



Consumer and carer engagement in residential aged care

ANNOTATED BIBLIOGRAPHY

Prepared for TasCOSS – Consumer Engagement First Forum:

Sharing of Current Innovative or Good Practice

November 2009

This annotated bibliography contains a series of national and international studies describing practice of engagement and involvement of consumers and carers in residential aged care. Electronic links to these documents are provided.

Perceptions of nurses, families, and residents in nursing homes concerning residents' needs

Merav Ben Natan

International Journal of Nursing Practice. Volume 14, Issue 3, Pages 195-199

Published Online: 5 May 2008

<http://www3.interscience.wiley.com/cgi-bin/fulltext/119415062/PDFSTART>

Abstract

This study examined the congruence between needs identified as significant by older adults in comparison with caregivers (nurses) and elders' families. The study involved 44 patients, 94 nurses and 44 families from the Shoham Geriatric Center in Pardes Hanna, Israel. The findings are based on data gathered through questionnaires distributed at the nursing home. The findings indicate a discrepancy between residents' needs as identified by the staff, the families and the elderly residents themselves. An analysis based on primary needs showed that in comparison with the residents and their families, the nurses attributed greater significance to values and personal outlook of the residents, provision of proficient physical care, skilled mental support, social life and institutional requirements. Families attributed the most significance to the provision of information and family involvement, and in contrast, according to the residents, the most important area was skilled mental/emotional support.

Having a voice and being heard: nursing home residents and in-house advocacy.

Walent RJ, Kayser-Jones J.

J Gerontol Nurs. 2008 Nov;34(11):34-42; quiz 44-5. USA

As part of an ethnographic study exploring what it means for nursing home residents to "do well," we examined patterns of advocacy on which they relied to have an effective voice. The purposive sample included 17 older, long-stay residents from a for-profit chain nursing home and a large public skilled nursing facility. Data collection included in-depth interviews, participant observation, and document review. Depending on personal history, health status, and facility context, participants relied on family and friends, trusted staff, fellow residents,

or themselves as advocates. Although residents varied in their abilities and willingness to express concerns, a program matching staff advocates with residents at the chain nursing home fostered participants' sense that they were heard and their needs addressed. Attending to patterns of advocacy and the effect of the nursing home environment on resident communication are essential for individualizing care and promoting systems to ensure residents have a voice and are heard.

NOTE: This article is not freely available
<http://www.jognonline.com/view.asp?rID=32499>

Facilitating family involvement in a residential care setting

Associate Professor Peter Foreman and Ms H Russell

La Trobe University (LTU), Australian Institute for Primary Care

<http://www.aro.gov.au/aro/researchEntryView.do;jsessionid=DJHEPGDCIIAI?id=2611&type=keyword>

The study was based on the recognition that ongoing caring relationships between family members and residents in residential care facilities are extremely important to residents' quality of care and quality of life. The overall objective of the study was to examine ways in which these relationships can be maintained once an older person moves into residential care. The long-term aim of the study was to facilitate and enhance **family participation** in a residential care setting through changes to organisational policies and procedures.

The study was undertaken in a 90 bed residential facility in Bundoora, a northern suburb of Melbourne. Specific study aims were

- (i) to identify the range and type of participation and involvement by families in the lives of older residents in an aged care unit;
- (ii) to understand the perceptions of family, staff, residents and management in relation to the role of the family in an aged care setting and to identify similarities and differences between the two groups in their perceptions;
- (iii) to identify the factors that facilitate or inhibit family participation in a residential care setting, and to identify ways in which family participation in a residential care setting can be enhanced;
- (iv) to develop a strategic plan for the care provider which identifies the key issues, objectives and specific strategies for enhancing family involvement.

The methodology involved three key stages.

- Firstly, separate focus groups with each stakeholder group, families, staff management and residents.
- In the second, a survey of all families involved with the facility was conducted regarding current level of visiting, activities during visits and satisfaction with visiting.
- In the final stage, a strategic plan for family participation will be developed.

Data from the focus groups indicate a common understanding of families' experience of visiting. For example, staff demonstrated a sensitivity and awareness of the emotional turmoil associated with visiting, families' need for

support in the early period, for help in finding the right level of visiting and in facing the decline in their relatives' condition. Reciprocal needs were also demonstrated between staff and families. Staff commented on the presence of families' providing a more 'normal' and homely work environment. Families commented on conversation and communication with staff being the measure of a good visit. Unfamiliar staff, unfriendly staff were barriers to visiting.

