Original Article

Tools to Assess Pain or Lack of Comfort in Dementia: A Content Analysis

Jenny T. van der Steen, PhD, Elizabeth L. Sampson, MD, Lieve Van den Block, PhD, Kathryn Lord, MA, Hana Vankova, MD, Sophie Pautex, MD, An Vandervoort, RN, PhD, Lukas Radbruch, MD, PhD, Pesach Shvartzman, MD, Valentina Sacchi, MD, Henrica C.W. de Vet, PhD, and Nele J.A. Van Den Noortgate, MD, PhD, on behalf of the EU-COST Action TD1005 Collaborators

EMGO Institute for Health and Care Research (J.T.v.d.S., H.C.W.d.V.); Department of General Practice & Elderly Care Medicine (J.T.v.d.S.) and Department of Epidemiology and Biostatistics (H.C.W.d.V.), VU University Medical Center, Amsterdam, The Netherlands; Division of Psychiatry (E.L.S., K.L.), Marie Curie Palliative Care Research Department, University College London; Barnet Enfield and Haringey Mental Health Trust Liaison Team (E.L.S.), North Middlesex University Hospital, London, United Kingdom; End-of-Life Care Research Group (L.V.d.B., A.V.), Vrije Universiteit Brussel and Ghent University, Belgium, Brussels, Belgium; Faculty of Humanities and Third Faculty of Medicine (H.V.), Charles University in Prague, Prague, Czech Republic; Department of Community Medicine, Primary Care and Emergency Medicine (S.P.), Geneva University Hospitals and University of Geneva, Geneva, Switzerland; Department of Palliative Medicine (L.R.), University Hospital Bonn; Center for Palliative Care (L.R.), Malteser Hospital Seliger Gerhard Bonn/Rhein-Sieg, Bonn, Germany; Pain and Palliative Medicine Unit (P.S.), Division of Community Health, Department of Family Medicine, Siaal Research Center for Family Medicine and Primary Care, Faculty of Health Sciences, Ben-Gurion University of the Negev, Beer-Sheva, Israel; Lincolnshire Partnership Foundation Trust (V.S.), Lincoln, Lincolnshire, United Kingdom; and Department of Geriatric Medicine (N.J.A.V.D.N.), Ghent University Hospital, Ghent, Belgium

---

Abstract

Context. There is need for tools to help detect pain or lack of comfort in persons unable to communicate. However, pain and (dis)comfort tools have not been compared, and it is unclear to what extent they discriminate between pain and other possible sources of discomfort, or even if items differ.

Objectives. To map and compare items in tools that assess pain and the broader notion of discomfort or comfort in people with severe dementia or at the end of life.

Methods. Using qualitative content analysis with six classifications, we categorized each item of four thoroughly tested observational pain tools (Pain Assessment in Advanced Dementia [PAINAD], Pain Assessment Checklist for Seniors with Limited Ability to Communicate [PACSLAC], Doloplus-2, and draft Pain Assessment in Impaired Cognition [PAIC]), and four discomfort tools (including distress, comfort, and quality of life in severe dementia or at the end of life; Discomfort Scale—Dementia Alzheimer Type [DS-DAT], Disability Distress Assessment Tool [DisDAT], End-of-Life in Dementia—Comfort Assessment in Dying with Dementia [EOLD-CAD], and Quality of Life in Late-Stage Dementia [QUALID] scale). We calculated median proportions to compare distributions of categories of pain and discomfort tools.

Results. We found that, despite variable content across tools, items from pain and discomfort tools overlapped considerably. For example, positive elements such as smiling and spiritual items were more often included in discomfort tools but were not unique to these. Pain tools comprised more "mostly descriptive" (median 0.63 vs. 0.44) and fewer "highly subjective" items (0.06 vs. 0.18); some used time inconsistently, mixing present and past observations.

