff team prior to making discharge decisions or arrangements.

Case history

Mr R., aged 66, was admitted after a serious suicide attempt failed. He gave a history of depressive illness following unwelcome retirement on admission, but within a few days of his arrival on the ward he claimed to be back to his normal self and he and his family requested early discharge home. A family meeting was arranged in the family clinic and attended by Mr R., his wife, one son and daughter-in-law. All those present discussed the suicide attempt, events leading up to it and ways to help Mr R. adjust to his new lifestyle as a retired person. The family worked out with the therapists how they would like discharge to take place and what ongoing support/follow-up might be helpful and for whom. The relationship between team and family changed from one of suspicion and mistrust to one of collaboration in working towards shared goals.

A formal family clinic

We also run a formal family clinic which takes place weekly in a resource centre about 1.5 miles from the hospital. The clinic is staffed by a multidisciplinary team including community nurses, medical staff, psychologists, nurses from other settings (especially day hospital), social workers and occupational therapists. Families are seen for about 1–1.25 hours by two therapists, and the rest of the team act as a consulting team, offering reflections to the therapists before and after the meeting and during a short intermission before the family meeting closes. We have found that the use of co-therapists allows us to be open and creative with families. We usually work with a mixed-gender co-therapy team.

A video link allows the team to watch and listen to family sessions and we usually (when the family agrees) make a recording of the session.

Outcome and effects of family therapy

The study of outcome in family therapy is problematic. Controlling studies can be difficult and outcome measures are not well established, particularly when working with a family coping with a terminal illness such as a dementia. We have used team consensus ratings (Benbow *et al.*, 1993) but these are blunt instruments and open to observer bias. We have also experimented with asking families to rate the outcome of their contact with the clinic. This can also be difficult to interpret because families where the team rate the outcome as 'considerably helped' have sometimes expressed the view that they have not been helped at all since the eventual outcome has not been the one which individual members of the family were originally hoping for. An example would be where a son wanted to move in with his mother and care for her, but they both decided after meetings in the clinic that she should move into a residential home. Part of the work with the family would perhaps be to consider for whom and how this was a good outcome, but ratings made by the family may be coloured by the difference between outcome and original intent.

Currently we are looking at how to combine therapist/team ratings with family ratings. Another approach would be to agree with the family at the outset what they are looking for from the family clinic, in order that family and therapists can then look back at how goals have been met. The area of work may, however, evolve as the family are seen over time, so that initial goals may not always be relevant at the end of therapy.

References

- Andersen, T. (1992) Reflections on reflecting with families. In *Therapy as Social Construction* (eds S. McNamee & K. J. Gergen), pp. 54–68. London: Sage.
- Barrowclough, C. & Tarrier, N. (1992) *Families of Schizophrenic Patients: Cognitive Behavioural Intervention*. London: Chapman & Hall.
- Benbow, S. M., Egan, D., Marriott, A., et al (1990) Using the family life cycle with later life families. *Journal of Family Therapy*, 12, 321–340.
- , Marriott, A., Morley, M., et al (1993) Family therapy and dementia: review and clinical experience. *International Journal of Geriatric Psychiatry*, 8, 717–725.
- Bonjean, M. & Spector, R. (1988) Empowering the elderly. *Networker*, July/August, 25–29 & 76–79.
- Carter, B. & McGoldrick, M. (1989) Overview: the changing family life cycle – a framework for family therapy. In *The Changing Family Life Cycle – A Framework for Family Therapy* (2nd edn), pp. 3–28. London: Allyn & Bacon.
- Combrink-Graham, L. (1988) Adolescent sexuality in the family life spiral. In *Family Transitions: Continuity and Change over the Life Cycle* (ed. C. J. Falicov), pp. 107–131. London: Guilford Press.
- Jones, E. (1993) *Family Systems Therapy Developments in the Milan-Systemic Therapies*. Chichester: John Wiley & Sons.
- Ratna, L. & Davis, J. (1984) Family therapy with the elderly mentally ill. Some strategies and techniques. *British Journal of Psychiatry*, 145, 311–315.
- Roper-Hall, A. (1992) Better late than never? Family therapy with older adults. *Clinical Psychology Forum*, October, 14–17.

Multiple choice questions

- Which of the following statements about family therapy techniques are true:
 - the family life cycle emphasises the important development tasks of later life
 - the genogram is a useful way of summarising information about a family
 - circular questions involve asking the same question of several different family members
 - reflecting teams are therapy teams separated from the family by a one-way mirror
 - these techniques can only be used in formal family therapy clinics.

- Family therapy with other adults:
 - can be used alongside other psychiatric treatments
 - is contraindicated by a diagnosis of dementia
 - may raise questions regarding confidentiality
 - may involve a small number of meetings over a long period of time as families adjust to chronic illness
 - helps professionals to take a holistic approach to care.
- Family therapy:
 - may be helpful in working with families coping with chronic physical illness in later life
 - has clearly established outcome measures
 - using a systemic approach aims to change family members' beliefs
 - can use a psychoeducational model to try to reduce levels of emotional expressivity
 - can help families to generate their own ways of dealing with a situation.
- Within a psychiatry service:
 - family therapy training is useful for staff meeting with families in the community
 - family therapy ideas can have effects throughout the service
 - in-patient care is not compatible with formal family therapy
 - family therapy can alter the relationship between professionals and families
 - family therapy should be evaluated and audited.

MCQ answers

1	2	3	4
a F	a T	a T	a T
b T	b F	b F	b T
c F	c T	c T	c F
d F	d T	d T	d T
e F	e T	e T	e T

Publication 5.

Benbow, S.M. & Crentsil, J. (2004). Subjective experience of ECT. *Psychiatric Bulletin*. 28 p. 289-291.

Psychiatric Bulletin (2004), 28, 289-291

SUSAN M. BENBOW AND JOE CRENTSIL

Subjective experience of electroconvulsive therapy

AIMS AND METHOD

People receiving electroconvulsive therapy (ECT) in one clinic completed side-effect rating questionnaires during treatment, and a questionnaire rating their experience of different aspects of treatment on completion of the treatment course.

RESULTS

Side-effects were commonly reported, but predominantly rated as mild or moderate. Most people reported that ECT had made them a little or a lot better, and that the treatment had been fairly or very well explained. Fewer than a fifth of respondents rated ECT as slightly or much worse than going to the dentist.

CLINICAL IMPLICATIONS

We recommend routine monitoring of the subjective experience of ECT, during treatment and on completion of the course. Ratings should inform the treatment plan, the policies and procedures of the ECT clinic.



Recently the efficacy and safety of electroconvulsive therapy (ECT) in depressive disorders has been reviewed, and ECT was found to be effective in the short-term treatment of depression, 'probably more effective than drug therapy' (UK ECT Review Group, 2003). Patients' perspectives on ECT have also been reviewed (Rose *et al.*, 2003), and memory loss was highlighted as a particular concern. The American Psychiatric Association Task Force Report (2001) recommended that efforts should be made to minimise adverse effects during treatment. The National Institute for Clinical Excellence (NICE) published guidance on the use of ECT in April 2003 (National Institute for Clinical Excellence, 2003). It recommended that ECT is used only to achieve 'rapid and short-term improvement of severe symptoms after an adequate trial of other treatment(s) ... and/or when the condition is considered to be potentially life-threatening, in ... severe depressive illness, catatonia and a prolonged or severe manic episode'. This recommendation is regarded as controversial and at odds with modern ECT practice by many psychiatrists. The NICE document states that the Committee took 'special note' of the evidence given by users relating to adverse effects and further notes that outcome measures should include user perspectives of treatment with ECT. We present here the results of users' routine ratings of side-effects experienced during a course of ECT in one treatment clinic, and their ratings, after the course was completed, of aspects of the treatment procedure.

Methods

People who were receiving ECT were asked routinely by nursing staff to complete a side-effects form (ECT questionnaire 1) weekly during their course of treatment. The form listed five possible specified side-effects (memory difficulty, headache, confusion, dizziness and vomiting) and also a sixth category of 'another side-effect which was ...'. This list of side-effects was used in a previous study (Benbow, 1988). For each possible side-effect, they were asked to circle one of four options: severe, moderate, mild and none. They were also asked 'how much do you think ECT is helping you so far', with a choice of four options: not at all, a little, moderately and

a lot. Forms were returned to the ECT clinic in order that any side-effects could be taken into account during treatment.

At the end of their ECT course, a further questionnaire (ECT questionnaire 2) was sent to patients, either on the ward prior to discharge or by post following their discharge. This questionnaire consisted of two parts: part 1 asked patients to rate various aspects of treatment on one of five options: very unpleasant, slightly unpleasant, neutral, slightly pleasant or very pleasant. Part 2 asked three further questions: how much did the treatment help you (options: much worse, slightly worse, no different, a little better, a lot better), how was the treatment explained to you beforehand (options: not at all, very badly, rather poorly, fairly well, very well), and how did ECT compare with going to the dentist (options: much worse, slightly worse, no different, a little better, a lot better).

Results

Four hundred and thirty-four side-effects forms were collected (a mean of almost five forms per course), giving information on 90 courses of ECT given to 70 individuals (one person received six courses, three received three courses and nine received two). Over 95% of people were receiving ECT for a depressive disorder: their ages ranged from 16 to 91, with a mean of 64 years. For 12 courses of ECT (13%), the patient did not report any side-effects at all. Fifty-four copies of ECT questionnaire 2 were received.

For each of the six side-effects, a mean score was calculated for the whole course by adding the scores on all forms returned for that course and then dividing the sum by the number of forms returned. For reported memory problems, 29% of respondents had a mean score of 0 across the course as a whole, indicating that they did not report memory difficulties on any of the returned side-effects forms for that course. Fifty-two per cent of respondents had a mean score for memory problems between 0.1 and 1.0. This could be achieved by reporting mild memory problems (scoring 1) on each form or by scoring more severe memory problems (moderate

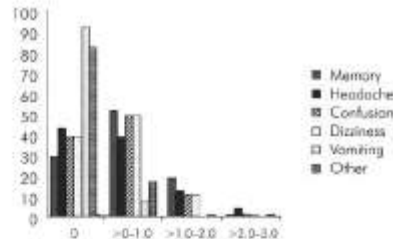


Fig. 1. Average rating score for six listed side-effects over a course of ECT. Options were scored as follows: severe 3, moderate 2, mild 1, none 0. For each individual an average score was calculated by adding the score for each side-effect across the course, and dividing it by the number of forms returned. This gave an average rating score for each side-effect for each person treated. Shows percentages of patients whose average side-effects rating falls into each of scoring bands: 0 side effect not reported, >0-1.0 mild, >1.0-2.0 moderate, >2.0-3.0 severe.

Table 1. Percentage of people treated with electroconvulsive therapy (ECT) who reported a severe or mild/moderate side-effect on any side-effects form related to each of 90 courses of ECT*

Side-effect	Severe (%)	Mild/moderate (%)
Memory problem	10	62
Headache	11	44
Dizziness	10	52
Confusion	3	41
Vomiting	0	9
Other**	7	11

*Thus, if a person returned 5 forms in respect of one ECT course and on one form rated themselves as having severe memory impairment (even if the other 4 forms were rated as no memory impairment) they are included within the severe category.

**Other side-effects: Stiff/aching/weak/painful muscles (2 people); Urinary incontinence (2 people); Dry mouth; Nausea/vomiting; Palpitations; Feeling weak; Anxiety; Nausea; Shaking (1 person each).

or severe) on some of the forms returned. Nineteen per cent of respondents scored above 1 and below 2 on memory problems, and no one scored more than 2.

Figure 1 compares the scores for all six side-effects across the course as a whole and their severity. Table 1 sets out the percentage of people who reported a side-effect as severe or mild/moderate at any stage of their treatment.

The ECT staff and 'falling asleep' (Table 2) were aspects of the treatment procedure that were given a positive rating by most respondents. 'Waking up' was the only treatment aspect rated negatively by 50% or more of the respondents, although few people rated the waiting period, the anaesthetic injection and the recovery period positively.

Most people (85%) rated themselves as a little or a lot better at the end of the course of treatment. It was more common for people to find ECT a little or a lot better than going to the dentist (27%), than to find it much or slightly worse (20%). Most people (78%) thought that the treatment had been fairly or well explained.

Discussion

This was initially designed as an audit. However, in view of the NICE recommendations, its findings are important and merit dissemination. The side-effects forms were returned to the ECT clinic staff in order that action could be taken to alleviate side-effects where possible, and were not returned anonymously. Actions taken depended on discussion between patient, ECT clinic staff and ward staff. If a person reported headaches, they would be offered treatment for this after subsequent treatments. If confusion or memory problems were reported, the ward doctor was asked to review concurrent medication as a first step. However, if the problem persisted, a change from bilateral to unilateral treatment or an increased inter-treatment interval might be recommended. Returns

Table 2. Patients' ratings of different aspects of electroconvulsive therapy (ECT) at the end of their treatment course (n=54)

	Very unpleasant (%)	Slightly unpleasant (%)	Neutral (%)	Slightly pleasant (%)	Very pleasant (%)
Waiting	11	35	44	6	2
ECT staff	2	2	4	9	83
Anaesthetic injection	13	35	39	9	4
Falling asleep	0	9	39	13	39
Waking up	6	44	30	11	7
Recovery period	2	37	39	11	11
	Much worse (%)	Slightly worse (%)	No different (%)	A little better (%)	A lot better (%)
It made me	0	2	9	37	48
Compared with the dentist	6	11	44	20	7
	Not at all (%)	Very badly (%)	Rather poorly (%)	Fairly well (%)	Very well (%)
How was the treatment explained?	2	6	6	52	26

of questionnaire 2 (relating to 60% of treatment courses) were lower than questionnaire 1, but people were often discharged soon after completing a course of treatment, and therefore had less of a chance to complete the questionnaire.

One criticism of our method of monitoring side-effects is that it may have increased people's reluctance to report side-effects, since they were reporting them to the staff responsible for their treatment. Patients were actively encouraged to report any problems in order that action could be taken to alleviate side-effects, and in an endeavour to avoid under-reporting. However, Rose *et al* (2003) reported that satisfaction tends to be higher when clinic staff members, rather than a fellow service user or neutral person, administer questionnaires. This might have led to under-reporting of side-effects and poor outcomes. A further possible factor, which may have led to over-reporting of side-effects, is that people rated as side-effects symptoms that their treatment teams regarded as being no different from those experienced prior to treatment. These are considered to be depressive symptoms or side-effects of concurrent medication. This was taken into account in deciding what action to take in response to side-effects ratings, but is not reflected in the raw results. Although side-effects were commonly reported, they were predominantly rated as mild. Only a small proportion of people reported any moderate or severe side-effects. Our findings provide potentially useful information regarding patients' experiences during treatment, which can inform the discussions with people who are considering having ECT and their families.

In future, people who are about to start a course of ECT will be asked to rate the symptoms, which were listed as possible side-effects of treatment, prior to receiving ECT. This is because some individuals were recorded in their case notes as complaining of a symptom before receiving treatment, and it was regarded by their word team as being a symptom of depressive illness (e.g. headaches) rather than a side-effect of ECT. It is more

difficult to tease out the effect of ECT on an established symptom during a course of treatment. It would also be useful to record how often treatment is changed as a result of side-effects monitoring. Feedback on wider aspects of the treatment from people who have received ECT could usefully be incorporated into planning policies and procedures in the clinic, in order to minimise waiting times, and to make the recovery period as comfortable as possible, for example.

We recommend that people who are receiving ECT should be encouraged to feed back to staff their subjective experiences of treatment, and to rate the occurrence and severity of side-effects. This does not remove the need for staff to monitor side-effects objectively (e.g. by standardised memory tests), but provides a fuller picture and allows changes to be made to treatment techniques and procedures where appropriate. Furthermore, we recommend that consideration should be given to patient follow-up after completion of treatment, with a questionnaire designed to assess longer-term side-effects and outcome.



References

- AMERICAN PSYCHIATRIC ASSOCIATION TASK FORCE (2001) *The Practice of Electroconvulsive Therapy: Recommendations for Treatment, Training and Privileging*. Washington, DC: American Psychiatric Association.
- BENBOW, S. M. (1988) Patients' views on electroconvulsive therapy on completion of a course of treatment. *Convulsive Therapy*, **4**, 146–152.
- NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE (2003) *Technology Appraisal 59: Guidance on the Use of Electroconvulsive Therapy*. London: NICE.
- ROSE, D., REBSCHAW, R., WYNES, T. *et al* (2003) Patients' perspectives on electroconvulsive therapy: systematic review. *BMJ*, **326**, B63.
- UK ECT REVIEW GROUP (2003) Efficacy and safety of electroconvulsive therapy in depressive disorders: a systematic review and meta-analysis. *Lancet*, **361**, 799–808.
- *Susan M. Benbow: Consultant Psychiatrist, Wolverhampton City Primary Care Trust and Professor of Mental Health & Ageing, University of Wolverhampton, Penn Hospital, Penn Road, Wolverhampton WV4 5HN. E-mail: susan.benbow@wlv.ac.uk. Joe O'Neill: ECT Manager & Education and Training Coordinator, ECT Unit, Manchester Royal Infirmary.

Publication 6.

Benbow, S.M. & Jolley, D. (2006). Organisation of services in geriatric psychiatry. In J. Pathy, A. Sinclair & J. Morley, eds. *Principles & Practice of Geriatric Medicine*. 4th ed. Wiley, Chichester: Wiley. Ch. 99, pp. 1163-1171.

Organization of Services in Geriatric Psychiatry

Susan M. Benbow and David Jolley
University of Staffordshire, Staffordshire, UK

INTRODUCTION

Old age psychiatry is a relatively young speciality of psychiatry: the first pioneers of "psychogeriatrics" began to develop specialist services for older people in the United Kingdom in the 1960s and 70s. Early service principles included:

- a comprehensive age-related catchment area service;
- assessment at home before admission by a senior member of the team;
- diagnosis followed by active treatment;
- team working;
- close liaison with GPs, geriatricians, and social services.

The introduction of mixed sex wards was a radically progressive move at the time, and home visits were perhaps the first steps toward assertive outreach. In 1989, old age psychiatry was recognized as a speciality by the Department of Health, and by the millennium the Royal College of Psychiatrists recognized over 350 specialists in the psychiatry of old age. A recent report on progress in older people's health over the past 3 years gives the current number of old age psychiatrists, as of June 2004, as 444 (Department of Health, 2004).

It is useful to revisit the reasons why old age psychiatry first developed. Within an all-age adult psychiatry service, older adults did not receive the dedicated care and attention that a specialist service provides, as they were in competition with younger adults who present high profile risks and are valued more by society, perhaps because they are regarded as potentially economically active. This ignores the enormous contribution that older adults make to society: most voluntary organizations would disappear without the input they provide, many continue to work long after retirement age, many take up or continue roles as carers (to younger people, people with learning disability, to

other elders), and others continue to make their wisdom and talents available to the rest of society. In addition to these ageist and attitudinal obstacles, mental illness in late life is complicated by cumulating physical illnesses, the physical and psychological changes associated with aging, and increasingly by the coexistence of cognitive impairment, all of which demand special skills of the mental health professionals who aim to provide appropriate assessment, diagnosis, treatment, rehabilitation, support and care for this group, and a service orientated to the practical needs of many elders.

The National Service Framework for Older People (NSF-OP) in Standard 7 set out a service model for a comprehensive mental health service for older people (Department of Health, 2001a). Components of the model service should include

- mental health promotion;
- early detection and diagnosis;
- assessment and treatment;
- support for carers;
- specialist mental health services, which will include acute admission and rehabilitation beds, day hospitals and memory clinics, domiciliary and outreach care, and outpatient/community clinics.

The NSF-OP was warmly received by many old age psychiatrists as it embeds mental health as integral to the health of older people and its core principles ("rooting out age discrimination" and "person-centered care") are potentially powerful influences for positive change in older people's mental health.

The National Service Framework for Mental Health (NSF-MH) had been less well received (Department of Health, 1999) as it excluded older adults and focused on services to working aged adults. Monies and developments associated with the NSF-MH therefore excluded older adult

services and have led to expansion of working aged adult mental health services at the expense of services to older adults. The NSF-OP states that older people with severe mental illness will require the packages of care set out in the NSF-MH. The same standards must apply irrespective of age, and care should be provided within the framework of the Care Programme Approach (CPA) (Department of Health, 2002). This requirement seems to have gone largely unnoticed until recently.

The exclusion of older people from the NSF-MH could be regarded as ageist, but it is equally ageist to deny that this group has special needs to which services should be sensitive, and in dealing with which the service organization and response must be competent. What is right for adults of working age will not always be right for older people. Older people need a special service. This should not be one confined to problems of dementia, but should encompass the whole range of mental disorders of late life. Thus, the issue of age discrimination in mental health is a challenge for services, which must be tailored to need and not to rigid age cutoffs. This is an important principle in service planning and delivery.

MENTAL HEALTH PROMOTION FOR OLDER PEOPLE

Mental health promotion is defined as "any action to enhance the mental well-being of individuals, families, organizations and communities, and a set of principles which recognize that how people feel ... (has) a significant influence on health" (Friedli, 2000). This is a daunting challenge, yet aspects of mental health promotion are already incorporated into good service planning and operation. Extending from this base provides the potential for improved services, and for improving the quality of life for people using those services by treatment of symptoms and reducing the likelihood of relapse.

Mentality's briefing paper on evidence-based mental health promotion (Mentality, 2003a) sets out a range of possibilities: opportunities for social and physical activities, access to information and practical help, volunteering, discussion and self-help groups are all linked with an evidence base showing a positive effect on mental well-being. The links between physical and mental health are also highly relevant to older adults (Mentality, 2003b).

Mental health professionals often encourage people to modify their lifestyle following an episode of mental ill-health, in order to improve their resilience. The challenge is to incorporate routine use of mental health promotion techniques into the design of clinical services.

EARLY DETECTION AND DIAGNOSIS: INTERFACE WITH PRIMARY CARE

The vast majority of people with mental health problems in late life will never be seen by a specialist service. Many

will remain unrecognized even when they have contact with primary and social care services. Family doctors are, however, well placed to identify cognitive problems and mood disorders early, to provide people with information and to introduce them, where necessary, to further investigations, treatment, and support. Those working in primary care see many elders with physical problems regularly, and this gives the opportunity to assess and monitor the person's mental health in a familiar setting. An established relationship with their family doctor or practice nurse may also help an older adult accept the need for referral to specialist services for assessment, treatment or support, or to social services or voluntary organizations. The family doctor is an essential and central person in care coordination. A useful opportunity for early detection presents when people are being seen in primary care for other reasons. For example, people at high risk of arteriosclerosis are also at high risk of developing a vascular dementia, and family doctors screen people routinely for cardiovascular disease. Those who are identified as *at high risk* are examined regularly and have renal function and lipid levels checked. Some family doctors add a cognitive test to the cardiovascular assessment, and use this opportunity to detect cognitive problems.

One of the milestones set out in the Older People's NSF (Department of Health, 2001a) was that Primary Care Trusts (PCTs) were required by April 2004 to ensure that every general practice was using a protocol agreed with local specialist services for the diagnosis, treatment, and care of older adults with depression or dementia. Protocols for the treatment of people with Alzheimer's disease may set out physical investigations and cognitive testing which can be carried out in primary care, in order to facilitate early detection and rapid access to antimentia drug treatment if appropriate.

Some services are developing formal links with primary care: nurses identified to link with particular practices offer one possible model; formal meetings between secondary and primary care staff offer another.

CARER SUPPORT

Carers in the United Kingdom have the right to an independent assessment of their needs (but not a right to services) under the Carers (Recognition and Services) Act (Department of Health, 1995), if the person they care for has a right to a community care assessment. Many people who care for elders are themselves older adults (often spouses) and they may themselves be stressed or have mental health problems. The National Institute for Social Work (Levin, 1997) has identified 10 key requirements for carers:

- early identification;
- comprehensive assessment (including medical and social assessment);
- medical treatment of treatable problems;

prompt referral to other sources of help;
information, advice, and counseling;
continuing support and review, preferably from a person
known and trusted by the carer;
regular help with domestic tasks and personal care;
regular breaks from caring (respite);
financial support;
access to permanent residential care when needed.

Thus, carer support is a fundamental component of all aspects of service provision. One specialist model, available in some parts of England, is the Admiral nurse service, which aims to support the carers of people with dementia. More commonly available are carer support groups, which may be aimed at particular groups and their needs, for example, early onset services often have active carers groups, and our local service has a thriving support group for Asian carers (paper submitted). The Alzheimer's Society produces an advice sheet for carers (Alzheimer's Society, 2004), which addresses how carers can care for themselves, but the challenge for services is to ensure that they care for the carers as well as the person who is seen as their client or patient. This will often involve sensitive negotiation with carer and service user, who will not uncommonly have differing views. In accommodating disparate views, it is vital that social and health-care staff work with families long term to establish a trusting relationship and also have access to a broad range of flexible services. Respite is a big issue and the Audit Commission (2000) found that the need for more respite was the most common comment made by the carers of people with dementia: over one-third of carers reported difficulty in accessing respite care (Audit Commission, 2002). Respite includes a range of possible provisions, including day care, respite admissions to residential or nursing care, regular or planned respite admissions, and respite within the home, for example, day and night sitting services. The lack of good written information about services was also highlighted by the Audit Commission (2002).

COMMUNITY MENTAL HEALTH TEAMS FOR OLDER PEOPLE

The NSF-OP (Department of Health, 2001a) sets out the disciplines who should be core members of the CMHT-OP: this should include community mental health nurses, consultant old age psychiatrists, clinical psychologists, social workers, and occupational therapists. A range of other disciplines is listed as needing to have agreed working and referral arrangements with the team but not working as full members of it.

One of the big issues for a CMHT-OP is that of "integration". In this context, integration usually refers to the integration of health and social care. Lingard and Milne (2004) have written a scholarly commentary and resource document on the topic which describes the different components of integrated teams. The Durham mapping project

pilot in older people's mental health services uses four main criteria for an integrated CMHT-OP:

- The team should include interagency multidisciplinary staff involving health and social services.
- It should provide integrated assessment, care planning and care coordination.
- It should use shared recording systems and IT, supporting both CPA and the Single Assessment Process (SAP).
- There should be a single point of entry to specialist mental health assessment.

How teams work in relation to team members' responsibility is another major issue. This has become increasingly important because of high consultant psychiatrist vacancy levels in the United Kingdom (running at around 12–14%) with associated problems of recruitment and retention. There is evidence that consultants are overburdened, stressed (Benbow and Jolley, 1997) and retiring earlier (Mears *et al.*, 2004a). Factors in this may include large and increasing caseloads, style of working (Mears *et al.*, 2004b) and the increasing pressure to avoid risk. Locum consultants are in short supply and attract high rates of pay. Thus, reliance on them may compromise service development and lead to a perverse incentive, which encourages doctors to continue working as locums rather than accept a reduced salary together with greater responsibility in a substantive post.

- Do doctors have to see and take responsibility for every person known to the CMHT-OP?
- How is responsibility carried or shared by team members?

These questions have been explored by a working party on new ways of working for consultant psychiatrists (Royal College of Psychiatrists Scoping Group on the Roles and Values of Psychiatrists, 2004; National Steering Group, 2004).

The way ahead is seen as requiring

- a single point of entry to the CMHT (for older people);
- the definition of the responsibilities of team members with agreement of when and why people need to see psychiatrists;
- better IT support to the team;
- clarification of issues of team members' responsibility, power, and accountability.