Results from the survey showed a high level of visiting by families and friends. Incorporating the focus group data, many areas were identified where there was a need for organisational change in order to provide increased support, communication and information to families. Family concerns were categorised into four areas and became the basis for the strategic plan:

- (i) communication: how can staff and families have better communication and better relationships;
- (ii) achieving the best quality of care and quality of life for residents;
- (iii) family/carer support and encouragement;
- (iv) education and information.

Consumer Involvement in Dementia Care Research, Policy and Program Evaluation

Report on Alzheimer's Australia Research Ltd Travelling Scholarship

Colleen Doyle

August 2008

Australian Institute for Primary Care (AIPC)

<http://www.alzheimers.org.au/upload/Doyle.pdf>

Society is recognising that people with dementia have worthwhile opinions on their care despite living with cognitive disabilities. In both the USA and the UK, independent organisations and governments are developing structures and processes to accommodate a more active role for people with dementia.

The societal ethos of involving people in decisions about the care they receive is continuing to gain ground. Investigations summarised here pointed to some issues yet to be resolved, such as representativeness, the empowerment of marginalised cultural groups and cost-benefit implications when resources are scarce. The issues are complex; inevitably, it has not been possible to cover all aspects fully in this paper. Nevertheless, the activities reported here have provided valuable lessons for Australian practice. (p.1)

Cheston et al. (2000) identified five methods of involving people with dementia in the evaluation of services:

1. Focus groups: these can be used to help people with dementia to discuss the services they receive. However, the facilitator needs to be skilled at helping people with fewer verbal skills to be heard if they are in a mixed group with others more adept at expressing themselves.
2. Questionnaires or structured interviews: for people with mild cognitive impairment, questionnaires administered in-person and concentrating on social aspects of care can be used to communicate either a positive or negative view of the service. More rigid or structured questionnaires are not suitable.
3. Semi-structured interviews: these follow a general series of topics, and allow the person with dementia to raise issues not on the original topic list.

4. Observation: techniques like Dementia Care Mapping can be used in residential settings; observation lasts at least six hours and can be a means of evaluating quality of care as well as giving feedback to staff.
5. Advocacy: this is the more commonly used method of involving people with dementia. Advocates can be legal, professional, family, public, or citizen.(p.25)

NOTE:

Cheston, R., Bender, M., & Byatt, S.

Involving people with dementia.

Journal of MentalHealth, 9(5), 471-479. 2000

<http://informahealthcare.com/doi/pdf/10.1080/09638230020005200?cookieSet=1>

The model for participatory research used by Roulstone et al. (2007) in the UK would seem a good one to apply to dementia care evaluation in Australia. They used three groups to steer their research:

- (i) The research team: this consisted of three academic staff from the University of Sunderland and the co-ordinator of Sunderland Carers Centre.
- (ii) Carers' Participation Reference Group: Local carers were part of a carer participation reference group that also included academic researchers. This group managed the day-to-day operational aspects of the research.
- (iii) Research Review Group: This group involved carers and key carer stakeholders from England, Wales, and Northern Ireland. It met four times throughout the research and had a strategic overview of research progress.

It is immediately obvious that this amount of consumer input is expensive, and would add considerably to the total cost of research or evaluation. Efforts are now being made to evaluate whether the benefits would outweigh costs. (p.27)

NOTE: Carer participation in England, Wales and Northern Ireland: A challenge for interprofessional working

Alan Roulstone and Val Hudson

Journal of Interprofessional Care, 1469-9567, Volume 21, Issue 3, 2007, Pages 303 – 317

Not freely available

Below there are a series of examples from the UK taken from Doyle's report.

▶ The UK dementia initiative

A new dementia strategy is being developed in the UK, starting from August 2007. As part of the dementia initiative development, a new resource was produced on strengthening the involvement of people with dementia (Care Services Improvement Partnership, 2007). People with dementia and their carers were involved in its development, and the document is expected to be a key resource in improving dementia care in the UK. The document outlines the advantages of involving people with dementia in services.

Table 4: Advantages of involving people with dementia in service evaluation and policy development

For people with dementia

As a person using a service you have a right to be involved:

- You have a personal perspective about dementia that no-one else can provide.
- Involvement can increase confidence and self-esteem.
- It can provide a role and occupation and contribute to a better quality of life.
- You can provide positive examples of living with dementia encouraging others to get involved.
- You will contribute to removing the stigma associated with dementia as well as mental health in general.

