

## Journal Pre-proof

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## BRIEF COMMUNICATION

### Knowledge, competence and educational needs of mental health staff on palliative care for the elderly with dementia

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#### -----ABSTRACT-----

Dementia is a clinical syndrome for which the benefits of palliative care have been recognized. The aim of this study was to investigate the knowledge and educational needs of mental health physicians and nurses and also their perceptions of their competence regarding palliative care for the elderly with dementia. A total of 96 mental health professionals (doctors, nurses) working in a public psychiatric hospital and its allied community mental health settings participated in the study. The Palliative Care Quiz for Nursing (PCQN) was used to detect their knowledge on palliative care as well as a questionnaire to collect participants' demographics, their perceptions about their competence in palliative care provision and their educational needs on the basic domains of palliative care for the elderly with dementia. Results revealed participants' significant lack of knowledge (PCQN =7.79/20) and low perception of competence regarding palliative care for elderly persons with dementia. Participants who were psychiatrists, who had work experience between 16-20 years and provided care to more than ten patients with terminal dementia per year, showed higher PCQN scores at a statistically significant level ( $p=0.001$ ). The majority (93.6%) of participants considered training in palliative care for dementia patients as necessary, particularly in providing information to family/carers, relieving the psychosocial burden of family/carers, managing the terminal stage of dementia, providing information to dementia patients and planning their advanced care. The findings of this study could inform the design of training programs on palliative care for the elderly with dementia in Greece.

**KEYWORDS:** Elderly, dementia, palliative care, mental health professionals, knowledge, competence, educational needs.

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## Introduction

Dementia is a clinical syndrome affecting an increasing population of older people worldwide, for which the benefits of palliative care have been recognized.<sup>1</sup> This approach focuses on improving the quality of life of patients and their families through prevention, early detection, comprehensive assessment and management of dementia symptoms and impact as well as

the psychosocial and spiritual suffering of both the individuals and their families.<sup>2</sup> The supportive and palliative care needs of people with dementia have been shown to be similar to those of cancer patients; however, they differ due to the unique characteristics of dementia, such as neuropsychiatric and cognitive symptoms, and its unpredictable long course.<sup>2,3</sup> Benefits of palliative care provision for dementia patients, include improving patient and caregiver satisfaction, enhancing their quality of life, better management of end-stage symptoms, and increasing discussions about prognosis, avoidance of hospital readmissions and goals of care in advanced dementia.<sup>4,5</sup>

Literature, however, shows deficiencies in health professionals' knowledge on palliative care, a fact that hinders the recognition of its appropriateness for individuals with dementia.<sup>6,7</sup> Inadequate training regarding palliative care knowledge and skills, and also poor recognition of its appropriateness for persons with dementia, comprise significant barriers in providing palliative care for this population,<sup>8</sup> a fact also identified in psychiatric contexts.<sup>9</sup>

Although the importance of palliative and supportive care for patients with dementia has been recognized in Greece,<sup>10</sup> the level of knowledge of mental health personnel in this field, has not been investigated. The aim of this study was to explore the knowledge and educational needs of mental health physicians and nurses as well as their perceptions of their competence regarding palliative care of the elderly with dementia. Possible correlations between knowledge, educational needs, perceived competence and demographic and professional factors, were also explored.

## **Material and Methods**

The sample included 96 mental health professionals (doctors, nurses), working in a public Psychiatric Hospital (eight psychiatric clinics) and its allied community mental health settings (two mental health centers and four psychosocial rehabilitation contexts). Data collection took place between March and April 2022, after study approval by the Research and Ethics Committee of the University of West Attica (a.n. 25531-14/3/2022) and the Scientific Council of the Psychiatric Hospital (a.n. 33423-21/12/2021).