Three options were identified for consultant responsibility as team members:

Option 1 involves *no change* to consultant responsibilities from the present. The characteristics of this model are that the consultant psychiatrist within a team continues to carry responsibility for large numbers of patients and other professionals are less autonomous. This model is anticipated to lead to continuing workload problems for psychiatrists with an increasing demand for doctors and a lag before medical school output increases sufficiently to provide more potential psychiatrists.

Option 2 is characterized by consultant psychiatrists carrying smaller caseloads with responsibility *delegated* to other professionals. In this model, although team consultants carry a smaller personal caseload, they remain responsible for large numbers of patients and all outpatients are required to have a named consultant. The relationship between consultant psychiatrist and other team members is regarded as *supervisory*, although other professionals are more autonomous than in option 1.

Option 3 is characterized by responsibility being *distributed* amongst members of the team. The consultant psychiatrist is therefore directly responsible for fewer patients and is freed up to concentrate on high risk or complex cases (although complexity will need to be defined). The consultant's relationship to other team members is that of a *consultant* and other professionals are more autonomous in this model. Guidance from the General Medical Council on medical responsibility is anticipated in 2005, and is expected to support doctors in moving toward this model, which has been strongly supported by the Faculty of Old Age Psychiatry within the Royal College of Psychiatrists.

COMMUNITY TREATMENT

One of the early principles of old age psychiatry was assessment at home by a senior member of the old age psychiatry team (Arie, 1970). This led on to the concept of a community clinic (Benbow, 1990), and many services carry out the majority of their assessment, treatment, and follow-up by seeing people in their homes, coordinating the activity of different disciplines using IT support and close liaison between team members. Perhaps the recent move to extend the principles of the NSF-MH to older adult services might lead to an expansion in the home treatment element of the CMHT-OP.

Community treatment for older people will involve close working with social services (particularly with day centers for older adults and domiciliary services) and voluntary organizations, and close links between the CMHT-OP and places where older adults are resident, including sheltered and extra care housing, and the residential and care home sector.

HOSPITAL-BASED FACILITIES

Acute Inpatient Beds

Community-orientated services need access to inpatient beds for the assessment and treatment of older people with a range of diagnoses, who cannot be managed in the community, a small proportion of whom will be detained under mental health legislation. The main distinction is between people who have an organic brain disorder and those with so-called functional disorders, the most common of which is depressive

illness. Current thinking often supports separate inpatient provision for people with organic brain disorders and those with other mental health problems in later life (Audit Commission, 2000, 2002). The distinction is often neither clear nor absolute in practice, and flexibility and tolerance are needed when accommodating the various and changeable complex needs of very ill/disturbed older people. It is not usually appropriate to care for older adults with complex needs on wards for younger adults (Audit Commission, 2002); this would place them at risk and deprive them of the specialist nursing, medical, and other care which they require.

Day Hospitals

Day hospitals for older people are widely available across the United Kingdom but the literature supporting their role is remarkably sparse. The Faculty of Old Age Psychiatry carried out a survey of old age psychiatric day hospitals, published in a report in June, 2001: (Audini *et al.*, 2001). Three quarters of day hospitals operated a mixed service to people with organic and functional illnesses in late life. The study found that people attend day hospitals for a great many different reasons and for varying periods of time: over a third of people attend for over one year. Carer support is a common feature of a day hospital service, and some units aim to provide a respite service for people with dementia in association with particularly challenging behaviors, which restrict the availability of alternative sources of respite.

Possible aims for an old age psychiatry day hospital include the following:

- Reduction of inpatient bed use by functionally ill older people.
- Prevention of admission: by supporting CMHTs in maintaining ill people in the community during crisis.
- Prevention of readmission through relapse prevention.
- Prevention of readmission through prevention of recurrence.
- Reduction of duration of an episode of inpatient treatment.

Outpatient Clinics

For many services, the majority of activity takes place in the community using a community clinic model. Some older adults may prefer to be seen in a traditional outpatient clinic, and there may also be specialist clinics, for example, clinics carried out jointly with geriatric physicians, and memory clinics (though memory clinics may themselves work primarily in the community or in a day hospital.) Other models involve clinics carried out in GP surgeries, day centers, nursing or residential homes. There are also clinics specializing in family therapy (Benbow and Marriott, 1997).

Memory Clinics

The number of memory clinics in the British Isles has been increasing in recent years. In 1993, Wright and Lindsay (1995) carried out a survey which identified 20 clinics, largely offering a multidisciplinary specialized hospital-based assessment service. When the survey was repeated in 1999–2000 (Lindsay *et al.*, 2002), 58 active memory clinics were identified, and over a quarter were partly or wholly based in the community. The authors concluded that the growth in memory clinics has been stimulated by the licensing of drug treatments for Alzheimer's disease and that they have now moved into mainstream clinical services. They reported that the term "memory clinic" has extended to a wider range of service models, with a less academic, more service orientated focus. They are closely associated with antidementia drug treatments, but also with psychosocial interventions: over half of the clinics surveyed offered memory training and anxiety management. The authors also suggest that memory clinic development has been driven by a need for services for people with early onset dementia syndromes.

Services to the General Hospital

Older people are frequently admitted to hospital because of intercurrent illness. Some will have preexisting psychiatric problems, others may develop them in association with their acute physical illness. All deserve attention to the full range of their needs. Unhappily, the environment of large general hospitals is often less than helpful to frightened, confused old people. The pressure to move on from assessment ward to treatment ward and out may compound their difficulties. Formal Liaison Psychiatric services have not, traditionally, taken a major interest in older people, and Old Age Psychiatry services have often given greater priority to patients in the community. This failing is being addressed in some centers and there is progress toward generalizing good practice (Holmes *et al.*, 2002). Admission to hospital for physical illness may provide an opportunity to recognize a memory problem and initiate referral to the old age psychiatry service. Figure 1 sets out the referral pathway for people with a suspected dementia and illustrates the overlap between physical and mental health services in late life (Figure 1).

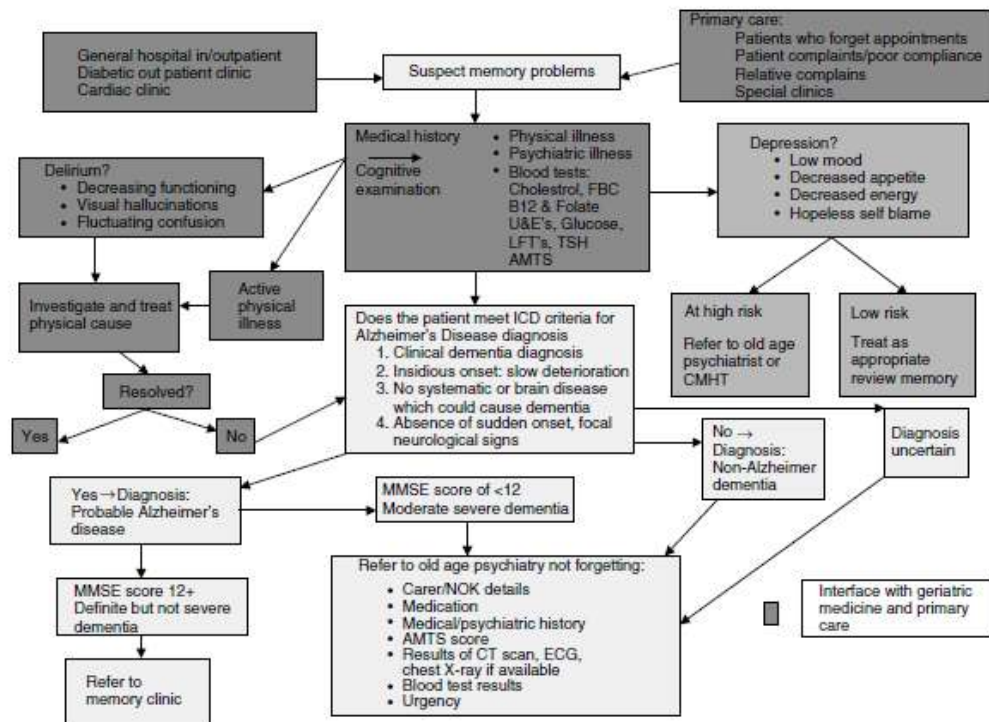


Figure 1 Dementia referral pathway

SPECIAL GROUPS

Elders with Learning Disability

People with a Learning Disability are much more likely to survive into their 60s and beyond now, than was the case in the past (Collacott, 1997). People with Learning Disability may develop problems characteristic of late life earlier than the general population. People with Down's Syndrome are particularly at risk of Alzheimer's Disease (Holland and Oliver, 1995), which requires skillful care in its terminal phases.

Thus, older people with Learning Disability may have complex needs which cross the interface between old age psychiatry, geriatric medicine, and learning disability services. Good practice will often require that services work together to best meet an individual's needs (Department of Health, 2001b). Flexibility and trust are vital. Users and their families need to be clear about care plans: who is taking responsibility for what, and how they might be contacted. Commissioners need to ensure that this group is not neglected in service planning.

Early Onset Dementia Services

In 2000, the Royal College of Psychiatrists (2000) published a Council Report which recommended that each district should have a named consultant responsible for the service for younger people with dementia and that old age psychiatrists should take the lead. Subsequently, the Alzheimer's Society carried out a postal survey of all members of the Faculty of Old Age Psychiatry, to assess members' awareness of the report and determine what developments in service provision had occurred since its publication. Awareness of the report was comparatively high, but no area met all the report's recommendations. There was evidence of improvement in service provision, and many respondents outlined plans for future development. Currently, the Council Report is being revised and the revised document is likely to recommend that commissioners should have

- a named individual who takes responsibility for commissioning services for younger adults with dementia and
- specific contractual arrangements for a specialized service for younger people with Alzheimer's disease and other dementias, including programed time from a named consultant (usually an old age psychiatrist).

The Alzheimer's Society (1996) has a charter for younger people with dementia and their carers, which supports early diagnosis, assessment and referral, and access to specialist services.

People with Enduring or Relapsing Mental Illness

Those individuals who lived out their lives with chronic schizophrenia, manic-depressive psychosis, brain damage

or personality disorders in large mental hospitals, were overlooked by the psychogeriatric services of the 1970s and 1980s. Closure of the hospitals and changing expectations have meant that the new generations of "graduates" with a psychosis live within the community, often in hostels or nursing homes. There they may have remained in touch with mental health services, or drifted out of touch. They are at risk of neglect or misunderstanding or of falling into a gap between different services (Jolley *et al.*, 2004). Their plight has been recognized, and existing guidance encourages all authorities to recognize them, discover their needs, and agree the best arrangements for their care within the range of available local resources (Royal College of Psychiatrists, 2002).

People in Residential and Nursing Care

Despite the emphasis on supporting people in their own homes and providing alternative and innovative housing solutions for older, frailer people, large numbers spend their last months or years in residential homes or nursing homes. In many residential homes, 40% or more of the residents have dementia, and up to 20% are depressed or demonstrate other psychiatric morbidity (Mann, 1991). Roughly, half of the population with a diagnosis of dementia in the United Kingdom is in care at any one time. For most, this is terminal care. The transfer of care from large, ill-sited, ill-equipped, and poorly staffed mental hospitals to community-based homes nearer their families represents progress for many people, but there are continuing concerns over the quality of life available to residents, particularly those with mental illness or dementia. Early progress in service improvement followed scandals relating to hospital care (Arie and Isaacs, 1978). A recent driver for improved standards in inpatient care has been the Rowan Report (Commission for Health Improvement (CHI), 2003). Rowan ward was an "isolated facility": it was a ward that was left behind when the rest of a large hospital closed and became a building site. Allegations of physical and emotional abuse led to an investigation by the then Commission for Health Improvement (CHI), who produced a report in September 2003. This revealed a poor and institutionalized ward environment with low staffing levels, high use of bank/agency staff, little staff development and poor supervision. The culture was described as closed and inward looking with weak management at ward and locality level. Although the history of inpatient older people's mental health (OPMH) care reveals a progression of similar reports, this report attracted a lot of publicity, attention to current inpatient standards, and reflection on acceptable standards of care. It was followed by an audit of inpatient care carried out by Strategic Health Authorities across England, which moved OPMH up the agenda nationally.

It is essential that specialist services, both medical and mental health, take responsibility for the care of older people in the time of their greatest need, be this in residential or nursing homes, or the much diminished National Health Service (NHS) continuing care sector.

Black and Minority Ethnic (BME) Elders

The Royal College of Psychiatrists (2001) published a report on psychiatric services for BME elders in 2001. This made five main recommendations:

- assessment and treatment should remain within mainstream psychiatric services;
- continuing care services should be targeted at particular user groups;
- services should endeavor to recruit a mix of staff reflecting the ethnic mix of the local population;
- good practice should be established and shared, perhaps using a website;
- staff should be trained in culturally sensitive issues.

There are already examples of good practice developing around the country. In Wolverhampton alone, there are several initiatives:

- social services and health staff have jointly undertaken a course in basic Punjabi;
- staff at a local day center for Asian elders undertake exchanges with staff at the Resource Center for older adults with mental health problems;
- a specialist community psychiatric nurse (CPN) is employed to work with Asian elders presenting to old age psychiatry;
- a support group for Asian carers of older adults with mental health problems has been established.

This experience must be multiplied many times around the country, as services increasingly address the needs of ethnic elders within their localities.

SPECIAL ISSUES

Access to Psychological Therapies

The NSF-OP states that a full range of psychological treatments should be available for older people with mental health problems. This is probably not the case at present: Evans (2004) found that provision varies widely across the United Kingdom and is of unknown quality. Hepple (2004) recently reviewed psychological therapies for older adults and states that their slow development is due to ageism. It is likely that upcoming cohorts of older adults will be more likely to expect access to psychological therapies and that this aspect of service provision will need to respond to their demands in future.

Intermediate Care for Older People with Mental Health Problems

Intermediate care is an emerging concept in health care, which may offer alternatives to hospital care. It was conceived originally in response to the increasing demand for

acute hospital services, and the fact that a high proportion of acute hospital beds is occupied by older people. The British Geriatrics Society (2001) quotes several definitions of intermediate care: one simply describes intermediate care as delivered by those health services that do not require the resources of a general hospital but are beyond the scope of the traditional primary care team. The NSF-OP sets out the following aims for intermediate care in Standard 3: to provide integrated services to promote faster recovery from illness, prevent unnecessary acute hospital admissions, support timely discharge, and maximize independent living. Its two main thrusts are prevention of admission and facilitation of early discharge. Ways of preventing acute admissions amongst people with mental health problems include the provision of specialist home care/community support, access to specialist community nursing, home-based respite services, assertive in-reach/outreach projects, flexible, and rapid access to intensive home care. Ways of facilitating early discharge of people with mental health problems from hospital beds include liaison services which work across the interfaces of care, and rapid easy access to short periods of postdischarge intensive home support. Intermediate care is as relevant to older people's mental health services as it is to everyone who has access to acute hospital services (Read, 2004). People with dementia, depression, and other mental health diagnoses should have access to intermediate care services, whether or not they have a physical illness. In the past, intermediate care services have, not uncommonly, excluded people who they identify as having mental health problems, but there has been growing recognition that this is unacceptable and that older people with dementia and other mental disorders must have appropriate access to intermediate care. There are a range of ways in which this can be done, for example, by setting up specialist provision, by ensuring close links between specialist OPMH service and generic intermediate care services, and by placing mental health staff within generic intermediate care services. The development of intermediate care offers an opportunity to investigate a range of options for flexible community treatment and support.

AN INTERNATIONAL PERSPECTIVE

This chapter is written from the vantage of developments and current considerations in the United Kingdom. The speciality of old age psychiatry is one of the gifts of British medicine to advances in the twentieth century (Arie and Jolley, 1999). Yet the importance of mental health problems in late life is a global phenomenon, as developing countries join developed countries in seeing life-expectation rise beyond 60 years from birth (Kalche, 1996).

From the mid-1970s British pioneers encouraged colleagues in Europe, America, Canada, and Australia to follow their designs for community-based services through the medium of personal lecture tours (Pitt, 1974). Professor Arie's Nottingham courses, sponsored by the British

Council, shared principles and practicalities with a wider audience and were followed by the establishment of the European Association of Geriatric Psychiatry (EAGP) and the International Psychogeriatric Association (IPA). Professional advice has been supported by the interest of voluntary organizations. Alzheimer's International, for instance, currently lists 72 active national centers. Thus, the countries of the world are responding to the needs of older people with mental health problems in different ways according to their economies, philosophies, and health-care configurations. But they are in touch with approaches used elsewhere and most use elements of the comprehensive services outlined here within the British model.

These principles were affirmed in the Lausanne Technical Consensus statements on the psychiatry of the elderly by the World Psychiatric Association in 1999. Many examples of friendly, supportive international collaboration exist, as experienced practitioners and researchers add to their own breadth of understanding by working in new situations for the benefit of others. One notable example is that of the Alzheimer's International 10/66 Dementia Research group (Prince *et al.*, 2004).

CONCLUSIONS

Older people's mental health services in the United Kingdom have developed rapidly over the last 30 years, despite a series of threats and uncertainties. Good has come from the Rowan Report (Commission for Health Improvement (CHI), 2003), which has moved OPMH up the national agenda. Other powerful forces for good include the Alzheimer's Society, Age Concern, and Rethink. The Dementia Services Development Centers continue working to improve standards in care, and recently the National Institute for Mental Health in England has launched a work program in OPMH. All of these are reasons for optimism. Generations of older adults in future (which include those of us writing and reading this chapter) are going to be increasingly demanding of services: we must design and operate services that we ourselves would be happy to use.

KEY POINTS

- Specialist older people's mental health services should address the needs of people with a range of mental disorders in late life.
- Early detection, diagnosis, and treatment are important principles of OPMH services.
- Active community assessment, treatment and support needs to be complemented by hospital-based services, including inpatient provision.
- A number of special groups will need be addressed in service planning, including elders with learning

disability, people with an early onset dementia, and those from minority ethnic groups.

- Liaison is needed across a broad range of voluntary and statutory agencies to provide flexible person-centered services.

KEY REFERENCES

- Audit Commission. *Forget-Me-Not. Developing Mental Health Services for Older People* 2000; Audit Commission, London, <http://www.audit-commission.gov.uk/Products/NATIONAL-REPORT/4EEC12F0-AA9A-4CB0-90AE-7FC5CB6584CE/ForgetMeNot.pdf>.
- Audit Commission. *Forget Me-Not 2002. Developing Mental Health Services for Older People* 2002; Audit Commission, London, <http://www.audit-commission.gov.uk/Products/NATIONAL-REPORT/3DHEF403-038C-464f-8518-441477E92B15/forgetupdate.pdf>.
- Department of Health. *National Service Framework for Older People* 2001a; Department of Health, London, <http://www.doh.gov.uk/nsf/olderpeople.htm>.
- Holmes J, Bentley K & Cameron I. *Between Two Stools: Psychiatric Services for Older People in General Hospitals* 2002; University of Leeds Academic Unit of Psychiatry, Leeds, <http://www.leeds.ac.uk/medicine/psychiatry/lporeport.pdf>.
- Lingard J & Milne A. *Integrating Older People's Mental Health Services Community Mental Health Teams for Older People. A Commentary and Resource Document* 2004, http://www.nimhe.org.uk/downloads/newCMHT_OPs_July_042004JL.pdf.

REFERENCES

- Alzheimer's Society. *Younger People with Dementia: a Review and Strategy* 1996; Alzheimer's Society, London.
- Alzheimer's Society. *Caring for Someone with Dementia* 2004, Advice Sheet http://www.alzheimers.org.uk/Caring_for_someone_with_dementia/Coping_with_caring/info_yourself.htm.
- Arie T. The first year of the Goodmayes psychiatric service for old people. *Lancet* 1970; ii:1175-8.
- Arie T & Isaacs A. The development of psychiatric service for the elderly in Britain. In A Isaac & F Post (eds) *Studies in Geriatric Psychiatry* 1978, pp 241-62; John Wiley & Sons, Chichester.
- Arie T & Jolley D. Psychogeriatrics. In H Freeman. (ed) *A Century of Psychiatry* 1999, pp 260-4; Mosby-Wolfe, London.
- Audini B, Lelliott P, Banerjee S *et al.* *Old Age Psychiatric Day Hospital Survey. Final Report* 2001; Royal College of Psychiatrists Research Unit, London, <http://www.rcpsych.ac.uk/college/faculty/oap/dayhospitals/OAPDayHospSurvey.pdf>.
- Audit Commission. *Forget-Me-Not. Developing Mental Health Services for Older People* 2000; Audit Commission, London, <http://www.audit-commission.gov.uk/Products/NATIONAL-REPORT/4EEC12F0-AA9A-4CB0-90AE-7FC5CB6584CE/ForgetMeNot.pdf>.
- Audit Commission. *Forget Me-Not 2002. Developing Mental Health Services for Older People* 2002; Audit Commission, London, <http://www.audit-commission.gov.uk/Products/NATIONAL-REPORT/3DHEF403-038C-464f-8518-441477E92B15/forgetupdate.pdf>.
- Benbow SM. The community clinic - its advantages and disadvantages. *International Journal of Geriatric Psychiatry* 1990; 2:119-21.
- Benbow SM & Jolley D. Old age psychiatrists: what do they find stressful? *International Journal of Geriatric Psychiatry* 1997; 12:879-82.
- Benbow SM & Marriott A. Family therapy with elderly people. *Advances in Psychiatric Treatment* 1997; 3:138-45.

ORGANIZATION OF SERVICES IN GERIATRIC PSYCHIATRY

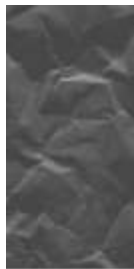
1171

- British Geriatrics Society. *Intermediate Care – Medical Guidance for Purchasers and Providers* 2001, <http://www.bgs.org.uk/compendium/comd4.html>.
- Collacott R. Psychiatric problems in elderly people with learning disability. In O Russell (ed) *Seminars in the Psychiatry of Learning Disabilities* 1997, pp 136–47; Royal College of Psychiatrists, London.
- Commission for Health Improvement. *Investigation into Matters Arising from Care on Rowan ward, Manchester Mental Health and Social Care Trust* 2003, http://www.chi.nhs.uk/eng/organisations/north_west/man_mh_sc/inv2003/man_mh_rowan_ward.pdf.
- Department of Health. *Carers (Recognition and Services) Act* 1995; Department of Health, London, http://www.legislation.hms.gov.uk/acts/acts1995/Ukpga.19950012_en.1.htm.
- Department of Health. *National Service Framework Mental Health* 1999; Department of Health, London.
- Department of Health. *National Service Framework for Older People* 2001a; Department of Health, London, <http://www.doh.gov.uk/nsf/olderpeople.htm>.
- Department of Health. *Valuing People: A New Strategy for Learning Disability* 2001b; HMSO: London.
- Department of Health. *Care Management for Older People with Serious Mental Health Problems* 2002, <http://www.dh.gov.uk/assetRoot/04/07/32/80/04073280.pdf>.
- Department of Health. Better health in old age. *Report from Professor Ian Philp, National Director for Older People's Health to Secretary of State for Health* 2004; Department of Health, London.
- Evans S. A survey of the provision of psychological treatments to older adults in the NHS. *Psychiatric Bulletin* 2004; **28**:411–4.
- Friedli L. Mental health promotion: rethinking the evidence base. *Mental Health Review* 2000; **5**:15–8.
- Hepple J. Psychotherapies with older people: an overview. *Advances in Psychiatric Treatment* 2004; **10**:371–7.
- Holland AJ & Oliver C. Down's syndrome and the links with Alzheimer's disease. *Journal of Neurology, Neurosurgery and Psychiatry* 1995; **59**:111–4.
- Holmes J, Bentley K & Cameron I. *Between Two Stools: Psychiatric Services for Older People in General Hospitals* 2002; University of Leeds Academic Unit of Psychiatry, Leeds, <http://www.leeds.ac.uk/medicine/psychiatry/lpopreport.pdf>.
- Jolley D, Kosky N & Holloway F. Older people with long-standing mental illness: the graduates. *Advances in Psychiatric Treatment* 2004; **10**:27–36.
- Kalche A. Ageing worldwide. In S Ebrahim & A Kalache (eds) *Epidemiology in Old Age* 1996, pp 22–31; BMJ Publishing Group, London.
- Levin E. *Carers: Problems, Strains and Services* 1997; Oxford University Press, Oxford.
- Lindesay J, Marudkar M, Van Diepen E *et al.* The second Leicester survey of memory clinics in the British Isles. *International Journal of Geriatric Psychiatry* 2002; **17**:41–7.
- Lingard J & Milne A. *Integrating Older People's Mental Health Services Community Mental Health Teams for Older People. A Commentary and Resource Document*. 2004, http://www.nimhe.org.uk/downloads/newCMHT_OPsJuly042004JL.pdf.
- Mann A. Epidemiology. In R Jacoby & C Oppenheimer (eds) *Psychiatry in the Elderly* 1991, pp 89–112; Oxford Medical Publications, Oxford.
- Mears A, Kendall T, Katona C *et al.* Retirement intentions of older consultant psychiatrists. *Psychiatric Bulletin* 2004a; **28**:130–2.
- Mears A, Pajak S, Katona C *et al.* Consultant psychiatrists' working patterns: is a progressive approach the key to staff retention? *Psychiatric Bulletin* 2004b; **28**:251–3.
- Mentality. *Making it Effective a Guide to Evidence Based Mental Health Promotion. Radical Mentalities Briefing Paper 1* 2003a; mentality, London.
- Mentality. *Not all in the Mind: the Physical Health of Mental Health Service Users. Radical Mentalities Briefing Paper 2* 2003b; mentality, London.
- National Steering Group. *Guidance on New Ways of Working for Psychiatrists in a Multi-disciplinary and Multi-agency Context. Interim Report August 2004* 2004; Department of Health, London, <http://www.nimhe.org.uk/downloads/Nat%20Steering%20Interim%20Rep.pdf>.
- Pitt B. *Psychogeriatrics* 1974; Churchill-Livingstone, London.
- Prince M, Graham N, Brodarty H *et al.* Alzheimer's Disease International 10/66 Dementia Research Group: one model for action in developing countries. *International Journal of Geriatric Psychiatry* 2004; **19**:178–81.
- Read K. Intermediate care: the new pathway to rehabilitation or widening the chasm? In M Marshall (ed) *Perspectives on Rehabilitation and Dementia* 2004, pp 39–49, Jessica Kingsley Publishers, London.
- Royal College of Psychiatrists. *Services for Younger People with Alzheimer's Disease and Other Dementias*, Council Report CR77 2000, Royal College of Psychiatrists, London.
- Royal College of Psychiatrists. *Psychiatric Services for Black and Minority Ethnic Elders* Council Report CR103 2001, Royal College of Psychiatrists, London, <http://www.rcpsych.ac.uk/publications/ct/council/cr103.pdf>.
- Royal College of Psychiatrists. *Caring for People Who Enter Old Age with Enduring or Relapsing Mental Illness* Council Report CR110, 2002, Royal College of Psychiatrists, London.
- Royal College of Psychiatrists Scoping Group on the Roles and Values of Psychiatrists. Remedies for work overload of consultant psychiatrists. *Psychiatric Bulletin*, 2004; **28**:24–7.
- Wright N & Lindesay J. A survey of memory clinics in the British Isles. *International Journal of Geriatric Psychiatry* 1995; **10**:378–85.

