Managing diabetes in people with dementia: a realist review

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Declared competing interests of authors: Antony Bayer was a member of the Health Technology Assessment (HTA) Dementia Themes Call Board from 2010 to 2011. Greta Rait is a member of the HTA Mental Health Methods Group and Panel. Jo Rycroft-Malone is the Director of the Health Services and Delivery Research (HSDR) programme and editor of the National Institute for Health Research HSDR journal. The authors declare no other financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years.

Published December 2017
DOI: 10.3310/hta21750

Scientific summary

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Health Technology Assessment 2017; Vol. 21: No. 75
DOI: 10.3310/hta21750

NIHR Journals Library www.journalslibrary.nihr.ac.uk

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Background

Dementia and diabetes mellitus are common long-term conditions that may coexist in a large number of older people. People with dementia may be less able to understand and manage their diabetes and may be at risk of complications such as hypoglycaemic episodes, cardiovascular conditions and amputations, which place a huge burden on health and social care economies. Moreover, the impact of dementia and diabetes on patients and their families is considerable. There is a need to consider what kind of programmes or interventions are needed for the effective management of diabetes in people with dementia, including how interventions work, for whom and in what contexts, and how interventions might be tailored to this patient group.

Objectives

The overall objectives were to identify key features or mechanisms of programmes and approaches that aim to improve the management of diabetes in people with dementia, to understand how those mechanisms operate in different contexts to achieve particular outcomes for this population, to make explicit the barriers to, and facilitators of, implementation and to identify areas needing further research.

Methods

The review followed recognised realist principles and published guidance. We used an iterative four-stage approach that optimised the knowledge and networks of the research team. Stakeholders were involved in developing the scope of the review, refining the review questions, developing the programme theory and interpreting the evidence. The four phases were as follows:

1. Development of initial programme theories through a first scoping of the literature and consultation with key stakeholder groups (user/patient representatives, dementia-care providers, clinicians, dementia and diabetes researchers, and diabetes specialists).
2. Systematic searches of the evidence to test and develop the theories identified in phase 1. Data sources (searched with a date range of 1990 to March 2016) included MEDLINE (PubMed), Cumulative Index to Nursing and Allied Health Literature, Scopus, The Cochrane Library (including the Cochrane Database of Systematic Reviews), DARE (Database of Abstracts of Reviews of Effects), the Health Technology Assessment (HTA) database, NHS EED (NHS Economic Evaluation Database), AgeInfo (Centre for Policy on Ageing – UK), Social Care Online, the National Institute for Health Research (NIHR) portfolio database, NHS Evidence, Google (Google Inc., Mountain View, CA, USA) and Google Scholar (Google Inc., Mountain View, CA, USA).
3. Validation of programme theories with a purposive sample of participants from phase 1. This involved face-to-face interviews and a consensus conference.
4. Development of actionable recommendations for the management of diabetes in people living with dementia.

Results

We included 89 papers, 10 of which focused directly on our target group of people living with dementia and diabetes. The majority of the remaining evidence related to people with dementia or diabetes or other long-term conditions and was included because of the opportunities it provided for transferable learning.

Our review has resulted in six context–mechanism–outcome (CMO) configurations that provide an explanatory account of how interventions might work to improve the management of diabetes in people living with dementia. Although designed to be specific to people with dementia, the CMOs are also likely to be transferable to other groups who experience problems with diabetes management, for example older people with complex health and social care needs.

Context–mechanism–outcome 1: embedding positive attitudes towards people living with dementia

Health and social care systems need to foster a belief in health-care professionals (HCPs), people living with dementia and their family carers that people living with dementia have the potential to be involved in self-management (SM). Components of SM interventions that are likely to be important for people with dementia and diabetes include focusing on strengths and abilities, being emotion focused rather than problem focused, respecting autonomy and working to build confidence and empowerment. The involvement of family carers in programmes is key, but it is important to balance the needs of the person with dementia and the carer to ensure that people living with dementia are not disempowered. More research is needed relating to SM in people living with dementia and diabetes.