Conclusion. This analysis may inform a more rigorous theoretical underpinning and (re)development of pain and discomfort tools and calls for empirical testing of a broad item pool for sensitivity and specificity in detecting and discriminating pain from other sources of discomfort. J Pain Symptom Manage 2015;50:659—675 © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words
Dementia, pain measurement, palliative care, quality of life, symptom assessment

---

Address correspondence to: Jenny T. van der Steen, PhD, Department of General Practice & Elderly Care Medicine, EMGO Institute for Health and Care Research, VU University Medical Center, Van der Boechorststraat 7, 1081 BT Amsterdam, The Netherlands. E-mail: j.vandersteen@vumc.nl

Accepted for publication: May 31, 2015.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2015.05.015

Introduction

Pain and lack of comfort or discomfort are common in people with severe dementia and at the end of life.[1] Self-report is the gold standard and should be encouraged, but because of cognitive impairment, these patients may not be able to indicate pain or other sources of suffering such as hunger, constipation, cold, emotional distress, or other needs. This puts patients at risk of inadequate diagnosis and inappropriate treatment.[1–3]

Facial expressions,[4,5] vocalization,[6–8] and restlessness[8] may indicate pain, as may agitation.[9] Although there is no gold standard in this population, tools used to observe behavior aim to recognize the various ways in which pain or discomfort is being expressed. A systematic assessment of these symptoms is consistent with a palliative care approach.[10] Valid observational tools in dementia and end-of-life care are vital to recognizing pain and other discomfort and should trigger additional examination and treatment if needed.

Whereas pain assessment tools assume the source of observed discomfort is pain, tools for discomfort such as the classic Discomfort Scale—Dementia Alzheimer Type (DS-DAT)[11,12] cover pain in addition to a broader spectrum of possible sources. That is, although pain involves discomfort, discomfort is not invariably the result of pain. Furthermore, conceptually, as health is more than the absence of disease,[10] comfort or the lack of it may be more than the absence of discomfort or pain. Comfort relates to the broader concept of quality of life the main treatment goal for both palliative[13] and dementia care approaches.[14] In clinical practice, the distinction between pain and discomfort resulting from other sources is important in guiding appropriate management.

In general, pain and discomfort tools have been developed from a small evidence base.[15,16] Therefore, items in existing tools that measure the same concept may differ substantially; this is indicated, for example, by the wide range and number of items needed to assess pain.[17–20] Both the content and methods of measuring may differ, for example, not all require familiarity with the patient. There has been little cross-validation of pain and discomfort tools.[21,22]

In this study, we use an open, inductive and iterative method as a first step to an evidence-based approach to tool (re)development, with the optimal item pool representing discomfort as a result of pain or other causes. Rather than directly comparing specific tools, we map and compare in detail item pools through mapping individual items included in the most prominent pain assessment tools and the available (dis)comfort tools in severe dementia or end of life. We used theoretical constructs and developed classifications to quantify the ways in which the items differ both conceptually and in ways relevant to practice.

Methods

Background

This work was conducted as part of a European Cooperation in Scientific and Technology (COST) action fostering collaboration (on “Pain Assessment in Patients with Impaired Cognition, especially Dementia,” TD 1005).[16] The action’s main goal was development of a comprehensive assessment tool kit targeting various aspects of pain, including a meta-tool. One of five working groups focused on palliative care and involved members from eight countries with expertise in medicine, psychology, nursing, medical sociology, and epidemiology.

Tools

We selected for analyses the most thoroughly tested, long-standing, influential, and widely used observational pain tools (Fig. 1), intended for clinical use:[16–19] Pain Assessment in Advanced Dementia (PAINAD),[23] the original version of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC),[24] and the Doloplus-2.[25] We assessed whether limiting analyses to 21 of 31 items that were unchanged in the recently developed PACSLAC-II[15] changed results.

We also mapped the content of the preliminary version of the COST tool, the draft Pain Assessment in Impaired Cognition (PAIC) meta-tool.[16] The PAIC is based on the mapping of items from 12 earlier tools that fit the three most descriptive American Geriatrics Society (AGS) categories (facial expressions, verbalizations and vocalizations, and body movements; not changes in interactions, activities, and mental status).[26] It covers frequently used items evaluated by an expert panel to have face validity and to be promising in capturing pain accurately while feasible in practice. The PAINAD, Doloplus-2, and PACSLAC were among the 12 tools and also the DS-DAT (Fig. 1). A recent meta-review provides an overview of psychometric properties of these tools.[27]

Based on a previous review[20] and through our research and networks, we identified further observational tools for clinical use to measure discomfort (or distress) in severe dementia (DS-DAT[11] and the Disability Distress Assessment Tool [DisDAT][28,29]); a tool developed to assess comfort in dementia at the end of life (End-of-Life in Dementia—Comfort Assessment in Dying with Dementia [EOLD-CAD][22,30]); and a tool to assess quality of life specifically in severe dementia (the Quality of Life in Late-Stage Dementia