For commissioners

Involving people who use a service is a policy requirement:

- It can provide evidence where services are no longer required and how new services should be shaped optimising the value of available resources.
- Feedback through involvement gathers data for audit and evaluation purposes and feeds into performance assessment frameworks.
- It ensures fair access to public services and benefits.
- It ensures equality of treatment and protection.
- Involvement improves standards and responsiveness.
- Involvement generates new ideas.

For practitioners

- People who are involved, whether practitioners or those receiving services, feel empowered:
- Information gathered and acted upon ensures the most relevant services are provided.
- It meets the personal and social needs of people using services.
- It can assist people with dementia and practitioners to develop their potential.
- It illustrates respect for individuals and their communities.
- It promotes dignity, individuality, rights, responsibilities, identity, and personal preferences.
- Involvement promotes trust in services and may guard against abuse.

NOTE:

The *Strengthening the involvement of people with dementia*. A resource for implementation is available at:

<http://www.dhcarenetworks.org.uk/library/Resources/Dementia/CSIPComment/strengthening-the-involvement-of-people-with-dementia.pdf>

The *Strengthening the involvement of people with dementia*. Supplementary resource is available at

<http://www.mentalhealthequalities.org.uk/silo/files/supplementary-resource-final.pdf>

► ***Involving people with dementia in education and training of dementia care workers***

Apart from direct involvement in service development and evaluation, people with dementia are beginning to take part in the development of education and training of the health care staff who will be looking after them. The Bradford Dementia Group are leaders in involving people with dementia in the education and training of dementia care workers through the courses provided at the University of Bradford. All courses for health professionals who work in the NHS have to have patient and public involvement in their development, design, and delivery. This requirement is being addressed through a network (PEPIN) of information sharing, and a higher education dementia network.

A survey of higher education institutions providing modules on dementia and older people with mental health needs found that some were involving carers, but Bradford is one of the few institutions involving people with dementia as well. Bradford has a person with early vascular dementia on the course management team, which is a team of stakeholders that meet twice a year to advise on courses and to look at course evaluations. The person with dementia is met with separately before the meeting to brief her on the content of the meeting.

NOTE:

The Bradford dementia Group web site is
<http://www.brad.ac.uk/health/dementia/>

► ***Canvassing opinions at Dementia Cafés***

Staff from the Bradford Dementia Group have attended dementia cafés to find out what people thought about health services for people with dementia in the area. Semi-structured, informal interviews were undertaken successfully with people attending the cafés. Other UK dementia workers have also involved people with dementia in the development of dementia cafés. For example, Penny Redwood, Leeds Social Services, evaluated the dementia café DeCaf by sending questionnaires to people with dementia and their carers, conducting face-to-face, semi-structured interviews at the café, and distributing questionnaires to staff as well. These informal approaches are well received by users of the dementia cafés.

NOTE: This is described on page 16 of a newsletter available at
http://www.leeds.nhs.uk/attachment/00000000aef19d22636b62a8a8a96c10/dce_d5433a31c20aa8fb5a39b9f4a5cfd/PHil17+pages+13-20.pdf

► ***Dementia Services Development Centre Stirling***

Malcolm Goldsmith, from the Dementia Services Development Centre in Stirling, initiated some work on involving people with dementia in evaluation of services, resulting in the publication of 'Hearing the voice of people with dementia: opportunities and obstacles' (Goldsmith, 1996). His work pointed the way towards changing the attitudes of health workers to people with dementia.

NOTE: This is a book
Goldsmith Malcolm
Hearing the voice of people with dementia: opportunities and obstacles
London: Jessica Kingsley, 1996. 192p..

Kate Allan (2000) extended Malcolm Goldsmith's work, writing about a project in which she explored how residential care staff could encourage service users with dementia to express themselves regarding their view of the help they were receiving. Action research was used to try a wide variety of approaches to fostering better communication. Allan found that organisational factors, such as

- the general ethos of the organisation,
- staffing levels,
- diversity of the people with dementia,
- routines, and
- limitations imposed by shifts, were important in modifying the involvement of people with dementia in their care.

Staff factors had a big impact on the success of communication with people with dementia. Such staff factors included attitudes and behaviour, self-esteem and confidence, personality factors, relationships with individual service users, variability in the wellbeing of staff, illness, and absence.

