

## Introduction

Welcome to the eighth edition of Research Focus from the PSSRU at the University of Manchester. In this edition, we begin a discussion of survey data received from Community Mental Health Teams and Care Homes providing an overview of mental health support currently available. The second study looks at a standardised scale concerning person-centredness, which allows quality improvement instrument in the community support of older adults with mental health problems. The scale is a holistic approach

to services offered and allows a tailored approach for personal care to each individual. The final study is a two-part evidence synthesis of home support for dementia care which identified interventions designed to aid both carer and person with dementia. Stage 1 was an extensive overview identifying existing interventions irrespective of the setting in which they were conducted. The second part is a systematic literature review designed to provide information to guide practice in home support.



## Specialist mental health outreach to older residents in care homes: national surveys

### Background

Two national surveys were undertaken: Community Mental Health Teams for Older People (CMHTsOP) and Care Homes. Both described existing patterns of specialist mental health outreach for older care home residents and detailed manager perspectives of the quality and sufficiency of this care. The surveys were informed by a systematic literature review which explored the patterns of specialist mental health care home outreach service delivery and organisation in the UK.

### CMHTsOP survey

A national cross-sectional survey of all CMHTsOP in England was undertaken in 2011/2012 to provide an overview of the nature and extent of the mental health support provided to care homes for residents with depression and dementia. Data were collected via a questionnaire sent to managers on the following key areas:

- Outreach activities provided by CMHTsOP staff
- Professional involvement of external groups (for example GPs or pharmacists)
- CMHTsOP managers' views of mental health provision provided to care homes

### Care Home survey

A questionnaire was developed to determine the sufficiency and quality of mental health support received by care homes for residents with depression and dementia from external health-care services. The Care Quality Commission provided a list of 1000 care homes. The research team stratified this list to include care homes with and without nursing and provision for people with dementia. These were completed by managers in 2011/2012.

### Some key findings

Questionnaires were received from 231 CMHTsOP managers, a response rate of 55 per cent. Almost all (97%) reported that their team offered support to care home residents but this varied in intensity and type. Only one-third of staff had dedicated ring-fenced time for care home outreach activities and the staff groups undertaking this were mainly old age psychiatrists and community psychiatric nurses.

A relatively high proportion of managers reported their teams undertook both mental health and medication use reviews. Most did not commonly undertake systematic case finding nor run open clinics, however, they regularly visited care homes and provided telephone advice. Just over two thirds reported that teams had processes in place for the initiation, review and cessation of antipsychotics for residents with dementia. Most (85%) felt that care home staff did not have the skills to care for older people with mental health problems yet only 41 per cent of teams provided formal training to these staff.

Three hundred and ninety one questionnaires (40%) were returned by care home managers. Only a low proportion (18%) reported they were able to refer residents directly to mental health services, rather than through the GP. More mental health support to care homes was provided by GPs and community psychiatric nurses with less by specialist mental health practitioners. Most (85%) managers rated the quality of mental health support to their care home as at least 'fair'.

There was low overall provision of education and training within care homes from external health professionals and only one-third of homes were confident that their staff were appropriately trained to care for residents with mental health needs.

Differences were evident between the categories of homes (with and without nursing and provision for people with dementia) but were mainly as might be expected. However, an interesting finding was more care homes

with nursing and no people with dementia rated the mental health support received as 'poor' and overall did not receive enough support for residents' mental health needs.

### Conclusion

A comprehensive overview of mental health support for older people in care homes was provided by these two surveys. Both revealed that regular training for care home staff was viewed as insufficient and was mainly provided by means of one-off events. Case-finding (early diagnosis and treatment for older people with dementia) despite its importance was uncommon in both surveys.

Care home managers were less able to provide prevalence figures for the early screening for depression and reported less use of standardised screening tools. Difficulties in accessing mental health services were noted by care home managers, largely due to their inability to refer residents directly to CMHTsOP.

They also stated that their staff did not have the skill to care for older people with mental health problems. Both surveys revealed a lack of confidence about the capacity of care home staff to meet the mental health needs of older residents.

These findings suggest that specialist mental health outreach support services could in future refocus on building the skills and confidence of care home staff.

