



Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study

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Review

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3 1 **ABSTRACT**

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6 2 **Aims and objectives.** To explore hospice, acute care and nursing home nurses' experiences
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8 3 of pain management for people with advanced dementia in the final month of life. To identify
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10 4 the challenges, facilitators and practice areas requiring further support.

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13 5 **Background.** Pain management in end-stage dementia is a fundamental aspect of end of life
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15 6 care; however, it is unclear what challenges and facilitators nurses experience in practice,
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17 7 whether these differ across care settings, and whether training needs to be tailored to the
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19 8 context of care.

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22 9 **Design.** A qualitative study using semi-structured interviews and thematic analysis to
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24 10 examine data.

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28 11 **Methods.** 24 registered nurses caring for people dying with advanced dementia were
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30 12 recruited from ten nursing homes, three hospices, and two acute hospitals across a region of
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32 13 the United Kingdom. Interviews were conducted between June 2014 and September 2015.

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34
35 14 **Results.** Three core themes were identified: challenges administering analgesia, the nurse-
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37 15 physician relationship, and interactive learning and practice development. Patient-related
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39 16 challenges to pain management were universal across care settings; nurse- and organisation-
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41 17 related barriers differed between settings. A need for interactive learning and practice
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43 18 development, particularly in pharmacology, was identified.

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47 19 **Conclusions.** Achieving pain management in practice was highly challenging. A number of
48
49 20 barriers were identified; however, the manner and extent to which these impacted on nurses
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51 21 differed across hospice, nursing home and acute care settings. Needs-based training to
52
53 22 support and promote practice development in pain management in end-stage dementia is
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55 23 required.

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3 24 **Relevance to clinical practice.** Nurses considered pain management fundamental to end of
4
5 25 life care provision; however, nurses working in acute care and nursing home settings may be
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7 26 under-supported and under-resourced to adequately manage pain in people dying with
8
9 27 advanced dementia. Nurse-to-nurse mentoring and ongoing needs-assessed interactive case-
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11 28 based learning could help promote practice development in this area. Nurses require
12
13 29 continuing professional development in pharmacology.
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20 31 **WHAT DOES THIS PAPER CONTRIBUTE TO THE WIDER GLOBAL**
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22 32 **COMMUNITY?**
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- 25 33 • Globally, pain management in palliative care is a health policy priority; however, it is
26
27 34 unclear what barriers and facilitators are experienced by nurses caring for people with
28
29 35 advanced dementia in the final month of life and whether these differ across care settings.
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31 36 • Patient-related barriers to pain management were universal across nurse participants and
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33 37 care settings. However, the barriers arising from nurse-related and organisational factors,
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35 38 and extent to which they impacted on nurses' experiences of pain management, varied
36
37 39 across acute care, hospice and nursing home care settings.
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39 40 • This study identified a gap between health policy recommendations for pain management
40
41 41 in palliative care and availability of resources to support nurses working in different
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43 42 healthcare settings in implementing these recommendations in clinical practice.
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51 44 **KEYWORDS:** pain, palliative care, dementia, nurse, nurse education
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56 46 **INTRODUCTION**
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3 47 Dementia has become a leading cause of disability and a significant contributor to mortality
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5 48 in developed countries propelling it to priority status in healthcare policy, research and
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7 49 education globally (World Health Organisation 2012, van der Steen *et al.* 2014). A recent
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9 50 study estimated that the prevalence of dementia worldwide has reached 46.8 million; a figure
10
11 51 expected to reach 74.7 million by 2030 (Prince *et al.* 2015). The potential impact of the
12
13 52 increasing global and local prevalence of dementia on healthcare services and staff, who will
14
15 53 be managing this population to the end of life, requires consideration. The complex pattern of
16
17 54 behavioural and cognitive deficits displayed in dementia results in a patient population whose
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19 55 care requirements differ from those in whom these abilities remain functional. Whilst models
20
21 56 of palliative care may be extrapolated from one health context to another (e.g. the application
22
23 57 of the palliative care model for cancer to other terminal conditions), they are often not
24
25 58 appropriate for use in patients who are unable to participate in, comprehend or consent to,
26
27 59 decisions regarding their own care (Rabins and Black 2007). Institutional settings, such as
28
29 60 nursing and residential homes, hospitals and hospices, are commonly the last place of care for
30
31 61 many older adults with dementia (Ahmad & Mahoney 2005, Houttekier *et al.* 2010).
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33 62 Understanding the barriers to and facilitators of care experienced by healthcare professionals
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35 63 in these settings therefore becomes critical to identify areas where patient needs are not met
36
37 64 and in the development of efficient and feasible strategies which adequately support staff in
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39 65 their practice.
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46 66 Optimal palliative care for people with dementia, including the management of pain, has been
47
48 67 highlighted as a priority in health policy globally (Department of Health 2009, van der Steen
49
50 68 *et al.* 2014). However, evidence suggests suboptimal pain management in people with
51
52 69 dementia compared to cognitively intact older people, including under-prescribing of
53
54 70 analgesia for people with dementia in long-term care, in cancer, after hip fracture and in
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56 71 postoperative care (Bell 1997, Horgas & Tsai 1998, Kaasalainen *et al.* 1998, Morrison & Siu
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3 72 2000, Nygaard & Jarland 2005, Cornali *et al.* 2006, Reynolds *et al.* 2008, Monroe *et al.*
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5 73 2013).

