Challenge Demcare: management of challenging behaviour in dementia at home and in care homes – development, evaluation and implementation of an online individualised intervention for care homes; and a cohort study of specialist community mental health care for families

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Scientific summary

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Scientific summary

Background

The aim of this programme was to study the management of challenging behaviour (CB) in people with dementia living at home and in care homes. CB associated with dementia includes a wide range of symptoms and behaviours. Often it is a manifestation of distress experienced by that person, whose cognitive impairment increasingly limits their ability to carry out desired actions, to express their needs or to inhibit their own behaviour.

The phenomena are also referred to as neuropsychiatric symptoms (NPSs) or behavioural and psychological symptoms of dementia (BPSD). These concepts acknowledge the psychological suffering in people with dementia, but are limited in their reach of the multiple interacting contextual factors around BPSD, some of which have little to do with dementia itself. Other health, psychosocial and environmental factors can contribute to an episode of CB. For example, undetected discomfort because of pain can result in resistance to care or misunderstanding of need and the way care is carried out can precipitate an episode of aggression.

Therefore, we defined CB as 'a manifestation of distress or suffering for the person with dementia or of distress in a carer or others, thus threatening the quality of life of one or both parties'.

Overall, two related but distinct programmes of work were planned, with development work leading to two cluster randomised trials (CRTs). These were set within the real world of 63 care homes with 861 care staff, and in seven large specialist NHS mental health organisations across England, with 33 mental health teams who provided care to people with dementia and CB living at home.

The first CRT (ResCare) and its embedded process evaluations examined an intervention of e-learning and e-tool decision support for 'action plans' to assist staff in care homes in the effective management of people with dementia and clinically significant CB. The second study (FamCare) aimed to assist specialist community mental health practitioners working with families to deliver such interventions for people with dementia and clinically significant CB living in their own homes, and to evaluate this within a CRT.

The FamCare CRT could not proceed because of a lack of referrals from the community mental health teams for older people (CMHTsOP) that were commissioned to support home-dwelling people with dementia and CB. At the start of recruitment, continuing for an average of 31 weeks, 33 CMHTsOP across seven NHS organisations received 5360 new referrals; only 452 (8.4%) patients referred had dementia and were potentially eligible for this study. The remaining profiles of those referred to CMHTsOP for specialist mental health care were no dementia diagnosis, but other mental health conditions present ($n = 198$, 37%); resided in care homes ($n = 1190$, 22%); dementia, but no informal carer ($n = 307$, 5.7%); or had died or had been admitted to hospital before evaluation ($n = 41$, 0.8%). A further 25.8% of new cases ($n = 1385$) were signposted elsewhere before being assessed by the CMHTsOP.

Therefore, the FamCare CRT, to study the management of dementia with clinically significant CB in families, continued as an observational cohort study in six NHS organisations. Recruitment was slow, continuing for 15 months, with ongoing stakeholder consultations across each NHS organisation. Later recruitment strategies resulted in 16.6% of participants being located in newly emerging Memory Assessment Services and memory clinics.

Rationale for the intervention

The intervention was refined from the behaviour management literature that was outlined in the 2007 National Institute for Health and Care Excellence (NICE)–Social Care Institute for Excellence (SCIE) National Clinical Practice Guideline Number 42 as 'behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers' (National Collaborating Centre for Mental Health. *Dementia: A NICE–SCIE Guideline on Supporting People with Dementia and their Carers in Health and Social Care*. Leicester: The British Psychological Society and the Royal College of Psychiatrists; 2007. p. 260). We updated this with a Cochrane review (Moniz Cook ED, Swift K, James I, Malouf R, De Vugt M, Verhey F. Functional analysis-based interventions for challenging behaviour in dementia. *Cochrane Database Syst Rev* 2012;**2**:CD006929), which concluded that functional analysis-based interventions continue to show promise. These interventions essentially involve a biopsychosocial approach to assessment, analysis and systematic testing, with adjustment, where necessary, of the most relevant interventions for a particular case of CB. The approach is also known as individualised formulation-led intervention (Holle D, Halek M, Holle B, Pinkert C. Individualized formulation-led interventions for analysing and managing challenging behavior of people with dementia – an integrative review. *Aging Ment Health* 2016;**10**:1–19) and is usually algorithmic to enhance case specificity.