NOTE: Reproduced with permission. With thanks to John Wiley & Sons for kindly supplying a high quality pdf.

Publication 7.

Ong, Y.L., Benbow, S.M., Black, S. & Garner, J. (2007). A Consumer Group: Reflections on experience of involving users and carers in the work of the Faculty of Old Age Psychiatry. *Quality in Ageing*. 8 p. 45-49.



A consumer group

Reflections on experience of involving users and carers in the work of the Faculty of Old Age Psychiatry

Yong Lock Ong, Susan Benbow, Sarah Black and Jane Garner

Yong Lock Ong is a Consultant Psychiatrist in the Psychiatry of Old Age with North East London Mental Health Trust at Goodmayes Hospital, and has just completed a term as the Finance Officer for the Faculty of Old Age Psychiatry, Royal College of Psychiatrists.

Susan Benbow is Professor of Mental Health and Ageing at the Centre for Ageing and Mental Health based at the University of Staffordshire, Consultant in Old Age Psychiatry with Wolverhampton City PCT, and has just completed a term as Chair of the Faculty of Old Age Psychiatry.

Sarah Black is Consultant Psychiatrist in Old Age Psychiatry for Devon Partnership NHS Trust at Wonford House Hospital, Exeter, and is currently Honorary Secretary to the Faculty of Old Age Psychiatry.

Jane Garner is Consultant Psychiatrist in the Psychiatry of Old Age with Burnet, Enfield and Haringey NHS Mental Health Trust and former Honorary Secretary to the Faculty of Old Age Psychiatry.

ABSTRACT

The Faculty of Old Age Psychiatry, Royal College of Psychiatrists, has been involving users and carers in its work since 2002. The model that has been developed involves regular meetings of a consumer group, which was set up in partnership with the Alzheimer's Society and Age Concern, and which meets with the officers of the faculty. This development is in line with a number of recent policy initiatives and has had considerable influence on the work of the faculty.

KEY WORDS

service users	older people's mental health
carers	older adults
collaboration	partnerships

CONTEXT

The NHS Plan (Department of Health, 2000) initiated a shift in the balance of power in health services towards the service user, and aimed for increased user involvement and greater public participation in all aspects of healthcare:

'For the first time patients will have a real say in the NHS. They will have new powers and more influence over the way the NHS works.' (p12)

It describes users as 'disempowered' and states that the user's voice does not sufficiently influence provision of services. It aims to:

'bring patients and citizens into decision-making at every level... (to) enhance and encourage the involvement of citizens in redesigning the health service from the patient's point of view' (p95).

Since then other policy documents have reinforced the move towards greater involvement by users and carers in health and social services at all levels, coupled with greater choice for users and carers. Independence, well-being and choice (Department of Health, 2005) looked at the future social care of adults in England and highlighted the need for individuals to have greater choice and control. Our health, our care, our say (Department of Health, 2006) also picks up the theme of supporting choice and giving people a say. In addition, service users and carers are becoming increasingly involved in education and training (Tew, Gell & Foster, 2004).

The Royal College of Psychiatrists and the Princess Royal Trust for Carers ran a campaign called Partners in Care, from 2004 to 2005, and initiated a dialogue between users and carers of all ages and their respective service professionals. Its aims included drawing attention to problems faced by carers of people with mental health problems and encouraging partnership between carers, users and professionals: more ambitiously it aimed to change attitudes (Shooter, 2004).

This article reports initiatives by the Faculty of Old Age Psychiatry to involve users and carers in its work, starting in 2002. These

led to the development of a consumer group, jointly with the Alzheimer's Society and Age Concern, and are perceived as having had a major influence on the work of the faculty.

HISTORY OF THE GROUP

There were lengthy discussions at the Faculty of Psychiatry of Old Age's Executive Committee regarding different ways of involving users and carers in the work of the faculty in 2002. In 2003 an exploratory meeting was held with representatives of the Alzheimer's Society to explore two main areas:

- the involvement of users and carers in the work of the faculty
- joint working between the Alzheimer's Society and the faculty.

During discussion it became clear that the faculty should also approach another organisation (Age Concern) in order to ensure involving users and/or carers across the range of mental health problems in late life.

Suggestions for joint working were:

- to invite user/carer representatives to sit on the faculty's Executive Committee
- to set up a consumer group involving users and carers prepared to comment on the faculty's work
- to involve users/carers in commenting on documents by email
- to hold workshops at residential faculty conferences, either a combined meeting between the executive committee and consumer group or a user/carer themed workshop
- to hold joint seminars/meetings on areas of mutual interest.

The option that was agreed with the Alzheimer's Society and Age Concern was to take forward a consumer group, involving the faculty's officers meeting with interested parties from both organisations. Inviting representatives onto the Executive Committee was not thought to be a good use of users' and carers' time, as the faculty deals with an enormous volume of business, which is not always relevant to the partner organisations. It was agreed that the Executive Committee agenda should be made available to partner

organisations in order that they could raise any items they wished at the consumer group meetings or request any papers they wished to see or comment on.

EARLY ISSUES

A number of issues were resolved in the early stages of developing the group.

Timing of consumer group meetings

The initial proposal was to hold the meetings early in the morning, before the Executive Committee to allow joint discussion, but an early meeting was not ideal for users or carers, who, in some cases, travelled long distances to join the meetings. This also encroached on the Executive Committee starting time. Subsequently, it was agreed that meetings should be held a couple of weeks before the Executive Committee to allow any issues raised by consumers to be discussed by the following Executive Committee meeting. The consumer group would therefore act as a reference group and a consultative committee.

The agenda

It was agreed that members of the group, Age Concern and Alzheimer's Society staff and the faculty officers could all add items to the agenda and, in practice, all did so. The meetings have developed flexibly so that issues which people bring on the day can also be addressed if time allows, or planned for the next meeting. Thus, a range of diverse subjects has been raised and *ad-hoc* items added as topical issues arose.

Chairing the group

Members of the group decided it would be best for a single chairperson (in this case Jane Garner) to take the meetings, in order to provide continuity and consistency rather than taking up an alternative suggestion of a rotating chairperson.

Recording the minutes of meetings

Individual users and carers did not feel they wanted to take on this task, so the three organisations have taken turns in recording the minutes.

Financial implications for the faculty

Travel expenses for users and carers who attend the consumer group are paid by the faculty as agreed by the Faculty Executive Committee. The financial implications are greater than anticipated, as carers and users have become involved in other meetings with resulting additional costs to the faculty.

THE CONSUMER GROUP IN ACTION

The group has proved to be a lively and constructive forum that is enjoyed and appreciated by the faculty's representatives who feel that it has had a strong influence on the work of the faculty. In practice, the group has several distinct roles.

- It allows the faculty to ask users and carers to comment on documents and proposals, including the faculty response to NICE's proposed Health Technology Assessment on drug treatments for Alzheimer's disease (Faculty of Old Age Psychiatry, 2004a) and a faculty document on copying letters to patients (Faculty of Old Age Psychiatry, 2004b).
- Proposed pieces of work can be raised at the consumer group in order to plan how they might be taken forward and how users and carers might be involved, eg. one member of the group agreed to take part in the working group that is updating Council Report CR110 (Royal College of Psychiatrists, 2002) and a meeting of the consumer group was dedicated to issues for ethnic elders, which has led to joint working to update Council Report CR103 (Royal College of Psychiatrists, 2001).
- Members of the group are able to raise issues they feel the faculty should be addressing and to discuss how these might be taken forward, eg. some of the consumer group felt that the faculty should be taking action on the interface between primary care and old age psychiatry services in relation to services for people with dementia and their families, discussions on this led to a joint seminar (Alzheimer's Society, 2005). Issues raised in this way may then be discussed further in the Executive Committee or might lead on to other action.

- Members of the group have all shared their frustrations and concerns with regard to mental health services for older adults. There have been times when professionals and/or users and/or carers have had differing perspectives (and indeed felt strongly) on particular issues (one example was the use of anti-psychotic drugs for people with dementia (Faculty of Old Age Psychiatry, 2004c) but recognising and debating these differences has proved to be productive and fruitful. The group has been clear that this is not a support group although being involved may offer support, to professionals, users and carers.
- The group has provided a forum where future strategies can be discussed by all three organisations and individual group members.
- Carer representatives in the consumer group repeatedly expressed a need to report on their individual experiences, which they felt would be instructive to service providers. This led to a proposal that carers write narratives, from which common themes could be drawn by one member on behalf of the group (YLO). A later meeting was dedicated to carers' needs and experiences, using the themes from the narratives.

DISCUSSION

This group was a new initiative for the faculty. All participants reported a positive and enjoyable experience. The representatives of the Alzheimer's Society and Age Concern gave a joint presentation about their experience of working in this group at the Annual meeting of Patients and Carers involved in the work of the College (Hart, 2005). The faculty officers enjoyed the interaction with users and carers, who at times were challenging, refreshingly politically incorrect and unafraid to raise any issue that concerned them: they felt the group was valuable in ways that had not been anticipated.

This model of a consumer group forum could be copied locally. The consistently high attendance of users and carers may reflect the strength of their feelings and their engagement in the group. There was strong user and carer representation in seminars and working groups. The consumer group minutes clearly show a growing appreciation by users, carers and professionals that we are all striving to

improve the experience that users and carers have in their contact with services, and to improve the services available to people. At times the meetings highlighted the fact that the needs of users and carers may conflict, as may the needs of NHS organisations and the families using their services, and all involved need to acknowledge this openly.

The faculty members of the group had ideas about what the group might achieve and what role it might fulfil, but were challenged by a group within the meeting which did not want to work to the faculty's agenda, and instead saw this as their opportunity to get the faculty to take the actions they think are needed. This led to ongoing problems in taking forward some agenda items with old age psychiatry, eg. difficulties identified in primary care, general hospital settings and nursing homes. The faculty has initiated invited seminars with other organisations to begin discussion of these issues, so members of the group have indeed influenced the faculty's work in directions that may not otherwise have been taken.

CONCLUSION

The consumer group has been a new and creative initiative for the Faculty of Old Age Psychiatry. It has taken on the roles anticipated by the faculty but has also had a more profound influence on its work by involving users and carers in many areas of faculty work and by raising issues which might otherwise not have been addressed.

Acknowledgement

The authors wish to thank all their colleagues in Age Concern and the Alzheimer's Society who have given freely of their time and energy to support the work of the Faculty of Old Age Psychiatry through the consumer group and who have taught us such a lot.

Address for correspondence

Professor Susan M Benbow
Centre for Ageing and Mental Health
Faculty of Health and Sciences
Staffordshire University
Blackheath Lane
Stafford ST18 0AD
Email: drsmbenbow@aol.com
Tel: 07789 485435

Declaration of interests

None

References

- Alzheimer's Society (2005) *Working with people with dementia. Integrated care pathways for dementia*. Seminar summary available at: www.alzheimers.org.uk/Working_with_people_with_dementia/carepathways.htm.
- Department of Health (2000) *The NHS Plan: A plan for investment. A plan for reform*. London: Department of Health. Available at: www.nhs.uk/nhsplan/nhsplan.pdf.
- Department of Health (2005) *Independence, Well-being and Choice*. London: Department of Health. Available at: www.dh.gov.uk/assetRoot/04/10/64/78/04106478.pdf.
- Department of Health (2006) *Our Health, Our Care, Our Say: A new direction for community services*. London: Department of Health. Available at: www.dh.gov.uk/assetRoot/04/12/74/59/04127459.pdf.
- Faculty of Old Age Psychiatry (2004a) Submission on behalf of the Royal College of Psychiatrists by the Faculty of Old Age Psychiatry to the National Institute for Clinical Excellence. *Health Technology Appraisal: Drugs for the treatment of Alzheimer's disease*. London: Royal College of Psychiatrists. Available at: www.rcpsych.ac.uk/pdf/FOAPfinalNICEsubmission.pdf.
- Faculty of Old Age Psychiatry (2004b) *Copying Clinical Letters to Patients. Guidelines for old age psychiatrists*. London: Royal College of Psychiatrists. Available at: www.rcpsych.ac.uk/pdf/guidelinesCopyingPatients.pdf.
- Faculty of Old Age Psychiatry (2004c) *Atypical Antipsychotics and BPSD. A prescribing update for old age psychiatrists*. London: Royal College of Psychiatrists. Available at: www.rcpsych.ac.uk/pdf/Atypicalguidance.pdf.
- Hart D (2005) *Minutes of Annual Meeting of Special Committee for Patients and Carers (SCPC)*. Royal College of Psychiatrists.
- Royal College of Psychiatrists (2001) *Psychiatric Services for Black and Minority Ethnic Elders College Report CR103*. London: Royal College of Psychiatrists. Available at: www.rcpsych.ac.uk/publications/collegereports/cr/cr103.aspx.
- Royal College of Psychiatrists (2002) *Caring for People who Enter Old Age with Enduring or Relapsing Mental Illness ('graduates')*. College Report CR110. London: Royal College of Psychiatrists. Available at: www.rcpsych.ac.uk/publications/collegereports/cr/cr110.aspx.
- Shooter M (2004) Partners in care? *Psychiatric Bulletin* 28 313–314.
- Tew J, Gell C and Foster S (2004) *Learning from Experience: Involving service users and carers in mental health education and training*. Nottingham: Higher Education Academy/National Institute for Mental Health in England/ NHA Workforce Development Confederation.

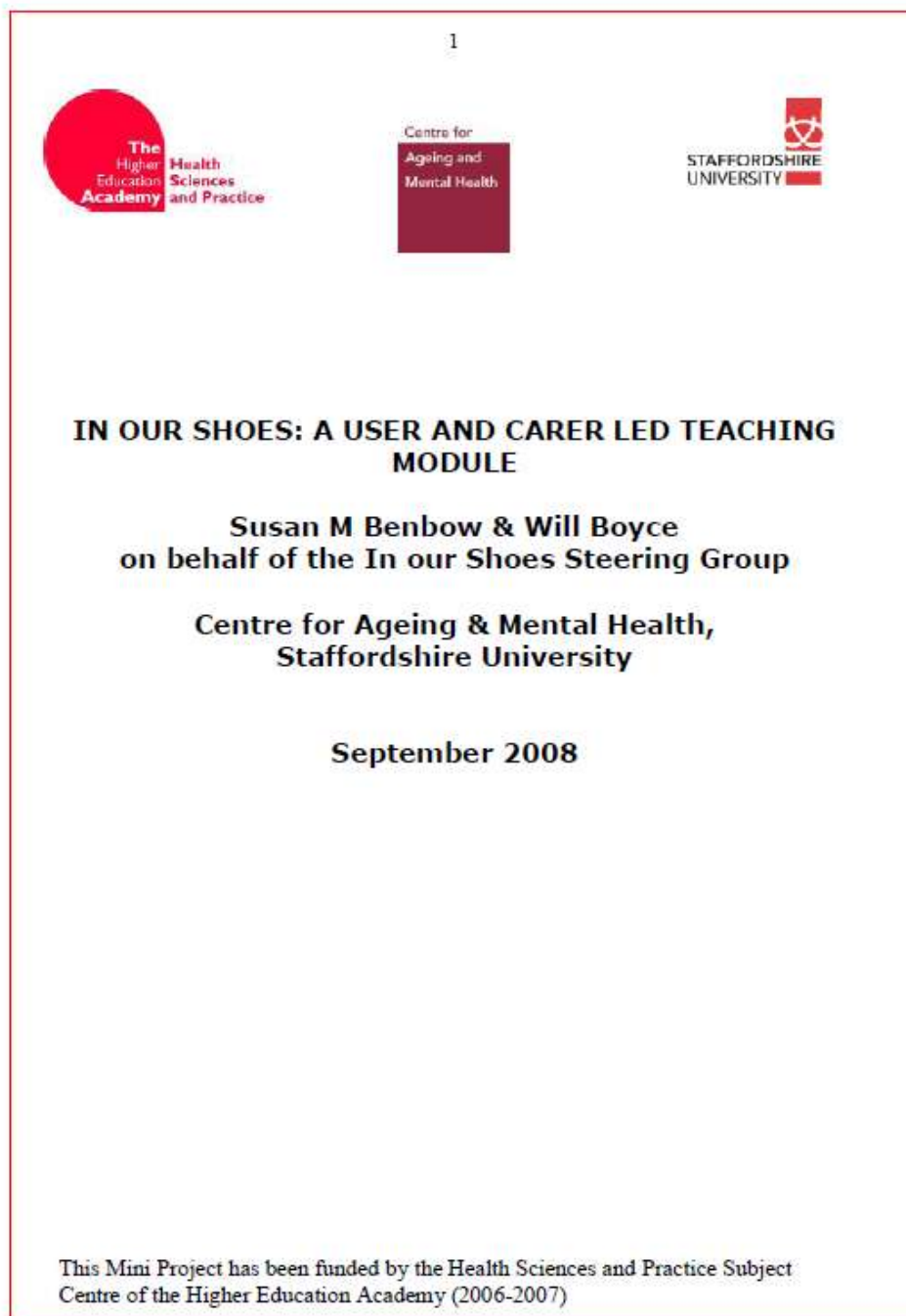
NOTE: Reproduced with permission. With thanks to Pier Professional for kindly supplying a high quality pdf.

Publication 8.

Benbow, S.M. & Boyce, W. (2008). *In our shoes: a user and carer led teaching module*. Higher Education Academy Mini-Project report. Available at:

<http://www.health.heacademy.ac.uk/publications/miniproject/benbow.pdf>

[Accessed 2 August 2010].



Contents

Foreword	
Kath Morgan	3
Graham Hughes	4
Background	5
The policy context	5
The personal context	6
The university context	7
Preparation of the Module	8
Establishing the steering group	8
Developing the teaching plan using focus groups	8
The Resource List	9
Recruiting users and carers to teach	9
Module delivery	10
Module evaluation plan	11
Discussion of evaluation	11
Student evaluation	11
Teacher evaluation	11
Co-leaders reflections	12
Conclusions	14
Table 1 Involvement of users, carers and others in module delivery	15
References	16
Acknowledgements	18
Appendix 1: Members of the In our Shoes Steering Group	19
Appendix 2: Teaching plan for In our Shoes	20
Appendix 3: Student Feedback Form	23
Appendix 4: Teachers' Feedback Form	25
Appendix 5: Outputs from the Project and related work	26

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Foreword

I was originally lured into teaching, very sneakily I might add, by Dr Benbow, who put it to me as a "talk" to students, so here I am talking to you about my experience on the modules, we have all been taking part in.

For me my teaching on the module was very rewarding, as I felt the module was a moving forward into making a difference. It supports my theory and drum beating that all departments of the system need to come together, communicate their findings to each other. On this module I feel that this has happened; as proof, we are all here, passing on what we have learnt, teaching each other.

In my teaching I hope I have been a voice for the needs and position of users in the system and community. The teaching is, and was, a two way thing; I myself learnt things about myself and the system. As users teaching gives a prime opportunity to show the true realism of mental deterioration and the complex problem of finding a care system that will work for all. The module gave me that chance: for who better to teach than those who live it and those who live with it, first hand teaching, knowledge to be passed on. Teaching how it is when people you have known all our life, treat you as if you are already dead, teaching when you remember the far past but not the past of yesterday, valuable teaching.

To my mind teaching is a sharing of knowledge and information and this module has enabled us to come together to pool our different and unique fields of knowledge, to make that better system of care we all aspire to. I was able to bring my voice and views in the hope of teaching where I felt changes needed to be made, teach the practical side of mental disturbance, to marry it with theory. I see us as segments of an orange, no shape or form, unless we hold together; teaching gives us that, learning gives us freedom.

People say "why bother, nothing will change", but it can and will. We have to believe that, working together, users, carers, and professionals teaching one another, surely, surely will make a difference.

Kath Morgan

Note: Kath presented these thoughts in a talk at the workshop entitled Piecing together the jigsaw: sharing experiences of involving users & carers in education at Staffordshire University on April 25th 2008 when teams from Staffordshire, Wrexham, Leicester and Nottingham came together to share their experiences.

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Foreword

It was always difficult to conceive how a carer might portray experiences to an audience with the capacity to effect change but "In our shoes" seemed to present this possibility. Being a carer is a shock to the system (and that probably includes or will include most of us!) but few perhaps have the opportunity to reflect in a really positive way. The conception of this course was not stereotyped but came as the result of brainstorming, adjusting and readjusting sights, and the realisation (for me) that experiential learning could and should be the backbone of a course which had the capacity to change the attitudes of professional practitioners. More questions than answers would inevitably be raised but this was a strength of a course designed to make participants think and consider their position in relation to the enormous and growing problem of ageing and mental health. Personally it was a privilege to think that my own experience and reflection might in some small way enable others to benefit. Despite some reservations, meeting the students was positive and reassuring because they had a genuine concern to listen. This course is a small but unique start to effect change which could touch the lives of many thousands of, as yet, unsuspecting people.

Graham Hughes

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Background

Several important strands form the context of this project:

- policy context
- personal context
- university context

The policy context

A shift in the balance of power in health services towards the service user was initiated by the NHS Plan (Department of Health, 2000). The Plan aimed to increase both user involvement and public participation in all aspects of health care:

For the first time patients will have a real say in the NHS. They will have new powers and more influence over the way the NHS works.
(page 12).

This shift has continued over recent years: health and social care has been moving towards greater patient choice, greater patient influence in services at all levels, and more personalised health and social care (Department of Health, 2005a; Department of Health, 2005b) alongside stronger public involvement (Department of Health, 1999; Department of Health 2002; Department of Health, 2006). Person-centred care is included as standard 2 in the National Service Framework (NSF) for Older People (Department of Health, 2001), and carer support is one of the standards in the NSF for Mental Health (Appleby, 2004). One of the challenges of this policy imperative is how to change organisational culture in order that users, carers and the public can have a voice and influence services. The House of Commons Health Committee (2007) highlights two important points:

Structures and procedures will have little effect if the health service is not prepared to listen and make changes as a result of what they learn.

and furthermore

Effective patient and public involvement is about changing outcomes, about the NHS and social care providers putting patients and the public at the heart of what they do.
(page 5)

Skills and training have been identified as key issues in developing the involvement of patients and the public (Picken et al, 2002). However, if learning from, and working with, users, carers and the public is seen solely as a policy imperative it is unlikely to become embedded in future practice. Rose et al (2002) put this clearly:

There is a danger that government demands for agencies to demonstrate user involvement may mean that user activities become a formal procedure to be ticked off, rather than an embedded and powerful organisational practice.
(page 16-17)

Involvement is more likely to succeed if health and social care professionals at all levels are able to experience the benefits that follow from developing partnership with both those who use their services and those who might.

Does education offer a way of influencing the system? It can be argued that the involvement of users and carers in education at all levels is essential if health and social

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

care services are to develop partnership working with people using their services in line with these recent policy initiatives, and Tew, Gell & Foster (2004) describe how this may involve users and carers in a range of activities, including:

- direct delivery of learning and teaching
- course / module planning
- programme management
- recruitment & selection of students
- practice learning
- student assessment
- course evaluation
- joining courses as participants

Involving users and carers at all levels of education sends a powerful message to the professionals they train about the value and importance of hearing and attending to the voices of those using their services.

The personal context

Katz and colleagues (2000) described the development of a Council of Elders: *an educational innovation in which we invited community elders to function as our 'Senior Faculty', to whom medical residents present their challenging and heartfelt dilemmas in caring for elder patients. In the conversations that ensue, the elders come to function not simply as teachers, but collaborators in a process in which doctors, researchers, and elders together create a community of resources, capable of identifying novel ways to overcome health-related difficulties which might not have been apparent to either group separately.*

They argue that this model not only allowed the elders to provide good advice on dilemmas presented to them, but to provide 'life world and value orientation' which helps the professionals involved to appreciate better the experience of older adults and what matters most to them. They also noted how it addresses ageism and stigma. This work was presented at a powerful workshop¹ in 2003 by Arlene Katz and Glenda Fredman.

Some national work at the Royal College of Psychiatrists also influenced thinking about this project. The Royal College of Psychiatrists and the Princess Royal Trust for Carers ran a campaign called Partners in Care between 2004 and 2005. It aimed to draw attention to the problems faced by carers of people with mental health problems and to encourage partnership between carers, users and the professionals working with them: it also aimed to change attitudes (Shooter, 2004). The Campaign encouraged the Faculty of Old Age Psychiatry to pursue the involvement of users and carers in its work in collaboration with the Alzheimer's Society and Age Concern, and led to the development of a Consumer Group, which was perceived to have a powerful and creative influence on the work of the Faculty itself (Ong et al, 2007). As part of the Consumer Group's work, carers, who wished to share their experiences, prepared narratives for the Group and the narratives themselves provided the impetus and inspiration for further partnership work (Benbow et al, 2008).

¹ Workshop title: Collaborative Conversations: Reflections on our Practices, at the meeting entitled A space for age and a place for families: a systemic focus in older adult services

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

The university context

The involvement of users and carers in teaching (and in health and social care generally) is an area of growing interest. Lloyd, Carson & Bleakley (2007) recently reported on a project which investigated the needs of service users involved in planning and delivering mental health services and education: they also produced a toolkit for developing the role of users and carers in education, planning and research. Similarly, Anderson, Ford and Thorpe (2008) have described interesting work with people with communication needs. The Centre of Excellence in Interdisciplinary Mental Health at the University of Birmingham and Suresearch (<http://www.ceimh.bham.ac.uk/centre/CarerInvolve.shtml> and <http://www.suresearch.org.uk/index.html>) support user and carer involvement in research and education and some useful resources are available on their websites. Other resources are available through the Centre for Excellence in Healthcare Professional Education (see <http://www.cetl4healthne.ac.uk/CETLPlone/strands/2018people-with-experience2019-2013-user-involvement>).

Staffordshire University offers a Master of Science in Applied Studies in Ageing and Mental Health. Students on the course come from a wide range of professional backgrounds, including occupational therapy, medicine, mental health nursing, residential/ nursing homes, and are normally working in a setting with older adults who have mental health problems during the course. During the academic year 2005-2006 as part of the MSc module in assessment and care planning, a user was asked to teach one session and two carers taught sessions. The aim of involving them was to give students a different experience of assessment and care planning, and to bring into the classroom the experiences of users and families involved in assessment and care planning in older people's mental health services and similar settings. The user session attained the highest score of all module sessions on the three aspects rated by students in their feedback, namely information, interest and enjoyment (Benbow, Taylor & Morgan, 2008).

Module evaluation by the student group provoked debate and reflection about the 'added value' of the user-led session. Teaching staff hypothesised that the session 'brought to life' the experience of going through an assessment and care-planning process in a way that can only be done by those who have had that experience.

Subsequent meetings led to a proposal to develop a new module designed and run by users and carers for future inclusion on the MSc course. A group put together a proposal to the HEA for funding for a mini-project with the following aims:

- To establish a curriculum group to write a module on user and carer experience in older people's mental health for MSc students
- To establish and train users and carers to teach and assess on the module
- To run the module starting September 2007
- To evaluate the module and revise as necessary
- To disseminate the findings
- To consider how to generalise the module/ learning to other courses

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

8

The outcomes expected were as follows:

- Module guide
- Final Report
- Publications in professional journals
- Presentations to conferences/ learned societies

Preparation of the Module

Establishing the steering group

The first stage of the Project was to establish a Steering Group which met throughout. Members of the Steering Group are listed in Appendix 1 and included:

- Staff of the Centre for Ageing and Mental Health
- A contact from Users in Partnership
- A carer who had made contact with the Centre
- A contact from the Alzheimer's Society
- A user who had taught on the MSc previously
- The Chief Officer of a local voluntary organisation

Members of the group discussed how to develop the curriculum and identified the following aims for the module:

By the end of the module students should

1. understand some of what it is like to live with a mental health problem in later life
2. understand some of what it is like to be a carer of an older adult with a mental health problem in late life
3. have re-evaluated the relationship between health and social care professionals and the users and carers they work with
4. have re-evaluated what health and social care professionals have to offer in their relationship with users and carers.
5. have experienced learning from the people they work with in their professional capacity

The Steering Group agreed on the following assignment:

An ASSIGNMENT length 3500 WORDS weighted at 100%.