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74 **BACKGROUND**

75 The prevalence of comorbidities in people with dementia often necessitates pain management
76 throughout disease progression and into the final months of life (Mitchell *et al.* 2009,
77 Klapwijk *et al.* 2014, Hendriks *et al.* 2015). The challenges of assessing and managing pain
78 in this complex population have attracted sustained research attention, particularly with
79 regards to the attitudes, knowledge and practices of nursing staff who play a significant role
80 in pain assessment and management (Kovach *et al.* 2000, Nygaard & Jarland 2005,
81 Kaasalainen *et al.* 2007, Zwakhalen *et al.* 2007, Barry *et al.* 2012). Nurses' attitudinal beliefs
82 towards, and knowledge of, the presence, experience and impact of pain on older adults with
83 and without dementia, have critical implications for assessment and treatment, and have been
84 linked to delayed assessment of pain, suboptimal treatment and underuse of *pro re nata*
85 (PRN) analgesia (Kovach *et al.* 2000, Nygaard & Jarland 2005, Kaasalainen *et al.* 2007,
86 Zwakhalen *et al.* 2007, Barry *et al.* 2012).

87 A substantial body of compelling evidence has identified deficits in nurses' knowledge of
88 pain assessment, pharmacology, side-effects and dosing schedules and the presence of
89 misguided perceptions regarding the use of opioids and regularly prescribed analgesics,
90 suggesting that nursing staff are inadequately educated on the use of analgesics in palliative
91 care for people with dementia (Kovach *et al.* 2000, Auret & Schug 2005, Barry *et al.* 2012,
92 Ghandehari *et al.* 2013). Poor pain management has a number of adverse outcomes for
93 patients including the manifestation or exacerbation of neuropsychiatric symptoms, agitation,
94 depression, challenging and resistive behaviour and sleep disturbance (Cipher & Clifford
95 2004, Hadjistavropoulos *et al.* 2007). Previous studies have focused on nurses' experience of

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2
3 96 pain management prior to the end of life but little is known about attitudes of and competence
4
5 97 in pain management in the final weeks. A small qualitative study by Brörson and colleagues
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7 98 (2014) explored the experiences of nurses working in a Swedish hospital dedicated to the care
8
9 99 of patients with neuropsychiatric disorders including dementia. Barriers to pain management
10
11 100 identified included difficulties obtaining analgesic prescriptions, anxiety regarding use of
12
13 101 morphine, and problems with nurse-physician communication (Brörson *et al.* 2014). To the
14
15 102 knowledge of the authors, no studies have been conducted to date which explore nurses'
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17 103 experiences and perspectives of pain management for people with advanced dementia nearing
18
19 104 the end of life across multiple care settings including hospice, acute care and nursing home
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21 105 contexts. This study aims to address this gap in the literature.
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28 107 **AIM**

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31 108 The aim of this research was to explore hospice, nursing home and acute care nurses'
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33 109 experiences of pain management, the perceived barriers to and facilitators of pain
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35 110 management, and perspectives on training needs in managing pain in people with advanced
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37 111 dementia in the final month of life.
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43 113 **METHOD**

44 114 **Design**

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49 115 This qualitative study forms part of a larger programme of research aimed at exploring
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51 116 nurses', physicians' and healthcare assistants' experiences of pain assessment and
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53 117 management for people with advanced dementia in the final month of life with a view to
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55 118 developing a complex intervention to address clinical and professional issues identified, to
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3 119 improve pain assessment and management for this vulnerable patient group. This qualitative
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5 120 study used face-to-face, semi-structured interviews to explore nurses' experiences.
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11 122 **Data collection**

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14 123 *Ethics*

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17 124 Ethical approval was granted by the Office for Research Ethics Committees Northern Ireland
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19 125 (ORECNI) (14/NI/0013). The study protocol and supporting materials were reviewed and
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21 126 approved by independent ethics committees in the participating hospices, in one large chain-
22
23 127 owned nursing home and by the participating HSC Trusts.
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29 129 *Sample and recruitment*

