The effectiveness of non-pharmacological interventions to prevent wandering in dementia

A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use

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Executive summary

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Executive summary

Background

Wandering occurs in around 15–60% of people with dementia. It can be beneficial, providing exercise and improving circulation, but may be problematic to both people with dementia and their carers, causing physical harm, emotional distress and early institutionalisation. Non-pharmacological interventions are recommended, but there is limited evidence for their effectiveness and ethical concerns exist around some. This review considers the following non-pharmacological interventions: physical barriers/restraints, electronic devices (tagging and tracking), distraction therapies (music, walking/exercise), sensory therapies (massage, aromatherapy, multi-sensory environments), behavioural therapies, carer interventions and environmental modifications.

Objectives

The objectives were to determine, through a systematic review, the effectiveness and cost-effectiveness of non-pharmacological interventions (excluding subjective barriers) in the prevention of wandering in people with dementia, in comparison with usual care, and to evaluate through the review and a qualitative study the acceptability to stakeholders of such interventions and identify ethical issues associated with their use.

Methods

Systematic review

Data sources

- Electronic searches including the Cochrane Library, MEDLINE, EMBASE, Central CINAHL, Social Science Citation Index, Science Citation Index, PsycINFO, ADEAR, National Research Register, ETHX database, Bioethicsweb.
- Grey literature: ISTP, ZETOC.
- Handsearching of relevant journals: *Journal of Dementia Care* (1999–2004), *Dementia* (2002–4).
- Personal contact with specialists in the field.

Data searching continued up until 31 March 2005.

Study selection

Studies to evaluate the effectiveness of interventions included randomised controlled trials (RCTs), non-randomised controlled trials, controlled before-and-after studies, cohort studies (both prospective and retrospective) and case–control studies (both prospective and retrospective).

Studies to evaluate cost-effectiveness of interventions included those costing the intervention strategies or wandering behaviour and full economic evaluations assessing the intervention strategies.

Studies to evaluate acceptability/ethical issues included surveys of opinion, qualitative studies and discussion papers.

Studies could be published in any language.

Included studies could take place in any care environment and involved participants with dementia (DSM or ICD diagnostic criteria) and acquired cognitive impairment. Primary outcome measures included any measure of wandering behaviour.

Data extraction

Checklists for each study were completed independently by two reviewers. For the effectiveness review, data extracted included details of participants, setting, methodology and results/relevant data; for the acceptability/ethics review, narrative and empirical data were extracted.

Data synthesis

The results of two of the efficacy studies which used similar interventions, designs and outcome measures were pooled in a meta-analysis; results for other studies which reported standard deviations were presented in a forest plot. Owing to a lack of cost-effectiveness data, a modelling exercise could not be performed.

Qualitative study

Four focus groups were carried out with relevant stakeholders (n = 19) including people with dementia and formal and lay carers to explore ethical and acceptability issues in greater depth. Transcripts were coded independently by two reviewers to develop a coding frame. Analysis was via a thematic framework approach.

Results

Effectiveness

Ten studies met the inclusion criteria (multi-sensory environment, three; music therapy, one; exercise, one; special care units, two; aromatherapy, two; behavioural intervention, one). There was no robust evidence to recommend any non-pharmacological intervention to reduce wandering in dementia. There was some evidence, albeit of poor quality, for the effectiveness of exercise and multi-sensory environment.

Cost-effectiveness

There were no relevant studies to determine the cost-effectiveness of the interventions.

Acceptability/ethical issues

Findings from the narrative review and focus groups were comparable. Exercise and distraction therapies were the most acceptable interventions and raised no ethical concerns. All other interventions were considered acceptable except for physical restraints, which were considered unacceptable. Considerable ethical concerns exist with the use of electronic tagging and tracking devices and physical barriers.

Existing literature ignores the perspectives of people with dementia. The small number of participants with dementia expressed caution regarding the use of unfamiliar technology. Balancing risk and risk assessment was an important theme for all carers in the management of wandering.

Conclusions

Implications for healthcare

There is no robust evidence to make any reliable recommendations for clinical practice.