Written paper of 3500 words reflecting on an innovation in practice with users and carers.

Developing the Teaching Plan using Focus Groups

The Steering Group arranged to set up focus groups with users and carers to explore with them what they would like professional staff to learn on the course. Three focus groups

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

were organised one with carers, one with users, and one with users and carers together, using links from the steering group.

The focus groups addressed the following areas: the aims of the module, what service users and carers would wish to teach professionals, what challenges they would anticipate and what training might be needed. Focus group participants agreed to the group discussions being tape-recorded. The tapes were transcribed and analysed by a member of university staff not involved in the project. Her detailed thematic analysis was then fed back to the steering group who identified major themes around which they designed the teaching plan (paper in preparation). The final teaching plan is set out in Appendix 2. The design of the teaching plan includes the requirement for the students to interview users, carers or families (with their consent) on various topics at regular intervals during the course, and then briefly present their learning during teaching sessions. This feature of the course grew from the work of Katz et al (2000).

The Resource List

During the initial preparation period a Resource List was developed. This did not aim to be comprehensive but instead to offer suggestions of items to stimulate reflection and learning in various areas. The students were recommended to read a broad range of literature, including fiction and non-fiction, poems and plays, as well as reflecting on works of art and other sources. The Module Resource List (as at January 2008) is available on the In our Shoes website but is a document in evolution.

Recruiting users and carers to teach

In late June 2007 a recruitment workshop for users and carers who might be interested to be involved in teaching took place at the university. It was advertised through steering group contacts as follows:

We are looking for individuals who would be interested in finding out more about teaching on the above module. The workshop will cover the delivery format of the module; what will be involved, travelling costs and how to sign up.

The workshop was attended by nine users and carers. It ran for two hours and covered the following areas:

- Introduction to the university and to the people involved in the course
- Practical aspects of teaching
- Different ways of teaching and support on offer
- What is it like to teach?
 - This talk was given by a user who had previously taught at the University on the assessment and care planning module. A podcast of the talk is available on the In our Shoes website.

Challenges in the early stages

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

An interim report on the project (available on the In our Shoes website) was produced in July 2007 and identified several challenges in the early stages of the project which have continued throughout the course of the project:

- **Maintaining engagement**

The main initial challenge involved consolidating the engagement of the organisations which were involved at the start of the project but whose circumstances fluctuated over time. Users in Partnership was heavily involved initially but changes in the organisation and funding of the National Institute for Mental Health England led to uncertainty regarding its future. North Staffordshire Pensioners Convention was involved in the initial stages of planning the project and also contributed a teaching session. The Alzheimers Society and Approach (a mental health organisation based in Staffordshire) came on board at a later stage and were enthusiastic in organising the focus groups to develop the teaching plan. The Alzheimer's Society introduced the Phoenix Centre which hosted focus groups. A lot of work was expended in keeping up and building on these links and liaising with the individuals involved.

- **Supporting user and carer teachers.**

Potential user and carer teachers were invited to the recruitment workshop at the university. Some committed to involvement at that stage and the module co-leaders have supported them throughout the preparatory, delivery and feedback phases. The time expended on this has been regarded as important to the success of the project but should not be under-estimated. The support of other Centre for Ageing and Mental Health staff has also been important: the Centre Administrator achieved honourable mentions in feedback and other Centre staff have gone out of their way to welcome and engage with the visiting users and carers.

- **Maintaining the focus of teaching.**

Much of the preparation work involves focussing on the learning objectives set for the teaching sessions and how they will be met. The preparation involved is considerable.

A further challenge for the team was a last minute change in timescale. The original plan was that the module was due to run for the first time starting in September 2007 and finishing in December 2007, but it was deferred at short notice to start in January 2008. The delay had one advantage: it allowed time for revision so that the Module became a core module on the MSc rather than an option (as previously planned) so in future all students undertaking the MSc in Applied Studies in Ageing and Mental Health will be required to undertake the module.

Module delivery

The module was delivered over 13 weeks from January to April 2008. The teaching plan is set out in Appendix 2. The original plan was to involve a user or carer or both each week with one module co-leader working alongside them, firstly to prepare the session and secondly to deliver it. Inevitably there were weeks when last minute problems necessitated a change of plan, so some weeks a video of a user, carer or similar was used in teaching. Table 1 shows the people involved and use of videos for 11 weeks of teaching in the classroom. One week was allocated as a reading week and the final session was devoted to feedback and review of the module.

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Module evaluation plan

Evaluation was built in throughout module delivery. Students were asked to complete feedback forms after each teaching session (Appendix 3 sets out the Student Feedback Form) and users, carers and others were sent feedback forms with a letter thanking them for their involvement (Appendix 4 sets out the User/ Carer Feedback Forms). These latter forms could be returned by post (stamped addressed envelope was supplied) or provided by email or completed over the telephone if preferred (one person opted for telephone completion).

In addition during the final session a focus group was conducted with students to get their ideas about the added value of involving users and carers in teaching, whether the module had achieved its intended aims, ideas about future changes to the module and their views about the use of videos.

A focus group arranged with users and carers who had been involved in teaching took place at Approach in Stoke-on-Trent in order to get more detailed feedback from user and carer teachers about their experience on the module (publication in preparation).

Discussion of module evaluation

Student evaluation

The students evaluated the Module positively and made many helpful comments. They felt that the weeks when videos were used could not be expected to have the same impact as when users and carers were present in the classroom as the possibility for dialogue with users and carers was lost. They made a number of suggestions of how to improve the course in future.

The student focus group feedback included some practical suggestions, including

- Could use a webcam for people who are too anxious to speak in front of others
- The module could be made into a roadshow to access a wider group
- It might be helpful sometimes to include users, carers and the professionals from both health and social care who have worked with them to get their perspectives
- It might be powerful to 'follow a person' through different parts of their journey
- Another possibility would be to ask a family to talk from their differing perspectives and to track their experiences

Teacher evaluation

All the invited teachers felt that their sessions had gone well, that they had been supported and put at ease at the University, and that the students had been respectful and interested. All but one reported that they had enjoyed themselves: one reported feeling under pressure to perform:

I felt it was about achievement rather than enjoyment

All reported that they would consider teaching again. One person had seen their involvement as a one-off and one person didn't answer this question.

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

The main area identified for attention was the question of payment and expenses. In setting up the Module the team had believed that users and carers would be paid lecturer fees and travelling expenses, but the University had tightened its procedures before the Module started and had limited access to lecturer payments. This caused confusion and lack of clarity. It is an area which has been brought to the University's attention as needing to be resolved before the Module runs again.

The teachers focus group feedback highlighted some practical suggestions:

- Asking the students to pose questions to users and/or carers in advance of session
- From two couples came the suggestion of perhaps giving carers time to talk on their own with the student group and the users separate time to talk with the students
- Preparing useful teaching tips for users and carers
- Perhaps also preparing some tips for professionals who are involving users and carers in teaching eg don't call it teaching!
- Offering people the opportunity to observe sessions before they go and teach

Co-leaders reflections

The role of co-leader was stimulating because, despite much preparation, it was difficult to predict how the teaching sessions would go on the day, so the co-leader needed to be prepared to improvise and be highly flexible. Liaising with and supporting the teachers who came in to the university demanded a great deal of time over the course of preparing for and delivering the Module. It was useful to have some videos in case the invited speaker was unable to come at short notice but tailor-made videos are probably better teaching aids than others, as they focus on the topic and learning objectives for the session.

By including interviews with users and carers and feedback from them throughout the module, the teaching team aimed to give students the opportunity to have new and different conversations with the people they work with. In evaluating the module it is not possible to investigate whether the students will practice differently in future, but this is an area which could usefully be investigated in future. One of the stated module aims was that students should:

"have re-evaluated the relationship between health and social care professionals and the users and carers they work with".

A big challenge for the future is to work to understand how we can help people to work differently within the constraints of the health and social care system. This project is a small step towards understanding how to do this.

One issue raised in discussion has been the 'generalisability' of experience described by users and carers (Schofield, 2007). Inevitably, in starting to involve users and carers as teachers, the individuals who take this on will be special people, who could be described as 'trailblazers', people with the confidence, energy and communication skills to take on a

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

challenge whilst coping with an illness themselves or caring for someone who is. Offering a variety of different ways to be involved may enable a wider range of people to consider involvement and developing the teaching team's confidence and skill in supporting users and carers and working alongside them is also important. The teaching team came to the view that the individual material brought by users and carers, whilst clearly important and influential, is only part of the learning experience and the process of the sessions is equally powerful, ie learning from users and carers, having the opportunity to talk, question and debate with them in an educational environment.

McNamee (2007) has written about teaching as conversation. During module delivery users and carers brought their experiences and aspirations to life in the classroom, and allowed the co-leaders and students to share them in conversation. All concerned testified to the impact this had during the evaluation process.

The very nature of experiential learning raises many questions and has the ability to challenge working practice. Most of the students had many years experience of working in health and social care settings, supporting older people with mental health issues and their families. This wealth of knowledge was juxtaposed in discussion against the experiences and accounts of those using health and social care services. This coming together of health/social care professional and patient/service user/ carer in a common purpose of greater understanding and knowledge of individual needs demonstrates that people's experience of services has tremendous power when delivered in a face-to-face environment. It acts as a catalyst to change a 'one size fits all' approach, to a measured and considered individually tailored (handmade shoe) model of social and health care provision. To facilitate, and sometimes empower, people that use services is a humbling experience for all participants who embrace a person centred approach to health and social care practice. For users and carers teaching has a part to play in this.

Conclusions

The project has achieved the aims set out at the outset:

- A curriculum group was established and developed a module on user and carer experience in older people's mental health for MSc students. Users and carers were involved in curriculum design and throughout the delivery of the teaching.
- The team established links with users and carers, and offered them support and training to enable them to teach and assess on the module. The project demonstrated that users and carers who have traditionally been regarded as hard to involve can make a powerful contribution to the design and delivery of teaching, with support and commitment from their colleagues in education.
- The module was successfully delivered in early 2008
- A detailed evaluation was conducted and demonstrated the powerful impact of the course on students.
- The findings have already been shared in a variety of different settings and further presentations and publications are anticipated.

The final aim:

- To consider how to generalise the module/ learning to other courses

This is currently under discussion, alongside an exploration of how to implement an equitable system for paying expenses and fees to users and carers who teach on future modules.

The project provides a 'case example' of the involvement of users and carers in postgraduate teaching which may be useful for teachers of other higher educational courses who wish to involve users and carers in their study programmes.

The main action for the team to take forward is to further this work and to encourage those within the University and in a range of other clinical and educational contexts to take up the challenge of working with users and carers to better train the health and social care professionals of the future. The team aims equally to inform users and carers involved in older people's mental health services of how powerful and unique their contribution can be, and to encourage them to become involved in teaching. In Kath's words:

"users, carers, and professionals teaching one another, surely, surely will make a difference".

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Table 1: Involvement of users, carers, others and videos in module delivery

Persons Involved	Number of sessions
Users only	2
Carers only	2
Users and carers jointly	2
Community group	1
Speciality made video with user	1
Teaching video of family	1
Commercially made video	2

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

References

Anderson ES, Ford JS & Thorpe LN (2008) Listening to users and carers who have limited communication capacity or skills. Report to the HEA. Download at: <http://www.health.heacademy.ac.uk/publications/miniproject/2008anderson.pdf> (Accessed 26/9/08).

Appleby L (2004) The National Service Framework for Mental Health – five years on. Department of Health: London. Download at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4099120 (accessed 26/9/08).

Benbow SM, Ong YL, Black S, Garner J (2008) Narratives in a user and carers' group: meanings and impact. *International Psychogeriatrics*, in press.

Benbow SM, Taylor L & Morgan K (2008) Multiple perspectives: Involving users and carers in educating health and social care professionals. *Quality in Ageing* (2008) 9(2): 12-17.

Department of Health (1999). Patient and Public Involvement in the New NHS. NHS Executive: Leeds. Download at: http://www.dh.gov.uk/en/PublicationsAndStatistics/LettersAndCirculars/HealthServiceCirculars/DH_4004176 (accessed 26/9/08).

Department of Health (2000) The NHS Plan: A plan for investment. A plan for reform. Department of Health: London. Download at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002960 (accessed 26/9/08).

Department of Health (2001) National Service Framework for Older People. Department of Health: London. Download at: http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_4003066 (accessed 26/9/08).

Department of Health (2002). Shifting the Balance of Power: The Next Steps. The Stationery Office: London. Download at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008424 (accessed 26/9/08).

Department of Health (2005a) Creating a patient-led NHS: delivering the NHS improvement plan. Department of Health: London. Download at: http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4106506 (accessed 26/9/08).

Department of Health (2005b) Independence, well-being and choice: our vision for the future of social care for adults in England. Department of health: London. Download at: http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4106477 (accessed 26/9/08).

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Department of Health (2006). A stronger local voice: A framework for creating a stronger local voice in the development of health and social care services. Department of Health: London. Download at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4137040 (accessed 26/9/08).

House of Commons Health Committee (2007). Patient and public involvement in the NHS: Third report of sessions 2006-7 Vol 1. HMSO: London. Download at:

<http://www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/278i.pdf> (accessed 26/9/08).

Katz AM, Conant L, Inui TS, Baron D & Bor D (2000) A council of elders: creating a multi-voiced dialogue in a community of care. *Social Science and Medicine*, 50: 851-860.

Lloyd M, Carson A & Bleakley C (2007) Exploring the needs of service users involved in planning and delivering mental health services and education. Report to the HEA. Download at:

http://www.health.heacademy.ac.uk/projects/miniprojects/mlloyd_reportsummary (Accessed 26/9/08).

McNamee S. (2007) Relational practices in education: teaching as conversation. In: H. Anderson & D. Gehart (Eds) *Collaborative therapy. Relationships and conversations that make a difference*. Pp 313-335. Routledge: London.

Ong YL, Benbow SM, Black S, Garner J (2007) A Consumer Group: Reflections on experience of involving users and carers in the work of the Faculty of Old Age Psychiatry. *Quality in Ageing* 8: 45-49.

Shooter M (2004) Partners in care? *Psychiatric Bulletin*, 28: 313-314.

Picken C, Popay J, Staley K, Bruce N, Jones C & Gowman N (2002). Developing a model to enhance the capacity of statutory organisations to engage with lay communities. *Journal of Health Service Research and Policy* 7(1): 34 – 42.

Rose D, Fleischmann P, Tonkiss F, Campbell P & Wykes T. (2002) User and carer involvement in change management in a mental health context: Review of the Literature. Report to the National Coordinating Centre for NHS Delivery and Organisation R&D (NCCSDO). NCCSDO: London (revised 2003). Download at:

<http://www.sdo.nihr.ac.uk/files/project/17-final-report.pdf> (accessed 26/9/08).

Schofield JW (2007) Increasing the generalisability of research. In: M. Hammersley (Ed) *Educational Research and Evidence-based Practice*. Pp. 181-203. Sage: London.

Tew J, Gell C & Foster S (2004) *Learning from Experience. Involving service users and carers in mental health education and training*.

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Acknowledgements

Thanks go to all those many people who helped with this project.

Thank you to members of the steering group, who were supportive throughout, to Clare Baguley who has offered practical suggestions and wise counsel and to Elaine Stanway who nurtured and supported all of us, users, carers and professionals alike.

Special thanks must go to the Phoenix Centre and the Alzheimer's Society who helped with focus groups to design the curriculum; special thanks also go to Approach who helped with the focus groups and recruited many of the user and carer teachers and to Nageen Mustafa who has assisted in thematic analysis of the focus groups.

A number of people, users, carers and members of the public, were generous with their time and taught on the module as well as giving feedback to the steering group. Thank you for your honesty and generosity: it has been a privilege for us to work with you.

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Appendix 1

Members of the In our Shoes Steering Group

Clare Baguley	HEA/ Manchester University
Susan M Benbow	Professor of Mental Health & Ageing, Staffordshire University (Chair)
Will Boyce	Chief Officer, Approach
Donna Doherty	Senior Lecturer, Staffordshire University
Angela Hill	Users in Partnership/CSIP
Graham Hughes	Carer
Elaine Ivis	Regional Manager, Alzheimer's Society
Paul Kingston	Professor of Health and Social Care, Staffordshire University
Kath Morgan	User
Elaine Stanway	Centre for Ageing & Mental Health Administrator, Staffordshire University

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Appendix 2

The Teaching Plan for In our Shoes

	Topic	Learning objectives	Preparation for next week
1	Introduction to the module. Relationships between users, carers & professionals	<ul style="list-style-type: none"> To reflect on the relationships between users, carers and health & social care professionals To consider what is known about what influences the relationship & implications for practice 	Students interview briefly one of their clients about their experience of relationships with health & social care professionals (week 1 interviews).
2	Communication : the importance of listening and talking	<ul style="list-style-type: none"> To reflect critically on the interaction between users/ carers & health and social care professionals To reflect on what is known about ways to ensure that users/ carers can express their feelings/ needs/ desires to professionals To consider how professionals can improve their skills in listening to & understanding users & carers 	Students to interview a user or carer or user and carer dyad about their experience of care and how person centred it has been (week 2 interviews). Does the user feel that they have been treated as an individual and that their carer has been too? Does the carer feel that they have been understood and treated as an individual as well as their relative?
3	People not patients 1: getting to know the person	<ul style="list-style-type: none"> To critically examine professionals' interactions with users/ carers in relation to whether or not they are person-centred To reflect on different ways of being more person-centred 	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
4	People not patients 2:	<ul style="list-style-type: none"> To reflect on how person centred current practice 	Students to interview a user/ carer or user/ carer

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

	tailoring care/ services to the individual	is and ways of making practice more person-centred	dyad about how far they feel professionals understand their difficulties and feelings (week 4 interviews).
5	People not patients 3: acknowledging the experiences & needs of carers	<ul style="list-style-type: none"> To reflect on the role of the carer when professionals have contact with users and how far their own needs are acknowledged and reflected in care plans 	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
6	Choice: being realistic about choices when resources are finite	<ul style="list-style-type: none"> To consider whether users/ carers are currently given choice in their interactions with health & social carer professionals To reflect on what choice might mean for users and carers and how practice might change as a result 	Students to interview (week 6 interview) a user/ carer or user/carer dyad about their journey: in what ways have they experienced continuity of care and what ways do they feel care has been fragmented and discontinuous. How would they like to see things change?
7	What is important to users & carers?	<ul style="list-style-type: none"> To consider during an interaction between a user, carer and professional what is important to each and how they influence the outcome of the contact To reflect on ways to make the users and carers wishes more powerful in the system 	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
8	Continuity of care: the 1:1 relationship & time	<ul style="list-style-type: none"> To reflect on the patient journey and the importance of continuity of care to users/ carers To consider the advantages and disadvantages of continuity of care for all parties involved To consider how the 1:1 	Students to reflect on what they wish to do differently in future and how they would like their service to change in order to address the needs of users and carers.

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

		relationship between professional and user/ carer fits into the complexities of modern health & social care	
9	The role of the environment	<ul style="list-style-type: none"> To consider the role of the environment in how a user/ carer presents themselves to professionals To reflect on ways of understanding the changes that people exhibit in different environments To consider what this means for professionals in their contacts with users/ carers 	Students to interview a family who have had contact with their service about how far they feel they have all been able to be involved & have their needs/ wishes/ anxieties addressed (week 9 interview). How do they feel professionals could do this better?
10	How to work with differing perspectives	<ul style="list-style-type: none"> To consider how to acknowledge & take account of the differing perspectives of those involved when working with service users To reflect on how practice might need to change as a result 	Choose one or two items from the reading list, read them through and spend time reflecting on them and your learning so far. Make notes on your thoughts and how useful the items are.
11		READING WEEK	
12	Sharing experiences: learning from each other	<ul style="list-style-type: none"> To reflect on every contact between professional and users/ carers as a learning experience To consider how learning can be maximised for all parties involved and how this might impact on professionals' future practice 	Look through your notes on the reading list items you have read and bring them along next week to the feedback session.
13	Looking backwards to look forwards	<ul style="list-style-type: none"> Review and reflection on the module To consider ways to put learning into practice and how to continue learning into the future 	

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Appendix 3: Student Feedback Form

FEEDBACK FROM WEEK N: IN OUR SHOES

Please indicate your rating on the line:

1. How informative did you find this session?

10	0
Extremely	Not at all informative
informative	
2. How interesting did you find this session?

10	0
Extremely	Not at all interesting
interesting	
3. How enjoyable did you find this session?

10	0
Extremely	Not at all enjoyable
enjoyable	
4. How helpful was this session for your professional practice?

10	0
Extremely helpful	Not at helpful
5. How actively did you feel you participated in this session?

10	0
Very much	Not at all
6. How well did you prepare for this session?

10	0
Very well	Not at all
7. How would you rate the session overall?

10	0
Extremely good	Extremely poor
8. What do you think you might do differently in your professional practice as a result of this session?

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

9. What would you suggest we do differently next time?

Please add any other comments you have below. Thank you.

This Mini Project has been funded by the Health Sciences and Practice Subject
Centre of the Higher Education Academy (2006-2007)

Appendix 4: Teachers' Feedback Form

FEEDBACK FROM TEACHING ON THE "IN OUR SHOES" MODULE

1. How did you feel the teaching went?
2. Were you properly looked after while you were at the university?
3. Were you given a claim form to claim expenses etc?
4. What could we do better in future for people who are teaching on courses at the university?
5. Were the students respectful and interested?
6. Did you enjoy yourself?
7. Would you teach again if we run the course in future?
8. Please add overleaf any other comments that might help us improve the experience for users, carers & others who come to teach.

THANK YOU

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Appendix 5: Outputs from the Project and Related Work to July 2008

Published papers

Benbow SM

Wearing purple. EFTA Newsletter (2007) November, no 3. Download from:
http://www.eftacim.org/doc_pdf/benbow.pdf

Benbow SM, Taylor L, Morgan K

Multiple perspectives: Involving users and carers in educating health and social care professionals.
 Quality in Ageing (2008) 9(2): 12-17

Presentations

Users Teaching in Partnership

Oral presentation by SM Benbow at Users in Partnership Christmas meeting, Birmingham, 15 December 2006.

User and carer led teaching: an innovative development at Staffordshire University.
 Poster presented jointly by SM Benbow, P Kingston, J-A Andrews and A Hill at the European Regional Meeting of the International Psychogeriatric Association, Multidisciplinary Approaches to Psychogeriatric Care, Istanbul, 3-6 May 2007.

Different voices: users and carers as teachers

Poster presented jointly by L Taylor, SM Benbow and J-A Andrews at the The Pilgrims Progress: the pathway to better care in Geriatric Psychiatry, Santiago de Compostela, Spain, 20 - 23 June 2007.

Wearing purple.

Invited sub-plenary presentation by SM Benbow at the 6th European Congress of Family Therapy & 32nd Association for Family Therapy and Systemic Practice UK Conference, Scottish Exhibition and Conference Centre, Glasgow, 4 – 6 Oct 2007.

Standing in our shoes: teaching with a difference

Joint showcase presentation by SM Benbow, W Boyce, A Hill & J Wenyss at Authenticity to Action, Grange-over-Sands, 8 Nov 2007.

Walking the Path Together: the important teaching role of users & carers.

Joint oral presentation by SM Benbow and K Morgan as part of Symposium co-chaired by SM Benbow and M O'Connell at the International Psychogeriatric Association Regional Meeting and Faculty of Old Age Psychiatry residential conference 9-11 April 2008. Dublin, 10 April 2008.

In our Shoes: Involving individuals with dementia and their carers in delivering teaching.

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Oral presentation by SM Benbow and K Morgan at HEA Mental Health Special Interest Group meeting, Meaningfully Involving Service Users & Carers in Learning & Teaching. Kings College London, 16 April 2008.

Learning from Service Users.

Oral presentation by SM Benbow at half day conference Vulnerable Older Adults as part of The Health Factor 2008. Staffordshire University, 23 April 2008.

In our shoes: users & carers teaching

Joint oral presentation SM Benbow, W Boyce & K Morgan at HEA Workshop Piecing together the jigsaw: sharing experiences of involving users & carers in education. Staffordshire University, 25 April 2008.

Resources on the In our Shoes website

Resource List from In our Shoes Module January 2008

Videocast of talk by K Morgan at recruitment workshop

Kath's Ten Top Teaching Tips for Users and Carers

Interim Report to the HEA

Final Report to the HEA

This Mini Project has been funded by the Health Sciences and Practice Subject Centre of the Higher Education Academy (2006-2007)

Publication 9.

Benbow, S.M., Taylor, L. & Morgan, K. (2008). Multiple perspectives: Involving users and carers in educating health and social care professionals. *Quality in Ageing*. 9 (2) p. 12-17.



Multiple perspectives: involving users and carers in educating health and social care professionals

Susan M Benbow, Louise Taylor and Kathleen Morgan

Susan M Benbow is Professor of Mental Health and Ageing at the Centre for Ageing and Mental Health, Staffordshire University, and Consultant Psychiatrist (Old Age Psychiatry) at Wolverhampton City PCT.

Louise Taylor is Principal Lecturer in the Faculty of Health at Staffordshire University.

Kathleen Morgan is a service user who teaches on courses organised by the Centre for Ageing and Mental Health, Staffordshire University.

ABSTRACT

The authors describe how a user and carers were involved in teaching as part of the MSc in Applied Studies in Ageing and Mental Health at Staffordshire University, the impact that this had on students on the course and evolving plans to develop the work further.

KEY WORDS

ageing

mental health

user/teacher

user involvement

carer involvement

CONTEXT

We describe the first steps towards involving users and carers as partners in teaching as part of the MSc in Applied Studies in Ageing and Mental Health at Staffordshire University. Students on the course come from a wide range of professional backgrounds, including

occupational therapy, medicine, mental health nursing and residential/nursing homes and are normally working in a setting with older adults who have mental health problems.

As part of the module in assessment and care planning, a user was asked to teach one session and two carers also taught some of the sessions. The aim was to give students a

different experience of assessment and care planning, to highlight the experience for users and families who are involved in assessment and care planning in older people's mental health services or similar settings.

METHOD

The user who agreed to teach was a woman living with Alzheimer's disease. Prior to her teaching she was visited by the module leader to discuss various possible methods of running the session, including the following:

- reading a prepared talk
- inviting and responding to questions from the student group
- being interviewed either by the module leader or by a member of the student group
- asking the group to send questions in advance for which she could prepare answers.

After discussion she chose to prepare a talk outlining her experience and to ask the student group to send her a list of questions in advance so that she could prepare written answers before the session. On the day of the teaching she spent about an hour on her talk and the prepared answers. After a break she then offered to take questions from the floor and spent an additional 45-minute period in discussion with the student group.