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32 130 Registered nurses (RNs) with responsibility for caring for people with advanced dementia
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34 131 who were nearing the end of life and/or who had died were eligible for participation. We
35
36 132 aimed to recruit a maximum variation sample (regarding age, job role, educational attainment
37
38 133 and length of clinical experience) of nurses within hospice, acute care hospital and nursing
39
40 134 home care settings. Index contacts in each of these settings were approached for participation
41
42 135 in the first instance and subsequent participants were contacted through an onward process of
43
44 136 nominative sampling. Nursing home managers and hospice medical directors distributed
45
46 137 study materials to eligible participants within their respective care settings. In acute care,
47
48 138 consultant physicians (in geriatric medicine, care of the elderly and palliative medicine)
49
50 139 distributed study information, comprising an invitation cover letter and participant
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52 140 information sheet, to eligible nursing teams within their hospitals. All nurses who responded
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54 141 to the participation call were recruited into the study. Twenty-four nurses were recruited from
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3 142 three hospices, two acute care hospitals and ten nursing homes. These settings cover four out
4
5 143 of the five regional Health and Social Care (HSC) Trust areas in Northern Ireland (NI),
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7 144 United Kingdom (UK). Recruitment ceased when no further novel data were identified in
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10 145 transcripts at the within-group and across-group levels and data saturation was achieved.

11 12 146 *Data collection tools*

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15 147 Semi-structured, in-person interviews were conducted with nurses at their place of work. All
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17 148 participants provided written informed consent. An interview topic guide of open-ended
18
19 149 questions was used; this was developed from a review of the literature and refined to suit the
20
21 150 focus of the study. Interview topics covered: experiences of managing pain in people dying
22
23 151 with advanced dementia, barriers to and facilitators of, pain management, and training needs.
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26 152 All interviews were digitally audio-recorded and transcribed verbatim. Interview duration
27
28 153 ranged from 31 minutes to 45 minutes (average 37.9 minutes). Shorter duration interviews
29
30 154 reflect the challenges of interviewing hospital nurses. Data were collected between June 2014
31
32 155 and September 2015.

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37 38 39 157 **Data analysis**

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41 158 Data management and analysis were facilitated using NVivo10 software (QSR International
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43 159 (UK) Ltd, Cheshire, UK). Thematic analysis using Braun and Clarke's (2006) paradigm was
44
45 160 the analytical approach taken to data analysis. Following several re-readings of each
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47 161 transcript, passages of text comprising feelings, thoughts, short narratives, perspectives and
48
49 162 experiences were assigned descriptive codes reflecting the concepts expressed by those data.
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51 163 To ensure consistency, coding was performed in constant comparison to coding completed in
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53 164 prior transcripts and a coding frame was developed. Codes were reviewed and grouped by
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55 165 concept (e.g. 'route of administration') and then arranged by theme (e.g. 'challenges
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3 166 administering analgesia'). To identify whether differences in nurses' experiences of pain
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5 167 management were differentially impacted by the care setting in which they practised, analysis
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7 168 was performed at two levels. In the first instance, data were analysed at the level of the care-
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10 169 setting for each group (hospice nurses, acute care nurses and nursing home nurses) and
11
12 170 subsequently expanded to cross-group comparison (hospice versus acute care versus nursing
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14 171 home).

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18 19 20 173 **Validity and reliability/Rigour**

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22 174 Recommendations from established and recent literature on demonstrating validity, reliability
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24 175 and rigour in qualitative research were adopted and employed throughout this study (Rolfe
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26 176 2006). All interviews were transcribed verbatim by the research fellow (Initials); these were
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28 177 checked for accuracy against the original digital recordings by two members [Initials of
29
30 178 academic professor 1] and [initials of Patient and Participant Involvement Representative] of
31
32 179 the Project Management Group (PMG). Primary data analysis was performed by the research
33
34 180 fellow, after which a selection of transcripts were independently analysed by [initials of
35
36 181 Principal Investigator] and [initials of academic professor 1]. The process of data analysis and
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38 182 identification of the core themes were discussed and agreed between the three authors and
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40 183 presented to and discussed in bi-monthly meetings of the PMG; a group comprising two
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42 184 practising academic-physicians in geriatric/dementia and palliative care, four academics
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44 185 specialising in palliative care, nursing and palliative care and pharmacy, three General
45
46 186 Practitioners (GPs) with a special interest in older adults, dementia and palliative care, and
47
48 187 one Patient and Public Involvement representative (also a retired GP). An audit trail of the
49
50 188 analysis was kept, detailing steps in the development of the coding frame and each level of
51
52 189 analysis.

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191 **RESULTS**

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193 A total of 24 participants comprising hospice nurses (n=6), acute care nurses (n=6) and
194 nursing home nurses (n=12) were recruited. The majority were female (n=23). Participants
195 had an average age of 36.8 years (range: 25 to 59 years) and an average of 13.8 years'
196 nursing experience (range: 3 months to 34 years). Seven participants had postgraduate
197 qualifications including a diploma or master's degree in palliative care, and one participant
198 was undertaking the first year of doctoral study in palliative nursing at the time of the study.
199 Nurse grades ranged from staff nurse to nurse manager. Participant characteristics are
200 presented in full in Table 1.