NOTE:

Communication and consultation. Exploring ways for staff to involve people with dementia in developing services

Kate Allan

The Policy Press and the Joseph Rowntree Foundation 2001

<http://www.jrf.org.uk/sites/files/jrf/186134810x.pdf>

Another example of people with dementia being involved in developing services was provided by Bamford and Bruce (2000), who used a group session to ask people with dementia what types of outcomes they were interested in from community care services. It appears that consultation with people with dementia about the care they receive is further developed in residential care services than in community care.

NOTE:

Bamford, C. & Bruce, E

Defining the outcomes of community care: the perspectives of older people with dementia and their carers. *Ageing and Society* 20(5), 543-570. 2000

<http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=64045&fulltextType=RA&fileId=S0144686X99007898>

▶ **London Centre for Dementia Care**

The London Centre for Dementia Care (LCDC) is part of the network of Dementia Services Development Centres and was established in 1998. It is hosted by University College London and provides a range of educational and support services for people interested in dementia care. There is also a specialist library on patient and public involvement in care. The LCDC has a strong volunteer tradition. The LCDC is a collaborative venture between the academic, statutory, and voluntary sectors. A number of supporters have contributed to its work on a voluntary basis as members of the Steering Group, representing the LCDC at events and attending meetings on the centre's behalf.

The centre's website details a range of activities in which people with dementia can be involved <http://www.ucl.ac.uk/dementia>

▶ **Alzheimer's Society UK and consumer involvement – QRD Consumer Network.**

The Alzheimer's Society UK includes among its roles the management of funding for research into dementia cause, cure, and care in the UK. The Society contributes approximately GBP1.6 million in research funding. Currently (September 2007), the society is funding nineteen projects, eight fellowships, and two PhD studentships. The Alzheimer's Society in the UK has an active group of consumers — the **Quality Research in Dementia Consumer Network** — who set priorities for research, select proposals for funding, monitor ongoing projects, and assist in disseminating the outcomes of research. One hundred and eighty consumers in twelve Alzheimer's Society regions have been recruited to take part in the program, which has been running since 1999. All are volunteers.

Consumers are involved in:

- Reviewing grant applications.
- Committees that make funding decisions.
- Steering committees for funded projects.
- Disseminating and implementing research findings.

Consumers undergo training in four modules to support them in their role. The modules cover

- what research is;
- personal development;
- critical appraisal skills; and
- working collaboratively with 'professionals'.

A manual was produced in 2004, and revised in 2007. The approximate cost of maintaining the consumer network was reported to be GBP60,000 per year, of which GBP25,000 is postage costs, as many of the consumers do not yet have access to broadband Internet. The network is expanding under current direction, and is expected to reach 200 consumers with a full-time liaison person to support them in future. A demographic survey in 2004 showed that the consumers' average age was 67, with 60% being female.

Shirley Nurock was the first consumer to be awarded an Alzheimer's Society research grant, in partnership with a researcher. On writing up one of the papers for publication there were fundamental differences between Shirley's conclusions and those of the researchers. "Is this what happens when a carer and researchers look at an emotive question from very different perspectives? But why is my perspective any less valid than theirs?"

Overall, Shirley felt that her experience of being the first carer to be awarded a grant by the Alzheimer's Society had been very positive and recognised that the dissemination of findings, by an involved consumer, seems to have more impact on audiences than when spoken by a researcher or clinician. (Involve, 2003)

NOTE:

Quality Research in Dementia Consumer Network

<http://alzheimers.org.uk/site/scripts/documents.php?categoryID=200296>

▶ **Alzheimer's Research Trust**

The Alzheimer's Research Trust is a registered charity in the UK that provides ten different types of research support, and is funding grants to a total of GBP3 million for dementia research in 2006 (www.alzheimers-research.org.uk). Grants are made to applications reviewed by an Expert Referee Panel and Scientific Advisory Board. The Scientific Advisory Board has **two lay members**, the other members being scientists with expertise in dementia research. The Expert Referee Panel consists of national and international experts in dementia research, but no consumers or 'lay' members.

▶ **The James Lind Alliance**

This organisation uses partnerships between consumers and clinicians to improve communication between the two groups. The James Lind Alliance (JLA) is about 'tackling treatment uncertainties together'. Patient organisations and clinician organisations will work together to confront uncertainties about the effects of treatments. JLA Working Partnerships consist of at least **one patient organisation** and at least one clinician organisation.

Whenever possible, patients themselves should present their interests and views in JLA Working Partnerships. When they are unable to do so, for example, when suffering from cognitive impairment, the families or other carers of patients, or other non-clinician advocates, may try to represent their interests. The clinicians comprising the other half of each JLA Working Partnership must include those who are routinely involved in treating patients with the health problem(s) being considered.