Recommendations for research

The authors recommend the following research:

- High-quality studies, preferably RCTs, to determine the clinical effectiveness and cost-effectiveness of non-pharmacological interventions that allow safe wandering and are considered practically and ethically acceptable by carers and people with dementia. Such interventions include walking/exercise, music therapy (most acceptable), aromatherapy, massage, multi-sensory environments and environmental modifications/design (acceptable).
- Large-scale, long-term cohort studies to evaluate the morbidity and mortality associated with wandering in dementia for people both in the community and in residential care. Such data would inform future long-term cost-effectiveness studies.

The diversity of behaviours encompassed by the term 'wandering' should be acknowledged, with future studies measuring explicit outcomes which reflect:

- the consequences of wandering, for example successful elopement and getting lost
- the physical safety of the person with dementia (e.g. number and nature of physical injuries, number of hospital admissions)
- participant-centred outcomes that reflect the desired quality of life for both people with dementia and their carers, and also the acceptability of the intervention.

The views of people with dementia on the acceptability of non-pharmacological interventions to reduce wandering should be determined. This is particularly relevant for the use of assistive technologies in wandering. As the rapid development of relevant assistive technologies allows for a more diverse and sensitive range of electronic devices, research into users' views of their acceptability and feasibility should precede expensive and complex quantitative studies to evaluate their effectiveness.

There is a need to explore in greater depth the process of risk assessment and management by carers for people with dementia who wander, in addition to evaluating the effectiveness and acceptability of specific interventions to promote safe wandering.

There is a need to explore with all relevant stakeholders the boundaries between walking, safe wandering and unsafe wandering. Such in-depth qualitative research would help identify mutually agreed significantconsequences/outcomes of wandering and provide better understanding of the different perspectives held by professional/lay carers and people with dementia, and may help facilitate a shift from the prevention of wandering to the promotion of safe walking.

Publication

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NHS R&D HTA Programme

The research findings from the NHS R&D Health Technology Assessment (HTA) Programme directly influence key decision-making bodies such as the National Institute for Health and Clinical Excellence (NICE) and the National Screening Committee (NSC) who rely on HTA outputs to help raise standards of care. HTA findings also help to improve the quality of the service in the NHS indirectly in that they form a key component of the 'National Knowledge Service' that is being developed to improve the evidence of clinical practice throughout the NHS.

The HTA Programme was set up in 1993. Its role is to ensure that high-quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most efficient way for those who use, manage and provide care in the NHS. 'Health technologies' are broadly defined to include all interventions used to promote health, prevent and treat disease, and improve rehabilitation and long-term care, rather than settings of care.

The HTA Programme commissions research only on topics where it has identified key gaps in the evidence needed by the NHS. Suggestions for topics are actively sought from people working in the NHS, the public, service-users groups and professional bodies such as Royal Colleges and NHS Trusts.

Research suggestions are carefully considered by panels of independent experts (including service users) whose advice results in a ranked list of recommended research priorities. The HTA Programme then commissions the research team best suited to undertake the work, in the manner most appropriate to find the relevant answers. Some projects may take only months, others need several years to answer the research questions adequately. They may involve synthesising existing evidence or conducting a trial to produce new evidence where none currently exists.

Additionally, through its Technology Assessment Report (TAR) call-off contract, the HTA Programme is able to commission bespoke reports, principally for NICE, but also for other policy customers, such as a National Clinical Director. TARs bring together evidence on key aspects of the use of specific technologies and usually have to be completed within a short time period.

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Reports are published in the HTA monograph series if (1) they have resulted from work commissioned for the HTA Programme, and (2) they are of a sufficiently high scientific quality as assessed by the referees and editors.

Reviews in *Health Technology Assessment* are termed 'systematic' when the account of the search, appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

The research reported in this monograph was commissioned by the HTA Programme as project number 03/16/04. The contractual start date was in March 2004. The draft report began editorial review in May 2005 and was accepted for publication in December 2005. As the funder, by devising a commissioning brief, the HTA Programme specified the research question and study design. 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 referees 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.

The views expressed in this publication are those of the authors and not necessarily those of the HTA Programme or the Department of Health.

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