

Title:

Palliative Care for the Person With Dementia: Evidence-Based Guidance on Pain Assessment and Management

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Session Title:

Innovations in Mental Health

Slot:

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Scheduled Time:

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Keywords:

Evidence Based Guidance, Pain Assessment and Management and Palliative Care in Dementia

References:

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Abstract Summary:

Guidance on evidence based practice is scarce in palliative care for persons with dementia, particularly in the area of pain management. This session delineates the process involved in developing national guidance on this topic. This guidance document includes fact sheets and case studies for use by professional and lay carers.

Learning Activity:

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
The learner will be able to describe the systematic process for developing evidence based guidance documents for clinical practice	The learner will be provided with a case study outlining the step by step process of guidance development underpinned by best practice as per the National Clinical Effectiveness Committee (NCEC) and NICE.
The learner will be able to develop an understanding of the challenges in developing guidance for lay and healthcare professionals on the topic of pain in dementia	The learner will be provided with information on the challenges encountered by the team over the 18 month period of development. Tips and advice on dealing with multiple stakeholders will also be discussed.
The learner will be able to apply the principles of 'fact sheet' design and be aware of importance of adhering to international criteria on user accessibility and readability.	The learner will be provided with e-resources on literacy and fact sheet design when developing clinical guidance documents.
The learner will be able to describe and adapt the rigours and systematic method of literature searching used, in the development of this guidance document, to enhance their own research skills	The learner will be provided with an overview of the systemic review methods applied to this project, the use of PRISMA flow diagram to present information and the importance of data

	extraction table when organising and critiquing your literature
The learner will be able to appreciate and gain insight into the topic of pain assessment and management in persons with dementia and learn about best practice in this area	The learner will be provided with information on the most current and up-to-date evidence on pain assessment and management of pain in person with dementia from a palliative care perspective, as contained in the guidance document, an e-version of the document will also be shared with the audience and limited numbers of hard copies of the 57 page document will also be provided.

Abstract Text:

Background:

It is estimated that approximately 86% of people with dementia in Ireland are over 70 years old (Pierce et al, 2014) and this is a population within which the detection of pain is particularly challenging, since some people may believe that pain is an inevitable aspect of aging or may not self-report for fear of admission of frailty and subsequent institutionalization (SCIE, 2012). Coupled with a diagnosis of dementia, the situation becomes increasingly more difficult particularly due to difficulties with communication as dementia advances, and there is considerable evidence to suggest that the pain experience can be extremely challenging for people living with dementia and many variables e.g. depression, fatigue and agitation can influence responses (Abbey et al, 2004). People with dementia experience pain just as much as anyone else. Uncontrolled pain can seriously affect a person's quality of life. Central to the philosophy of palliative care is effective pain management, working within the concept of 'total pain' as being physical, psychological, social and spiritual (Richmond, 2005). As dementia advances, the manner by which a person communicates pain can change. Pain may be expressed in lots of different ways (e.g. nonverbally – grimacing, frowning, vocalizations, body language, being distressed/ crying/ behavior changes like not eating, being unusually quiet, not wanting to do things they would ordinarily do through to being agitated and responsive behaviors).

It is vital that pain is measured as accurately as possible. The consequences of untreated pain include depression, fatigue, anxiety, social withdrawal, and increased use of health services (Ferrell et al, 2002) that can subsequently impact on quality of life and may present as responsive behavior. Pain is associated with agitation and when pain as a cause of such behavior goes unrecognized, it can result in a person being prescribed sedatives or neuroleptics inappropriately or receiving some level of restraint (chemical or physical). Recognition of pain is therefore important, however, deficits in the assessment and management of pain in people with dementia are well documented (Sampson, 2010; Horgas et al, 2007; Cunningham, 2006). For example, in an acute setting, a randomized controlled trial (Morrison et al, 2000) found that 76% of people with dementia did not receive regular post-operative pain relief following surgery for an associated hip fracture. Furthermore, they only received one third of the pain relief offered to the cognitively intact older adults in the study. Evidence suggests that responsive pain management given post operatively can reduce patient confusion in the ward setting, reduce recovery time and reduce the demand on nurses (Rogers et al, 2002). In the community, the prevalence of chronic pain has been estimated to vary between 20% and 50% among older adults (Barkin et al, 2005) and is reported to range up to 40–80% among older adults residing in long-term care facilities (Zwakhlen et al, 2012). Pain in the latter group is often undiagnosed or undertreated, as a result of the person's inability to self-report because of dementia (Apinis et al, 2014).

Existing guidance documents for the assessment and management of pain for people with dementia within a palliative care framework are limited and the majority of those that exist lack rigor when evaluated

using the Appraisal of Guidelines for Research and Evaluation (AGREE) instrument (Brouwers et al, 2010).

Aim:

The aim of this project was to provide caregivers of people with dementia with evidence-based information and guidance to support the assessment and management of pain.

Method:

The guidance document was developed over an 18 month period by a project team and overseen by a national steering committee, using the systematic and rigorous process of clinical guideline development (National Clinical Effectiveness Committee, 2013) as outlined in the following six stages;

1. Completion of scoping review of the literature.
2. Collation of key review themes to inform the guidance and principles of pain assessment and management.
3. Preparation of Draft 1 of guidance document for comment by the project steering committee and national/international experts in the field of Pain, Gerontology, Dementia and Palliative Care.
4. Preparation of Draft 2 for external consultation.
5. Assimilation of feedback from external consultation to final draft.
6. Final version published.

Results

Structure & scope of guidance document

The guidance provided in the 57 page document focuses on four key areas, based on the agreed key themes emerging from the scoping review considered most beneficial for caregivers. These areas are examined together with the overarching assumptions, rights and values that guide ethical decision-making. Where applicable, we have signposted available e-resources and practice based tools. Four areas for guidance include; recognizing pain in dementia, pain assessment in mild through to severe dementia, developing a pain management plan, referral to specialist services.

Graphically designed 'fact sheets' accompany the guidance document and they can be used by lay and professional care givers. In its current format the guidance document can be used to inform principles of best practice in the community, long-term care or acute care when looking after people with dementia. In essence it serves to influence clinical practice and advance health and nursing care. As part of a planned translational research project (2017/2018) this guidance document will form the foundation of a quality improvement initiative to improve pain management in long-term care in Ireland.