NOTE:

A series of methods used by the James Lind Alliance are available at http://www.lindalliance.org/JLA_Method.asp

▶ **The Scottish Dementia Working Group**

Alzheimer's Scotland is a separate organisation from Alzheimer's Society, which covers England, Wales, and Northern Ireland. Alzheimer's Scotland has branches throughout Scotland, with the head office in Edinburgh. The Scottish Dementia Working Group allowed me to attend one of their regular meetings. This group is based in Glasgow, and meets at the Alzheimer's Scotland office monthly (approximately). It consists of people diagnosed with dementia. Most are men, in their 60s or 70s. They are campaigning for improved services for people with dementia in Scotland. The national coordinator, Philip Bryers, helps with administration of the meetings. Funding is received from Alzheimer's Scotland and Comic Relief. The annual budget to support the group is approximately GBP60,000, although funding for 2008 was recently increased to GBP90,000, which will allow for more meetings and extension of the group to other towns such as Inverness.

Members speak at conferences, and have been meeting the Scottish Minister regularly in 2007 to discuss development of services. In March 2006, the first UK convention for, and by, people with dementia was organised by Dementia North, the Scottish Dementia Working Groups and the Living with Dementia team

NOTE:

The *Scottish Dementia Working Group* web site is <http://www.sdwg.org.uk/>

Conclusions from Doyle's report

The stand-out lessons learnt during this exploration were:

1. Some people with dementia who are young and diagnosed early are very keen to have a public role in the development of policy, services, and evaluation.
2. There are growing roles for such people, who can join groups to put their ideas forward, and there is both independent organisational support as well as government encouragement of such roles overseas.
3. People with dementia and their family carers find it satisfying to be involved in research and evaluation; it gives them confidence and makes them feel they are valued members of society.
4. Older people with dementia, and those with moderate to severe dementia, are mainly involved on a one-to-one basis in having a say about their own care rather than at a policy or service development level.
5. Advisory boards, working groups, and groups of people who have volunteered for policy development roles are not representative of the general population.
6. If such groups have priority setting roles, they should be supplemented with population surveys if the priorities assigned are to be truly indicative of what the community as a whole wants.
7. The UK health service has a strong consumer involvement ethos in all areas, not just in dementia care. (p.28)

Involving people with dementia in service planning

Caroline Cantley, Monica Smith and Janet Woodhouse
NAIDEX – CPD (Continuing Professional development) – UK
24 November 2005
Available at: <http://www.naidex.co.uk/page.cfm/link=118>

This report is a culmination of a project carried out by Dementia North, the department of Health-funded dementia services development centre for the north and Yorkshire region. The project explored new ways and existing good practice in user involvement work with people who have dementia.

Residents' choice of and control over food in care homes

Winterburn S.
Nurs Older People. 2009 Apr;21(3):34-7
Sheffield Hallam University, Sheffield. USA
<http://www.ncbi.nlm.nih.gov/pubmed/19363950>

This study aimed to map food pathways in care homes to identify how residents exercised choice and control over their food intake and any associated or influencing factors. Four homes were visited, interviews were conducted with chefs and nursing staff and the dining facilities were noted. It was found that residents were dependent on the care home for the provision of food. There was almost no direct contact between residents and external food retailers. A food

map was constructed, which identified three routes for potential improvements in practice: supply and delivery of food; serving of food; and consumption of food. Residents' choice and control over food could be improved through the design of new products for serving and consumption of food and eating aids, access to local food retailers and nutritional training.

Family involvement in the nursing home: Family-oriented practices and staff-family relationships

Marie-Luise Friedemann, Rhonda J. Montgomery, Bedonna Maiberger, A. Ann Smith

Research in Nursing & Health Volume 20 Issue 6, Pages 527 - 537

Published Online: 7 Dec 1998. USA

<http://www3.interscience.wiley.com/cgi-bin/fulltext/48247/PDFSTART>

Table 2. Family Opportunities in Nursing Homes

- Staff calling family for advice with resident problems
 - Personal invitations to family activities
 - Permission to call unit day or night
 - Meetings to plan care
 - One-to-one counseling for family members
 - Assignment of staff contact person
 - Education about nursing home programs
 - Use of a room for family privacy
 - Volunteer organization
 - Family council
 - Guest meals
 - Hands-on care by families
 - Support groups for families
 - Instruction in patient care for families
 - Family group to help solve nursing home problems
 - 24 hr visiting
 - Educational materials for families to borrow
 - Advisory board open to family members
 - Classes to learn about chronic illness, etc.
 - Transportation for family to the nursing home (p.532)
-