201

Table 1. Participant characteristics

202 Participants' experiences were characterised into three core themes: (1) challenges
203 administering analgesia, (2) the nurse-physician relationship and (3) interactive learning and
204 practice development. The theme "challenges administering analgesia" reflects challenges
205 arising from the inherent complexity of the patient population (people dying with advanced
206 dementia) and as such, nurses' experiences were universal and not differentially impacted by
207 setting. The second and third core themes comprised both commonalities of experience
208 across settings, with sub-themes reflecting setting-specific challenges. In these cases,
209 experiences were common to nurses within a specific care setting (e.g. acute care) but
210 differed from experiences of nurses in other settings (e.g. hospice). Core themes and sub-
211 themes are presented in Table 2.

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3 213 **Table 2. Core themes and sub-themes identified in within-group and cross-group**
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5 214 **analysis**
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11 216 **Challenges administering analgesia**
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14 217 Commonly experienced challenges with the administration of analgesia comprised patient
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16 218 refusal of pain relief and difficulties with routes through which analgesics could be
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18 219 administered.
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24 221 *Medication refusal*
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27 222 Patient refusal of analgesia (and other medications) was commonly experienced by
28
29 223 participants with most perceiving refusal as the result of patient anxiety and/or fear regarding
30
31 224 medication use. It was believed that profound deficits in cognition prevented patients from
32
33 225 recognising medications as such, and impairments in communication removed the possibility
34
35 226 of engaging in nurse-patient dialogue to explain the need for, and benefits of, analgesia,
36
37 227 through which patients' fears and anxieties might be allayed.
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41 228 It can be difficult then to explain that this is what is working for you and we think that
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43 229 this will help you". (NURS022 - Hospice nurse)
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46 230 In some cases, patients' inability to understand the purpose of pain relief provided, combined
47
48 231 with the pain they were experiencing, culminated in aggressive resistance to treatment.
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51 232 Some of them would be aggressive, they will just full stop not take any pain relief
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53 233 from you and yet you know they need the pain relief. (NURS02 – Nursing home
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55 234 nurse)
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3 235 Many nurses expressed deep empathy for patients, reflecting that fear and/or anxiety were
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5 236 natural responses in dying patients who are entirely dependent on others for care and who
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7 237 cannot understand or adequately express their needs.
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10 238 Put yourself in the shoes of the resident, you're lying there, you can't talk, you can't
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12 239 understand. You're really at the mercy of the people looking after you. (NURS016 -
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14 240 Nursing home nurse)
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20 242 *Route of administration*
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23 243 Participants reported barriers to pain management in patients dying with advanced dementia
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25 244 resulting from constraints on available and appropriate routes of administration. Oral
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27 245 administration of analgesia was challenging in dying patients with frequent and/or excessive
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29 246 drowsiness or who were asleep for extended periods of time. Analgesic use in tablet and
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31 247 liquid formulations carried a high risk of aspiration pneumonia for patients with dysphagia, a
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33 248 common feature in end-stage dementia, often necessitating a review of patients' analgesic
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35 249 regimens.
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39 250 The challenge is they can't take it orally a lot of the time because their swallow
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41 251 deteriorates and they frequently get aspiration pneumonia so whatever oral pain relief
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43 252 they would have been on previously, they can't take anymore. (NURS09 – Acute care
44
45 253 nurse)
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49 254 Participants reported that syringe drivers, injections and intravenous administration could be
50
51 255 challenging when used for end-stage patients with dementia with low body fat, little
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53 256 musculature and cachexia.
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56 257 People with advanced dementia tend to have skin and bones as they haven't been
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3 258 eating great so even like giving subcut [subcutaneous] injections or intramuscular
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5 259 sometimes there's nowhere to put it that's not going to cause more pain whenever
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7 260 you're administering it. (NURS020 – Acute care nurse)
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10 261 Many expressed concern regarding the use of needles in dying patients due to beliefs that
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12 262 these routes were painful and distressing for patients, especially for those who were already
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14 263 anxious and/or agitated.
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17 264 ...they can become more anxious coming near the end...if they see a needle they're
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19 265 freaked out so you have to assess the situation, is it really worthwhile me putting such
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21 266 and such through this here? (NURS06 – Hospice nurse)
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24 267 Respondents preferred less invasive methods such as suppositories and transdermal patches
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26 268 over subcutaneous and intravenous delivery in the final weeks of life and for the imminently
27
28 269 dying; these were considered to be minimally invasive with low risk of injury to patients
29
30 270 during administration.
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34 271 We start with a patch of some description for pain relief, so that keeps them pain free.
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36 272 I find that for people who have dementia, you don't tend to need syringe pumps,
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38 273 you'd use paracetamol suppositories, maybe diazepam suppositories. (NURS09 –
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40 274 Acute care nurse)
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46 276 **The nurse-physician relationship**

