Title: Comorbidity and dementia: a mixed method study on improving healthcare for people with dementia (CoDem)

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Scientific summary

Background

Dementia is a significant public health problem with far reaching health, social and economic impacts and the prevalence of dementia in the UK is set to rise significantly. Evidence suggests that amongst people with dementia there is a high prevalence of comorbid medical conditions and complaints but little is known about the effects of comorbidity on processes and quality of care, patient needs, or how services are adapting to address the particular needs of this population. Dementia is often viewed as an isolated condition with little understanding of how other complex health needs might impact on patient and carer experiences or service use and provision.

Aims

The overall aims of this study were to explore the impact of comorbidities, for a person living with dementia (PLWD), on access to non-dementia services and identify ways of improving integration of services for this population. We focused specifically on three conditions, diabetes, stroke and vision impairment (VI).

Methods

We used a mixed methods approach informed by theories of continuity and access to care. This included:

a. A scoping review of relevant literature, to map what is currently known about comorbidity and dementia
b. Cross-sectional analysis of the CFAS population cohort database (Cognitive Function and Ageing Studies) to explore health and social service use in people with a diagnosis of dementia and a comorbid medication condition
c. Qualitative study exploring the views and experiences of people with dementia and comorbidity, their family carers, and health care professionals
d. Consensus methods to help develop recommendations for practice

Results

Scoping review

We included 76 studies or reports that addressed issues around dementia and comorbidity, focusing on diabetes, stroke and VI. There was evidence of a lack of continuity in health care systems and structures for people with dementia and comorbidity, with little integration or communication between different teams and specialities. Thirty-one studies reported prevalence, either of one of our three target comorbidities in people with dementia or of dementia in people with stroke, diabetes or VI. Whilst heterogeneity in the populations and differences in the way that conditions were ascertained make comparisons across studies difficult the data do suggest that rates of diabetes in people with dementia may be between 13-20% and of stroke between 16- 29%. Of the 11 studies that compared access to treatment or receipt of services in groups with and without dementia, 10 found some evidence that people with dementia were less likely to receive the same quality of care or access to services compared to those without dementia.

Cognitive Function and Ageing Studies (CFAS)

In CFAS II the prevalence of dementia of those living in the community was 5.3%. Of these people with dementia 17% had diabetes, 18% stroke and 17% vision impairment. The aim of the CFAS II only analysis was to see whether there was any difference in service use by those with dementia and a target health condition when in comparison to either dementia alone or the health condition alone. Out of all the services unpaid care was the most commonly used service in CFAS II. When comparing unpaid care use by those with dementia and a target health condition to those with only the health condition, in every case unpaid care was used considerably more by those with dementia and a target health condition). As well as unpaid care, those with dementia and a target health condition also used a home care assistant, day centre and care worker more than those with the health condition alone. When comparing hospital service use by those with dementia and a target health condition to those with dementia alone, inpatient services were used more by those with dementia and a target health condition.

The comparison analysis between CFAS I and CFAS II looked at whether there were any differences in service use over the last decade. The main difference seen was in hospital service use which increased dramatically over this time due to the increase in use of day patient and outpatient services. There was also a marked increase in the use of unpaid care by those with dementia and either diabetes or vision impairment. However, the numbers of those with dementia and a target health condition were not large enough in the CFAS I ten year follow up wave to test this formally.

Interviews and focus groups

We conducted interviews with 28 people with dementia and 33 family carers, and focus groups or interviews with 56 health care professionals (HCPs) specialising in primary care or one of our three target comorbidities (diabetes, stroke, VI). Of the PLWD over 50% had diabetes, 45% had some form of vision impairment and 28% had had a stroke. Our two overarching themes were:

1) Negotiating continuity, including relationship, management and informational continuity,

2) Negotiating access to care, including appropriateness, comprehensiveness and equity

Negotiating continuity

The personal characteristics of HCPs, and the communication of information in a timely and sensitive manner, appeared to be key to developing a trusting relationship with a health care professional. The absence of a standardised approach to sharing information about a person's dementia and how it might affect the management of other conditions was a recurrent issue. This had implications for how appointments were planned and organised and how carers were involved. HCPs involved in delivering care for people with our target comorbidities commented that they were often unaware that someone had dementia. Instead informational continuity was often provided by family carers attending appointments and transferring information between specialities. We found little evidence of services developing processes to support informational continuity or using tools such as "This is Me" to support continuity of information.

Family carers often played a significant role in managing and coordinating the care of their relative; this sometimes involved having to learn new skills such as checking blood sugar or giving insulin injections. The transition from self-management to dependency could be gradual or sudden, and was often unpredictable or only understood in hindsight. Health care professionals we spoke to acknowledge the vital role that family carers play but from carers' accounts it was clear that this recognition did not translate into routine involvement or engagement of family carers in appointments or decision making about their family member.

Negotiating access

We found many examples where systems or environments had unintentionally blocked access to care for PLWD. For example, appointments made over the phone, long waits in busy clinic environments, tests that were not appropriate for PLWD, new technology introduced without proper explanation, lack of involvement of family carers, and a failure to engage with social care as the main source of support for PLWD at home. Despite evidence of awareness among staff that PLWD could need more time for consultations, clinic structures and pressures of patient numbers meant that there was generally little capacity to do this for PLWD. Pathways and guidelines for our three target conditions did not address the possibility of a dementia diagnosis or provide decision making support for practitioners trying to weigh up the risks and benefits of treatment for PLWD. Moreover many HCPs in our study reported that they felt underprepared to care for PLWD. There were examples of good practice but this tended to be about the behaviour of individual practitioners rather than system based approaches. Decisions about treatment for PLWD were made in the context of clinicians' attitudes and perceptions of dementia, and concerns about polypharmacy, consent, multimorbidity and concordance.