Optimizing Patient and Family Involvement in Geriatric Home Care

Jennifer L. Wolff 1 , Debra L. Roter 2 , Barbara Given 3 , Laura N. Gitlin 4

Journal for Healthcare Quality Volume 31 Issue 2, Pages 24 - 33

Published Online: 26 Feb 2009. USA p. 25

<http://www3.interscience.wiley.com/cgi-bin/fulltext/122220926/PDFSTART>

Table 1. Salient Patient Attributes for Health Care Decision-Making, Problem Solving, and Management

Construct	Definition	Strategies
Static Attributes: Potential for Compensation or Accommodation		
Cognition	Mental processes involved in gaining knowledge and comprehension, including thinking, knowing, remembering, judging, and problem solving	Involving family in health care processes, use of simple language and graphics
Vision and Hearing	Sensory functioning that is influential to the exchange of health care information	Large print materials, slowing the rate and using louder speech
English Proficiency	Ability to read, write, speak in English, compute and solve problems to achieve one's goals, develop one's knowledge and potential	Simple language, use of graphics and pictures, translation of information to other languages
Health Literacy	Functional and context-specific oral (listening; speaking) and written (reading; writing) skills	Simple language, use of graphics and pictures, slowing the rate of speech, use of simple language, prompting patients to ask questions or restate information
More Modifiable Factors: Potential for Capacity Building		
Self efficacy; Personal Mastery	Belief in one's capabilities to organize and execute the courses of actions required to produce given attainments; behavior specific	Pre-visit education and coaching using written materials, videos, audiotapes, and/or face-to-face sessions to encourage patients to be more proactive and engaged within a health care encounter by prompting them to ask questions, raise concerns, request clarification, or negotiate decisions; Self management programs that rely on education and problem solving
Internal Locus of Control	Individual's perceived internal control; sense of responsibility for health outcomes	
Readiness to Change Health Behaviors	Behavior change as an individual process based on decisional balance (benefits and costs), self-efficacy, and temptation	
Patient Activation	Knowledge, skills, beliefs, behaviors needed to self manage health care	

The role of carers in evaluating mental health services for older people

Tom Denning and Claire Lawton

International Journal of Geriatric Psychiatry, Volume 13 Issue 12, Pages 863 -870

Published Online: 8 Jan 1999. UK

<http://www3.interscience.wiley.com/cgi-bin/fulltext/5001831/PDFSTART>
p.865

Table 1. Four 'levels' of carer involvement

1. Carer organizations
2. Carer input into purchasing and policy
3. Carer input into planning service provision
4. Carer input into existing services
 - (a) Initiatives for carers:
 - Carer education programmes
 - Relative support groups
 - (b) Evaluation of services
 - Routine practice eg care programme reviews
 - Specific components of service eg day care, respite care
 - Specific projects eg Cambridge Community Team study

Changes comprised:

- expansions of our existing community resource teams,
- transfer of the acute functional illness ward from the psychiatric hospital site to the acute general hospital,
- changes in respite care, and
- the closure of two continuing care wards for dementia and their replacement with beds in new independent nursing homes.

Carers and relatives have been involved in three ways:

- (1) during an initial period of public consultation;
- (2) extensive and repeated discussions with individual relatives, particularly those associated with patients in continuing care beds scheduled for closure; and
- (3) as part of a strategy liaison group which was set up to coordinate the process of communication regarding the changes. The liaison group has been chaired and serviced by the Trust.

Relatives representing each of the wards involved have attended as well as other carers with particular interests, for example early onset dementia. Other members of the group have come from social services, the voluntary sector, housing associations and the community health council. The Trust's project manager also produces a newsletter, which is widely distributed.