48 277 *Positive relationships*

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52 278 All hospice nurses reported positive nurse-physician relationships which were characterised
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54 279 by mutual professional respect, trust and collaboration. They perceived themselves to be
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3 280 working in successful partnership with medical staff towards a common goal of pain
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5 281 management.
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8 282 I think we're doing quite well [in managing pain], but I think it is because we have
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10 283 such a good, you know, we have a good team and we have specialists, you know, as
11
12 284 well, I think that all ties in together. (NURS017 – Hospice nurse)
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15 285 Just over half of nursing home nurses and acute care nurses also reported positive nurse-
16
17 286 physician relationships. These nurses perceived that physicians responded promptly to reports
18
19 287 of pain and to prescription requests, demonstrated shared goals of care, and valued nurses'
20
21 288 contribution to patient care. Open and articulate communication facilitated a collaborative
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23 289 relationship between nurses and physicians in which disciplinary knowledge was shared to
24
25 290 meet the challenges of managing pain as well as other aspects of patient care.
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29 291 The GPs are there all the time to help, they always go with us because they know that
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31 292 we are the ones seeing [the patients] everyday, we know each and every difference in
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33 293 them from yesterday, today, tomorrow. So when we explain, they have trust in us.
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35 294 (NURS013 – Nursing home nurse)
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42 296 *Difficult relationships*
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44 297 Difficult nurse-physician relationships were reported by both nursing home and acute care
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46 298 nurses. Some nurses felt that physicians were reluctant to conduct patient assessments and
47
48 299 ignored requests for help with complex cases.
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52 300 Some will say: well, what's wrong with them? And try and diagnose over the phone,
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54 301 rather than actually coming out and doing a home visit. Probably one of the biggest
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3 302 issues that we have, is that the GPs wouldn't always come out and help us assess.

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5 303 (NURS015 – Nursing home nurse)

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8 304 Negative relationships were also reported where participants experienced difficulties or
9
10 305 delays in obtaining scripts, where prescribing decisions were perceived (and/or transpired) to
11
12 306 be sub-therapeutic, and where treatment appeared to be unreflective of patient needs.

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15 307 Sometimes I think there's reluctance on the part of the medical [staff], especially if
16
17 308 it's a junior medic, you know, to even prescribe something. (NURS021 – Acute care
18
19 309 nurse)

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22 310 Senior acute care and nursing home nurses felt confident in advocating for patients in cases
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24 311 where nurses' and physicians' goals of care were perceived to be discordant but
25
26 312 acknowledged that confidence to query prescribing decisions varied among nurses.

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30 313 Some [GPs] have their own thoughts and trends in their head and what they believe is
31
32 314 right. I think they open a book and it says A, B, C and D to them and therefore they
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34 315 want to follow A, B, C and D to do their best, but sometimes they forget to listen to
35
36 316 the nurses who do know. I think it depends on how empowered a nurse is to actually
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38 317 say to a GP: hold on a minute, and to be an advocate for our residents. (NURS03 –
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40 318 Nursing home nurse manager)

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44 319 Nurses with 20 or more years' nursing experience believed that poor communication skills
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46 320 and inadequate reporting among nursing staff contributed to the difficulties experienced in
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48 321 nurse-physician relationships. Failure to provide salient, contextual information about
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50 322 patients (such as changes in swallow) clouded the clinical picture for physicians, especially
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52 323 for those not present in the care setting daily, in some cases resulting in clinical errors and/or
53
54 324 inappropriate treatment.

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3 325 If it's a GP writing up, their initial thing would be to write up the ordinary capsules
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5 326 but it's the nurses being proactive to say, whenever they're getting it prescribed: "Oh
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7 327 this patient's swallow is quite impaired, is there any other form that can be given in?"
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10 328 So it's not the GP's fault, it's the nurses not informing them of the actual situation.
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12 329 (NURS010 – Nursing home nurse)

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18 331 **Interactive learning and practice development**19
20 332 *Hospice nurses*21
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23 333 Hospice nurses perceived themselves to be fortunate in being able to readily access ongoing
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25 334 professional development across many aspects of dementia care including pain management.26
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28 335 I think we are quite lucky here because we get quite a lot of training [...]. You're
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30 336 getting your practical training, you have your mentor, and you learn so much from
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32 337 your mentor. And then we have online training and we have certain study days
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34 338 dedicated to it [dementia] and if we want we can get external training as well.
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36 339 (NURS05 Hospice nurse).37
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40 340 Hospice nurses expressed preference for interactive, group discussion of patient cases
41
42 341 alongside structured didactic teaching, reporting that these approaches facilitated and
43
44 342 encouraged knowledge exchange between nursing staff.45
46
47 343 Usually here we would have small groups [...] and it's very interactive and it's not
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49 344 very formal but it's very, very, informative, very good. And then you can bounce
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51 345 ideas off each other, it's very good I think. (NURS011 – Hospice nurse)52
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58 347 *Acute care and nursing home nurses*

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3 348 These nurses' experiences of training and development differed substantially to those of
4
5 349 hospice nurses. Opportunities for professional and practice development were often limited
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7 350 for acute care and nursing home nurses due to constraints on staff time, heavy workload and
8
9 351 the need to travel to training events.