### ***Study questionnaires***

a) Demographic and occupational data questionnaire (gender, age, specialty, employment status, years of experience, work setting, education in palliative care). Participants were also asked to indicate the approximate number of people with dementia they care for per year, as well as the annual number of advanced dementia patients during the last 6 months of their lives, to evaluate on a 4-point Likert scale (1=not at all, 2=a little, 3=adequately, 4=a lot) their level of competence in managing various aspects of caring for people with dementia as well as to identify their educational needs. The domains of competence and educational needs were determined based on the core areas of palliative care in dementia described by the European Palliative Care Association (symptom management, psychosocial impact, informing individual/caregivers, family involvement in care, advanced care planning, and managing the challenges of dementia).<sup>11</sup>

b) The Palliative Care Quiz for Nursing (PCQN) was used for the evaluation of participants' knowledge in the following three main fields of palliative care: (i) its philosophy and basic principles, (ii) the management of pain and other symptoms, and (iii) the psychosocial aspects of care.<sup>12</sup> A total score of 15/20 or higher is an indication of sufficient knowledge in palliative care. PCQN has been used in many countries, including Greece, for assessing palliative care knowledge of healthcare professionals with various backgrounds.<sup>13-14</sup> In the present study, the Greek version of PCQN was used with permission.<sup>13</sup>

### ***Statistical analysis***

SPSS v.25 software was used for data analysis. Normality was tested through Shapiro-Wilk and all variables followed a normal distribution. The t-test was used for the analysis of possible correlations between two independent categories and the one-way ANOVA was used for independent variables in more than two categories. Pearson correlation analysis was also applied to investigate correlations between variables. The level of statistical significance was set at  $p < 0.05$ .

## Results

Participants' demographic and occupational data are listed in Table 1. A percentage of 48% reported providing care to more than 20 elderly people with dementia per year, while 34% reported providing care to more than 10 older adults with dementia during the last 6 months of their lives, per year.

### Table 1

Participants reported feeling competent for managing dementia symptoms (average score 2.83), addressing patients' psychosocial needs (average score 2.75), and their personal burden due to terminal care challenges (average score 2.74), managing family's psychosocial burden (average score 2.66), providing information to families and patients (average score 2.55) and advanced care planning (average score 2.54) (Supplementary Table 1).

The majority of participants (93.6%) considered training in palliative care for the elderly as necessary, particularly about providing information to family/caregivers (average score of 3.27), addressing the psychosocial burden on family/caregivers (average score of 3.19), managing the terminal stage (average score of 3.18), providing information to patients and planning for their future care (average score of 3.14) (Supplementary Table 2).

PCQN showed extremely low scores in all sections, while the overall score was 7.79/20, a result well below the acceptable limit (15/20), indicating a significant knowledge deficit in all three key areas of palliative care (Table 2).

### Table 2

Statistically significant higher PCQN scores were identified for psychiatrists ( $p=0.001$ ), men ( $p=0.004$ ) participants having 16–20 years of work experience ( $p=0.001$ ), and those providing care to >10 people with end-stage dementia per year ( $p=0.000$ ) (Supplementary Tables 3-6). Higher PCQN scores showed statistically significant positive correlation with participants' perceptions of their competences, with management of organic symptoms showing the strongest correlation ( $r=1$ ), (Supplementary Table 7), as well as statistically significant negative correlation with their educational needs, mainly in managing the psychosocial impact of dementia on patients ( $r=-0.45$ ) (Supplementary Table 8).

## Discussion

Results highlighted a significant knowledge deficit in all key areas of palliative care, a finding also supported by the international literature.<sup>6-9,15-17</sup> Particular mention merits participants' limited knowledge on addressing patients' psychosocial needs given that, according to the study of Evenblij et al.<sup>9</sup> regarding palliative care provision in psychiatric institutions in the Netherlands, focus on psychosocial and spiritual parameters is greater in the case of psychiatric patients, including those with dementia, in relation to palliative care for people with non-psychiatric conditions.

The statistically significant correlations found between participants' knowledge and years of work experience are also supported by Chen et al.,<sup>6</sup> possibly suggesting that healthcare staff rather rely on clinical practice for becoming familiar with palliative care, than on the availability of special education programs. The need for training mental health staff in palliative care for patients with dementia is also found in the literature, where it is highlighted that specialized training is critical for enhancing professionals' competence and skills in palliative care, understanding its appropriateness for dementia patients and reconstructing common misunderstandings such as that it is only indicated for terminal dementia.<sup>15-17</sup>