Nonetheless, despite the extensive efforts at consultation and communication, there has at times been some dissatisfaction. In part, this must be due to the ways in which carers are excluded from the most fundamental levels of decision-making. In our local example, carers would not have chosen to reduce the numbers of hospital beds; they were consulted more as to how this would happen. The health authority would argue that, as it carried the overall financial responsibility for this strategy and the other competing claims on its budget, it should also make the basic choices. Clearly there is a trade-off between carer power and responsibility in this area. The question as to whether the health authority would make better decisions if it were obliged to involve carers in its

decisions is an empirical one and could be evaluated. It also emerged that many carers were bewildered and traumatized by the changes in health and social policy which underlay the strategy, particularly the shift from state (NHS) to personal (means-tested) funding of continuing care provision. For several, this has represented a betrayal of the aims of the original NHS Act, and it profoundly influenced their contribution to the discussions and their wishes for their relatives' care. (p.866-867)

There do not appear to be any formal studies of the use of relatives' groups in monitoring service provision. Probably it would be more appropriate for research purposes to establish and study ad hoc focus groups with independent facilitation rather than relatives' support groups as such. The most active support groups are likely to be the relatives of those receiving continuing care for dementia, since the patient population is relatively stable.

Given the dependency and potential vulnerability of the patients, this seems a good thing. Our local experience has been that such groups come into their own at times of change, with the relatives' groups being galvanised by the proposed changes and the planned ward closures. The presence of the group complemented, but did not replace, the process of communication with individual relatives.

From our point of view as providers, it was possible to encourage the group to represent their views independently and critically when required, particularly in relation to the health authority. The group could, of course, represent the interests of those few patients who had no supporters, and could also help inform some of the frailer relatives who found it hard to grasp the situation when it was first explained.

Carer education programmes have become widespread and numerous examples have now been described. The best and most convincing evaluations are those by Brodaty et al. (1997) in Sydney and Mittelman et al. (1996) in New York, which have demonstrated benefits in terms of carer symptoms and delayed institutionalization. However, both of these programmes involved quite intensive input, so it is then important to identify which elements of the programme are effective and at what stage of the natural history of dementia they are most useful (though Brodaty suggests as early as possible, which makes intuitive sense).

Experience from family education programmes in schizophrenia suggests that not all carers will attend such sessions, and that relatively little knowledge is acquired, but there may be gains in terms of attitudes and optimism, as well as the development of links between carers which persist after the end of the formal programme (Berkowitz et al., 1984; McCreddie et al., 1991).

Our own local experience has been with a less intensive, non-residential programme run over 3 days. One of the features is that all the participants are visited prior to the sessions, and the content of the sessions can be adjusted to address their particular needs and difficulties. The stated aims include increasing carer knowledge and decreasing carer stress, but there is also the opportunity to learn more about the carers' views of the services. The first programme showed evidence of effectiveness with a modest reduction in carers' GHQ scores and a significant improvement in an ad hoc knowledge questionnaire found 1 month afterwards.

Several future developments are under consideration, for example adding a legal speaker, extending the programme to other settings and holding an annual

carers' conference. Carers may also be involved in the most direct sense of evaluating services. As mentioned above, this happens to some extent in routine practice, but various recent initiatives provide particular opportunities for carers to feed back their views of services. For example, in the UK, packages of care are allocated on the basis of needs-led assessments, which should encourage carers to say how their needs have been met or how they might be met in future. Similarly, the Care Programme Approach, with its built-in notion of regular reviews, potentially offers the same kind of opportunity. Specific research projects looking at the direct contribution of carers to service evaluation are not common. Such studies as exist are not usually specific to mental health, nor is it usually clear how the information obtained has been used to modify the services in accordance with the findings.

Brown et al. (1997) from Ontario, Canada, used focus groups of older people, informal and formal caregivers and health care providers to examine 'barriers and facilitators' to seniors' independence. The study examined primary care rather than mental health. They concluded, uncontentiously, that health providers needed to communicate better, foster more positive attitudes towards the elderly and improve accessibility, coordination and continuity of services. Caregivers placed particular value upon good relationships, especially access and continuity, with primary care physicians.

Noelker and Bass (1995) interviewed 401 informal carers in Cleveland, Ohio, looking at the extent of their use of services and what factors predicted such usage. Their particular interest was in the implications of this for case managers. Again, the study did not focus upon mental health, nor upon using the views of the carers to measure service quality or efficacy.

Gold et al. (1995) from Montreal examined carers' views on the single issue of ending home care for their relatives, and studied the impact of ending or continuing home care on the carers' health and levels of functioning. Most carers were satisfied with having ended home care, and most had better health and quality of life than carers still providing home care.