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12 352 I think the problem with the training is the training days aren't local for the staff and
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14 353 there might only be one training day and not all the nurses can go on that one day.

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17 354 (NURS08 – Acute care nurse).

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20 355 Opportunities for learning and development were also often negatively impacted by the
21
22 356 financial resources available in their respective organisations.

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25 357 ...the problem is that a lot of the training is quite expensive so the nursing homes are
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27 358 not subscribing to it. I mean some of these training days can cost £1200 for the day.

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29 359 (NURS10 – Nursing home nurse)

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31
32 360 Barriers to training and practice development resulted in some staff having received no
33
34 361 training in dementia care including in pain management.

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37 362 I haven't had any training with regards to dementia so it's just something that I'm
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39 363 maybe learning from colleagues. (NURS20 – Acute care nurse).

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45 365 *Whole-group perspectives on interactive learning and practice development*

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48 366 All respondents believed that access to ongoing professional development was critical in
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50 367 empowering staff to effectively and safely manage pain and provide a good standard of
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52 368 holistic care to people dying with advanced dementia. When asked to describe their
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54 369 preferences for training approach, the large majority believed that mentoring and/or
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56 370 shadowing experienced nurses constituted an ideal approach to training. Senior and less
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3 371 experienced nurses believed that 'leading by example' and 'learning by example' were
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5 372 methods most likely to encourage and promote professional and practice development for
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7 373 nurses.
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10 374 I'm saying to them think about it yourself: if co-codamol isn't strong enough, what
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12 375 would be your next pain relief that you would use? If someone's on this [analgesic]
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14 376 now, how much morphine is this? And if I had to change it, what would I do next?
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16 377 And the staff find that approach is very helpful. (NURS05 - Hospice nurse)
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20 378 Participants emphasised that training and practice development should be an ongoing process
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22 379 and required a needs-based approach with input from nursing staff.
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25 380 You would have to do a needs assessment around the staff and it should be a continual
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27 381 thing not a one-off. But I think staff need to sit down together and start off deciding
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29 382 what their needs are and then they can grow from there. (NURS24 - Nursing Home
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31 383 Nurse)
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34 384 All nurses reported training in pharmacology was required; some reflected on the dichotomy
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36 385 of holding a position with legal and professional responsibility for administering a large
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38 386 number of medications to vulnerable patients daily without full understanding of what they
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40 387 were providing.
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44 388 I think nurses are very guilty of sometimes handing out all these medicines and, you
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46 389 know, we hand them out because they're prescribed by the GP but do we really know,
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48 390 you know, do we know the action of these drugs? Do we, you know, are we sure that
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50 391 they're not going interact with any of the other drugs that they have? (NURS01 –
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52 392 Nursing home nurse)
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3 393 All participants in this study expressed that having the appropriate skills and knowledge to
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5 394 competently and confidently manage patients dying with dementia to a 'good death' was of
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7 395 paramount importance.
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10 396 I want to feel totally equipped to be able to deal with all aspects of their care and
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12 397 never to feel that there was something extra that I could have done...Something that I
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14 398 should have done. (NURS03 – Nursing home nurse)
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20 400 **DISCUSSION**

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23 401 This study reported on the experiences of nurses from hospice, acute care and nursing home
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25 402 settings in managing pain for people dying with advanced dementia. Although healthcare
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27 403 policy and clinical guidelines identify symptom management, including pain, as a
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29 404 cornerstone of care at end of life, participant experiences reported in this study illustrated that
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31 405 nurses can find this highly challenging to achieve in practice (van der Steen *et al.* 2014). This
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33 406 study found that pain management in the final weeks of life was impacted by a number of
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35 407 patient-related, nurse-related and organisational factors. Whilst patient-related factors
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37 408 appeared to be universal across the settings, nurse-related and organisational factors varied
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39 409 between care settings, differentially impacting on nurses' experiences of pain management.
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44 410 *Challenges administering analgesia*