The two carers who agreed to run sessions both had a parent with a dementia. They gave talks on their experiences and then spent some time in discussion with the students, responding to their questions. They were not sent questions in advance of the sessions.

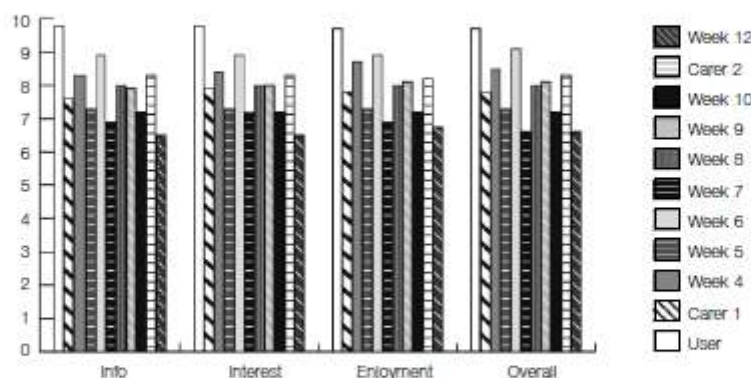
EVALUATION AND IMPACT ON STUDENTS

The sessions were well received by the student group who rated each session anonymously on a Likert scale of 0–10 (10 was the maximum score) for: information; interest; and enjoyment of the session. The user session attained the highest score out of all the sessions in the module, on all three aspects rated (see *Figure 1* for collated ratings).

Below are some of the students' written feedback comments on the user session.

- *'A first-hand account was invaluable.'*
- *'[It gave me] insight into the reality of the experience and the effect our interactions have on individuals.'*
- *'It gave another perspective to assessment and diagnosis; it gave an understanding to the person being assessed.'*
- *'It caused me thinking in more depth about how my actions affect clients – also, how important communication is.'*

Figure 1: Collated student ratings for each teaching session



The sessions run by carers also received very positive feedback from the student group.

- 'How assessment really feels from a practical point of view rather than just theoretical.'
- 'I think that [the carer's] experience teaches us that generalisation of any kind cannot address individuals' problems adequately.'
- 'The difference between what professionals feel should be included in a plan of care and what a carer feels they need.'
- 'Appreciation of needs of elders from diverse backgrounds. Highlights deficiencies and problems with service provision.'
- '...that the problems can be overwhelming and assessment must be performed with great forethought'.

An interactive feedback and review session was held at the end of the course and the majority of students rated the user session as the 'top session'. One suggestion for the future was for students to put together in advance a list of questions for the carers that they would like them to consider and address in their teaching sessions in order to help focus the session. This might be a way of ensuring that carers are able to share a broad range of experiences, both good and bad, with the students.

PRACTICE ACTION POINTS NOTED BY STUDENTS

In their feedback some of the students noted concrete ideas that they had taken from the user session and intended to implement in their practice.

- 'The need to give feedback [to the user in the form of] a written copy of questions asked during the assessment, in order for the person to reflect and discuss any queries during any follow up meetings.'
- '...writing things down for user to read afterwards'.
- 'Need to identify goals keeping into account the individuals' remaining skills.'
- 'Need to communicate clearly and not give too much information at any one time.'

- 'Need to allow the opportunity to hear both user/patient and relatives' views on services.'

Action points suggested by students from the carer sessions included the following:

- 'include carers'
- 'ensure good communication skills are in place'
- 'include carers in plan'
- 'hold regular meetings and [include] all involved in care for discussion/co-ordination'
- 'one person to be responsible for care co-ordination'
- 'need to assess carers' needs in order to develop a comprehensive assessment'.

EXPERIENCE FOR THE USER

The user subsequently presented at a workshop to other users and carers who are considering becoming involved in teaching. She spoke about her experience:

'I'd never done any teaching before, in fact I'd never stood up in front of any group of people and spoken, but it turned out not to be as daunting as I thought it would be. But when I came to prepare my talk I thought, where do I begin? What do I say? How do I start? And so after lots of thought, I thought, well I'm not a professional teacher so I could talk or teach of my experiences, my fears, my disappointments with the system, and my experiences, just my personal story. And over a couple of weeks I just jotted down things as they came to me and in the end I thought I will put them all together. So I wrote down all these thoughts and ideas and then I thought: well, how am I going to sort of talk this talk? So I decided I would approach it like... I would approach the students as if I was telling friends I had not met for some time how things were, how I had come to be in the position I was in (you know like we do when we catch up with people) and this way it helped me feel more relaxed... when I came to the end of my talk I said

if the students had any questions I would do my best to answer them, but I did wonder would I be up to it? Would it be ok? But it turned out all right, although afterwards I thought, "oh I should have said...", "oh I should have told them that" and "I forgot this or that". But the second time I did it the students were asked if they wanted to ask any questions, now I answered these prior to my talk which I found better because I could answer them more fully and take time over answering them and then the only questions that came up were those linked with what I'd talked about that day. And I don't think if I was asked to do any more teaching that I could really do it any different... you just need time to prepare, get it all together and have a clear idea of what is wanted or expected.

The teaching I did, for me, was one of the most rewarding things I have done because in a way I thought I was useless. By the way the students listened and the questions they asked it gave me the feeling that maybe I had contributed into making them think outside the box, help them understand how and why the system needs to change. Everyone's talk will be different, unique, personal to them, just think of the variety of information the students will get: practical teaching to go hand and hand with the theory they learn and we all know theory needs the support of practical feedback and that is what my and your input can achieve... it's personal to us who live it and to carers who live with it and through teaching things can change. Through teaching you have that power to make a difference – so go for it."

REFLECTIONS AND FUTURE PLANS

What is the 'added value' of involving users and carers as teachers in courses such as the one described here? From studying the comments received in the feedback process, the greatest impact on students was probably

in getting them to stop and think about their work from the perspectives of the user and carer. Although health and social care professionals might consider that they are doing this throughout their working lives, the course gave space and opportunity for participants to reflect on their practice in a way that is unusual in the course of busy working lives. The significant power and impact of the user's session related to her ability to tell of the 'lived experience', which was a powerful learning medium. Her presentation had an immediacy that is inevitably lacking when professionals present on similar topics: even when they recount the stories of service users, their account is second hand. The user was able to bring her experiences to life in the classroom and to give the students the privilege of sharing them, in a personalised manner, in conversation (McNamee, 2007). Seeing a user as a teacher on the course probably also challenged the students' attitudes, values and beliefs. In everyday practice professionals are expected to act as the experts; by turning the situation round, and having a user as a teacher, students are confronted with what is a completely different experience. They can take the opportunity to question and research in a new way and are freed up to learn (Rogers, 1983). These factors may go some way to explain why the user session was so highly rated by the student group.

The carer sessions were rated less highly, probably for one main reason: the carers who spoke were seen as powerful, confident, articulate individuals who had been through unique experiences and, although there were important learning points throughout their sessions, the view was expressed that they were not 'typical' carers. This, in itself, raises important issues:

- What is a typical carer?
- Is there such a thing as a typical carer?
- If, as professionals, we believe there is a 'typical carer', what influence does this have on our practice?

Perhaps the user managed to break the stereotype of a user, but the carers were regarded as less informative, and their experiences as less generalisable, since they didn't fit a stereotype. Future teaching will need to address the issue of generalisability

(Schofield, 2007). It was not intended that the carers who taught should be 'atypical' individuals but it is probably inevitable that, in starting to involve users and carers as teachers, the individuals who take this on are not 'typical'. The first people to tackle a new initiative of this sort will inevitably be trailblazers, with the confidence, energy and communication skills to take on a challenge, despite the stresses of caring or coping with an illness themselves. The teaching team hope that, as the work develops, a network of people from a variety of backgrounds and experiences will become involved and share their experiences. The team's skills and experience in supporting the users and carers were limited during the teaching described here, but a lot has been learned from the experience. We suspect that the users and carers who are involved in future courses will be seen as more 'typical' and their experiences as more generalisable.

The teaching team also hope that the inclusion of users and carers as teachers has demonstrated to students that they can ask users and carers to comment on their experiences in everyday practice. This helps students to consider and influence the assessment and care planning process (as well as other aspects of their health and social care). However, commenting in the context of one's own care plan might raise anxieties about how negative or critical comments might influence relationships with professionals and the impact it could have on one's own care plan. Many of the students' ideas involved ways of ensuring that users and carers are able to take a more active part in their own assessment and care planning. They particularly focused on ways of improving communication, such as writing down key points for users and carers, sharing letters with them and inviting them to join and actively contribute to care planning meetings. One of the key questions for the teaching team in taking this work forward is how to bring about change. Future courses could usefully involve a way of following students up afterwards to investigate whether they feel their practice has changed.

Greater patient choice and more personalised care are themes of various policy initiatives in health and social care (eg. Department of Health, 2005a;

Department of Health, 2005b). The National Service Framework (NSF) for Older People (Department of Health, 2001) includes a standard on patient-centred care and the NSF for Mental Health (Appleby, 2004) includes a standard on carer support. Tew, Gell and Foster (2004) have looked at the involvement of users and carers in education, emphasising that they offer distinct but complementary perspectives from one another (and from health and social care staff). The involvement of both users and carers is essential if health and social care services are to develop partnership working with people and their families who are using their services.

CONCLUSION

The overall evaluation of this module by the student group was very positive and it was thought-provoking for teaching staff. The user, who had been living with Alzheimer's for several years and had no teaching experience, ran a session that students felt was more informative, interesting and enjoyable than sessions run by highly experienced teachers. The session 'brought to life' the experience of going through an assessment and care-planning process. Future possibilities include couples or families running sessions in order to try to address the complexities of how assessment and care-planning impacts on relationships (or may not take relationships into account). Another option would be to use a similar model to the Council of Elders (Katz *et al.*, 2000) and to include sessions where students present anonymous case scenarios from their own practice to users and carers for discussion and debate. We have also recently been awarded a grant from the Higher Education Academy to develop a module designed and run by users and carers for future inclusion on the MSc course, which will give the opportunity to try out some of the ideas arising from the experiences we describe here.

Acknowledgements

The authors would like to thank the students who provided detailed feedback during the module and the people who contributed to the teaching described here.

Address for correspondence

Professor Susan Benbow
Professor of Mental Health and Ageing
Centre for Ageing and Mental Health
Staffordshire University
Blackheath Lane
Stafford ST18 0AD

Tel: 01785 353718
Fax: 01785 353731
Email: drsmbenbow@aol.com

References

- Appleby L (2004) *The National Service Framework for Mental Health – Five years on*. London: Department of Health. Available from: www.dh.gov.uk/assetRoot/04/09/91/22/04099122.pdf [accessed 14/03/08]
- Department of Health (2001) *National Service Framework for Older People*. London: Department of Health. Available from: www.dh.gov.uk/assetRoot/04/07/12/83/04071283.pdf [accessed 14/03/08]
- Department of Health (2005a) *Creating a Patient-led NHS – Delivering the NHS improvement plan*. London: Department of Health. Available from: www.dh.gov.uk/assetRoot/04/10/65/07/04106507.pdf [accessed 14/03/08]

Department of Health (2005b) *Independence, Well-being and Choice. Our vision for the future of social care for adults in England*. London: Department of Health. Available from: www.dh.gov.uk/assetRoot/04/10/64/78/04106478.pdf [accessed 14/03/08]

Katz AM, Conant L, Inui TS, Baron D and Bor D (2000) A council of elders: creating a multi-voiced dialogue in a community of care. *Social Science and Medicine* 50 (6) 851–860.

McNamee S (2007) Relational practices in education: teaching as conversation. In: H Anderson and D Gehart (Eds) *Collaborative Therapy: Relationships and conversations that make a difference* pp313–335. London: Routledge.


Rogers CR (1983) *Freedom to Learn for the 80s*. Columbus OH: Charles Merrill.

Schofield JW (2007) Increasing the generalizability of research. In: M Hammersley (Ed) *Educational Research and Evidence-based Practice* pp181–203. London: Sage.

Tew J, Gell C and Foster S (2004) *Learning from Experience. Involving service users and carers in mental health education and training. A good practice guide*. Available from: www.mhhe.ltsn.ac.uk/docs/lifeguide/Learningfromexperience.pdf [accessed 14/03/08]

Subscription rates		
Institutional with multi-user online access	Institutional with single-user online access	Individual
<input type="checkbox"/> UK £295 <input type="checkbox"/> Europe £385 <input type="checkbox"/> ROW £415	<input type="checkbox"/> UK £195 <input type="checkbox"/> Europe £225 <input type="checkbox"/> ROW £235	<input type="checkbox"/> UK £25 <input type="checkbox"/> Europe £65 <input type="checkbox"/> ROW £75
Payment Details By Debit/Credit Card – please debit my account if: <input type="checkbox"/> Visa/MasterCard <input type="checkbox"/> Maestro <input type="checkbox"/> American Express Card number: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Security number (on 16 digit card only): <input type="text"/> <input type="text"/> <input type="text"/> Valid from: <input type="text"/> / <input type="text"/> / <input type="text"/> Expiry date: <input type="text"/> / <input type="text"/> / <input type="text"/> Registered cardholder's name: <input type="text"/> Signature: <input type="text"/>		
By Cheque – I enclose a cheque payable to Pavilion Journals (Brighton) Ltd for £ <input type="text"/>		
By Invoice* – Please invoice me for: Name: <input type="text"/> Company Name: <input type="text"/> Address: <input type="text"/> Postcode: <input type="text"/> Daytime Tel/Fax: <input type="text"/> Email: <input type="text"/> Date: <input type="text"/>		
<small>* Institutional subscribers must be made by personal cheque/credit card and submitted to a named address. # Correspondence to: info@paypub.com </small>		

I would like to subscribe to **Quality in Ageing**



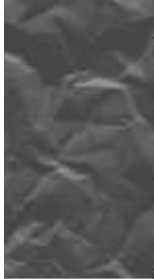
Subscribe online:
www.paypub.com/journals

To subscribe return form to:
 PROSPER BLIZZ-ATUL-ATUL, Pavilion Journals
 (Brighton) Ltd, Richmond House, Richmond Road,
 Brighton, East Sussex BN1 3RL
 Fax: 01273 890 1081
 Tel: 01273 890 1080
 Email: info@paypub.com

NOTE: Reproduced with permission. With thanks to Pier Professional for kindly supplying a high quality pdf.

Publication 10.

Clark, M., Benbow, S.M., Moreland, N., Scott, V. & Jolley D. (2008). Copying letters to older people in mental health services – policy with unfulfilled potential. *Quality in Ageing*. 9 (3) p. 31-38.



Copying letters to older people in mental health services – policy with unfulfilled potential

Michael Clark, Susan Mary Benbow, Vanessa Scott, Neil Moreland and David Jolley

Michael Clark BA (Hons), MPhil, PhD is Research Manager for the National Institute of Mental Health in England, working across research, policy and practice to support better evidence informed policy and practice in mental health.

Susan Mary Benbow is Old Age Psychiatrist and Family Therapist in Wolverhampton, and Professor of Mental Health and Ageing at Staffordshire University based at the Centre for Ageing and Mental Health.

Vanessa Scott is Adult Services Manager within South Staffordshire and Shropshire NHS Foundation Trust. She was previously Head of Nursing within Wolverhampton City PCT Mental Health Directorate.

Dr Neil Moreland spent most of his working life in teacher education at the University of Wolverhampton. In 2000 he left to pursue his interests in research. Neil became a Research Fellow at the Open University while also becoming involved in Dementia Plus West Midlands.

David Jolley MSc FRCPsych pioneered the development of services for older people in the north west of England. He was Professor of Old Age Psychiatry and Medical Director Wolverhampton 1995–2003. Having retired, he still maintains clinical activities and academic links.

ABSTRACT

The important initiative from the Department of Health (Working Group on Copying Letters to Patients, 2002) to require that letters between clinicians should be copied to the patient has not been implemented as widely as was intended. There have been concerns about logistics and fears that patients might be confused or frightened by communications they are not equipped to understand. Yet, modifications of the system to allow patients the choice to receive or not receive such letters and suitable training for clinicians offer safeguards. There is no doubt that copying letters provides an inexpensive mechanism for involving patients in their own care and treatment, offering transparency and confirming respect for equality in the relationship between patient and clinician. This paper reports experience with copying letters to patients and families with dementia. The process was warmly received by patients and carers, including families in a black and minority ethnic (BME) community, and few adverse comments were made. The routine application of this initiative will have benefits for the quality of service experience for older people, including those with dementia.

KEY WORDS

copying letters

patients

clinicians

carers

dementia

In the NHS Plan (Department of Health, 2000) the government wrote that '*letters between clinicians about individual patient's care will be copied to the patient as of right*' (Paragraph 10.3). A working group and pilot initiatives explored how to make this reality and in November 2002 Harry Cayton, the National Director for Patients and the Public, made a speech (Cayton, 2002) setting out a vision of the future for the '*empowered patient*' in which copying letters played a key role: supporting immediate communication and care, but also trust between clinicians and the public and redressing the power imbalance between them. This underpinned a vision of health care with a new relationship between clinicians and the public based on '*openness, mutual respect, sharing of expertise and joint decision-making*'. The Department of Health website lists the benefits of this policy as:

- more trust between patients and professionals
- better-informed patients
- better decisions
- better compliance
- more accurate records
- better consultation
- health promotion
- clearer letters between professionals.

On the face of it, implementing this policy should be straightforward – a matter of generating an extra copy to a patient whenever a letter about them is written between healthcare professionals. On closer examination, however, a number of issues arise. These include:

- choice to receive letters or not
- consent
- mental capacity
- data protection and confidentiality – including professional confidentiality risk
- rights of parents and carers
- communication of bad news
- technical and resource implications.

The Department of Health (2003) issued *Good Practice Guidelines* drawing on the working group report and findings from the pilot sites (Harris and Boaden, 2003). From April 2003, NHS organisations were to begin implementing this policy, with full implementation required in 2004. This has not happened but, as there

has been no formal change of policy, the intention seems to remain that the policy will become standard practice across the NHS. Yet, there is a danger that this good idea will be lost in the swirl of subsequent initiatives: reorganisation of health care, choice and mixed market service provision. Boaden and Harris (2005) noted that '*copying letters*' is not mentioned in the revised GP contract.

This article revisits the policy and lessons to be learned in the context of mental health care for older people. It reports two projects undertaken as, first, development work, then audit of this in one mental health service in the Midlands. It might be thought that people with a dementia, which impairs understanding and retention of information, would be unable to make use of written materials designed for communication between doctors. In practice, people with dementia often remain functional because their lives are shared closely by one or more main carers, so that communication relates to the carer/cared-for partnership as well as to the individuals concerned. This requires honesty and trust between the partners and an appreciation of individual views and rights by professionals. Matters might be viewed as potentially even more difficult where the person with dementia and/or their carer is from a minority group and lacking in English language skills. Thus, experiences in this situation represent a hard test of the virtues and practicability of the policy of copying letters to patients.

BACKGROUND

Communicating more transparently with patients through giving them better access to letters and professional notes written about them predates the Department of Health policy initiative (Gill and Scott, 1986). Over the past decade there has been a general shift towards advocating greater understanding between patients and clinicians (Jelley and van Zwanenberg, 2000) and, although some commentators are cautious – citing language and medico-legal issues as barriers, many clinicians welcome transparency as a way of improving the relationship with patients to enhance care and outcomes, and increasing patient satisfaction (Saunders *et al.*, 2003; Working Party of the Royal College of

Physicians, 2005; McKinstry *et al.*, 2006). Patients appreciate receiving copies of letters written to general practitioners or consultants. The practice helps them feel involved in the referral process and in planning their treatment, care and follow up (Jolley and van Zwanenberg, 2000). Tomkins *et al.* (2004) pointed out that the cost (approx 25p per letter) is a small price to pay for better communication and a stronger therapeutic relationship between clinician and patient.

EXPERIENCES OF IMPLEMENTING THE POLICY

Wolverhampton is a city of 300,000 with an elderly population of 45,000 (aged 65 years and over) and an ethnic minority population (predominantly Punjabi Sikh and African-Caribbean) of 17%. It provides a specialist service for older people with dementia and other mental health problems (Jolley *et al.*, 1997).

VIEWS OF BLACK AND MINORITY ETHNIC FAMILIES

A pilot site project supported by the Department of Health was undertaken in 2002 to investigate the views of carers of people with dementia from the local black and Asian communities. This was undertaken in the context of a series of studies of the experience of dementia and its care within these communities – the Twice a Child (TAC) projects (Dementiplus, 2001; 2003). It seemed particularly pertinent to investigate this group as they present issues of disenfranchisement by virtue of language, culture, age and mental capacity of patients. Thus, the pilot aimed to investigate the views of BME carers on approaches that would be acceptable to them and those they cared for, taking into account language limitations, cultural needs and the availability of resources to address these. An overriding consideration was the potential usefulness of the

communication in aiding understanding of the condition and the plans for care and support.

Method

Nine carers of African-Caribbean (n=4) and Asian (n=5) people with dementia identified within the TAC studies were approached for their views. People with dementia and their carers had been identified via community groups or through their referral to health or social care services. They had agreed to participate following initial contact, which was often informal through their existing network, but confirmed by interview and letter. Carers, rather than the patients, were approached as it was felt this added an extra dimension to the issue of copying letters, as in the latter stages of dementia it is likely to be the carer receiving the letters, but there are issues of confidentiality and consent to be considered. Thus, for this exercise the individuals with dementia were required to have capacity to agree to be included in the project and to agree that interviews be conducted with their main carer.

Semi-structured interviews were conducted by a research assistant already known to these individuals and comfortable with their language and culture needs. The research assistants were drawn from the relevant BME communities and had worked with both the individuals with dementia and their carers in the earlier Twice a Child studies. They had knowledge of dementia and needs arising from it and were well informed of cultural expectations within the community. It was understood that they were working in association with health and social care services, but independent of them.

Findings

Asian patients were more likely to be male (M:F 3:2), to be over 70 years (4:1) and still married (4:1). African-Caribbean patients were more likely to be female (M:F 1:4), to be aged less than 70 years (1:3); all were widowed. All Asian carers shared the same household as the patient – two wives, two daughters and one son. African-Caribbean carers, three daughters and a son provided support by visits in two instances, with two co-habiting with the patient.

On a five point Likert scale all interviewees responded that it would be 'very helpful' or 'helpful' to them and their relative with

dementia if clinicians' letters were copied to them. No one foresaw disadvantages. Carers from Asian backgrounds were more emphatic that they thought copying letters to them rather than the patient would be most helpful. Many did not believe this should depend on the stage of the patient's dementia but others remarked that that communication should take into account the capacity of the individual with dementia 'to deal with the information and its implications'.

Respondents said that they wanted information 'so that we know what is happening' and so 'carers and family would not be left in the dark as to what was happening to a loved one'.

Two Asian carers felt that having copies of letters would mean they could contribute more to decisions about best care for their relatives. One carer said if the family received a copy letter it would allow them to identify and correct any errors or omissions as 'carers could always look back and compare notes' and copies of letters would 'help clarify points or issues that may not have been discussed or explained well and understood during the consultation'.

One carer hoped that copy letters would make plain how well the care professionals are working together to co-ordinate their care (or not), and may even 'help establish better communication and links between the care team, including the carer and family members'.

In addition, carers thought copying of letters would help them tell others what was happening, making it 'easier to inform people involved in his care about his condition and needs for care'.

The interviewees were asked what information they expected in letters. They wanted letters written after initial assessments to indicate diagnosis and to say something about the nature and prognosis of the condition. Subsequent letters should describe progress and the arrangements for treatment and care, including names of key contacts. Asian carers also mentioned the need for cultural appropriateness. In large part they were referring to the way in which services are organised and the approach and attitudes of staff, rather than letters *per se*. The main consideration was that the letters be 'user-friendly' and 'not in medical jargon'. Translating letters into BME languages may

be desirable, but was not the essential thing for this group of carers: 'give us the information and we will find a way to make sense of it', was the overriding imperative.

Conclusion

Although with a small sample of people, these interviews that found carers overwhelmingly welcomed the prospect of receiving copies of letters. There was demand in the community, and the desire was for practical information presented as best as possible. This was in keeping with the national evidence of desire for information arising from the copying letters work. The insights gained from this project supported the feasibility of, and widespread support for, the principle of copying letters and issues of administration and translation were not seen as major. There was enthusiasm that doctors should begin to copy letters to patients and families in the older people's mental health service, although it was recognised this had to happen within a framework of good professional practice and clinical governance to address risks.

IMPLEMENTATION OF THE POLICY AND ITS IMPACT

After the pilot, the local Mental Health Directorate implemented the policy. Following local consultation with clinicians and planning for good clinical governance, it was ratified and recommended for endorsement by the trust board. It was widely accepted that any trust-wide ratification would necessitate the need for a training strategy to equip staff with the skills and the confidence to implement the policy, to be included in both the trust induction programme and mandatory updates.

Method for the audit of implementation impact

A survey was subsequently conducted of patients and carers cared for by the older people's mental health service in the south east sector of the locality. The consultant psychiatrist routinely asked patients if they

wished to receive a copy of the assessment letter, which would be prepared for their GP, and/or whether they wished a copy to be provided for a family carer. When copy letters were requested, a postal questionnaire was included with it, together with simple instructions for completion and return, and a return-addressed envelope. Questions were designed to discover how informative, accurate, useful and acceptable the copy letters were felt to be, and space was left for open comments: the questions were informed by the findings of the pilot project but aimed to access the views of patients and carers and to extend the pilot across a larger group of patients.

Findings

Forms were returned from 38 family carers and 31 patients (in 18 cases both carer and patient returned the feedback form). **Table 1** summarises the quantitative findings. Overwhelmingly, the response was that the letters received had been 'very' or 'fairly' clear to the families (38/38 or 100%) and patients (27/31 or 87%). In terms of the usefulness of the letter, 37 (98%) of carers and 27 (87%) of the patients replied that it had been 'very' or 'fairly' useful. Only one

carer felt that the letter had been 'not at all useful' and one patient reported that it was only a 'little bit' useful, three patients did not answer this question.

Seventeen family carers felt that some information had been missed or reported wrongly. Three carers gave additional information (regarding drug treatment, driving habits and their visits). Three carers offered corrections to information in the letter (one on timings and two on deaths of family members). One relative offered a plea for help. Seven patients replied that there was something missing from the letters. Three patients offered corrections to the information in the letter. Four patients gave additional information. One patient added a written thank you.

One relative wrote:

'Nothing was missed. The whole family thought it was a very good letter, easy for mom and dad to understand and a very true record of (the doctor's) visit.'

The original respondents were thanked for their help by return post and asked whether or not there was anything else they wanted to add with regard to the policy of copying

Table 1: Summary of quantitative data from the audit study

	Patients		Carers	
	N	%	N	%
Number of forms returned	31		38	
How clear was the letter?				
No answer	3	10	0	0
Not at all	0	0	0	0
A little	1	3	0	0
Fairly	8	26	6	16
Very	19	61	32	84
How useful did you find the letter?				
No answer	3	10	0	0
Not at all	0	0	1	3
A little	1	3	0	0
Fairly	9	29	6	16
Very	18	58	31	82
Did we miss anything out?				
Don't know	1	3	0	0
No	23	74	31	82
Yes	7	23	7	18
Any further comments?				
Don't know	2	6	0	0
No	19	62	9	24
Yes	10	32	29	76

letters to them. Ten (of 31) patients passed on comments: four offered their thanks or otherwise commented positively on the letter, three gave additional information, and three offered corrections to the content. One patient commented that the assessment had been 'inaccurate... and very unclear and very undefined'. Another patient commented:

'It was nice to be informed directly and treated as an active participant in rehabilitation process rather than a passive recipient of a care programme.'