Managing communication, psychosocial impact, and the terminal stage of dementia that were identified as educational needs in this study, comprise a finding supported by Bolt et al.<sup>16</sup> who found that the most commonly reported needs of nursing staff (n=416) providing palliative care to seniors with dementia included managing "difficult" behaviors, such as agitation and aggression (41%), recognizing and managing pain (38%), addressing emotional states such as sadness and anxiety (34%), guiding the family throughout the terminal stage (34%), and communicating with advanced dementia patients (33%). Findings regarding the educational needs of participants on informing families/carers and their participation in care, need special attention, as according to Küpper et al.<sup>3</sup> who investigated the challenges of caring for patients with advanced dementia in the United Kingdom, healthcare personnel often passed on to family members the responsibility of making decisions on terminal care who, however, did not have the appropriate information for this purpose, leading thus to the risk of under- or over-treatment of the sufferers, given also their reduced cognitive capacity for autonomous decision making. Findings on participants' limited competence regarding advance care planning for patients with dementia, also reported among their educational needs, are noteworthy, taking into consideration the importance of advance planning for the quality of care provided to patients facing advanced and terminal dementia.<sup>2</sup>

The study has certain limitations that need to be considered. Firstly, it focuses on the staff of one psychiatric hospital, which means that the findings cannot be applied to other settings. Secondly, PCQN explores general rather than dementia-specific palliative care knowledge, while participants' knowledge and competences in relation to dementia severity or their working settings, were not investigated. However, this is the first study to explore the knowledge, competences, and educational needs of mental health professionals in palliative care for people with dementia in Greece, a topic for which international research data regarding psychiatric contexts is also very limited. The findings of this study could contribute to designing appropriate educational programs addressed to health professionals regarding palliative care for patients with dementia and their families.

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**Tablet 1.** Participants' demographics (N=96)

Specialty	n
Psychiatry	12
Internal Medicine	4
Nursing	44
Nurse assistant	36
<b>Sex</b>	
Female	68
Male	28

<b>Age</b>	
20-25	10
26-30	4
31-40	28
41-50	34
51+	20
<b>Education</b>	
Secondary education	10
Vocational Training	28
University degree	40
Postgraduate	12
PhD	6
<b>Work setting</b>	
Psychiatric Clinic	74
Psychosocial Rehabilitation	14
Mental Health Center	8
<b>Years of work experience</b>	
0-5	32
6-10	14
11-15	6
16-20	10
21-25	20
26+	14

**Table 2.** PCQN scoring results

<i>Odd-numbered items, False = 1 point</i>	<b>N</b>	<b>True n (%)</b>	<b>False n (%)</b>	<b>I don't know n (%)</b>	<b>Score</b>
Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration	96	32 (33)	58 (60)	6 (6)	0.60
The extend of the disease determines the method of pain treatment	94	64 (67)	12 (12,5)	18 (19)	0.13
It is crucial for family members to remain at the bedside until death occurs	96	82 (85.5)	2 (2)	12 (12.5)	0.02
Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain	96	74 (77)	8 (8)	14 (14.6)	0.08
The provision of palliative care requires emotional detachment	96	50 (53)	36 (37.5)	10 (10.4)	0.38
Men generally reconcile their grief more quickly than women	96	18 (18.8)	56 (58)	22 (23)	0.58

The use of placebos is appropriate in the treatment of some types of pain	94	62 (64.6)	12 (12.5)	22 (20.8)	0.13
Suffering and physical pain are synonymous	94	40 (42)	42 (43.8)	12 (12.5)	0.44
The accumulation of losses renders burnout inevitable for those who seek work in palliative care.	96	66 (81)	16 (10.6)	14 (8.5)	0.17
The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate	94	76 (79)	10 (10.4)	8 (8.3)	0.10
<b><i>Even-numbered items, True = 1 point</i></b>	<b>N</b>	<b>True n (%)</b>	<b>False n (%)</b>	<b>I don't know n (%)</b>	<b>Score</b>
Morphine is the standard used to compare the analgesic effect of other opioids	96	42 (43.8)	24 (25)	30 (31.3)	0.44
Adjuvant therapies are important in managing pain	96	84 (87.5)	0 (0)	12 (12.5)	0.88
During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation.	96	44 (45.8)	18 (19)	34 (35.4)	0.46
Individuals who are taking opioids should also follow a bowel regime	96	56 (58)	4 (4.2)	36 (37.5)	0.58
During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea	96	10 (10.4)	38 (39.6)	48 (50)	0.10
The philosophy of palliative care is compatible with that of aggressive treatment	94	50 (53.2)	8 (8.5)	36 (38)	0.52
In high doses, codeine causes more nausea and vomiting than morphine	94	34 (35.4)	8 (8.3)	52 (54)	0.35
Pethidine is not an effective analgesic in the control of chronic pain	96	36 (37.5)	14 (14.6)	46 (48)	0.38
Manifestations of chronic pain are different from those of acute pain	94	74 (77)	6 (6.3)	14 (14.6)	0.77
The pain threshold is lowered by anxiety and fatigue	96	66 (69)	26 (27)	4 (4.2)	0.69
<b>Total score</b>					<b>7.79</b>