To widen the scope for delivery of interventions for the management of CB in dementia, we considered an online application of intervention algorithms based on functional analysis. This was because a review, unrelated to the dementia literature, of computerised clinical decision support systems by Garg *et al*. (Garg AX, Adhikari NK, McDonald H, Rosas-Arellano MP, Devereaux PJ, Beyene J, *et al.* Effects of computerized clinical decision support systems on practitioner performance and patient outcomes: a systematic review. *JAMA* 2005;**293**:1223–38) suggested that these may improve practitioner performance, but the effects on patient outcomes were understudied. In addition, a survey by Flint and Cream in 2014 (Flint V, Cream J. E-learning: does it work in dementia care? *J Dement Care* 2014;**22**:22–5) suggested that care staff were enthusiastic about e-learning opportunities about dementia care.

We were interested in determining whether or not the training provided by the bespoke e-learning would permit staff to utilise clinical protocols effectively with minimal supervision and support. In essence, we were building on preliminary work in the dementia literature that had separately demonstrated the value of clinical algorithms, and current interest in and the use of e-tool technology. If successful, we would have produced a cost-effective programme that enabled staff to assess problematic presentations; identify causes and underlying needs; develop appropriate care plans; and, based on the learning from the earlier training modules, execute the plans effectively, with minimal external supervision.

The intervention

The interactive online intervention comprised an e-learning course and two suites of decision support systems for the targeting of individualised interventions for CB in dementia: one for staff in care homes and the other for staff supporting family carers in the community.

Three e-learning modules introduced staff to observational skills and the algorithmic approach to intervention choice. The decision support system comprised relevant assessment tools to collect information of key contributory factors associated with CB, such as the person's current health and functional status, their life story, interpersonal and communication style and how others respond to the person during an episode of CB. Algorithms provided two sets of biopsychosocial groups of action plans, extracted from the literature as ways of meeting the person's health and/or psychosocial need. Actions for the third component arose from a new concept derived from our overview of the needs of the caregiving system. These were bespoke to the needs of family carers (Feast A, Orrell M, Charlesworth G, Melunsky N, Poland F, Moniz-Cook E. Behavioural and psychological symptoms in dementia and the challenges for family carers: systematic review. *Br J Psychiatry* 2016;**208**:429–34) and care home staff.

The ResCare trial and the FamCare study

We screened 2386 residents living in 63 care homes for people with dementia and CB. In all, we trained 92 care staff, from 27 care homes in Yorkshire, and 26 senior mental health practitioners, from six specialist mental health NHS organisations across England, in functional analysis to manage CB in dementia.

We then (1) developed and tested a computerised intervention; (2) conducted a CRT of this in care homes; (3) conducted a process evaluation of its implementation; and (4) conducted a longitudinal observational cohort study of 'usual care' (from CMHTsOP) for the management of people with dementia with CB living at home.

Study 1: development and testing of an online application of functional analysis approaches to intervention for challenging behaviour in dementia

Method

An e-learning course and two decision support e-tools were developed to help staff to use functional analysis-based interventions for up to 25 commonly reported CBs in dementia. The intervention was tested with 92 nominated 'staff champions', from 27 care homes, and 26 community mental health practitioners, from six NHS organisations across England.

Results

The course was well received and strongly recommended by care home staff champions ($n = 92$), but only when this occurred at an external venue, with opportunity for facilitated discussion and practice. Although freely available within homes, e-learning take-up by other staff was limited. Staff selected as champions by their managers were on average younger [$t(606) = 2.12$; $p = 0.032$], had higher educational attainment (Fisher's exact test; $p = 0.0448$) and were more likely to have had dementia training ($\chi^2 = 4.38$; $p = 0.036$) than others at the care homes. E-tool-assisted action plans were developed for 199 residents with CB. Immediately after training, staff appeared to have expanded the way they viewed some behaviour. They were less likely to perceive behaviour as 'challenging', with a significant reduction in ratings of CB following training [$t(178) = 7.4$; $p < 0.001$]. Community mental health practitioners, who tested the community decision support system for their home-dwelling patients with CB, valued its logical assessment framework and the 'if–then' algorithmic method for choosing potentially helpful case-specific interventions.