Twenty-nine (of 38) carers added comments: 14 reiterated that the letter had been useful and/or passed on thanks for receiving it, six offered updates on what had happened since the assessment, five stressed that they needed help or asked when appointments would come through, three offered helpful corrections (eg. letter had been addressed to the wrong GP partner), and one asked for more information. One family said it had been unhelpful:

'Mum was really annoyed... says she will not have anything more to do with doctors and said that it was my fault which really upset me at work.'

CONCLUSION

These findings confirm that patients and carers want copies of letters and find them useful, but that there is a potential to send letters to some who find them unhelpful, or are upset by them. These lessons have been borne in mind in developing the training and the practice of copying letters in the local mental health service. Copying letters can be helpful to all involved, but has to take place with an institutional framework of good professional practice and clinical governance to manage the issues raised here. It would also be helpful to carry out further research into information-sharing with patients and families – its benefits and drawbacks – in older people's mental health services. The authors' practice as a result of these findings is to encourage patients that they should have a copy letter unless there is a clear contraindication, such as a complete lack of insight or psychotic illness.

REFLECTIONS ON THE POLICY AND ITS IMPLEMENTATION

In the 'copying letters to patients' section of its website, the Department of Health states that 'engaging and informing patients is at the heart of good clinical practice'. Communication between patients, their families and health professionals is not solely about letters and, indeed, if health professionals rely on letters to give information they are missing the point. The principle is of good open communication between health professionals and those they are working with at all times during care – through open verbal communication, backed up with copying letters. If that is the case then copies of letters will hold no surprises and act as a helpful record of discussions that have already taken place (Faculty of Old Age Psychiatry, 2004). There are instances when the clinician and patient/carer feel that copying an unmodified letter to a professional is inappropriate and there is advantage in providing an additional version tailored to patient/carer needs: if letters are a record of discussions then those discussions will already have highlighted any contentious or provocative areas that can be taken into account when subsequently writing the letter. Some colleagues have adopted a practice of formulating letters primarily for patient/carer consumption, with copies for professionals. Our experience is that this is an important consideration, but applicable to a minority: most of the people interviewed preferred to have a copy of the letters designed for and sent to their doctor. This preference may have been based on appreciation of economy, but also avoids the possibility that issues of truth might be side-stepped in a tailored letter and has the advantage that the patient and carer know exactly when and what the GP has been told and asked to do. Only a small number of patients with no insight into their problems (and often where the initiative for their referral has come from a family member) are now selected out for individually written letters; these instances, which are few in number, are usually related to a dementia or a psychotic illness or the combination of both.

This philosophy behind copying letters is at the heart of good modern practice in mental health care, addressing issues of information, communication and power to form better partnerships of care between all involved, and it is time to take stock of how we can best implement it. We see copying letters as a helpful step in breaking down some of the barriers between services and the communities they serve, as advocated recently by Louis Appleby, the National Director for Mental Health (Department of Health, 2007). The shared letter negates any false boundaries between parties and recognises that professionals and those they are serving are equals. It enables patients and carers to play an active part in interpreting findings and making and evaluating plans for care and treatment.

From its inception, there was recognition in the copying letters policy that a one-size-fits-all approach would be inappropriate, both for organisations and for individual patients. Professional judgement, sharing of experience and a common-sense approach need to steer implementation and training of professionals. Letters must be individual rather than 'standard' and so need to be constructed in content and style with knowledge of, and respect for, the characteristics of all potential intended recipients, and with sensitivity to the different perspectives of those involved. The policy needs to be developed in a context of good professional practice and clinical governance, these being supportive of each other (complementary) if developed with sensitivity and regular feedback. Clear guidance, supportive policies, resources and robust governance mechanisms can operate together to support clinical judgement whenever a clinician faces the question of whether or not to ask a patient if they want to receive a copy of correspondence, or a copy for another party.

The practice of copying letters needs to take place in the context of good communications with patients. It is important that people feel free to ask questions for clarification or correction of what is written – this might need to be done repeatedly. It is easy for alternative interpretations of the same word to occur in either direction and there is the ever-present hazard of typos. There is a need to consider the

role of letters to communicate with carers too, especially in mental health settings (Pinfold *et al.*, 2004). Clear communication is given even greater significance with the 'choice' agenda within current policy – for real choice requires good information.

Untoward incidents involving inappropriate correspondence are always possible, as are breaches of confidentiality (Smith, 2002). There is additional potential for difficulties when patients or carers have mental health problems: these may influence capacity and ability to consent or to understand and interpret information, or may be associated with frank danger from altered behaviour. Clear means of managing these risks, learning from untoward incidents and sharing the lessons with colleagues are vital.

Training programmes should be carefully constructed, ensuring that the diversity of copying letters to patients is clearly communicated and that all health professionals and clinical and administration staff are included.

From 2002 'copying letters' became a top-down, mandated policy. It drew upon principles of common sense and good clinical practice, with some evidential support in the literature. The centrally driven urgency of that time may have dissipated, but the principles remain (Boaden and Harris, 2005). The danger is that, without a strong mandate for the benefits of this simple and inexpensive initiative, it may not be realised. Our experience suggests that, even in the complex situations encountered by individuals and families with dementia or other mental disorders of late life, there is real interest and appreciation of sharing information by copying professional correspondence to clients. When this is done in practice it has many advantages for patients and family carers: it establishes a culture of openness, inclusiveness and partnership between professionals and families, and improves the appropriateness of service responses. Our experience among older people with mental health problems identified few serious hazards or expressions of dismay, and these were greatly outnumbered by the gains from all perspectives. Other services should consider improving their information-sharing by adopting this approach – the costs are little and the gains considerable.

Details for correspondence

Michael Clark PhD
Research Manager
Care Services Improvement Partnership
Email: Michael.clark@csip.org.uk

References

- Boaden R and Harris C (2005) Copying letters to patients – will it happen? *Family Practice* 22 (2) 141–143.
- Cayton H (2002) *Copying Letters to Patients*. Speech available online at: www.dh.gov.uk/en/News/Speeches/Speecheslist/DH_4097895 [accessed 17/07/08].
- Dementia Plus (2001) *Twice a Child*. Available online at: www.fordementia.org.uk/documents/twiceachild.pdf [accessed 17/07/08].
- Dementia Plus (2003) *Twice a Child II*. Available online at: www.fordementia.org.uk/documents/twiceachild2.pdf [accessed 17/07/08].
- Department of Health (2000) *The NHS Plan*. London: Department of Health.
- Department of Health (2003) *Copying Letters to Patients – Good practice guidelines*. London: Department of Health.
- Department of Health (2007) *Breaking Down Barriers – The clinical case for change*. London: Department of Health.
- Faculty of Old Age Psychiatry (Royal College of Psychiatrists) (2004) *Copying Clinical Letters to Patients. Guidelines for old age psychiatrists*. Available online at: www.rcpsych.ac.uk/pdf/guidelinesCopyingPatients.pdf [accessed 17/07/08].
- Harris C and Boaden R (2003) *Copying Letters to Patients: Summaries of 12 pilot project sites*. Manchester: Health Organisations Research Centre, Manchester School of Management.
- Gill M and Scott D (1986) Can patients benefit from reading copies of their doctors' letters about them? *British Medical Journal (Clinical Research Edition)* 293 (6557) 1278–1279.
- Jolley D and van Zwanenberg T (2000) Copying general practitioner letters to patients. *British Journal of General Practice* 50 (457) 657–658.
- Jolley D, Jenkins R and Dixey S (1997) First light: old age psychiatry in Wolverhampton 1995–1996. *Psychiatric Bulletin* 22 503–505.
- McKinstry B, Ashcroft R, Car J, Freeman G and Sheikh A (2006) Interventions for improving patients' trust in doctors and groups of doctors. *Cochrane Database Systematic Review* 3 (CD004134).
- Pinfold V, Farmer P, Rapaport J, Bellringer S, Hurley P, Murray J, Banerjee S, Slade M, Kuipers E, Bhugra D and Waitere S (2004) *Positive and Inclusive? Effective ways for professionals to involve carers in information sharing*. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation RandD (NCCSDO).
- Smith PEM (2002) Letters to patients: sending the right message. *British Medical Journal* 324 (7338) 685.
- Saunders N, Georgala C, Blaney S, Dixon H and Tompnam J (2003) Does receiving a copy of correspondence improve patients' satisfaction with their outpatient appointment? *Journal of Laryngology and Otology* 117 (2) 126–129.
- Tomkins C, Brand J and Williams H (2004) Do dermatology outpatients value a copy of the letter sent to their general practitioner? *Clinical and Experimental Dermatology* 29 (1) 81–86.
- Working Group on Copying Letters to Patients (2002) *Copying Letters to Patients: A report to the Department of Health and draft good practice guidelines for consultation*. London: Department of Health.
- Working party of the Royal College of Physicians (2005) Doctors in society. Medical professionalism in a changing world. *Clinical Medicine* 5 (6 Suppl 1) S5–40.

NOTE: Reproduced with permission. With thanks to Pier Professional for kindly supplying a high quality pdf.

Publication 11.

Benbow, S.M., Ong, Y.L., Black, S. & Garner, J. al. (2009). Narratives in a user and carers' group: meanings and impact. *International Psychogeriatrics*. 21 p. 33-39.

International Psychogeriatrics (2009), 21:1, 33–39 © 2008 International Psychogeriatric Association
doi:10.1017/S1044610208007634 Printed in the United Kingdom

Narratives in a users' and carers' group: meanings and impact

Susan M. Benbow,¹ Yong Lock Ong,² Sarah Black³ and Jane Garner⁴

¹Centre for Ageing and Mental Health, University of Staffordshire, and Old Age Psychiatry, Walsingham City Primary Care Trust, U.K.

²Psychiatry of Old Age, Goodmayes Hospital, North East London Foundation Trust, London, U.K.

³Psychiatry of Old Age, Winford House Hospital, Devon Partnership NHS Trust, Exeter, U.K.

⁴Psychiatry of Old Age, Barnet, Enfield and Haringey NHS Mental Health Trust, London, U.K.

ABSTRACT

Background: Carers who wished to share their experiences with a national working group (the Consumer Group) prepared narratives as a way of identifying areas for discussion.

Methods: The narratives were submitted to one author and subjected to thematic qualitative analysis. The themes were fed back to the Group for discussion.

Results: Five main themes were identified: difficulties in obtaining a diagnosis; acting as an advocate; stresses of caring; practical problems with social care; and emotions experienced by carers.

Conclusions: The narratives provided a means of sharing carers' experiences and creating initiatives for further action by the Group. They have an impact on the people who hear or read them but may also be therapeutic for those who produce them. Narratives can also be a powerful tool in teaching and training, and in identifying areas for service and professional improvement.

Key words: carers, patient journey, geriatric psychiatry, advocates, dementia, burden of care

Introduction

It is widely accepted that narratives have a role in medicine. There are core texts on narrative-based medicine (Greenhalgh and Hurwitz, 1998; Launer 2002), and a trainee in psychiatry advocates the use of narratives within the specialty (Wallang, 2006). Taking a psychiatric history in a sensitive manner may help someone arrange a coherent narrative of their life. Listening to or reading a narrative can similarly have a profound impact.

The Faculty of Old Age Psychiatry is the specialist branch of the Royal College of Psychiatrists dealing with aspects of older people's mental health. The Faculty established a joint forum where users and carers who were identified through the Alzheimer's Society and Age Concern England met with Faculty officers (all practicing old age psychiatrists) and staff members of the two voluntary organizations to discuss matters of mutual interest: this group chose to be called the Consumer Group (referred to hereafter as the Group). The initiative to set up the

Group came from the Faculty and was linked with the Royal College of Psychiatry's "Partners in Care" campaign. The Faculty's aim was to get feedback from users and carers on the work being undertaken by the Faculty itself: for example, papers being produced by the Faculty were sent to the Consumer Group for comment and suggestions prior to being finalized, and members of the Group were invited to join other working groups. During their terms of office, the authors recognized that the Group had a strong influence on the work of the Faculty and have reported their reflections on the Consumer Group and its influence elsewhere (Ong *et al.*, 2007). Although the Faculty officers brought to the Group ideas about how it might work, users and carers joined the Group with their own ideas about how it should function and what the Faculty should do, and developed a profound influence on the Faculty's work which had not been anticipated by the Faculty officers. Some members travelled long distances to attend the Group from various parts of England. The Group itself has initiated work through the Faculty. It includes users and carers who are coping with dementia and other mental health problems in later life, and continues to meet quarterly. Despite active participation in the Group (for example, being able to raise issues for discussion and adding items to the agenda), members caring

Correspondence should be addressed to: Professor Susan M Benbow, Centre for Ageing & Mental Health, Faculty of Health & Sciences, Staffordshire University, Blackheath Lane, Stafford ST18 0AD, U.K. Phone: +44 (0)1902 575151; Fax: +44 (0)1902 444127. Email: drambenbow@aol.com. Received 15 Apr 2008; revision requested 4 Jun 2008; revised version received 17 Jul 2008; accepted 17 Jul 2008. First published online 17 October 2008.

for relatives with dementia expressed a wish to share their personal experiences. They recognized that the Consumer Group is a working group and not a support group, and that the timing, agenda and formality of meetings did not allow for detailed sharing of personal experience. It was suggested that they could prepare and share narratives as a way of informing the Group and initiating discussion about carers' issues.

Our paper describes the narratives arising from the Group, and considers their meanings, impact and potential use.

Method

Those members of the Group who wished to do so were asked to send a full written account of their experiences as carers of people with dementia to one of the authors. They were encouraged to prepare the narrative in any way they chose, whether chronological or not, which they felt might inform the Group. The intention was to ensure that carers' issues were properly acknowledged and addressed by the Group within a safe and secure setting, and then fed into the work of the Faculty. Carers were given several months to prepare narratives and a meeting of the Group dedicated to the narratives was organized at which the analyzing author presented his qualitative analysis (without identifying individuals) to the whole Group for further discussion and debate. The analyzing author read and re-read the narratives several times and carried out a qualitative thematic analysis, using methodology based on Balint's work (Balint *et al.*, 1993), with the aim of identifying major common themes.

Eight written narratives – four by daughters and four by spouses – were prepared and submitted for analysis by self-selected members of the Consumer Group: all were caring for people with dementia. Seven narratives were written specifically for this project. The eighth carer submitted a published paper from a qualitative research project of which he is a co-author (Galvin *et al.*, 2005).

Results

Five main themes were identified:

1. Difficulties carers have in obtaining a diagnosis from primary care services
2. Acting as advocate-cum-bridge between the private world of a person with dementia and the public world of health and social care

3. Stressors associated with caring for a person with a dementia
4. Difficulties with services offered by social services
5. Emotions experienced during the various stages of being a carer.

1. Difficulties in obtaining a diagnosis

The first theme identified was the difficulty carers have in obtaining a diagnosis from primary care services (Narrative 1):

"During the summer of 1998 I made a number of visits to our GP service encouraged by my brother-in-law who has a medical background and suspected my husband was showing signs of an early dementia.

Our GP [general practitioner] was sympathetic and understanding. His approach was to test for physical causes which made sense to me. He arranged for my husband to have a blood test. I heard nothing further.

I had to ask for an appointment. He informed me the results were not significant.

I asked him to see my husband alone to form an opinion. When my husband returned home he had with him a prescription for vitamins but could not tell me anything about the discussion with our GP. Shortly after, we received an appointment to see the practice counselor.

The meeting with the counselor was pointless. He was trying to deal with a couple with marital problems. My husband's reaction was a 'b... waste of time.'

I then saw the senior partner whose reaction was why put my husband through a mental health assessment when I already knew there was a problem.

In April 1999 my husband was admitted to hospital as his diabetes was out of control. One of the nurses asked me if I had noticed my husband appeared to be rather confused. I took a deep breath and explained how for the last seven months or so I had been trying without success to involve our GP. The diabetic consultant in charge took control and arranged a CT brain scan and an assessment by the clinical psychologist.

Thus it was some ten months after my initial approach to our GP we finally received a diagnosis of dementia."

2. Bridging private and public worlds

The second theme was that of the carer being an advocate-cum-bridge between the private world of the person with dementia and the public world of health and social care. The private world of the patient consists of their current neuro-psychiatric situation, increasing dependency, previous personality, relationships and experience. A carer often has access to this based on their close relationship, history and empathy with the person for whom they care.

Table 1. A classification of stressors contributing to the burden of care

PHYSICAL STRESSORS <ul style="list-style-type: none"> • concomitant physical illnesses, e.g. diabetes, strokes, carcinomas • frequent falls • incontinence • dehydration • change in eating habits 	PSYCHOLOGICAL STRESSORS <ul style="list-style-type: none"> • having to accept changes in personality and behavior • unable to share major life events and confidences • inability to communicate • feeling duty bound – despite breakdown in relationship • coping with deterioration • giving up care
SOCIAL STRESSORS <ul style="list-style-type: none"> • disrupted household • impact on working outside the home • financial consequences • ability to drive • isolation 	SEXUAL STRESSORS <ul style="list-style-type: none"> • loss of intimacy • sexual deprivation

They may be placed by health and social care staff in a position where they are required to interpret or advocate on behalf of their relative with dementia. Excerpts from several narratives illustrate this theme:

"Only after six months did I have a conversation with a social service supervisor. Their philosophy is not to move a person from familiar home surroundings until absolutely necessary as any move would lead to extra confusion. This is an admirable policy although both my sister and I would have liked mother to move closer to us. My mother has always been a happy and positive person. However she has recently become depressed. She feels she is not managing. We try to reassure her, reminding her she has lots of people coming in to help and she only needs to ask. She says she cannot remember this available help and what to ask for. It breaks my heart to see her so unhappy."

"He is a 'carrier' of complexity. Becoming increasingly public with his advocacy requires paradoxically that he engages in and draws on an intimate knowledge of how his wife is as her ability to communicate recedes" (Galvin *et al.*, 2005).

3. Stressors of caring

All narratives mentioned similar stressors contributing to the burden of care; these can be subdivided into physical, psychological, social and sexual. The most frequently mentioned are listed in Table 1.

4. Practical problems with social care

Another major recurrent theme was the ongoing difficulties carers had with the services provided by social services. There were a few examples of

positive experiences, but the majority of experiences were difficult, as illustrated by Narrative 2:

"Things came to a head one weekend when I felt I could continue no longer. Another social worker had in the meantime been given responsibility for our case. I had some difficulty contacting him. When I eventually spoke to him I said I couldn't cope any more. Things had got so bad that I was at the end of my tether and had felt desperate enough on occasion to consider walking out of the house. His response was 'there is no point in you making threats'. I was taken aback that a cry for help should be perceived as a threat."

When he visited four days later I gave him an account of my husband's rapid deterioration in the last few weeks including three falls, two of which had involved an ambulance call-out and one a 10 day stay in hospital. Having listened to this, his first question was whether with the existing level of home, day and respite care would I be able to carry on for another year? My response was an emphatic "no" as I reminded him that I was not coping now. He then agreed to recommend my husband for long term care but warned me that it would take some time to sort out funding. There was some suggestion that I was being manipulative.

This response was for me the last straw. I packed a suitcase for myself and another for my husband together with all his medication and instructions. I waited for the evening home carer to arrive and briefed her on what I intended to do. I then gave her the following letter to pass on:

TO WHOM IT MAY CONCERN

Please be aware that I am this evening leaving my house to go and stay with relatives and that I am leaving behind my husband who suffers with Alzheimer's disease and insulin-dependent diabetes. The wear and tear on myself, both physically and psychologically of caring for him at

home, is no longer acceptable or sustainable. In order that there is no ambiguity about the situation I am putting in writing that with immediate effect I am no longer prepared to be his carer. I can be contacted only via my daughter.

I have tried in vain to convey to social services that I can no longer manage this situation. I don't feel I have been heard or understood. I have always assumed social services would collaborate with carers and support them in the very difficult task they undertake: unfortunately my experience to date has been the complete reverse of this.

Following this action, emergency admission was made into a local care home and within two weeks I was contacted to say there was a permanent place for him. I feel angry I had to take such an extreme step in order to force the issue."

5. Emotions experienced by carers

The carer has the dual burden of the conscious often practical problems of coping with a close relative with dementia plus the unconscious conflicts evoked by being in this role (Garner, 2004):

"Carers either know or fairly quickly learn practical tasks they have to undertake. Sometimes with professional help from one or more agencies. What we need is to understand what is happening to us on an emotional level."

This is complicated by the quality, nature and history of premorbid relationships. The most frequent emotions described by carers are illustrated by the following quotations from the narratives:

1. Guilt: "I should have been more patient, spent more time with her, done more, etc."
2. Confusion: "I had no idea how my father was thinking. I fumbled around trying out different theories and occasionally got it right but often made my father unnecessarily unhappy."
3. Resentment: "I was aware I had to ration my own energies but had no idea of the time involved or the demands I would need to meet. My health has suffered over the last years."
4. Helplessness: "The opposition of social services to my father's wish to remain in his own home and the antipathy of some of my father's neighbors were difficulties I had not anticipated."
5. Grief/ sense of loss: "My major point is that the acute emotional strain and sense of loss takes a greater toll than the required physical effort experienced when providing 24-hour care for a loved one suffering from dementia."
6. Sadness: "I am sorry to say that I found the recollections were often quite distressing and I shed a few tears during the typing of my narrative. I guess

the other people who have sent you narratives will be similarly distressed by the task."

Discussion

Despite being drawn from memories, narratives are structured accounts of events across time and are inherently social (Mumby, 1993); they are created and shared through language. As Anderson (2007) states:

"stories are told and retold ... new versions or new meanings of old ones emerge from these tellings and retellings."

Thus narratives have a rhetorical power. They evolve and can be contested, negotiated, changed and act as an agent of change. Rather than listening passively, these accounts create a reaction (Gardner, 2002).

During repeated readings of the narratives in order to identify recurrent themes, the authors became aware that the narratives and themes within them reflected contributory ideas and opinions expressed by carers in the Consumer Group. The narratives thus serve as recorded self-contained accounts of the carers' contributions. They have impact for the carer in developing the narrative and for the reader/listener in terms of the potential influence of hearing that narrative. The process of feedback and discussion employed within the Group offered further opportunity for narrators and listeners to develop the themes and ideas further. Accounts such as Narrative 2 bring to life the realities of living with a person with dementia and make professionals face the discomfort of discovering how families can be let down by the services that should be supporting them.

Illness narratives have been divided into three categories by Frank (1998): the restitution story, the chaos story and the quest story. All our carers' narratives could be categorized as quest narratives, fulfilling the definition as unflinching views of the reality of dementia and of being a carer. In the face of this reality, our carers looked not to restitution, but rather to what can be reclaimed of life. What can be learned and how can this lesson be passed on to those who have not made their journey?

When the analysis of the narratives was presented to the Consumer Group, they discussed how the themes might be addressed in their ongoing work. One initiative which arose from these discussions was a one-day conference for primary care representatives, Faculty members, user and carer representatives. It aimed to give carers the chance to discuss perceived difficulties with primary care representatives and to address the first theme

(difficulties of obtaining a diagnosis) by allowing general practitioners to hear directly from carers in a setting outside the consultation room. The second and third themes (carers being the bridge between the person with dementia and the health system, and the stresses resulting from this) were partly addressed by carers' involvement in the Consumer Group, giving them a direct link to professionals, an influence within old age psychiatry at the Royal College of Psychiatrists and an arena where change could potentially be achieved. Their enthusiasm is reflected by their regular attendance at meetings with few absences or apologies and by the distances some people were prepared to travel in order to take part in the Group.

The fourth theme of practical difficulties with social services was not directly acted on, as social services professionals were not involved in the Group, although the need to have a holistic approach was acknowledged and, by acknowledging the theme, the professionals involved were made aware of its importance to families.

Dealing with the fifth theme (the emotional experiences of carers) proved to be more difficult as there was a working agenda of issues within the psychiatry of old age to occupy Group meetings, and the Group's agreed remit did not include support to users and/or carers. Recognition of the need for support had been part of the rationale behind the suggestion of writing narratives and the professional members of the Group hoped that writing narratives would itself be of some support to the carers involved. Furthermore they hoped that by identifying themes which could influence the Group's work and the work of the Faculty, carers would be able to help others learn from their experiences and that this in itself would be a positive experience for them. Narratives are known to offer a method for addressing existential qualities such as inner hurt, despair, hope, grief and moral pain which frequently accompany and may even constitute people's illnesses (Greenhalgh and Hurwitz, 1999). Our fifth theme well illustrated this aspect of narratives and alerted us to our carers' health and a need in some instances to try to bring peaceful resolution to the grieving process. Grief is a time to ask questions, and if answers are not found grief may be prolonged.

A main aim of good dementia care is to help people with a dementia and their families to enjoy life as much as possible while living through their illness. Losses may be mourned, but the ability to enjoy day-to-day activities, contact with friends and relatives, and to retain hope is part of life itself, and may be retained throughout the illness. This is clearly shown by the major debate in 1995 about the quality of De Kooning's paintings. The

conclusion was that De Kooning might not recover from his forgetting but he could live serenely within it (Shenk, 2001). Even if at times he confused his wife with his sister, De Kooning went on to create. His resurgence is a testimony to the potential of the human mind, and evidence for hope (Espinell, 1996). Espinell (2007) goes on to identify, in his later work, a syndrome called "creating in the midst of dementia" which may give further hope for dementia sufferers and their carers. We were disappointed that hope was not an emotion that was mentioned in these narratives. We anticipate that by using this, and similar information in teaching students about dementia care, we may improve the quality of dementia care, and increase users' and carers' hope.

Different meanings are associated with a dementing illness in a spouse or in a parent. Anthony-Bergstone *et al.* (1988) found an increase in hostility and anxiety in female carers, but an increase in depression only in wives. Balint's method of analysis would allow us further detailed analysis and information also of social perspectives on the differences between spouse carers and daughters along the lines of published work (Kirsi *et al.*, 2004; Ward-Griffin and Bol, 2007). It would also allow an exploration of concepts of the different kinds of grief (Garner, 1997). We were privileged to have this information but decided to focus on the main themes of the role of narratives in a Consumer Group.

This was not a Balint group but it had some resonances with his ideas. He wished to promote the psychological dimension of medical education. He wrote of the physician's role in organizing the illness through doctors' interventions (Balint, 1955). In this case the carers' experience was organized into themes and priority given to experience over theoretical abstractions. Balint wrote that his groups for doctors allowed a better understanding of the doctor-patient relationship. In this case, the Faculty officers were able to reflect on their role in similar situations to those described in the narratives.

The value of narratives for carers lies in helping them make sense of the experiences they have been through and in sharing those experiences in such a way that they might be able to influence others, whether users and carers, by sharing their wisdom/difficulties/solutions, etc, or professionals, by confronting them with the realities of care. The value of narratives for professionals lies in helping them to learn more about the impact of caring on families and the sobering reality of using health and social care services. Haeney *et al.* (2007) recently described how service users can be involved in psychiatric training. Tew *et al.* (2004) have looked at the involvement of users and carers

in education and stress that they offer distinct but complementary perspectives. Narratives are one way of involving carers (and users) in teaching, training and continuing professional education. Benbow and colleagues (2008) have described the powerful impact on students of involving a user in multi-professional postgraduate education and the user herself describes how she approached the teaching by talking openly about her own experiences. The work has been taken further with the development of a module at Staffordshire University dedicated to the experiences of users and carers in older people's mental health settings (Benbow and Boyce, 2008).