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46 411 Administration of analgesia was a challenge for all nurses in this study due to patient refusal
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48 412 and/or limited routes of administration. Most believed that patients' severe cognitive
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50 413 impairment and loss of communication inhibited their recognition of analgesia as such and
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52 414 their understanding of its need, prompting refusal. Many nurses were empathetic towards
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54 415 patients' perspectives but felt restricted in their approaches to encouraging compliance in the
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56 416 absence of the nurse-patient dialogue. Difficulties in nurse-patient communication in
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3 417 dementia are well recognised and methods to improve this have been well-researched;
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5 418 however, our findings suggest that many of these strategies may remain in the literature and
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7 419 fail to translate into clinical practice (Finke *et al.* 2008, Weitzel *et al.* 2011). Patients'
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9 420 physical decline (dysphagia, low body musculature etc.) and/or altered states of
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11 421 consciousness (drowsiness, excessive sleep etc.) limited routes by which analgesia could be
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13 422 administered. Oral, intravenous and subcutaneous administration were considered
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15 423 problematic and perceived to present a high risk of injury, pain and distress to dying patients.
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17 424 Most participants preferred the use of suppositories and transdermal patches, considering
18
19 425 them to be low risk and less invasive. Our findings did not elucidate whether difficulties with
20
21 426 administration resulted in non-compliance. There has been surprisingly little investigation
22
23 427 into the challenges of medication administration in dementia, despite the serious implications
24
25 428 of non-compliance for patient outcomes; this area warrants further investigation (Passmore *et*
26
27 429 *al.* 2010).

32 430 *The nurse-physician relationship*

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35 431 In this study, nurse-physician relationships appeared to be differentially impacted by care
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37 432 setting. Whilst hospice nurses unanimously reported good working relationships with
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39 433 physicians, acute care and nursing home nurses reported mixed experiences. Positive
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41 434 relationships were characterised by nurses' perceptions that their contribution towards patient
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43 435 care was valued, that they were working in collaborative partnership with physicians and
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45 436 where there was mutual professional respect. Difficult nurse-physician relationships were
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47 437 reported where nurses described themselves as working in parallel with physicians, where
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49 438 participants perceived physicians to be reluctant to assist with complex cases, and/or where
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51 439 pain was inadequately managed. Highly experienced nurses described instances where nurse-
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53 440 physician relationships were negatively impacted by poor communication skills and
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3 441 inadequate reporting among nursing staff, sometimes resulting in inappropriate patient
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5 442 treatment.
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8 443 The setting-specific differences in nurse-physician relationships reported here may, in part,
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10 444 reflect the palliative focus of the hospice setting, its ethos, the relative stability and continuity
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12 445 of staff and availability of additional organisational resources. Staff turnover in acute care
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14 446 and nursing home settings may inhibit the establishment and development of close working
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16 447 relationships between nursing and medical staff, particularly in the nursing home context
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18 448 where physicians are based in external surgeries (Tjia *et al.* 2009). Nurse-physician
19
20 449 communication and relationships have been studied extensively and positive relationships
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22 450 have been reported to result in higher job satisfaction for nurses and physicians, sharing of
23
24 451 disciplinary knowledge and improved patient outcomes (Prescott & Bowen 1985, Keenan *et*
25
26 452 *al.* 1998, Manojlovich 2010). Difficult relationships have resulted in poor job satisfaction,
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28 453 feelings of professional isolation, and errors in patient assessment and management (Donchin
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30 454 *et al.* 1995, Manojlovich 2010). Clarity in inter-professional working is essential in
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32 455 healthcare and is critical in patient populations unable to effectively communicate their
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34 456 needs; however, these relationships are complex and often impacted by professional
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36 457 boundaries, personal perceptions and organisational cultures.
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42 *Interactive learning and development*

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45 459 Hospice nurses were satisfied with the quantity and quality of opportunities for professional
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47 460 development. Acute care and nursing home nurses; however, experienced significant barriers
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49 461 to accessing training and practice development due to financial, travel and time constraints.
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51 462 Some nurses received no training in dementia; this is a significant concern given the
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53 463 complexities of these patients, their need for tailored care, the prevalence of dementia in these
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55 464 settings and the substantial evidence reporting poor outcomes for pain assessment and
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3 465 management in dementia as a result of inadequately trained staff (Brunier *et al.* 1995, Closs
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5 466 1996, Kovach *et al.* 2000, Weiner & Rudy 2002, Auret & Schug 2005, Plaisance & Logan
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7 467 2006, Barry *et al.* 2012, Ghandehari *et al.* 2013).

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10 468 Most respondents believed that learning through case-based discussion and/or mentoring by
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12 469 senior nurses were most likely to stimulate practice development and change. These
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14 470 opportunities needed to be ongoing and developed in consideration of nurses' needs.
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17 471 Participants emphasised that pharmacological training was required, with some expressing
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19 472 concern regarding their lack of understanding of the regimens they administered. This is a
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21 473 key area of practice development given the available evidence regarding inadequate
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23 474 pharmacology knowledge among nursing staff and medication administration errors,
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25 475 omissions and adverse events (McBride-Henry & Foureur 2006, Dilles *et al.* 2011).

