Management of pain in people with dementia living in care homes: Programme and intervention development

https://neurodegenerationresearch.eu/survey/management-of-pain-in-people-with-dementia-living-in-care-homes-programme-and-intervention-development/

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Management of pain in people with dementia living in care homes: Programme and intervention development

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1.3

Keywords
Research Abstract
The Programme Development Grant (PDG) will support key exploratory and preparatory work leading up to an application for the proposed research programme. This will involve six workstreams (WS).

WS1: Consultation with stakeholder groups

Focus groups will be held with key stakeholder groups to identify the main elements and challenges in identifying and managing pain in people with dementia living in care homes. The following groups will be convened:

1. Care home staff consultation: Two half-day focus groups will be held with care home staff to discuss how they conceptualise pain and what they believe to be the main sources of pain for residents. Their experience with individual residents will be sought to identify the language and signals they recognise to be associated with pain. Participants will be asked to reflect on the challenges involved in assessing and treating pain in people with dementia and to identify strategies and sources of support that they have found to assist them in this process. The groups will discuss different available pain assessment methods, including a new tool developed in an ongoing EU-COST initiative. They will particularly focus on which tools would be feasible and workable in a care home. The concept of a pain pathway will be introduced and their feedback regarding design and practical considerations will be recorded. These sessions will be chaired by a senior manager from a care provider.
2. Health professional consultation: Two two-hour focus groups will be convened with General Practitioners. These sessions will consider the role of the health professional in identification and treatment of pain and how they interact with care staff to achieve this. Key themes will include feasibility of non-pharmacological interventions and potential issues with fidelity regarding following stepped protocols involving combinations of pharmacological and non-drug approaches. The groups will also be asked for ideas around the design and structure of a pain pathway and how its use could be optimised. These sessions will be chaired by Professor Louise Robinson, Dementia Champion for the Royal College of GPs.
3. Lay representative consultation: Two half-day focus groups will be convened with family carers of people with dementia who are living in a care homes. This will be supported by Alzheimer's Society UK and will involve a representative from the British Pain Society. These sessions will focus on the needs of the person with dementia, highlighting important elements of basic care, person-centred principles and individual considerations that they feel should be included in a pathway. The groups will discuss the potential for individualisation of pain assessment and treatment, including what language and signs people associate with pain in their relatives and how those could be incorporated into a pathway. The groups will also discuss the role of family and next of kin in decisions around treatment and the practicalities of this. These sessions will be chaired by the lead applicant and lay co-applicant.

WS2: Expert consultation with specialist panel

A specialist panel will be convened consisting of clinicians, academics and patient representatives with expertise in assessment and treatment of pain, with a focus on older people and dementia. The panel will meet for a full day meeting which will focus on the following questions:

1. What are the unique challenges and needs involved in assessing and treating pain in

dementia? This discussion will consider the likely underlying causes of pain that may be unique or more common in people with dementia, the types of pain these will cause, and the complexities these conditions and needs will raise regarding assessment and treatment. A key issue is expected to be the frequency of neuropathic pain and the different treatment that will be required to address it.

2. What is the most effective way to assess pain in people with dementia? This discussion will consider the existing assessment tools and pain pathways for older people. The group will be tasked with providing suggestions for routes to overcome the challenge of tailoring tools for use in dementia. Key issues are expected to include the consideration of other medical co-morbidities that are likely to contribute to pain, and how these could influence the complexity of an assessment of pain.
3. What are the treatment options for pain in dementia and what governs the decision to treat? The panel will consider the evidence for both pharmacological and non-pharmacological treatment options to identify the most appropriate interventions. They will be asked to particularly consider the issues involved in decisions around level and intensity of treatment, how treatment decisions might be weighted by the choice of assessment method, knowledge of existing medical conditions and presence of neuropathic pain, and what level of emphasis is appropriate for treatment of distress and stress related to pain. The panel will discuss how decisions should be made concerning the selection of individual pharmacological agents, their route of administration and dosage. Finally, they will consider the suitability of specific non-pharmacological interventions such as physical therapies.

WS3: Initial development of assessment and treatment algorithm

The outcomes of WS1 and WS2 will be collated by a Pathway Development Advisory Group (PDAG), consisting of the co-applicants and selected representatives of the stakeholder and specialist groups. This information will be used to develop a preliminary algorithm for decision-making around assessment and treatment of pain in dementia. A key consideration is how to utilise the essential elements of complex assessment protocols currently used in clinical trials to produce a simple pathway for use in practice. The algorithm will include suggested questions and ratings for assessment of pain and a hierarchy of pharmacological and non-pharmacological treatment options that relate to the assessment outcome.

WS4: Feasibility pilot study

A small feasibility study will be undertaken in three care homes in South London, sampled purposively on the basis of type of home and size, as an initial refinement of the elements of the algorithm developed in WS3. The main aim of the pilot will be to assess ease of use, feasibility and fidelity of the algorithm. This will include qualitative methodology to analyse the response of residents, care staff and health professionals to the use of specific language and questions included in the suggested assessment pathway and the feasibility of specific elements of the treatment decision pathways within the algorithm. Focus groups will be coordinated with up to 12 care staff in various roles and health professionals working with the home to discuss their experience of using the algorithm in relation to specific cases. The groups will explore how widely the algorithm was used, how staff applied it and in what instances it proved helpful or unhelpful. The different components of the algorithm will be evaluated including the language of the questions in the suggested assessment pathway, their relevance and utility. All group

discussions will be audio-recorded and transcribed verbatim. Focus group data will be subjected to thematic analysis. The computer programme QSR N-VIVO will be used to process the transcripts of the focus groups, enabling us to code and retrieve a large volume of narrative data and to determine concepts, dimensions and relationships among these.

The feasibility study will also explore the attitudes and experiences of the pathway for residents with dementia, who are identified as having experienced pain in the trial period, and their family carers. A case study approach will be used, involving in-depth interviews with people with dementia and their family carer, used successfully in a recent study[17]. The results of the analysis will contribute to the optimisation of the pain management pathway.

WS5: Assessment of pain in care home residents and initial validation of a new assessment tool

The care homes involved in WS4 will also support a small study to assess pain in people with dementia living in the homes. The aim will be to document the intensity, cause and type of pain in the study sample. The six week study will involve measurement of pain using the validated MOBID-2 scale and a new tool, the Pain Assessment in Impaired Cognition (PAIC), developed by an ongoing EU-COST initiative involving the lead applicant and a number of co-applicants. The tool has been developed through an iterative consensus process with an expert panel to identify and refine the most important and informative assessment items from existing validated tools. WS5 will contribute to the wider validation study of PAIC underway across the EU. The findings from WS5 will also add to the discussions from the specialist panel in WS2 and inform the development of the theoretical pathway in WS6.

WS6: Creation of theoretical pathway

The final phase of the PDG will involve collation of the outcomes of the preceding five WS to create a theoretical pain management pathway to take forward into the future research programme. This phase will also include creation of a final report and planning for the application to the NIHR for PGfAR funding to take this work forwards.

Overall, the work involved in the PDG will provide an excellent platform from which to develop and evaluate an optimised pain management pathway in a full research Programme.

Further information available at:

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