Conclusions

Significant numbers of people with dementia have comorbid conditions such as stroke, diabetes and vision impairment; and many of them have multimorbidities. The presence of dementia complicates the delivery of health care, and magnifies the known difficulties people with long term conditions experience when navigating health and social care. The situation is further complicated as some people will develop comorbidity in the presence of already

diagnosed dementia and others will develop dementia subsequent to a comorbidity such as diabetes, stroke or vision impairment.

The delivery of high quality care to patients with dementia demands a particularly high standard of care across multiple domains, including communication, multidisciplinary care, clinical decision-making and engagement with families and carers. Effective care for older patients with dementia will help set a standard of care of universal relevance to vulnerable adults. Good care for PLWD and comorbidity may vary according to the type of condition/s that they have. However, key elements include: the PLWD and family carer at the centre, flexibility around processes, good communication between services, ensuring that all services are aware when someone has a diagnosis of dementia, taking into account the impact of a diagnosis of dementia on pre-existing conditions, and incorporating this into guidelines and care planning.

There is already a great deal of descriptive work on the experiences of PLWD and their family carers. This study adds to that by providing information about the prevalence of comorbidities, service use amongst PLWD and comorbidity, and how having dementia impacts on the management of comorbid health conditions in PLWD. Below we discuss the implications for practice and provide a number of recommendations for research. We suggest that future work needs to focus on the development and evaluation of interventions rather than further descriptive work. People with dementia should be included in the debate about the management of comorbidities in older populations and there needs to be greater consideration given to including them in studies that focus on age related healthcare issues.

Implications for practice

- The evidence suggests that tools such as the 'triangles of care' model should be used to ensure the input of family carers is properly recognised. This should include the identification of family carers, appropriate training in carer engagement for staff, and policy and practice protocols regarding confidentiality and information sharing.
- Our study suggests that systems for booking appointments need to be made more 'dementia friendly' – for example not booking appointments by phone, sending

reminders, including nominated family carers in all correspondence (this may not be the primary carer if the primary carer is a spouse with memory problems)

- The evidence suggests that staff at all levels, including more senior staff, need appropriate training on dementia. Some training may need to be tailored to specific conditions – e.g. what are the best strategies for the rehabilitation of PLWD who have a stroke?
- Professional bodies for HCPs need to consider how current provision of dementia training on undergraduate programmes can be improved.
- HCPs in specialist areas are often unaware that someone has dementia. Our evidence suggests that a diagnosis of dementia should be flagged up on medical/electronic records. This should include systems for automatic updates of a dementia diagnosis to be transferred to health care services the PLWD is already attending
- PLWD who live alone or who do not have family support may be particularly disadvantaged, they may need additional help to navigate systems and access care
- Services should consider giving PLWD longer appointments, both in primary and secondary care
- PLWD may need a suitably trained staff member to help them navigate clinic environments; they may also benefit from assessments done by specialists visiting them in their own home or in their local GP surgery
- HCPs caring for people with cognitive impairment and long term conditions such as diabetes need to regularly assess patients' ability to self-manage and identify when they may need additional support.
- Evidence suggests that there is a need for better integration of physical and mental health care systems, i.e. old age psychiatry teams and geriatric teams working together and community based geriatric teams having specialist mental health as an integral part of the team
- Our study suggests that for PLWD and diabetes, who need support from health and social care, there is a need to link medication and monitoring of diabetes with the provision of meals
- The evidence suggests that PLWD and diabetes may not be getting regular eye and foot checks.

Recommendations for future research

Potential areas for future research identified by the study include the following:

- What makes a 'good' dementia Quality Outcomes Framework (QoF), for example what components should be routinely included and should they include physical health checks?
- What is the impact of providing PLWD and their family carers support, either from a professional or a trained lay person, to help navigate health care systems?
- What are the impacts on PLWD, family carers and other HCPs of specialist dementia nurses, such as Admiral Nurses, working in hospital and community settings?
- Is a collaborative care approach, with a case manager to provide integrated physical and psychological care, an effective approach to the provision of dementia care for PLWD and comorbidity and which population of people with dementia are most likely to benefit from CM and at what stage?
- What is the impact of dementia case finding for older people with stroke, diabetes and vision impairment, for example evaluating the use of case finding on admission to hospital or at first clinic appointment?
- What is the impact of expanding the 'this is me' document to include health related information?
- How can patients, carers and health care professionals be encouraged to use the 'this is me' document?
- What interventions can be used to improve medication management in PLWD, for example what is the impact of pharmacists doing short cognitive screening on older patients with multiple medications?
- Diabetes – how can HCPs caring for people with long-term conditions and dementia be helped to recognise when a person is no longer able to self-manage
- Diabetes - what is the impact of self-management interventions for diabetes that involve family carers of adults with diabetes and cognitive impairment?
- Diabetes – what is the impact of personalised glycaemic targets for PLWD on outcomes such as hypoglycaemic attacks, hospital admissions and falls?

- Stroke – what are the most effective and cost effective approaches to stroke rehabilitation for people with dementia?
- VI – How can tests for vision impairment be made appropriate or adapted for PLWD?
- VI – Is it possible to fast track PLWD for treatment such as surgery for cataracts and if so what are the impacts of this?
- VI - How can ophthalmology clinics and other health care environments be made to be more dementia friendly, so that they are suitable for people with vision impairment or sight loss as well as dementias?

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