Durand et al. (1995), as part of the Canadian Study of Health and Aging, examined predictors of carers' dissatisfaction with community care services. Predictors of dissatisfaction were varied, but include the presence of dementia and/or disruptive behaviour, the carer living apart from the service recipient and the ethnic origin of the carer. Some other studies, such as those evaluating individual services, have mentioned the importance of involving carers, but have not been explicit about how they have used the carers' views in the overall evaluation (eg Stolee et al., 1996, Ontario). Philp et al. (1995) in Dundee, Scotland, looked at financial burden, service usage, perceived unmet needs and perceived needs for such services as help with supervision, housework and personal care in 114 patients with dementia and their carers compared with age- and sex-matched controls. This study found a high level of unmet need among the dementia group, even though they were already in receipt of more domiciliary and day care. The authors recommended increased domiciliary support for carers of patients with dementia, especially help with supervision.

The TAPS project in London, UK, evaluating the closure programme of two old psychiatric hospitals, examined the quality of life of former long-stay patients, many of them aged over 65, discharged to community residences. They found that most discharged patients did well and, in particular, there was greater satisfaction among relatives regarding the patients' living environments and quality of life (Le. et al., 1996).

The only such study specifically in an old age psychiatry setting was performed in Cambridge, UK (Bedford et al., 1996; Melzer et al., 1996). The study followed up 136 patients referred to four community resource teams over 6 months, looking at patient outcomes (such as survival, institutionalization and unmet needs) and carer outcomes, including carer stress levels measured using the General Health Questionnaire (GHQ, Goldberg, 1978). There were differences in outcomes between patients with dementia and those without at 6 months, only 54% of the dementia group were alive and living outside institutional care, compared with 79% of the non-demented. Unmet needs were commoner in the dementia group, mainly related to residential care and respite for carers. Outcomes for carers were judged poor in 15% of both groups, with over 10% of both groups of carers judged to be under severe stress.

The second part of the study (Melzer et al., 1996) comprised interviews with carers of those patients with dementia who were living in the community and supported by an informal carer. Thirty-nine people were approached and 34 (87%) agreed to be interviewed at 6 months after referral, mainly face-to-face but four by telephone. Thirty patients were female and most were over 75. At 6 months, 24 of the patients were still in the community, with three-quarters of them receiving home care services of various kinds. The study examined the types of services received, any crises which had arisen including hospital admission, unmet needs and carer stress, overall satisfaction with services and satisfaction with either residential care or community care. Eight carers (31%) had GHQ scores of 10 or more, but GHQ scores correlated poorly with keyworkers' assessments of the level of carer stress.

There are various reasons why this might have occurred. Just over half the sample regarded the services overall as good or very good, but even among these carers there were some adverse comments about one or more aspects of care. As regards residential care, the main problems were lack of choice and lack of information prior to choosing a home, and then also concerns about the standards of care, especially related to low staffing levels. Problems with community care included inflexibility of services, poor communication, unreliable private care services, and travel and limited availability with day care.

The strengths of this study are that the data ascertainment was reasonably good as the research team helped develop the standard assessment schedule used both by social services and by health personnel within the teams, and the presence of the researcher meant that incomplete schedules could be chased up.

The level of data collection and analysis was only modestly above that used in routine practice, so a similar study would be justified at a future time of strategic change. It would appear that the sole use of a questionnaire measure of carer stress (GHQ) would be inadequate for picking up the problems experienced by carers and that probably an interview with both structured and unstructured elements is required. From both the objective data and the carer interviews, it was clear that improvements were required both in community care provision, particularly in terms of its flexibility, and residential care, especially increased provision of nursing home beds able to care for people with dementia. These issues have been fundamental in the strategy that we are currently implementing.

POSSIBLE FURTHER DEVELOPMENTS

There is obviously scope for trying to bring feedback from carers as much into routine practice as possible. However, studies so far indicate that if this is made too reliant on simple measures or questionnaires, too much valuable information may be lost. As mentioned earlier, there is no validated measure for rating

satisfaction with services. Such a measure would have to find ways to explore the carers' expectations in relation to outcomes. It would also need to differentiate between services supporting care at home and residential care facilities. At present, the best way to obtain valid and useful input from carers would seem to be by means of interview. There are two important issues: first, about breadth versus depth of information gathering, and, second, about resources, which are required not just for interviewing but also for managing and analysing the data obtained, which must also then be available to inform the managerial and planning processes.

It certainly seems that carers could and should be more involved at the levels of policy and purchasing. In the UK, the Government white paper proposing new arrangements for the National Health Service contains a commitment to a national survey of users' and carers' views (Secretary of State for Health, 1997). In the light of the above discussion, this would be a valuable source of information and a welcome development. (p.867-869)

Prepared by Tere Dawson
November 2009
t.dawson@healthissuescentre.org.au