Conclusions

Worksite-based e-learning opportunities are not readily taken up by staff in care homes. Computerised decision support for interventions for CB appear premature in care homes, but show promise for training community dementia practitioners. However, usability will depend on successful collaboration between clinical experts, information technology advisors within NHS organisations and software engineers.

Study 2: Challenge ResCare – a cluster randomised trial of the effectiveness and cost-effectiveness of online training and decision support for care home staff to deliver functional analysis-based interventions for challenging behaviour in dementia

Design and methods

A CRT allocating 63 care homes in Yorkshire between intervention and usual care. The primary outcome was measured by the Neuropsychiatric Inventory (NPI) using frequency and severity scores taken at 4 months to examine whether or not the intervention reduces CB in dementia. Secondary outcome measures ($n = 21$) monitored both residents and staff and included resident quality of life, measured using the EuroQol-5 Dimensions. The statistical model for effectiveness analysed follow-up scores by treatment group,

corresponding baseline scores and other covariates for both residents and care home. Resources used by residents with CB were costed by adapting the Client Service Receipt Inventory (CSRI) to focus on health and social care over 4 months and assuming no marginal change in care home resources, as these are less likely to change and more difficult to cost.

Results

Eight hundred and thirty-two residents (555 with CB) and 609 care staff at baseline were reduced to 658 (79%) residents [428 (77%) with CB] and 436 staff (72%) at follow-up. The NPI showed that the intervention reduced the frequency of NPSs by 0.60 relative to treatment as usual, but this finding was not statistically significant. Though the intervention also reduced the severity of those symptoms by 0.45 [95% confidence interval (CI) –1.03 to 1.93], this also lacked statistical significance. Although 14 of the 21 secondary outcome measures showed positive effects of the intervention, none reached statistical significance. Furthermore, the intervention generated little change in the prescription of drugs relevant to dementia – notably antipsychotics ($\chi^2 > 0.999$), antidepressants ($\chi^2 = 0.635$), hypnotics and anxiolytics ($\chi^2 = 0.215$), anticonvulsants ($\chi^2 > 0.999$) and the anti-dementia drugs (such as the cholinesterase inhibitors) ($\chi^2 > 0.999$), or those for pain relief, both the opioids ($\chi^2 = 0.399$) and the non-opioids ($\chi^2 = 0.996$). Hence, there is no evidence that the intervention changed the care of CB in dementia. Health- and social-care costs over 4 months did not differ significantly between groups (mean cost was £331 lower in the intervention group, with bootstrapped 95% CI from –£927 to £272), and staff reports of quality-adjusted life-years over 4 months differed little between groups. Hence, there is no evidence that the online intervention was cost-effective.

Conclusions

This computer-assisted intervention was neither effective nor cost-effective. Comprehensive e-learning and assisted decision support to provide case-specific interventions for residents with dementia and clinically significant CB were not enough to reduce clinically significant CB in dementia in care homes.

Study 3: Challenge ResCare – a process evaluation of the implementation of e-tools for the management of dementia with challenging behaviour in care homes

Methods

Normalisation process theory and framework analysis were used in a re-analysis of ResCare study data to examine how innovations may become embedded in everyday work. Barriers to, and facilitators of, change in care homes were studied by considering 'process problems' in social care settings, and 'structural problems' affecting the integration of new systems into those settings. Following analysis of contextual data collected during the trial for the intervention homes, a typology of 'organisational cultures' for the computer-assisted intervention was developed. From this, four 'case study' homes were extracted and seven participants from a sample of 14 were individually interviewed. These participants included home managers, senior care staff and care assistants. A specialist dementia care intervention therapist and a research nurse, who collected data during the study, were interviewed together. Nine additional qualitative interviews with care home staff included those from the control condition, and three focus groups using nominal group techniques with a maximum variation sample ($n = 22$) of wider stakeholders, provided opportunities to consider how far the findings of the ResCare trial resonated with their experiences and how they interpreted the trial and its findings.