### Other reference

Challis, David, Tucker, Sue, Wilberforce, Mark, Brand, Christian, Abendstern, Michele, Stewart, Karen, Jasper, Rowan, Harrington, Val, Verbeek, Hilde, Jolley, David, Fernandez, Jose-Luis, Dunn, Graham, Knapp, Martin & Bowns, Ian (2014) National trends and local delivery in old age mental health services: towards an evidence base: a mixed-methodology study of the balance of care approach, community mental health teams and specialist mental health outreach to care homes. *Programme Grants for Applied Research*, 2 (4). pp. 1-480.

# Measuring Person-Centredness: The Development of a New Care Quality Scale for Older Adult Community Mental Health and Social Care Services

'Person-centredness' is a widely-used term across the health and social care system often used to signify high quality services closely aligned to individuals' needs and preferences. Researchers often turn to proxy indicators or ad-hoc satisfaction instruments which are found to be inadequate for the task.

Existing measurement to support Community Mental Health Team (CMHT) service improvement is weak, with a particular bias against the priorities of older adults. Consequently, these measures offer very little of value to service managers, practitioners or older adults themselves. However, in the absence of obvious alternatives, especially since general satisfaction schedules have been criticised conceptually as lacking validity amongst older adults (Owens & Batchelor 1996), a new schedule is required to match the importance of the service user experience in policy and legislation.

Research into the effectiveness of person-centredness is severely hampered by a similar lack of appropriate measures. Existing instruments appear unsuited to older adults with mental health needs, and alternative 'proxy' measures have questionable value. In a recent review of expert opinion in the field of person-centredness, poor quality measurement was identified as a priority theme for action (Harding et al. 2015). Without being able to measure person-centredness accurately, it proves impossible to model pathways through which it may lead to improved health outcomes. Fundamentally, the weakness in existing models lies in the absence of the service users' voice in their design.

This research aimed to develop and test a new multi-item measure of person-centredness for use in both research and as a quality improvement instrument in the community support of older adults with mental health problems. Questionnaire items were sourced from a group concept mapping approach with service users based on how they defined good care experiences. These were refined and tested face-to-face with 14 service users and carers and a questionnaire with 30 items was then tested in a postal mailing, with 636 replies (a response rate of 29 per cent) from

older adults using community mental health services.

The research produced a standardised scale with 12 items, titled the PERson Centred Care Instrument (PERCCI). The study found that the PERCCI had the following properties:

- It is 'essentially unidimensional', meaning that the 12 different questions in the PERCCI all measure one aspect of care quality. This was established using a bifactor model.
- It is a reliable measure, meaning that it produced stable results when comparing two PERCCI scores for the same person taken a short interval apart. This was found using a test-retest reliability method.
- It is a continuous measure, meaning that the PERCCI can be used to estimate sample means, standard deviations and parametric hypothesis tests. This was established using Rasch Analysis.
- It appears to be a 'concurrently valid' measure, meaning that it behaves the way we expect it would when being compared with other measures. This was tested with the Friends and Family Test and a satisfaction measure.

Using the PERCCI, it was found that respondents being supported by home care workers reported significantly poorer person-

centredness in care than other respondents. This indicates that home care quality is felt to be relatively impersonal, inflexible and lacking in the features of person-centredness so highly valued by service users. By comparison, where specialist support workers from community mental health teams were part of a person's care, respondents reported far greater person-centredness than others.

Important questions left unanswered include how much improvement in the PERCCI score would be meaningful to service users, and is the PERCCI associated with actual improvement in care outcomes.

## Other references

Harding, E., Wait, S. & Scrutton, J., (2015). **The State Of Play In Person-Centred Care: A Pragmatic Review Of How Person-Centred Care Is Defined, Applied And Measured.** London: *The Health Policy Partnership*. Available at: [www.healthpolicypartnership.com/wp-content/uploads/Stateof-play-in-person-centred-care-full-report-Dec-11-2015.pdf](http://www.healthpolicypartnership.com/wp-content/uploads/Stateof-play-in-person-centred-care-full-report-Dec-11-2015.pdf)

Owens, D. & Batchelor, C. (1996). **Patient satisfaction and the elderly.** *Social Science and Medicine*, [274] 42(11): 1483–1491.