## ΣΥΝΤΟΜΟ ΑΡΘΡΟ

**Γνώσεις, επάρκεια και εκπαιδευτικές ανάγκες ιατρονοσηλευτικού προσωπικού ψυχικής υγείας για την ανακουφιστική φροντίδα ατόμων τρίτης ηλικίας με άνοια**

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**ΙΣΤΟΡΙΚΟ ΑΡΘΡΟΥ:** Παραλήφθηκε 30 Αυγούστου 2023 / Αναθεωρήθηκε 10 Νοεμβρίου 2023 / Δημοσιεύθηκε Διαδικτυακά 27 Φεβρουαρίου 2024

### ΠΕΡΙΛΗΨΗ

Η άνοια αποτελεί μια κλινική συνδρομή για την οποία έχουν αναγνωρισθεί τα οφέλη παροχής ανακουφιστικής φροντίδας. Σκοπός της παρούσας έρευνας ήταν η διερεύνηση των γνώσεων και των εκπαιδευτικών αναγκών του ιατρονοσηλευτικού προσωπικού ψυχικής υγείας καθώς και των αντιλήψεών τους για την επάρκειά τους αναφορικά με την ανακουφιστική φροντίδα ατόμων τρίτης ηλικίας με άνοια. Στην έρευνα συμμετείχαν 96 επαγγελματίες ψυχικής υγείας (ιατροί, νοσηλεύτριες) εργαζόμενοι σε δημόσιο ψυχιατρικό νοσοκομείο και στις κοινοτικές του δομές. Χρησιμοποιήθηκε το Palliative Care Quiz for Nursing (PCQN) για την εκτίμηση των γνώσεων των συμμετεχόντων στην ανακουφιστική φροντίδα, καθώς και ερωτηματολόγιο δημογραφικών και επαγγελματικών δεδομένων, καταγραφής των αντιλήψεων των συμμετεχόντων για την επάρκειά τους ως προς τους βασικούς τομείς ανακουφιστικής φροντίδας, όπως και των εκπαιδευτικών τους αναγκών στο πεδίο αυτό. Η μελέτη ανέδειξε σημαντικό έλλειμμα γνώσεων (PCQN=7,79/20) και χαμηλά επίπεδα επάρκειας του δείγματος σε όλους τους τομείς της ανακουφιστικής φροντίδας. Οι συμμετέχοντες που είχαν την ψυχιατρική ειδικότητα, 16-20 έτη εργασιακής εμπειρίας και παρείχαν υπηρεσίες σε περισσότερα από 10 άτομα με άνοια τελικού σταδίου κατά έτος, εμφάνιζαν υψηλότερο σκορ στο ερωτηματολόγιο PCQN σε στατιστικά σημαντικό βαθμό ( $p=0,001$ ). Στην πλειοψηφία τους (93,6%) οι συμμετέχοντες θεώρησαν απαραίτητη την εκπαίδευσή τους στην ανακουφιστική φροντίδα ατόμων τρίτης ηλικίας με άνοια, ιδιαίτερα ως προς τη διαχείριση της ενημέρωσης της οικογένειας/φροντιστών, της ψυχοκοινωνικής επιβάρυνσης των μελών της οικογένειας/φροντιστών, του τελικού σταδίου της άνοιας, της ενημέρωσης του πάσχοντος ατόμου και του σχεδιασμού της μελλοντικής του φροντίδας. Τα αποτελέσματα της παρούσας μελέτης, μπορούν να αποτελέσουν τη βάση για τον σχεδιασμό εκπαιδευτικών προγραμμάτων στο πεδίο της ανακουφιστικής φροντίδας ατόμων τρίτης ηλικίας με άνοια και στη χώρα μας.

**ΛΕΞΕΙΣ ΚΥΡΕΤΗΡΙΟΥ:** Τρίτη ηλικία, άνοια, ανακουφιστική φροντίδα, επαγγελματίες ψυχικής υγείας, γνώσεις, επάρκεια, εκπαιδευτικές ανάγκες.

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