Results

Three explanatory themes for the findings of the ResCare trial emerged: variation in care home managers' trust of their staff; variation in the extent to which managers commissioned training; and variation in cultures of training and practices within care homes. The findings also suggest that care homes are not ideal environments for implementing new approaches, but implementation can be feasible in smaller care homes and in those with less hierarchical structures.

Conclusions

The implementation of interventions for the management of CB and dementia depends on the readiness of care homes to invest in innovation. Capable leadership and collective willingness are also important. The toolkit developed for implementing online interventions in care homes has scope for informing future practice innovations and research.

Study 4: Challenge FamCare – an observational study of people with dementia and challenging behaviour living at home and their carers

Aim

To describe the characteristics and resource use and changes over time over 6 months of a cohort of people with dementia and CB living at home, and their carers, referred to specialist community mental health NHS services for older people across England; and to elicit stakeholder views on CB service provision and about the findings from the cohort study.

Design and methods

Cohort study of people with dementia referred for CB to six NHS mental health organisations. Participants were people who met the diagnostic criteria for dementia and CB and their carers (dyads). The primary outcome measure was the Revised Memory and Behaviour Problems Checklist at baseline and at 2 and 6 months; and the extent and cost of formal and informal care – using an adapted CSRI and NHS records of contacts with specialist mental health practitioners. Secondary measures included quality of life for the person with dementia and the family carer; and distress, guilt, mood and coping (sense of competence) in the family carer. Stakeholders debated emerging findings.

Results

Over 15 months we recruited 157 dyads (154 included family carers), among which 61% of those with dementia had mild dementia with clinically significant CB; we followed up 126 dyads at 2 months and 117 dyads at 6 months. Dyads had an average of nine contacts with mental health practitioners over 6 months, but there was little overall change in levels of CB. Increased contact with practitioners significantly reduced levels of guilt ($p = 0.016$) among carers. There was significant variation in trends for CB among dyads, but no stable clusters of those who improved, remained the same or deteriorated over time were identified. Family carers estimated that they devoted an average of 112 hours a week to providing care at baseline, rising, though not significantly, to 129 hours at 6 months. They contributed over 80% of the total estimated cost of care. Stakeholder consultations revealed concerns about the equity of access to CB services for these carers.

Conclusions

People living at home with mild dementia can present with clinically significant CB. CB fluctuates for some, even over a short 6-month period. Families require trained practitioners, irrespective of where dementia service pathways are located, to systematically assess their varied needs and provide timely patient-specific interventions. Commissioning practice should reconsider the priority given to specialist assistance for families experiencing CB.

Discussion: key findings, limitations and conclusions

The research was about the management of dementia and clinically significant CB. Therefore, we used setting-specific measures and cut-off points for clinically significant CB, for both care home and family care studies.

Our attempt to produce a cost-effective online program that enabled staff to manage dementia with clinically significant CB in care homes with minimal external supervision was not successful. Aside from the

significant difficulties we encountered with technology, a key limitation was lack of data comparing algorithm-led clinical protocols for functional analysis-based interventions used by therapists with the online intervention.