Context–mechanism–outcome 2: person-centred approaches to care planning

The SM of diabetes in people with dementia is likely to be contingent on the development of trusting relationships between HCPs and the person with dementia and their family, involving understanding and incorporating patient priorities and how this may change over time. This in turn facilitates a person-centred approach to care planning and diabetes management. There is currently little research that looks at a person-centred approach to diabetes management in people living with dementia. Further research is needed to develop interventions that support partnership working and that incorporate the consideration of the risk–benefit balance for different treatment options.

Context–mechanism–outcome 3: developing skills to provide tailored and flexible care

To be able to provide flexible and individualised care for people living with dementia and diabetes, HCPs need to prioritise communication, negotiation and partnership working. They need to be provided with appropriate training and support so that they have the confidence to focus more on quality of life and patient abilities and less on biometrics and clinical targets. However, currently the evidence to link this with glycaemic control or a reduction in adverse diabetes-related events is limited.

Context–mechanism–outcome 4: regular contact

Continuity of care and regular contact are important for people with dementia and those with diabetes, but they are likely to be even more critical for those with both conditions. Continuity can help professionals recognise times of transition (e.g. worsening symptoms of dementia impacting on diabetic control and increased risk of hypoglycaemia) and provide patients and family caregivers with appropriate support. Ensuring that all professionals have expertise in dementia and diabetes would be difficult; collaborative practice is likely to be necessary for people with both conditions, particularly for more complex cases such as people who are insulin dependent or those with advanced dementia.

Context–mechanism–outcome 5: family engagement

Self-management for people with dementia and diabetes needs to be conceptualised as an activity that frequently involves not just the person with dementia but also their family members. Interventions need to take into account the needs and capabilities of family carers and the anxieties associated with managing medication and diet and preventing adverse events such as hypoglycaemic attacks. Including the family carers of people with dementia and diabetes should be the default option, and they should be included early, when the person living with dementia still has the capacity to decide and before SM breaks down.

Context–mechanism–outcome 6: usability of assistive technology

Evidence suggests that to make assistive technology usable to both people living with dementia and diabetes and their families, it needs to be focused on the needs of the user (e.g. maintaining autonomy),

involve people with dementia and their carers in its development, and include family carers in installation and training. Telehealth and telecare should be designed to involve (as the default option) care partners such as other members in the family network. Appropriate support in the form of face-to-face contact appears to be an important contextual factor that may lead to improved motivation and adherence.

Summary of context–mechanism–outcome configurations

The CMOs require changes in individual or organisational behaviour or understanding, and in many cases both. For example, CMO 3 – which focuses on skills development – requires the development of skills at an individual level but also organisational changes that legitimise the importance of those skills and allow the time for them to be acquired and practised. The outcomes we specified in the protocol for this synthesis included a number of clinical outcomes, such as the prevention of hypoglycaemia, the management of cardiovascular risk factors and the identification and management of long-term complications such as neuropathy. However, the outcomes that emerged from the evidence available are primarily experiential rather than clinical, focusing on the need to trigger mechanisms such as trust, confidence and empowerment.

Conclusions

This realist synthesis provides a theory-driven understanding of the factors influencing the management of diabetes in people living with dementia and the conditions under which interventions are more likely to be successful. A general metamechanism that emerges is that there is some form of synergy between an intervention strategy, disease progression (in particular the progression of dementia) and social and environmental factors, in particular the involvement of family members. We suggest that a flexible service model for people with dementia and diabetes would enable this synergy in a way that would lead to improved management of diabetes in people living with dementia.

This review suggests that there is a need to prioritise quality of life, independence and patient and carer priorities over a more biomedical, target-driven approach. Much of the research included in this review, particularly that specific to people living with dementia and diabetes, identifies deficiencies in, and problems with, current systems. Although we have highlighted the need for personalised care, continuity and family-centred approaches, there is much evidence to suggest that this is not currently happening. Future research on the management of diabetes in older people with complex health needs, including those with dementia, needs to look at how organisational structures and workforce development can be better aligned to the needs of people with dementia and diabetes.