Wilberforce M, Davies L, Roberts C, Kelly MP, Challis D & Loynes N (2016). **Person-centredness in the care of older people: a systematic review of questionnaire-based scales and their measurement properties.** *BMC Geriatrics*. 16(63): 1-12.

**Table 1. Question and their relating property of investigation**

Question	Measurement property
... take what I have to say seriously	Friendly, caring and respectful interactions
... treat me with kindness, as though I matter to them	Friendly, caring and respectful interactions Reciprocity in care relationship
... can tell my good days from my bad day	Understand the personal experiences of illness/disability
I feel I have developed a close connection with ...	Reciprocity in care relationship
... understand the areas of my life that I need help with	Knows the different dimensions of life requiring support
I am given enough time to say everything that I want to say	Friendly, caring and respectful interactions
I am helping to keep in touch with my local community	Person is involved in decision-making process
I get help with the things that are most important to me	Knows the different dimensions of life requiring support Person's wishes shape decisions and care plans
My opinions about my care and support are respected	Person's wishes share decisions and care plans
... helps me to feel optimistic about what I can still do	Positive attitude to person's capabilities and roles
... helps me build confidence	Positive attitude to person's capabilities and roles



# Effective Home Support in Dementia Care: Evidence Synthesis of Home Support Interventions

Dementia is a major public health concern with a growing number of people affected by the condition. Home support for people with dementia and their carers is an important element of care since an estimated 60 per cent of people with dementia live in private households. It includes the contribution of informal carers (spouses or children), estimated to provide about 40 percent of care (Schneider et al., 2003), and formal support from professionals and support workers. Although many dementia home support interventions have been reported (e.g., Samus et al., 2014; Vernooij-Dassen et al., 2000), their efficacy requires investigation. In particular, it is unknown which components, of these interventions might offer the greatest benefits.

The PSSRU was commissioned by the National Institute for Health Research (NIHR), Programme Grants for Applied Research, to investigate home support in dementia, through a five-year research programme. As part of this, an evidence synthesis of home support for dementia care was undertaken to explore these issues (Clarkson et al., 2016). The synthesis was undertaken in two stages:

- In Stage 1, an overview of evidence for the effectiveness of psychosocial interventions to people with dementia and their carers was appraised to identify their components, irrespective of the setting in which they were conducted.
- In Stage 2, support provided to people with dementia and their carers at home was investigated through a systematic literature review. Overall, the evidence synthesis was intended to provide information to guide practice in home support and assist in the commissioning and redesign of multidisciplinary approaches to the care of older people with dementia and their carers.

Stage 1 found 36 systematic reviews of psychosocial interventions for dementia. For people with dementia, there was evidence of effectiveness for cognitive stimulation and cognitive training; but less evidence for sensory stimulation, reminiscence, staff education, behavioural therapy, and training in activities of daily living. For carers, there was evidence of effectiveness for education and training, psychotherapy and counselling. Few interventions were undertaken with people with dementia and their carers living at home. From these interventions, 14 components were identified, nine for people with dementia and five for carers (Table 1).

Stage 2 identified 70 evaluations of home support interventions. Most of these reported positive outcomes, although the interventions themselves were very varied, with differing outcome measures and sometimes were based on small samples. Studies had a variety of objectives and research designs and the quality of descriptions of the interventions

varied. Almost all interventions were directed towards family carers: either as a primary focus (N=33) or with people with dementia (N=35). Two studies focused solely on people with dementia. The Stage 2 review investigated the extent to which the components identified in Stage 1 were present in different models of support for people with dementia and carers delivered at home.

There were 14 single-component and 52 multi-component carer interventions and 21 single-component and 15 multi-component interventions for people with dementia. Home support interventions were discerned, which combined the components in different ways, to either carers or people with dementia. For carers, seven interventions were identified from grouping the components. Education/advice and behaviour management were the most frequent components for carers, and were often jointly employed. Information and advice was frequently provided alongside behavioural techniques, whereby carers are educated about the possible causes of their relative's behaviour problems. For people with dementia, two interventions were identified: one focusing on care coordination and the other on environmental modifications.