One of the greatest values of narratives for professionals may lie in identifying gaps and difficulties in service provision. It is important that users and carers have opportunities for their experiences to influence services and service providers. The use of "patient journey" or "carer journey" methodology is one way of doing this and has been helpful to members of the West Midlands Older People's Mental Health Collaborative in identifying areas for service improvement work (Doherty *et al.*, 2008).

In conclusion, the impact of narratives in this setting is similar to that of narratives used in other settings as a therapeutic tool. By writing these narratives, our carers confirmed their strong relationship with the Consumer Group, which they hope provides an opportunity to influence changes in dementia care.

Conflict of interest

None.

Description of authors' roles

All authors were involved in study design, discussion and contributed to writing up. Dr. Ong took a lead in analyzing the narratives.

Acknowledgments

The authors wish to thank all the members of the Consumer Group for their contributions to the discussions on the themes described here and, in particular, the carers who generously shared their experiences by writing their narratives. The authors confirm that all carers who submitted narratives have seen a draft version of this paper and gave their written consent to publication.

References

- Anderson, H. (2007). A postmodern umbrella: language and knowledge as relational and generative, and inherently transforming. In H. Anderson and D. Gehart (eds.), *Collaborative Therapy: Relationships and Conversations that Make a Difference* (pp. 7–19). London: Routledge.
- Anthony-Bergstone, C. R., Zarit, S. H. and Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementing patients. *Psychology and Ageing*, 3, 245–248.
- Balint, E., Courtenay, M., Elder, A., Hull, S. and Julian, P. (1993). *The Doctor, the Patient and the Group: Balint Revisited*. London: Routledge.
- Balint, M. (1955). The doctor, his patient and the illness. *Lancet*, 1, 683–688.
- Benbow, S. M. and Boyce, W. (2008). *In Our Shoes: A User and Carer Led Teaching Module*. Centre for Ageing & Mental Health, Staffordshire University. Available at www.staffs.ac.uk/schools/health/ihm/camh/WMOPMHC/IOS/ReportJuly2008.pdf.
- Benbow, S. M., Taylor, L. and Morgan, K. (2008). Multiple perspectives: involving users and carers in educating health and social care professionals. *Quality in Ageing*, 9(2), 12–17.
- Doherty, D., Benbow, S. M., Craig, J. and Smith, C. (2008). Patients' and carers' journeys through older people's mental health services: powerful tools for learning. *Dementia*, in press.
- Espinel, C. H. (1996). De Kooning's late colours and forms: dementia, creativity and the healing power of art. *Lancet*, 347, 1096–1098.
- Espinel, C. H. (2007). Memory and the creation of art: the syndrome, as in de Kooning, of "creating in the midst of dementia". *Frontiers of Neurology and Neuroscience*, 22, 150–168.
- Frank, A. W. (1998). Just listening: narratives and deep illness. *Families, Systems and Health*, 16, 197–212.
- Galvin, K., Todres, L. and Richardson, M. (2005). The intimate mediator: a carer's experience of Alzheimer's. *Scandinavian Journal of Caring Sciences*, 19, 2–11.
- Gardner, K. (2002). *Age, Narrative and Migration*. Oxford: Berg.
- Garner, J. (1997). Dementia: an intimate death. *British Journal of Medical Psychology*, 70, 177–184.
- Garner, J. (2004). Dementia. In S. Evans and J. Garner (eds.), *Talking over the Years: A Handbook of Dynamic Psychotherapy with Older Adults* (pp. 215–230). London: Brunner Routledge.
- Greenhalgh, T. and Hurwitz, B. (1998). *Narrative-Based Medicine: Dialogue and Discourse in Clinical Practice*. London: BMJ Books.
- Greenhalgh, T. and Hurwitz, B. (1999). Why study narrative? *BMJ*, 318, 48–51.
- Haeney, O., Moholkar, R., Taylor, N. and Harrison, T. (2007). Service user involvement in psychiatric training: a practical perspective. *Psychiatric Bulletin*, 31, 312–314. DOI: 10.1192/pb.bp.106.013714.
- Kirsi, T., Hervonen, A. and Jylha, M. (2004). Always one step behind: husbands' narratives about taking care of their demented wives. *Health Education Journal*, 8, 159–181.
- Launer, J. (2002). *Narrative-based Primary Care: A Practical Guide*. Abingdon: Radcliffe Medical Press Ltd.

- Mumby, D. K. (ed.)** (1993). *Narrative and Social Control: Critical Perspectives*. Newbury Park, CA: Sage.
- Ong, Y. L., Benbow, S. M., Black, S. and Garner, J.** (2007). Reflections on experience of involving users and carers in the work of the Faculty of Old Age Psychiatry. *Quality in Ageing*, 8, 45–49.
- Shenk, D.** (2001). *The Forgetting. Alzheimer's: Portrait of an Epidemic*. New York: Doubleday.
- Tew, J., Gell, C. and Foster, S.** (2004). *Learning from Experience. Involving Service Users and Carers in Mental Health Education and Training. A Good Practice Guide*. Available at <http://www.mhhe.ltsn.soton.ac.uk/docs/lifeguide/Learningfromexperience.pdf>
- Wallang, P.** (2006). The use of literary analysis in advanced communication. *Psychiatric Bulletin*, 30, 432–434.
- Ward-Griffin, C. and Bol, N.** (2007). Mother-daughter relationship within Alzheimer's disease: daughters' perspectives. In I. Paoletti (ed.), *Family Caregiving for Older Disabled People: Relational and Institutional Issues*. New York: Nova Science Publishing.

NOTE: This publication is the copyright of Cambridge University Press.

International Psychogeriatrics online is available at

<http://journals.cambridge.org/action/displayJournal?jid=IPG>

Publication 12.

Doherty, D. Benbow, S.M., Craig, J. & Smith, C. (2009). Patients' and carers' journeys through older people's mental health services: powerful tools for learning. *Dementia*. 8 (4) p. 501-513.

ARTICLE

Patients' and carers' journeys through older people's mental health services

Powerful tools for learning



DONNA DOHERTY *Staffordshire University and West Midlands
Older People's Mental Health Collaborative, UK*

SUSAN MARY BENBOW *Staffordshire University and West
Midlands Older People's Mental
Health Collaborative, UK*

JULIE CRAIG *Wolverhampton City Council Adults & Community, UK*

CAROL SMITH *Wolverhampton City Council Adults &
Community, UK*

Abstract Mapping the patient journey is a way of investigating the experiences of people using older people's mental health services, particularly those with a dementia. It is a useful concept for patients and their families and enables them to tell their stories in a way which carries the potential for improving and developing the service. Similarly it is a useful concept for health and social care professionals in giving them the opportunity to understand, and reflect on, how their services work in practice for users and carers and how they might be improved. The collaboration between patients, carers and professionals may itself bring about broader benefits and changes in culture for the individuals and services involved. The West Midlands Older People's Mental Health Collaborative has encouraged the use of mapping by Collaborative teams in order to identify areas for improvement work.

Keywords care pathway; patient journey; process mapping; older people's mental health; user and carer involvement

The population is ageing, and the proportion of older people living with a long-term illness or disability increases with age (Office for National Statistics, 2005). Increasing numbers of people are living in the community with illnesses which impact on their everyday lives, and with predicted

DEMENTIA 8(4)

demographic changes this will increase further over the coming years (Toofany, 2008). Within older people's mental health services, dementia is an example of a progressive life-changing illness: however, other illnesses, which may be less commonly associated with later life, for example, recurrent depressive illness, or schizophrenia, also impact powerfully on the people living with them and their families (Age Concern England, 2007).

There is growing interest in patients' and carers' stories (narratives). These stories have several potential roles:

- They can be valuable to users and carers in helping them share and make sense of their experiences;
- They can be powerful tools in educating staff working in health and social care (Bleakley, 2005);
- They can be used as a way of analysing health and social care services provided in an attempt to improve and develop both the services and the ways in which the staff work within them (Blickem & Priyadharshini, 2007).

Context: Stories, narratives, journeys

There are different ways of investigating the experiences of patients and their families. Divinsky (2007) writes that 'stories offer insight, understanding and new perspectives', and argues that they can help people see different ways of doing things. She goes further in arguing that narrative medicine carries the potential for ameliorating the burnout, exhaustion and disillusionment of healthcare staff, by preserving, or even teaching, empathy. Charon (2007) argues that narrative training enables students to form stronger therapeutic alliances with patients and to have greater understanding of patients' and others' perspectives.

Wilcock, Brown, Bateson, Carver and Machin (2003) describe a process for listening to patients and carers and interpreting their experiences in order to improve care (the Discovery Interview Process): their focus is on local quality improvement projects. A similar concept is mapping the patient journey (Cayton, 2004): a way of looking at a person's experiences over time.

When someone first develops symptoms of what proves to be a dementia, they, and their families, start on a journey which only ends when they die. There is a growing realization that the journey itself is as important as the beginning (first symptoms, recognizing there is a problem, seeking help, getting a diagnosis) and reaching the end (death): quality of life is at least as important as the length of life (Lapsley & Groves, 2004). A series of policy documents and reports over the last few years have

highlighted the need to provide easy access to services, an early diagnosis, and to manage the transition from the uncertainties of mild cognitive impairment and changes in personhood through to the losses that dementia brings (Audit Commission, 2002; Department of Health, 2009; Woods et al., 2003).

Patients' stories or narratives have attracted increasing interest over recent years (Frank, 1998; Greenhalgh & Hurwitz, 1998) and can be a potent learning tool (Benbow, Taylor, & Morgan, 2008). They are known to offer a way to make sense of the strong emotions which may accompany a chronic illness (Greenhalgh & Hurwitz, 1999). One way of structuring a patient's narrative and using it in analysing and developing services is to use process mapping (NHS Institute for Innovation and Improvement, 2008).

Process mapping can be a useful diagnostic tool for examining how a service is functioning and where problems are occurring, and also a helpful tool for individual patients, carers and professionals. We describe the uses of patient/carer journey mapping from the perspective of an older people's mental health collaborative in the West Midlands using dementia as an example of a chronic progressive illness.

Is the patient journey a useful concept for patients and their families?

For many patients and their families the illness journey is a new experience, through uncharted territory – there is no A-Z or road atlas; Koppel and Dallos (2007) have described it as a journey into the unknown. From diagnosis, through treatment and to the end of life, the path is often not easy, and may be seen as a journey of epic proportions by those facing it. No-one can predict the twists and turns of the journey or how long it will last. Fernandez, Cortes and Tarragona (2007) offered a useful metaphor when they described their learning journey poignantly as 'making the path as [they] walked', translated from Antonio Machado as follows:

Traveller, there is no path
You make the path as you walk.

Some people are experts in their illness, others aren't and some people don't want to be an expert in their condition (Shaw & Baker, 2004). Despite this, the experience, life skills, coping styles, family supports and expertise that patients and carers have is valuable to understanding their views and situation, and influences their journey. They may well be relying on health and social care professionals to provide them with information about the route, and support as they move along it (Woods et al., 2003).

DEMENTIA 8(4)

The process of mapping their journey can give patients and their families the opportunity to tell their stories, to make sense of their experiences, and to reflect on what has happened to them in the company of family and supportive professionals (Dartington, 2007). In addition, knowing that they have contributed to identifying ways in which professionals and health/social care organizations can improve their services can be worthwhile outcomes for all concerned. It involves service users and carers becoming more than passive receivers of care (Calnan, 1997).

Is the patient journey a useful concept for professionals?

With a complex disease process such as a dementia, there is clearly no single patient journey, although the concept of an ideal journey is seductive. Ideas of the 'ideal' journey differ between healthcare professionals, people with dementia and their carers (Woods et al., 2003). The majority of literature available that provides examples of the patient journey, or what Aronson calls 'autopathography', fails to discuss dementia at all (Aronson, 2000). Mapping their journey with a patient or their family can give information about that person's experiences which may, in turn, give useful information about how the services they have been using have worked well, have failed them, or have been sorely lacking. Understanding the process from patients' and carers' perspectives is essential if the patient's journey is to be well managed by the professionals working with them and the organizations involved (Lapsley & Groves, 2004). Potentially this information can also be used in service development and improvement; it is in any case essential feedback for service providers and their commissioners and lets those who deliver (and commission) a service understand the journey from the patients' and carers' perspective (Scottish Government, 2009).

Process mapping as a useful tool along the journey

There are many different sources of information to help to map the journey, and which sources are selected will depend to some extent on what the intended outcomes of the process are. Potential sources include:

- looking through records;
- physically following a person's journey;
- interviewing the person;
- interviewing their carer;
- getting views and information from key personnel;
- getting all staff involved in the journey together (NHS Institute for Innovation and Improvement, 2008).

DOHERTY ET AL.: PATIENTS' AND CARERS' JOURNEYS

The West Midlands Older People's Mental Health Collaborative has encouraged members to carry out mapping in conversation with patients and/or their carers in order to investigate how their services are operating, consider what could be done to improve the experience for both patients and carers and look at what actions project teams might concentrate their improvement efforts on. This has been done in various ways, from formal and structured to an informal facilitated conversation. It is helpful to consider different ways of setting up the mapping exercise. Questions to consider (NHS Modernisation Agency, 2002; NHS Institute for Innovation and Improvement, 2008) include the following:

- Where should the mapping be carried out? The process needs careful planning and management with involvement of the whole team needed.
- How might the environment facilitate or constrain the conversation? Process mapping and recreating the patient journey needs to happen in a situation and environment such as an 'away day' or series of events to allow the team to focus without distractions and be productive. Some individuals may also need to work alone or in small groups depending on their role and needs.
- How do we help patients and carers to feel at ease? Examining practice and process is not complicated, but it needs to be viewed from the patient's and carer's perspective, rather than from a professional's viewpoint. The involvement of service users and carers during the process is vital, as is listening to their views on service provision and delivery.
- Who should be present and how will they affect the mapping process? Involving a cross section of relevant professions and disciplines from grass roots level is important. A range of service users and carers from all cultures is also necessary to ensure a broad range of experiences and journeys.
- How long should the process take: would it be better carried out in several interviews/sessions? The length of time taken will depend on the wishes of those involved, the needs of the service and the journeys being mapped: more than one session will ensure that mapping is comprehensive and inclusive.
- How will the journey be captured/recorded? Having an idea of where the journey starts and ends is useful, although patients and carers may have their own views on this. Flip charts, post it notes and a roll of wallpaper or similar are good ways of capturing ideas and mapping the journey. Journeys need to be mapped before a preliminary action plan can be created.

DEMENTIA 8(4)

- Who needs to be involved in order that actions can result? Project leaders and change agents need to be respected managerial or clinical staff who can facilitate, support and lead the process. Sponsors are those individuals who sanction the mapping event and ensuing action plan: they ultimately create an environment that allows change to happen. Champions are respected clinical staff who believe in the process, influence and reach those who are not so keen on change and contribute expertise and experience.
- How will any outcomes be communicated to the patients and carers? It is vital to think about involving service users and carers all the way through the process. Each process mapping team will need to identify the best and most effective ways to feedback to all involved and ensure that feedback takes place.

There are two phases to process mapping. Phase 1 involves understanding what happens to the patient, where it happens and who is involved, by constructing a map of the process. The process map is then examined to assess where problems with service design and delivery may be occurring (NHS Improvement Network East Midlands, 2008a; NHS Improvement Network East Midlands, 2008b). Initially the best way to process map is to do a quick mapping exercise with essential staff choosing clearly defined start and end points. There is an argument in favour of concentrating on 'high volume runner groups' (see Table 1 for explanation of terms) which are the most commonly presenting conditions with a higher number of patients who share common characteristics (NHS Institute for Innovation and Improvement, 2008) but services must be able to accommodate all those who use them and it is possible to learn from the experiences of any users. Patients and their carers are fundamental to the whole process. Once the process is mapped, taking into account hand-offs, multiple staff involvement, changes in location, loops and parallel processes, the journey must be 'walked' (see Table 1).

Mapping one patient journey is a useful exercise. However, mapping a number of patient journeys provides much more information and more clues about how a service operates and how it could be developed (Scottish Government, 2009). The literature suggests that looking at a group of new referrals as they come in is a useful tool. This will involve examining where referrals are coming from, what happens to them when they arrive and how long the process takes (Scottish Government, 2009).

Analysing the process map

Once the journey is mapped there are a number of questions that need to be asked by the process mapping team (NHS Modernisation Agency, 2002;

DOHERTY ET AL.: PATIENTS' AND CARERS' JOURNEYS

Table 1 Definition of terms used in the text (from NHS Modernisation Agency, 2002)

Term	Definition
High volume runner groups	Patient groups who present with the same issues/problems in large numbers whose appearance is predictable on any given day, week or month. Their care could be standardized based on good evidence based practice. Their care could also be relatively quick if the waits and delays were removed from the system. Their care could also be mainly pre-scheduled.
Hand-off	When the patient is passed on from one healthcare professional to another.
Multiple staff involvement	One patient may see multiple healthcare professionals in multiple locations throughout any one journey.
Loops and parallel processes	Different activities that take place in the same time period.
Backlog	Previous demand on services that has not yet been dealt with, showing itself as a queue or a waiting list.
Bottleneck	Part of the system where patient flow is obstructed.

NHS Improvement Network East Midlands, 2008a; NHS Improvement Network East Midlands, 2008b):

- How many times is the patient passed from one person to another ('hand-off')? Are these all necessary?
- Where are delays, queues and waiting periods built into the process? How could they be minimized? How could an organization cut waiting times and improve delays in appointments or treatment?
- Where are the bottlenecks? How can they be cut out or bypassed? Where is there a high demand on a service? Asking the question 'why' is essential to gather the information to improve services.
- What are the longest delays? How can they be avoided?
- What is the approximate time taken for each step ('task time')?
- What is the approximate time between each step ('wait time')?
- What is the approximate time between the first and last step?
- How many steps are there for the patient? The team needs to examine where patients join a queue or a waiting list and why.
- Are there things that are done more than once? Is this necessary? This could include tests and examinations.
- Look for 'rework loops' where activities are taken to correct situations that could be avoided. Processes that reproduce or duplicate work are unnecessary and create bottlenecks and delays for patients and their carers. Looking for ways to reduce these offers the potential for service improvement and making the patient's journey easier.

DEMENTIA 8(4)

- Is work being batched? If work is being allowed to accumulate it may lead to a lack of person-centred care as the task is the focus rather than the individual, leading to delays and increased waiting times.
- Where and what are the problems for the patients?
- Where and what are the problems for carers?
- At each step is the necessary action being undertaken by the most appropriate staff member?
- Where and what are the problems for staff?
- Finally, teams must ask themselves if the patient and carer are getting the most efficient care at the most appropriate time in the right place. Throughout this exercise the process must remain blame free!

Patient journeys

Below we outline two patient journeys as described by the nearest relatives of the two patients, both of whom had a dementia.

Mr A

Mr A's daughter first noticed changes in his memory, but this was overshadowed by her mother's terminal illness. Her father's behaviour was unusually negative, with arguments. He was visited by his GP who treated his physical health problems and ignored the concerns about Mr A's mental health, indicating it was due to a clash in personalities. When Mr A was knocked down by a car and suffered a fractured hip, the ward nurses did not appear to understand his needs and his daughter was repeatedly asked to visit her dad as he was being abusive to them. This created difficulties for her work, as she had to take time off. When he was discharged, Mr A left hospital with no follow-up support. A further visit was made to his GP who referred Mr A back to the Accident & Emergency department from which he was readmitted to the general hospital. An old age psychiatrist was asked to see him there and made a diagnosis of Alzheimer's disease. His daughter was given a contact number to call if needed and on discharge Haloperidol was prescribed. Again there was no arrangement for follow-up or post-discharge support.

Mr A's daughter contacted the local social work team to ask for help and a social worker was allocated, but only gave information relating to financial support which she found to be unhelpful. Describing her father's journey she could not recall how the Community Mental Health Team became involved in his care, but she felt the assessment had been more like a social chat than a formal assessment. By this time her father was becoming disorientated and getting lost on occasions. When he was beaten

DOHERTY ET AL.: PATIENTS' AND CARERS' JOURNEYS

up the police were unhelpful, giving the impression that the case was unproductive and just led to more paperwork having to be completed. She wrote to the social worker expressing concern and asking for support, as the only alternative she could see would be to send her father to live with a relative abroad. The social worker suggested that Mr A should move to residential care, but his daughter felt she was not ready for this yet and requested assistance during the night time period. She described how the social worker asked, 'who will pay for this', and she felt that the social worker was implying she could be accused of negligence if she declined the option of residential care. A CPN became involved again and arranged an emergency placement at a local Resource Centre followed by day care. Problems continued: the timing of transport varied between 8.30–10.00 a.m. and Mr A's daughter needed to plan her work schedule. On one occasion Mr A was dropped off when there was no-one in the house. The only option appeared to be to use a taxi. Mr A then started on regular periods of respite in a local Home.

Mrs B

At the age of 75 her closest relative noticed that Mrs B was becoming forgetful and repetitive in conversation, repeatedly asking for the day and the time. She also started to leave taps on in the house and to wander out of the house during the night. When she wandered out at night, the neighbours were helpful: they took her in and contacted the police, who were also friendly and very helpful. Her relative took Mrs B to see her GP who advised that nothing was wrong. A social worker became involved and supported the family in asking the GP to take Mrs B's problems seriously. Mrs B was referred to a specialist and eventually had a brain scan. The whole process took 12 months. A CPN became involved and the family was advised that the memory difficulties were the result of old age. Problems continued and Mrs B was later referred to an old age psychiatrist and attended a local Memory Clinic. There her memory was formally assessed over a 3 month period because her scores were varying. The assessment concluded that she had Alzheimer's disease and she was offered treatment with an anti-dementia drug.

Action points from the patient journeys

When staff reflected on the journeys described by these two relatives (and others) they identified a series of action points, including the following:

- It would be helpful to identify a key worker for each service user and their family.

DEMENTIA 8(4)

- Information available to patients and carers should be reviewed along with how and when it is made available to them. Information packs might be helpful but would need to be tailored to the family's needs.
- Direct Payments had never been considered with any of the carers involved and the staff have therefore requested teaching for the team about direct payments.
- Night services are almost non-existent in the locality involved and this is something which the managers are raising at a higher level.
- Transport to day care is not flexible enough to meet the needs of working relatives: possibilities for introducing flexibility (e.g. using volunteer drivers in association with a local voluntary organization) are being explored.
- Carers had not been given information about Power of Attorney – this is being addressed as part of the information review.
- Families from BME communities did not feel that their cultural needs had been met. The issue of employing BME workers is being raised with managers at a higher level in the organization.

Conclusions

Mapping the patient journey offers a way that health and social care professionals (and the organizations they work for) can learn from the people using their services and can generate valuable information for improving the services offered. The methodology fits in with current policy initiatives (e.g. greater patient choice [Department of Health, 2006]; patient and public involvement [House of Commons Health Committee, 2007]; healthy active democracy [Andersson, Tritter, & Wilson, 2006]) and links in with work on developing care pathways and integrated care (Care Services Improvement Partnership, 2005).

In addition, patient journey mapping engages users and their families with local organizations in a collaborative endeavour to develop services more appropriate to local needs, and may even have wider benefits in altering the relationship between users, carers and those professionals working with them by showing the practical benefits which come from listening to users and carers and respecting their views.

Acknowledgements

The authors thank all those who have been involved in the patient journey work as part of the Collaborative, particularly the carers who generously and honestly shared their experiences.

References

- Age Concern England (2007). *Improving Services and support for older people with mental health problems*. London: Age Concern England, Policy Unit.
- Andersson, E., Titter, J., & Wilson, R. (Eds.) (2006). *Healthy Democracy: The future of involvement in health and social care*. Involve and NHS National Centre for Involvement. Retrieved March 29, 2008, from http://83.223.102.125/involve/new/rmt/archives/blog_37/Healthy_Democracy/Healthy_Democracy.pdf.
- Audit Commission (2002). *Integrated services for older people. Building a whole system approach in England*. London: Audit Commission.
- Aronson, J.K. (2000). Autopathography: The patient's tale. *British Medical Journal*, 321, 1599–602.
- Benbow, S.M., Taylor, L., & Morgan K (2008). Multiple perspectives: Involving users and carers in educating health and social care professionals. *Quality in Ageing*, 9(2), 12–17.
- Blickem, C., & Priyadharshini, E. (2007). Patient narratives: the potential for 'patient-centred' interprofessional learning? *Journal of Interprofessional Care*, 21(6), 619–632.
- Bleakley, A. (2005). Stories as data, data as stories: Making sense of narrative inquiry in clinical education. *Medical Education*, 39(5), 534–540.
- Calnan, M. (1997). Citizens, users and healthcare (Guest Editorial). *European Journal of Public Health*, 7(1), 1–2.
- Care Services Improvement Partnership (2005). *Everybody's Business. Integrated mental health services for older adults: A service development guide*. Retrieved October 1, 2009, from <http://www.mentalhealthequalities.org.uk/our-work/older-life/everybodys-business/?keywords=everybody%26%23039%3Bs+business>
- Cayton, H. (2004). Telling stories. Choices and challenges on the journey of dementia. *Dementia*, 3(1), 9–17.
- Charon, R. (2007). What to do with stories. The sciences of narrative medicine. *Canadian Family Physician*, 53, 1265–1267.
- Dartington, T. (2007). Two days in December. *Dementia*, 6(3), 327–341.
- Department of Health (2006). *Our health, our care, our say: A new direction for community services*. London: Department of Health. Retrieved October 9, 2009, from <http://www.dh.gov.uk/assetRoot/04/12/74/59/04127459.pdf>
- Department of Health (2009). *Living well with dementia: A National Dementia Strategy*. Retrieved September 29, 2009, from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058
- Divinsky, M. (2007). Stories for life. Introduction to narrative medicine. *Canadian Family Physician*, 53, 203–205.
- Fernandez, E., Cortes, A., & Tarragona, M. (2007). You make the path as you walk: Working collaboratively with people with eating disorders. In H. Anderson & D. Gehart (eds.), *Collaborative Therapy. Relationships and conversations that make a difference* (pp. 129–147). London: Routledge.
- Frank, A.W. (1998). Just Listening: Narratives and deep illness. *Families, Systems & Health*, 16, 197–212.
- Greenhalgh, T., & Hurwitz, B. (1998). *Narrative Based Medicine: Dialogue and discourse in clinical practice*. London: BMJ Books.
- Greenhalgh, T., & Hurwitz, B. (1999) Why study narrative? *British Medical Journal*, 318, 48–51.
- House of Commons Health Committee (2007). *Patient and Public Involvement in the NHS Third Report of Session 2006–07*. Retrieved March 29, 2008, from <http://www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/278i.pdf>.