The priority for HCPs is how to accommodate the challenges of living with dementia as a long-term condition with the minimum requirements of good diabetic control, recognising that perceptions of ‘good’ are situation specific, differ for people with dementia and for family carers, and will change over time. This review suggests that there is a need for further work to establish a shared understanding of what needs to be in place to engage effectively with people living with dementia, including those with diabetes, and their supporters to establish how ‘good support’ is operationalised and measured.

Implications for practice

- Self-management for people with dementia and diabetes needs to be conceptualised as an activity that frequently involves not just the person with dementia but also their family members. Therefore, SM should include the identification of family carers, appropriate training in carer engagement for staff, and protocols regarding confidentiality and information sharing.
- Self-management support needs to be seen as a legitimate activity by HCPs. Pathways should be adapted to enable the regular assessment of SM capabilities and provide appropriate SM support for people living with dementia and diabetes and for their family carers.

- Family carers are likely to require diabetes-specific education and advice, for example on the appropriate timing of medication and access to food, how to recognise the common signs and symptoms of hypoglycaemia and how to distinguish between symptoms of dementia and those of diabetes.
- Staff caring for people with diabetes need appropriate training on dementia and how this might have an impact on the management of diabetes. This applies to staff at all levels, including more senior staff.
- Health-care professionals caring for people with dementia and diabetes need education in enablement approaches to SM.
- Health-care professionals caring for people with dementia and diabetes need to regularly assess patients' ability to self-manage and identify when they, or their family carer, may need additional support.
- Health-care professionals caring for people with dementia and diabetes may need training or guidance on how to incorporate ideas about deprescribing and minimally disruptive medicine (e.g. the management of uncertainty).
- There is a need for better integration of physical and mental health-care systems, that is, old-age psychiatry teams and geriatric teams working together and community-based geriatric and frailty teams having specialist mental health staff as an integral part of the team.
- People with dementia and diabetes who live alone, or who do not have family support, may be particularly disadvantaged and may need additional help and monitoring from health and care staff.
- People with dementia and diabetes are likely to benefit from longer appointments, both in primary and secondary care, and booking systems should allow for this.
- People living with dementia and diabetes, particularly those who live alone, are likely to need regular (preferably face-to-face) contact with HCPs who are familiar with their needs and problems.

Suggestions for future research

A number of potential areas for future research were identified by the review. These are listed in order of priority.

- What is the impact of SM interventions for people with dementia and diabetes that involve family carers?
- What interventions can be used to improve medication management in people with dementia and diabetes and their family carers; for example, what is the impact of pharmacist-led interventions?
- What sort of care pathway is most appropriate and effective [e.g. a specific dementia and diabetes pathway or a pathway for older adults with complex needs (vulnerability pathway)]?
- What sort of support do family caregivers of people with dementia and diabetes want, and how can interventions be designed to reflect this?
- How can professionals caring for people with dementia and diabetes be helped to recognise when a person is no longer able to self-manage, or when there is a need to 'gear-up' or 'gear-down' support?
- What are important outcomes and goals for people with dementia and diabetes and for their family carers?
- How can assistive technology support SM for people with dementia and diabetes and how do their needs change as the dementia trajectory progresses?
- How does the stage/extent of cognitive and physical impairment have an impact on the uptake and outcomes of interventions?
- Are interventions that take an assets-based approach to the care of people with dementia and diabetes (e.g. promoting confidence, empowerment, independence) more effective?

Study registration

This study is registered as PROSPERO CRD42015020625.

Funding

Funding for this study was provided by the HTA programme of the NIHR.

Health Technology Assessment

HTA/HTA TAR

ISSN 1366-5278 (Print)

ISSN 2046-4924 (Online)

Impact factor: 4.236

Health Technology Assessment is indexed in MEDLINE, CINAHL, EMBASE, The Cochrane Library and the Clarivate Analytics Science Citation Index.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

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This report

The research reported in this issue of the journal was funded by the HTA programme as project number 13/138/03. The contractual start date was in June 2015. The draft report began editorial review in February 2017 and was accepted for publication in August 2017. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

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