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28 476 These findings provide new insight into the experiences of nurses across three care settings in
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30 477 which patients dying with advanced dementia commonly end their lives and the gap between
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32 478 healthcare policy and clinical recommendations for pain management at end of life. Nurses'
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34 479 experiences revealed a number of barriers to pain management at end of life some of which
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36 480 corroborate those reported in Brörson *et al.* 2014. In addition, our findings highlight areas
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38 481 across and between settings in which nurses are under-supported and may be inadequately
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40 482 equipped to meet standards expected by policy makers.
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48 484 **Limitations**

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50 485 The nature of the self-selecting sample may have encouraged participation from nurses with
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52 486 an interest in research and those who felt comfortable describing experiences that included
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54 487 accounts of low confidence or competence, or which provided critical accounts of nursing
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56 488 staff and/or care organisations. Nursing home staff comprised 50% of the total sample.
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3 489 However, within whole-group analyses, nursing home nurses' experiences did not differ
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5 490 substantially from those of acute care and hospice nurses, and in other cases, their
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7 491 experiences reflected those of acute care nurses suggesting that the core themes emerging are
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9 492 not substantially biased to the nursing home context. It is acknowledged that acute care
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11 493 nurses were recruited from care of the elderly units linked to teaching hospitals and are likely
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13 494 to display greater awareness of pain in dementia than acute care nurses working in other
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15 495 wards. The findings reported here represent the commonalities of experience and perspectives
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17 496 of this participant sample, drawn from three different care settings and are likely to be
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19 497 reflective of nurses working with the same patient population in the same contexts of care
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21 498 (Mays & Pope 1995).
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29 **CONCLUSIONS**

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31 501 This study provides a comprehensive exploration of nurses' experiences of pain management
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33 502 for people with advanced dementia in their final month of life. The findings indicate that
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35 503 whilst nurses' beliefs about pain management accord with policy and clinical
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37 504 recommendations for pain management in the final weeks of life, nurses face many
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39 505 challenges in its achievement in practice. The inequality of training and development
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41 506 opportunities for hospice, nursing home and acute care nurses is a concern, given that the
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43 507 rates of referral to hospice and palliative care for people with dementia are consistently lower
44
45 508 than those for people with cancer and other comorbid conditions. Dementia care literature has
46
47 509 experienced significant expansion in recent years resulting in many empirically supported
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49 510 recommendations for appropriate, holistic, person-centred care for this patient population
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51 511 which often rely on the availability of appropriately equipped, well-trained staff who are
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53 512 confident and competent to provide this care. It is imperative that nurses are adequately
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3 513 supported and equipped with the appropriate knowledge and skills to efficiently manage the
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5 514 needs of what is widely recognised as a complex patient population.
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10 516 **RELEVANCE TO CLINICAL PRACTICE**

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13 517 People dying with advanced dementia have complex care requirements including pain and
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15 518 symptom management; however, in order for nurses to meet standards of care expected of
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17 519 them, nurses require adequate and appropriate support from healthcare providers. The current
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19 520 study indicates that acute care and nursing home nurses experience challenges in managing
20
21 521 pain for people with advanced dementia in the final month, and are at risk of being
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23 522 undertrained and under-resourced to meet these challenges. Nurses across all healthcare
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25 523 settings in this study self-reported a critical lack of understanding of pharmacology which
26
27 524 carries serious implications for patient safety. These findings have been used to develop and
28
29 525 pilot an interactive learning and practice development intervention appropriate for all nurses
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31 526 working in dementia, aimed at providing opportunities for sharing knowledge and skills,
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33 527 ongoing professional development and participation in a collaborative approach to patient
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35 528 care. Future work should examine other methods of interactive learning and ways to improve
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37 529 access to practice development.
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For Peer Review

Table 1. Participant characteristics

	n (%)
Gender	
Male	1 (4)
Female	23 (96)
Care setting (Specialty)	
Nursing homes	12 (50)
Acute care	6 (25)
Hospice	6 (25)
Years' experience	
<5	5 (21)
5-10	6 (25)
11-20	5 (21)
21-30	7 (29)
>30	1 (4)

Additional qualifications

None	17 (71)
Postgraduate degree in palliative medicine or related field	7 (29)

For Peer Review

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3 **Table 2. Core themes and sub-themes identified in within-group and cross-group**
4 **analysis**
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Core theme	Sub-theme
Challenges administering analgesia	(a) Medication refusal
	(b) Route of administration
The nurse-physician relationship	(a) Positive relationships
	(b) Difficult relationships
Interactive learning and practice development	(a) Hospice nurses
	(b) Acute care and nursing home nurses
	(c) Whole-group perspectives on interactive learning and development

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