DEMENTIA 8(4)

- Koppel, O.S.B., & Dallos, R. (2007). The development of memory difficulties. A journey into the unknown. *Dementia*, 6(2), 193–213.
- Lapsley, P., & Groves, T. (2004). The patient's journey: Travelling through life with a chronic illness. *British Medical Journal*, 329, 582–583.
- National Health Service (NHS) Improvement Network East Midlands (2008a). *Mapping the Existing Process*. Retrieved March 14, 2008, from <http://www.tin.nhs.uk/tools—techniques/process-mapping>.
- National Health Service (NHS) Improvement Network East Midlands (2008b). *More Information on Process Mapping*. Retrieved March 14, 2008, from <http://www.tin.nhs.uk/tools—techniques/process-mapping/more-information>.
- NHS Institute for Innovation and Improvement (2008). *A Conventional Model of Process Mapping*. Retrieved September 29, 2009, from http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/process_mapping—a_conventional_model.html
- NHS Modernisation Agency (2002). *Improvement Leaders' Guide to Process mapping, analysis and redesign*. Retrieved March 27, 2008, from <http://www.cancerimprovement.nhs.uk/documents/Publications%20from%20NHS%20Modernisation%20Agency/Process%20mapping.pdf>
- Office for National Statistics (2005). *Focus on Older People*. Available at http://www.statistics.gov.uk/downloads/theme_compedia/foop05/OlderPeopleOverview.pdf
- Scottish Government (2009). *Mental Health Collaborative Programme Toolkit*. Retrieved September 29, 2009, from <http://www.scotland.gov.uk/Resource/Doc/261001/0077874.pdf>
- Shaw, J., & Baker, M. (2004). 'Expert patient' – dream or nightmare? *British Medical Journal*, 328, 723–4.
- Toofany, S. (2008). How to promote a healthier tomorrow. *Nursing Older People*, 20(02), 17–20.
- Wilcock, P.M., Brown, G.C., Bateson, J., Carver, J., & Machin, S. (2003). Using patient stories to inspire quality improvement within the NHS Modernisation Agency collaborative programmes. *Journal of Clinical Nursing*, 12(3), 422–430.
- Woods, R.T., Moniz-Cook, E., Iliffe, S., Campion, P., Vernooij-Dassen, M., Zanetti, O., Franco, M., & INTERDEM (Early Detection and Intervention in Dementia) Group (2003). Dementia: Issues in early recognition and intervention in primary care. *Journal of the Royal Society of Medicine*, 96(7), 320–324.

Biographical notes

DONNA DOHERTY trained as RGN and RMN and worked in Dementia/Older Adult Care before entering academia. She has worked in nurse education since 2001, currently as Senior Lecturer at Staffordshire University where she works in pre-registration nurse education and also within the Centre for Ageing and Mental Health. Address: Faculty of Health, Staffordshire University, Blackheath Lane, Stafford, ST18 0AD, UK. [email: d.doherty@staffs.ac.uk]

SUSAN MARY BENBOW trained and later worked for a number of years in Manchester. She is currently an old age psychiatrist and family therapist in Wolverhampton, and Professor of Mental Health and Ageing at Staffordshire University based at the Centre for Ageing and Mental Health. Address: Centre for Ageing and Mental Health, Staffordshire University, Blackheath Lane, Stafford, ST18 0AD, UK. [email: drsmbenbow@aol.com]

DOHERTY ET AL.: PATIENTS' AND CARERS' JOURNEYS

JULIE CRAIG initially trained and commenced working within the social care field in Shropshire. She continued her mental health training and is currently Community Resource Manager at a resource centre for older people with mental health needs based in Wolverhampton. [email: Julie.Craig@wolverhampton.gov.uk]

CAROL SMITH trained in, and has worked in, the social care field for a number of years. She is currently Team Leader at a resource centre for older people with mental health needs based in Wolverhampton. [email: carol.smith@wolverhampton.gov.uk]

Publication 13.

Benbow, S.M. (2009). Older people, mental health and learning. *International Psychogeriatrics*. 21 (5) p. 799-804.

International Psychogeriatrics (2009), 21:5, 799–804 © 2009 International Psychogeriatric Association
doi:10.1017/S1044612009009053 Printed in the United Kingdom

GUEST EDITORIAL

Older people, mental health and learning

Context: population and political

The World Health Organization (2002) describes population aging as “one of humanity’s greatest triumphs” as well as “one of our greatest challenges.” Growth in the number of older people as a proportion of the total population (described as the graying of the world’s population) is a global phenomenon. With increasing age the causes of death and disease change: in early life communicable diseases, nutritional deficiencies and maternal/perinatal conditions are most important, but after midlife, chronic conditions assume increasing importance. Amongst the chronic conditions of later life, mental disorders feature prominently, the two most common being dementia and depression (Faculty of Old Age Psychiatry, 2006).

This demographic challenge, and the concerns about its political and economic implications (as well as social and health consequences), probably underlie increasing political interest in the U.K. in late life mental health, as illustrated by a series of high profile publications over recent years (Care Services Improvement Partnership, 2005; Office of the Deputy Prime Minister, 2006; Age Concern and The Mental Health Foundation, 2006; Age Concern, 2007; National Institute for Health and Clinical Excellence – Social Care Institute for Excellence (NICE-SCIE), 2007; National Audit Office, 2007; House of Commons Committee of Public Accounts, 2008). The report *Dementia UK* (Alzheimer’s Society, 2007) attracted a lot of interest and concern with its projections of the anticipated growth in numbers of people with dementia in the U.K. and detailed examination of the financial costs of dementia. Lowin *et al.* (2001) estimated the direct costs of Alzheimer’s disease in the U.K. to be greater than those of cancer, stroke and heart disease combined. The Department of Health has recently published a *National Dementia Strategy* for England (Department of Health, 2009).

Context: mental health in later life

Dementia becomes more prevalent with increasing age and, in broad figures, affects one person in 20 aged over 65 and one person in five aged over 80 (Hofman *et al.*, 1991). The Alzheimer’s Society

(www.alzheimers.org.uk) estimates that there are currently 700,000 people with dementia in the U.K. and that this will increase to 1 million by 2025. The most common forms of dementia are Alzheimer’s disease (62%) and vascular and mixed dementia (27%) (Alzheimer’s Society, 2007), but there are many other causes. Dementia can be viewed as a terminal illness and people will deteriorate until they need help with all the activities of daily living. There is no specific treatment for Alzheimer’s disease or vascular dementia, although drug treatments are available which are of benefit to some people (NICE, 2007).

Depression is a common mental health challenge in older people: around 15% of people aged over 65 have a depressive syndrome (European Commission, 2004). However, a much smaller proportion, about 2%, would meet criteria for a major depressive illness (European Commission, 2004). Depression is more common in care settings, including general hospitals (Wattis, 2008). Beeston (2006) points out that people over the age of 65 are more successful than any other age group in taking their own lives and about two-thirds of older people who kill themselves are depressed; despite this, the National Suicide Prevention Strategy for England (Department of Health, 2002) lacked a focus on older adults. In most Member States of the European Union suicide rates amongst older people are higher than in any other age group (Wahlbeck and Mäkinen, 2008).

Older people also present with a range of other disorders, including psychoses and substance misuse disorders (Hybels and Blazer, 2003).

What is learning?

Learning is the knowledge or skills acquired through study or by being taught. To learn is to be informed, to get to know, to gain knowledge, skill or ability. Learning can take many forms, including learning about health issues, such as the treatment and prevention of mental disorders. It is also the primary goal in an academic (i.e. formal or scholarly) sense, as in the case of the woman with recurrent depression following retirement who undertook a degree in Egyptology (personal communication), in the sense of developing new interests (for example, the man with recurrent depression in later life who enrolled on a computer course and the woman in

her 80s who took up classes in life drawing (personal communications)), and in developing existing skills (for example, the man who had enjoyed attending a gym over many years who was supported to continue despite developing progressive dementia (personal communication)). We can understand learning as a process (McNamee, 2007) where knowledge is not a package transferred from one person to another but instead emerges from the interaction between the people involved. Teaching is also learning, as it is a process by which ideas evolve over time through the interactions between "teacher" and students. Taking a systems perspective this learning or teaching process will impact on other roles and relationships which the learner or teacher undertakes. Involvement in learning will alter how individuals see themselves and how others see them.

The role of learning

Age Concern (2008a) identifies six roles for learning:

- maintaining mental and physical health
- pursuing interests and broadening horizons
- improving self-confidence
- gaining life skills
- reducing isolation, and
- contributing to the community.

These offer a useful framework. What evidence is there that engaging in learning activities enhances mental health in older adults? The World Health Organization (WHO) states that education in early life, combined with opportunities to engage in life-long learning can help people to develop the confidence and skills that will help them to adapt and remain independent as they grow older (WHO, 2002). Davey (2002) argues that lifelong learning assists the transition to retirement and later life. Glanz and Neikrug (1997) advocate that learning in later life should be regarded not as "leisure-time consumer activity" but as "social investment," since it encourages creativity, personal development and intellectual growth as well as combating ageism. Thus, older adults' learning can contribute to the life of the community as a whole: for example, a woman with recurrent anxiety and depression post-retirement undertook a course in food hygiene so that someone at her local community center was qualified and its work could continue (personal communication). Orte *et al.* (2007) maintain that education plays a fundamental role in quality of life and therefore fulfils a health-related function. Similarly, Schneider (2003) views learning as resulting in health-related behaviors:

"learning can compensate for aging." Duay and Bryan (2006) state that learning is a coping strategy which helps people cope with stress and major events/transitions, and these may be related to physical and/or mental health. The National Service Framework Mental Health (Department of Health, 1999) stresses the role of education in mental health promotion and social inclusion, and the Social Exclusion Unit Report (Office of the Deputy Prime Minister, 2004) highlights the need for people with mental health problems to be able to access education.

One possible obstacle to engaging older adults with mental disorders in learning might be the prejudice amongst people of all ages that learning/curiosity/enquiry is for the young (or perhaps for those who will use their skills in paid employment). Attitudes to learning and involvement in learning are likely to differ between generations and the older people of today may have grown up at a time when there was an emphasis on earning ability and duty in a setting of more rigid gender roles and less career flexibility.

Aspects of learning

In relation to older people's mental health, the benefits of learning can be considered in three main areas:

1. Practical: developing life skills/adjusting to illness
2. Psychological: maintaining/developing self-confidence and setting personal goals
3. Social: social contact, avoiding isolation and engaging with the community.

Practical aspects of learning

Learning about an illness (physical or mental) or about how to maintain health and avoid illness is an important practical area, but practical aspects may involve learning new skills (including problem-solving skills), developing existing skills or acquiring knowledge not related to health/illness. One example is adjusting to or preparing for retirement. Retirement can be a loss event which may precipitate depressive illness (Pitt, 1998), so preparation/adjustment may prevent depression or, when an individual has already developed depression, addressing the transition to retirement might be part of treatment and relapse prevention. Practical skills learned may impact beneficially on other areas; for example, learning computer skills may impact socially by enabling elders whose mobility is limited to keep in contact with members of their families electronically or to make new social contacts. Learning has been regarded as a coping strategy (Duay and Bryan, 2006) in helping

people deal with stress and helping them cope with major events and transitions (which would include retirement, major health challenges and bereavements). It can enable people to develop new skills which may compensate for some of the changes that come with aging; for example, learning electronic means of communication can enable people who are less mobile in later life to continue to keep in touch with existing family and friends, to make new friends, to access intellectual stimulation, and to contribute to the community; alternatively learning to drive may be another way to compensate for reduced mobility.

Case example (personal communication): a Gujarati-speaking woman with diabetes became unwell after failing to comply with her treatment. Despite mild memory problems related to cerebrovascular disease, she was helped to understand her treatment by repeatedly watching a video about diabetes with care staff in the home where she was in respite care.

Psychological aspects of learning

Learning can enhance self-esteem, self-efficacy and self-confidence (Mehrotra, 2003; Richeson *et al.*, 2007). It may increase motivation – for example, if it is enjoyable it will reinforce a person's desire to engage in further learning – and it encourages personal and intellectual growth (Glanz and Neikrug, 1997). Davey (2002) studied older adults undertaking university courses and found that they were more likely to study interest-based subjects and to have personal development as a goal. Engagement in learning may well involve a person in examining and redefining their concept of self. Learning offers a means of helping individuals develop new goals for the future and may also involve them in developing new roles and adjusting existing roles: this links with social aspects as it will affect not only how they see themselves but also how other people see them.

Case example: a woman with Alzheimer's disease became involved in developing a university teaching program (Benbow *et al.*, 2008) and delivered some teaching to the students, which was rated far more highly than the teaching of university staff. She later talked movingly about how this had brought some good out of her illness. She recognizes that her involvement impacted on a range of professional staff, but has also altered her family's view of her and her own view of herself.

Social aspects of learning

Involvement in learning activities may broaden an individual's social network and enrich existing social interactions, for example at a simple level by giving

people more conversational topics which will itself be socially reinforcing. It may also allow people to contribute to their communities; this potentially reinforces the psychological benefits of learning by impacting on an individual's self-esteem.

Case example (personal communication): the daughter of a depressed and socially isolated elderly woman said that she dreaded visiting her mum as she never had anything to talk about. After her mum started to go to a day center, where she developed an interest in artwork, her daughter reported that she found their time together more enjoyable as her mum talked about her new interest.

An example of all three aspects of learning is Peter aka geriatric1927 who is a serial YouTube blogger and has his own website (<http://www.askgeriatric.com>). He is a member of the internationally known band and social experiment The Zimmers, and is involved in silversurferadvocates.co.uk. He writes on the web that this is

"what this project is all about... to get the message out there of the joys of computing and pointing out all of the benefits. And let's not forget, apart from the pleasures, there are health benefits that accrue when the mind as well as the body is used and stretched."

He notes the practical difficulties of learning how to use a computer and learning what you can do with a computer. In an interview on YouTube he talks about the social benefits, about the community he has discovered through YouTube, "individual friends... people you become attached to... people come to visit." His ability to use his computer has given him a new sense of purpose and a desire to communicate with the online community. His 48,000+ subscribers and 2.2 million hits (as of 5 September 2008) testify to the fact that the community is listening, and, in the exchange, both parties are learning.

Application of learning to older adults' mental health

These three aspects of learning can be related to:

- the prevention of illness (health promotion),
- the treatment of illness,
- the prevention of relapse/promotion of mental health amongst people with ongoing mental health problems.

Prevention of illness (health promotion)

Learning about illness and the effect of a healthy lifestyle should have a beneficial impact on future health. With regard to depressive illness in later life, Age Concern (2008b) has recently published

a report which argues that education programs are needed that are aimed at older people and their families so that they know how to recognize and treat depression.

Involvement in other learning opportunities may involve people in being more active physically which will impact on their physical and mental health. If they make more social contacts it might reduce social isolation and loneliness: this may increase the likelihood of having close confiding relationships and a supportive social network with resulting benefits to mental health (Himmerson *et al.*, 1989; Turvey *et al.*, 2002). Alongside these benefits, a re-evaluation of the individual's role in late life may increase their psychological resilience. These impacts acting together may be able to protect against depressive disorders.

The European Commission Consensus paper on *Mental Health in Older People* (Jané-Llopis and Gabilondo, 2008) notes that there is evidence that involvement in meaningful activities (of various sorts) has been shown to improve the mental health of older people and contributes to well-being in later life, as do exercise and measures which maintain older adults' engagement with the community.

There is increasing evidence that the risk of dementia in later life may be minimized by maintaining physical and social activity and intervening earlier in life to modify major risk factors including hypertension, smoking, high blood cholesterol levels, and diabetes mellitus. Fratiglioni *et al.* (2007) note that people with less education are at higher risk of developing dementia and argue that intellectual stimulation protects against dementia. They regard an active life for older people (including mentally, socially and physically stimulating activities) as an important strategy in dementia prevention.

Learning could therefore play a potential role in prevention of both dementia and depressive disorder in later life and the promotion of mental (and physical) well-being.

Treatment of mental disorder

Moniz-Cook (2006) wrote about mental activity (or "mental exercise") as a psychological therapy for dementia but notes that there is confusion about what this might mean. She describes a broad range of activities that might come under this heading. The *National Service Framework for Older People* (Department of Health, 2001) recommends that the treatment of dementia "always involves" non-drug treatments such as mental exercise. Engagement in learning opportunities could constitute "mental exercise."

Richeson *et al.* (2007) reported an interesting study of a small group of people with early dementia who were offered a 13-week adult education class on health promotion. They found that it influenced measures of self-efficacy, mood and mental status and that the people concerned were interested in learning, growing and making connections despite their illness.

Dijkstra *et al.* (2006) demonstrated that people with dementia (with Mini-mental State Examination scores of 11–23, mean 17.8) could successfully teach students how to prepare recipes. They suggest that such success may impact on quality of life and feelings of self-worth as well as contributing to more rewarding social interactions. This is an illustration of older people (with dementia) as an untapped source of knowledge: tapping into that knowledge benefits both the older adults (who discover that they have unsuspected talents and wisdom) and the people who learn from them. Similarly Phinney *et al.* (2007) found that meaningful activities contribute to maintaining autonomy and personal identity amongst people with mild to moderate dementia.

These findings raise the question of whether engagement in learning/teaching could form part of dementia treatment in the future.

Simone and Haas (2007) investigated the influence of learning on mood amongst a group of older students attending classes at a university lifelong learning institute and found an improvement in mood at the end of the class. Although this study was open and uncontrolled it raises another interesting issue relevant to depressive illness: if mood improves following a learning experience in non-depressed older adults, might the same benefit occur in older adults with depression?

Prevention of relapse

Depressive illness in late life tends to be a relapsing disorder and the arguments regarding the role of learning in health promotion are equally applicable to the prevention of future episodes in someone with a history of depressive illness in late life. Similarly health promotion in someone with a diagnosis of dementia could involve a role for learning. Extending social networks and social support, improving self-esteem and developing skills are likely to decrease vulnerability to future relapses.

Conclusions

Learning may benefit older people regardless of whether they have a mental health problem, and there is no reason to think that people with mental

health problems in later life will benefit less than those without. It would seem more likely that they might gain more benefit, and there are some interesting studies which support this hypothesis. Therefore, opportunities for learning should be considered as part of mental health promotion in later life, and in connection with the management of people with existing mental health problems. These areas are assuming increasing importance as the world population grays and mental health disorders of later life become an increasing public health challenge. A recent paper in the *BMJ* (Butler *et al.*, 2008) argued for a concerted effort to slow down aging – learning might have a role here too.

There has been surprisingly little research focused on the role of learning in relation to older people's mental health and a number of interesting questions await answers:

- How is the process of learning beneficial?
- What is different about people who engage in learning in later life?
- Who will benefit from engagement in learning?
- How can clinicians use learning to promote and maintain mental health in older adults?

Conflict of interest

None.

Acknowledgments

This paper was produced for, and presented at, the third seminar in an ESRC seminar series entitled Older People, Learning and Society based at Leicester University, Leicester, U.K. My thanks go to those people who have discussed these ideas with me at the seminar and beforehand; to Kath, who has been an inspiration, and to Aled, who has contributed ideas and introduced me to geriatric1927.

SUSAN MARY BENBOW

Centre for Ageing & Mental Health, Staffordshire

University, Stafford, U.K.

Email: drsmbenbow@aol.com

References

- Age Concern and the Mental Health Foundation (2006). *Promoting Mental Health and Well-being in Later Life. A First Report from the UK Inquiry into Mental Health and Well-being in Later Life*. Available at: http://www.ageconcern.org.uk/AgeConcern/report_mentalhealthandwellbeing.asp (last accessed 22 February 2009).
- Age Concern (2007). *Improving Services and Support for Older People with Mental Health Problems. The Second Report from the UK Inquiry into Mental Health and Well-being in Later Life*. Available at: http://www.ageconcern.org.uk/AgeConcern/Documents/full_report.pdf (last accessed 22 February 2009).
- Age Concern (2008a). *"Keeping the Grey Matter Ticking Over". Learning after the Age of 50*. Available at: <http://www.ageconcern.org.uk/AgeConcern/BAF033B378C3478-AA006D78F47282865.asp> (last accessed 22 February 2009).
- Age Concern (2008b). *Undiagnosed, Untreated, At Risk. The Experiences of Older People with Depression*. Available at: http://www.ageconcern.org.uk/AgeConcern/Documents/PA0130708_depression_campaign_report.pdf (last accessed 22 February 2009).
- Alzheimer's Society (2007). *Dementia UK*. Available at: http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2 (last accessed 22 February 2009).
- Beeston, D. (2006). *Older People and Suicide*. Available at: <http://www.westmidlands.csip.org.uk/silo/files/suicide-in-elders-report.doc> (last accessed 22 February 2009).
- Benbow, S. M., Taylor, L. and Morgan, K. (2008). Multiple perspectives: involving users and carers in educating health and social care professionals. *Quality in Ageing*, 9 (2), 12–17.
- Butler, R. N. *et al.* (2008). New model of health promotion and disease prevention for the 21st century. *BMJ*, 337, 149–150.
- Care Services Improvement Partnership (2005). *Everybody's Business. Integrated Mental Health Services for Older Adults: A Service Development Guide*. Available at: <http://kc.csip.org.uk/upload/everybodysbusiness.pdf> (last accessed 22 February 2009).
- Davey, J. A. (2002). Active ageing and education in mid and later life. *Ageing and Society*, 22, 95–113.
- Department of Health (1999). *National Service Framework for Mental Health: Modern Standards and Service Models*. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009598 (last accessed 22 February 2009).
- Department of Health (2001). *National Service Framework for Older People*. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003066 (last accessed 22 February 2009).
- Department of Health (2002). *National Suicide Prevention Strategy for England*. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009474 (last accessed 22 February 2009).
- Department of Health (2009). *Living Well with Dementia: A National Dementia Strategy*. Available at: <http://www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastategy/index.htm> (last accessed 22 February 2009).
- Dijkstra, K., Bourgeois, M., Youmans, G. and Hancock, A. (2006). Implications of an advice-giving and teacher role on language production in adults with dementia. *Gerontologist*, 46, 357–366.

- Duay, D. L. and Bryan, V. C. (2006). Senior adults' perceptions of successful aging. *Educational Gerontology*, 32, 423–445.
- Emmerson, J. P., Burvill, P. W., Finlay-Jones, R. and Hall, W. (1989). Life events, life difficulties and confiding relationships in the depressed elderly. *British Journal of Psychiatry*, 155, 787–792.
- European Commission (2004). *The State of Mental Health in the European Union*. Available at: http://www.msc.es/organizacion/sns/planCalidadSNS/pdf/excelencia/salud_mental/opsc_est18.pdf.pdf (last accessed 22 February 2009).
- Faculty of Old Age Psychiatry (2006). *Raising the Standard*. Available at: <http://www.rcpsych.ac.uk/PDF/RaisingtheStandardOAPwebsite.pdf> (last accessed 22 February 2009).
- Fratiglioni, L., Winblad, B. and von Strauss, E. (2007). Prevention of Alzheimer's disease and dementia: major findings from the Kungsholmen Project. *Physiology and Behavior*, 92, 98–104.
- Glanz, D. and Neikrug, S. (1997). Seniors as researchers in the study of aging: learning and doing. *Gerontologist*, 37, 823–826.
- Hoffman, A. et al. (1991). The prevalence of dementia in Europe: a collaborative study of 1980–1990 findings, Eurodem Prevalence Research Group. *International Journal of Epidemiology*, 20, 736–748.
- House of Commons Committee of Public Accounts (2008). *Improving Services and Support for People with Dementia Sixth Report of Session 2007–08*. London: The Stationery Office.
- Hybels, C. F. and Blazer, D. G. (2003). Epidemiology of late-life mental disorders. *Clinics in Geriatric Medicine*, 19, 663–696.
- Jané-Llopis, E. and Gabilondo, A. (eds). (2008). *Mental Health in Older People. Consensus Paper*. Luxembourg: European Communities. Available at: http://www.ec-mental-health-process.net/pdf/mental_health_in_older_people_consensus_paper.pdf (last accessed 22 February 2009).
- Lowin, A., Knapp, M. and McCrone, P. (2001). Alzheimer's disease in the UK: comparative evidence on cost of illness and volume of health services research funding. *International Journal of Geriatric Psychiatry*, 16, 1143–1148.
- McNamee, S. (2007). Relational practices in education: teaching as conversation. In H. Anderson and D. Gehart (eds.), *Collaborative Therapy: Relationships and Conversations that Make a Difference* (pp. 313–335). London: Routledge.
- Mehrotra, C. M. (2003). In defense of offering educational programs for older adults. *Educational Gerontology*, 29, 645–655.
- Moniz-Cook, E. (2006). Cognitive stimulation and dementia. *Ageing and Mental Health*, 10, 207–210.
- National Audit Office (2007). *Improving Services and Support for People with Dementia*. Available at: <http://www.official-documents.gov.uk/document/hc0607/hc06/0604/0604.asp> (last accessed 22 February 2009).
- NICE (2007). *Donepezil, Galantamine, Rivastigmine (Review) and Memantine for the Treatment of Alzheimer's Disease (Amended)*. Available at: <http://www.nice.org.uk/guidance/TA111> (last accessed 22 February 2009).
- NICE-SCIE (2007). *Dementia: The NICE-SCIE Guideline on Supporting People with Dementia and their Carers in Health and Social Care*. National Clinical Practice Guideline Number 42. Available at: <http://www.nice.org.uk/cg42> (last accessed 22 February 2009).
- Office of the Deputy Prime Minister (2004). *Mental Health and Social Exclusion*. Social Exclusion Unit Report. Available at: <http://www.socialinclusion.org.uk/publications/SEU.pdf> (last accessed 22 February 2009).
- Office of the Deputy Prime Minister (2006). *A Sure Start to Later Life Ending Inequalities for Older People*. Social Exclusion Unit Final Report. Available at: <http://www.communities.gov.uk/publications/corporate/surestart> (last accessed 22 February 2009).
- Orte, C., March, M. X. and Vives, M. (2007). Social support, quality of life, and university programs for seniors. *Educational Gerontology*, 33, 995–1013.
- Phinney, A., Chaudhury, H. and O'Connor, D. L. (2007). Doing as much as I can do: the meaning of activity for people with dementia. *Ageing and Mental Health*, 11, 384–393.
- Pitt, B. (1998). Coping with loss: loss in late life. *BMJ*, 316, 1452–1454.
- Richeson, N. E., Boyne, S. and Brady, E. M. (2007). Education for older adults with early-stage dementia: health promotion for the mind, body, and spirit. *Educational Gerontology*, 33, 723–736.
- Schneider, K. (2003). The significance of learning for aging. *Educational Gerontology*, 29, 908–923.
- Simone, P. M. and Haas, A. (2007). The influence of lifelong learning on mood. *LLI Review*, 2, 36–42. Available at: <http://uvm.maine.edu/olli/national/pdf/LLI-Review-2007.pdf> (last accessed 22 February 2009).
- Turvey, C. L. et al. (2002). Risk factors for late-life suicide: a prospective, community-based study. *American Journal of Geriatric Psychiatry*, 10, 398–406.
- Wahlbeck, K. and Mäkinen, M. (eds). (2008). *Prevention of Depression and Suicide. Consensus Paper*. Luxembourg: European Communities. Available at: http://ec.europa.eu/health/ph_determinants/life_style/mental/docs/consensus_depression_en.pdf (last accessed 22 February 2009).
- Wattis, J. P. (2008). Affective disorders in the new millennium. In S. Curran and J. P. Wattis (eds.), *Practical Management of Affective Disorders in Older People: A Multi-professional Approach* (pp. 1–16). Oxford: Radcliffe Publishing.
- World Health Organization (2002). *Active Ageing: A Policy Framework*. Available at: http://whqlibdoc.who.int/hq/2002/WHO_NMH_NPH_02_8.pdf (last accessed 22 February 2009).

NOTE: This publication is the copyright of Cambridge University Press.

International Psychogeriatrics online is available at

<http://journals.cambridge.org/action/displayJournal?jid=IPG>