Together these interventions covered over four fifths (81%) of the studies in the Stage 2 review. A range of staff were employed in undertaking the interventions, including professionally and non-professionally qualified personnel and researchers. The key to designing more effective home support for dementia is to recognise that interventions will be based on a range of underlying components, whose actions combine to produce desired effects for people with dementia and their carers. This evidence synthesis has begun to discern the components included in many published evaluations of home support services for

dementia. The next step will be to combine this evidence together in a toolkit with which to synthesise the evidence for home support, providing guidance to managers and commissioners in the NHS and partner agencies.

## For further information, visit:

<http://research.bmh.manchester.ac.uk/pssru/research/DementiaHomeCare/EvidenceSynthesis/>

## Other references

Clarkson, P., Giebel, C.M., Larbey, M., Roe, B., Challis, D., Hughes, J., Jolley, D., Poland, F., Russell, I. & Members of the HoSt-D (Home Support in Dementia) Programme Management Group (2016). **A protocol for a systematic review of effective home support to people with dementia and their carers: components and impacts.** *Journal of Advanced Nursing*, 72, 186-196.

Samus, Q.M. et al. (2014). **A multidimensional home-based care coordination intervention for elders with memory disorders: the Maximizing Independence at Home (MIND) pilot randomized trial.** *American Journal of Geriatric Psychiatry*, 22(4), 398-414.

Schneider, J., Hallam, A., Islam, M.K., Murray, J., Foley, B., Atkins, L., Banerjee, S., Mann, A. (2003). **Formal and informal care for people with dementia: variations in costs over time.** *Ageing and Society*, 23(3), 303-326.

Vernooij-Dassen, M., Lamers, C., Bor, J., Felling, A. and Grol, R. (2000). **Prognostic factors of effectiveness of a support program for caregivers of dementia patients.** *International Journal of Aging and Human Development*, 51(4), 259-274.

Table 1

Component definition	Constituent elements
<i>For person with dementia</i>	
Sensory enhancement/relaxation	To increase or relax the overall level of sensory stimulation in the environment to counterbalance the negative impact of sensory deprivation/stimulation common in dementia.
Social engagement	To provide access to different forms of social contact to counterbalance the limited contact with others that may be characteristic of the experience of dementia. This social contact may be real or simulated.
Cognitive training	To provide enhancement and stimulation of cognitive functions through guided practice on a set of standard tasks, reflecting memory, attention or problem solving.
Emotional support	To address feelings and emotional needs through prompts, discussion or by stimulating memories and enabling the person to share their experiences; undertaken to counterbalance and help people manage difficult feelings and emotions.
Physical activity	To provide structured activities and/or exercise to provide meaningful and engaging experiences that can be a useful counterbalance to difficult behaviours.
Environmental modifications	To modify the living environment, including the visual environment, in order to lessen agitation and/or wandering and promote safety.
Behaviour management	To increase pleasant events and/or to identify and modify factors which lead to difficult behaviours or their consequences through distraction or communication.
Daily living assistance	To assist with basic care, e.g. provision of laundry services, basic nutrition and help with activities of daily living.
Care co-ordination	Connecting and bringing together different services around the person; advising on and negotiating the delivery of services from multiple providers on behalf of the person to provide benefit.
<i>For carer</i>	
Education/advice	Structured presentation of information concerning the condition and carer-related issues (e.g. legal issues, carer's health), including an active role for carers, e.g. role-playing.
Social support	The opportunity to share personal feelings and concerns and overcome feelings of social isolation.
Behaviour management	Education on techniques to identify and modify beliefs and develop new repertoires of behaviour to deal with behavioural challenges of the person with dementia.
Emotional support	To resolve pre-existing personal problems that can complicate caregiving and that can reduce conflicts between caregiver and person with dementia.
Respite	Planned, temporary relief through the provision of substitute care, e.g. day care, in-home sitting, residential care for the person with dementia.