However, a related important limitation, and an implication for practice and future research, surrounds the combination of support required for the delivery of functional analysis-based interventions in care homes. An Australian study by McCabe *et al.* (McCabe MP, Bird M, Davison TE, Mellor D, MacPherson S, Hallford D, *et al.* An RCT to evaluate the utility of a clinical protocol for staff in the management of behavioral and psychological symptoms of dementia in residential aged-care settings. *Aging Ment Health* 2015;**19**:799–807) using a clinical protocol for functional analysis delivered by trained dementia practitioners found that, compared with other conditions (i.e. training, clinical support and clinical protocol alone), the clinical protocol plus clinical support showed the most sustained effectiveness. The staff training literature for CB also concludes that the most beneficial training interventions are those combined with additional on-site visits, so care staff can have clinical supervision to work with individuals (Fossey J, Masson S, Stafford J, Lawrence V, Corbett A, Ballard C. The disconnect between evidence and practice: a systematic review of person-centred interventions and training manuals for care home staff working with people with dementia. *Int J Geriatr Psychiatry* 2014;**29**:797–807). A trained practitioner is usually required, as a key skill in working in this area is the ability to be flexible and have the capability to alter care plans as new needs arise. Therefore, the process remains iterative, but the functional analytical skills remain at the core of the plan. Many of the UK's specialist CB teams, which were conceived using the Newcastle clinical protocols (James IA. *Understanding Behaviour in Dementia that Challenges: A Guide to Assessment and Treatment*. London: Jessica Kingsley; 2011), now use a 12-week protocol when treating BPSD, with the final 6 weeks being a monitoring/support phase for the implementation of the care plan. The interventions included in our Cochrane review also used external clinical support, with access to multidisciplinary medical and psychologist expert professionals where the intervention phase was 4, 6 or 10 months. Specialist support following training to support staff in implementing care plans was described in some studies as occurring weekly or twice weekly.

Thus, we conclude that, as with staff training, e-learning does not, on its own, hold traction for the sustained reduction of CB in dementia in care homes. No one intervention can meet the case-specific needs of people with dementia and CB or the varying cultures and needs of staff in care homes. In addition to staff training, which may consist of online programs, clinical support from a practitioner trained in formulaic interventions remains a necessary ingredient for the management of dementia with clinically significant CB.

The Cochrane review found good evidence for functional analysis-based interventions conducted in family care settings. Relatively fewer studies conducted in care homes contributed to the evidence described. Our inability to deliver the intervention in wide-ranging NHS services was therefore disappointing, as was our observation of usual care from specialist services, where an average of nine clinical contacts over a 6-month period did not have an overall impact in reducing levels of CB. Families bear the majority of the care costs for dementia with CB, and stakeholder families reported difficulties in knowing when they were deserving of specialist support from the NHS. Furthermore, the changing landscape of NHS commissioning and practices may have undermined timely responses to dementia with CB. A care gap in the delivery of post-diagnostic help for families supporting relatives with dementia and significant CB at home has emerged.

Also disappointing, given the current policies to drive down the use of antipsychotics in dementia care (Banerjee S. *The Use of Antipsychotic Medication for People with Dementia: Time for Action.* London: Department of Health; 2009), was the overall suboptimal prescribing practices noted for both care home and family settings.

Future work

Priorities for a skilled NHS-led dementia workforce should shift from early diagnosis to early recognition and clinical support of family and staff carers supporting people with dementia and clinically significant CB. Caregiver contexts for delivery of interventions in care homes and family care are not equivalent. NHS service improvements, with separate resource bundles for care homes and family care support, may enhance the efficiency of delivery, and the quality of research on implementation into routine care.

High levels of CB were noted in family settings. There is an urgent need for evaluation of interventions for home-dwelling people with dementia with clinically significant CB.

Challenge Demcare has produced clinical protocols and resources for the recognition of clinically significant CBs and manualised guidance for practitioners to deliver such interventions. These require dissemination and further evaluative research across relevant pathways for both care home and home care settings.

There is scope for extending this intervention with additional communication and interaction training – CAIT [James IA. The use of CBT in dementia care: a rationale for Communication and Interaction Therapy (CAIT) and therapeutic lies. *Cogn Behav Ther* 2015;**8**:10] for carers.

Pilot work, extending the Newcastle clinical protocol, is currently ongoing. In this, specific CAIT has been added to the functional analysis approach to treatment within care homes. This will require future evaluation in care homes and family care settings. Realist evaluation (Wong G, Greenhalgh T, Pawson R. Internet-based medical education: a realist review of what works, for whom and in what circumstances. *BMC Med Educ* 2010;**10**:12) designs may illuminate how the intervention might work, and for whom, within the varying service contexts.

Trial registration

These trials are registered as Current Controlled Trials ISRCTN02553381 (the ResCare trial) and ISRCTN58876649 (the FamCare observational study).

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