# Recent Publications

## **Is integrated care associated with service costs and admission rates to institutional settings? An observational study of community mental health teams for older people in England**

Wilberforce, M, Tucker, S, Brand, C, Abendstern, M, Jasper, R & Challis, D (2016). *International Journal of Geriatric Psychiatry*, 31(11): 1208–1216.

The study aimed to evaluate the association between the degree of CMHT integration, the service costs of community mental health and social care provisions, and rates of admission to institutional settings (mental health inpatient wards and care homes). An observational study explored the costs of service receipt and rates of admission to mental health inpatient beds and care homes for a prospectively sampled cross-section of CMHT service recipients. Analyses compared patients on the caseloads of CMHTs categorised as 'high' and 'low' integration teams, with data collected at two time points.

The need for closer coordination between specialist mental health and social care is regarded as axiomatic in the long-term care of older adults with mental health problems. Yet given the considerable national and international attention devoted to its achievement, and the organisational and financial obstacles to success, it is legitimate to demand a more rigorous evidence-base to inform this ambition than currently exists.

It is widely presumed that the integrated mental health and social care team is the optimal organisational model to deliver high quality, person-centred care. Yet systematic reviews have highlighted the paucity of available evidence to support its elevated status in national and international fora. This new research compared the costs of service use and admissions to institutional care between patients seen by 'high' and 'low' integration CMHTs.

## **A systematic review of the economic evidence for home support interventions in dementia**

Clarkson, P, Davies, L, Jasper, R, Loynes, N, Challis, D & Home Support Dementia Group (2017). *Value in Health*, DOI: 10.1016/j.jval.2017.04.004

Recent evidence signals the need for effective forms of home support to people with dementia and their carers. However, the cost-effectiveness evidence of different approaches to support is scant.

A systematic literature review of full and partial economic evaluations was performed using the British National Health Service Economic Evaluation Database supplemented by additional references. Study characteristics and findings, including incremental cost-effectiveness ratios, when available, were summarized narratively. Study quality was appraised using the National Health Service Economic Evaluation Database critical appraisal criteria and independent ratings, agreed by two reviewers. Studies were located on a permutation matrix describing their mix of incremental costs/effects to aid decision making.

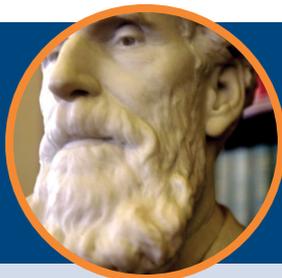
This review identifies three approaches for which there is positive cost-effectiveness evidence: occupational therapy, home-based exercise, and a carers' coping intervention. In particular, the approaches rely on the active components of environmental modifications, behaviour management, physical activity, and emotional support. However, better quality data is needed to judge the value of these and other interventions at particular points along the dementia care pathway. In particular, economic evidence of new approaches in early-stage dementia, such as home-based cognitive training, and in late stage, such as palliative care, is required.

## **People with dementia and carer preferences for home support services in early-stage dementia**

Chester, H, Clarkson, P, Davies, L, Sutcliffe, C, Davies, S, Feast, A & Hughes, J (2016). *Aging and Mental Health*, DOI: 10.1080/13607863.2016.1247424

At present, the cost of dementia in the UK is estimated at £26.3 billion and by 2026, the cost will rise to £34.8 billion in the UK. The immediate priority remains helping people to live well with dementia, through developing interventions likely to better difficulties and enhance well-being.

In this study, a discrete choice experiment (DCE) was conducted to establish the relative value of different attributes of home support from the perspective of both people with early-stage dementia and their informal carers. A key stage in the design of the DCE for this study was ensuring that relevant attributes (or components of the intervention) and levels were included and that these were described in a meaningful way. This was done by reviewing available literature in order to generate an initial list of attributes and levels for the DCE. Next, consultation meetings were held with two patient and public involvement reference groups in May 2015 to identify those attributes that were particularly salient to people in early-stage dementia and their carers. Seven attributes were selected for the DCE and the description of the attributes and levels were informed by the consultation groups. The main findings of this study are that, in early stages of dementia, the most preferred attributes for home support were support with personal feelings and concerns – provided by a trained counsellor at home and information on coping with dementia – provided by an experienced worker at home.



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