

Sara Vieira Silva

**HEALTHCARE PROFESSIONALS' PERSPECTIVES ON
EMERGENCY DEPARTMENT RESPONSIVENESS TO END-OF-
LIFE CARE IN DEMENTIA - a mixed-methods study**

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**Tese submetida à Faculdade de Medicina da Universidade do Porto para
obtenção do grau de Doutor em Cuidados Paliativos**



Title: Healthcare Professionals' Perspectives on Emergency Department Responsiveness to End-of-Life Care in Dementia - a mixed-methods

Advisors:

Professora Doutora Carla Margarida Teixeira, PhD
DACIE- Anesthesiology, Intensive Care and Emergency Department, ULSSA University
Hospital, Porto, Portugal
Associate Professor, ICBAS, School of Medicine and Biomedical Sciences, Porto
University
Investigator CRITICALMED – CINTESIS – RISE-HEALTH
Faculty of Medicine of Porto, Portugal

Professora Doutora Bárbara Antunes, Clin Psych, PhD
Centro de Estudos e Investigação em Saúde da Universidade de Coimbra

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Exma. Senhora

Mestre Sara Neves Vieira da Silva

neveessp@gmail.com

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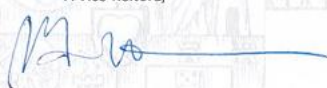
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UNIVERSIDADE DO PORTO, REITORIA
Praça Gomes Teixeira, 4099-002 Porto
TEL. +351 22 040 8000. FAX +351 22 040 8116/ 8117
URL: www.up.pt

**To my mother,
father, sister and my Joões**

Se dividirmos a morte pela vida, obteremos um círculo.
Colum McCann *in Apeirogon*

Porque o mundo não sabe que é mundo.

O mundo só se torna consciente no momento
em que é observado com assombro. É nesse
instante raro – quando alguém se curva
sobre uma pedra, não para classificá-la, mas para escutá-la – que a
matéria se anima,
como quem sonha com um animal que sonha com um homem que sonha
com uma
rocha, que sonha com o início de tudo.

José Eduardo Agualusa *in Tudo sobre Deus*

Nós somos o outro do outro.

José Saramago

O Corpo que não é

Nem isso, nem Aquilo: sou eu.
Não sou daqui, nem dali, sou de onde for não esteja.

Sou eternamente o eu e a outra.
Não sou poesia, nem prosa, sou um corpo.
O corpo que não é.
Medido a partir do seu próprio umbigo,
não é do Ocidente,
nem propriamente do Oriente.
Dizem que é do Médio,
Ou do Próximo,
Como se fosse mais aconchegante.
Sou um cruzamento
com mapas a invadirem o meu ser.
Ocupada, mas livre.
As minhas línguas são um muro.
Acontecem em mim em simultâneo
Tal como os meus sonhos.
Não estou aqui ainda
e já não me lembro dali.
Nem a memória nem o esquecimento,
sou o nunca-agora.
Escolhi viver na terra do mais ou menos.
Nem isso, nem Aquilo, um vai andando.
Um bacalhau demolido, nem cru, nem cozinhado.
Não é extremamente nem extremamente, é.
E eu sou exatamente e extremamente eu: nem isso, nem Aquilo.
Não sou aquela árvore, nem a outra, sou o entre bordado.

Sou o toque entre duas peles.
Na linha que nos separa eu habito.
Nem a pátria, nem o exílio é aqui.
Nem isso, nem Aquilo: sou eu.
Sou a própria fronteira.

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To my friends, my companions in joy, anxieties and dreams, in youth and with whom I have the pleasure of growing old. You are an inspiration.

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Declaration of honour for the preparation and organization of the thesis

This document is presented and written as an application for the degree of Doctor in Palliative Care from the Faculty of Medicine of the University of Porto. It was prepared according to Critérios Curriculares para Recrutamento na Carreira Académica e Admissão e Classificação de Provas Académicas of 21st of July of 2021.

The thesis is structured by the compilation of peer-reviewed published articles, in the form of complete original scientific articles, in which the candidate is the first author, and which have been published in indexed journals with an impact factor.

The five articles presented were submitted solely for the granting or recognition of the Doctorate degree and are reproduced in full in the thesis.

Furthermore, in the doctoral program, the candidate had the opportunity to publicly present and discuss some of these results and other associated results in the context of oral communication at national and international scientific conferences and reunions, referenced in the text, contained in the appendix and in the candidate's curriculum. They should be considered complementary to the published articles and relevant opportunities to disseminate and discuss the research project.

The thesis is structured as follows:

The abstract presents a summary of the overall research work and main findings.

Chapter 1 is an introduction to the rationale behind the topic of emergency care for patients with dementia at the end-of-life, the main aspects related to it, the reality in which the topic is embedded, and the respective knowledge gaps that motivated the candidate to investigate.

Chapter 2 clarifies the main objective of the research and thesis and its specific objectives.

Chapter 3 presents the scoping review of the literature, with an overview of the use of the emergency department and what is known about its ability to respond to the palliative care needs of patients with dementia at the end-of-life.

Chapter 4 provides a retrospective analysis of the prevalence of unmet palliative care needs among patients with dementia who use the emergency department at the end-of-life, based on a single-center retrospective study of emergency department visits in the last 12 months of life among patients with dementia.

Chapter 5 concerns the research on potentially avoidable emergency department visits by patients with dementia at the end-of-life, its main reasons and associated factors through a single-center retrospective study of the potentially avoidable visits to the emergency department. In addition, this chapter considers the research on the inappropriate diagnostic and therapeutic measures performed in the emergency department for patients with dementia in the last days of life and possible associated factors, based on a single-center retrospective study of emergency department visits in the last week of life among patients with dementia.

Chapter 6 explores the identification of the last days of life of patients with dementia in the emergency department through a retrospective qualitative analysis of emergency department medical record, and identify aspects of communication between healthcare professionals, patients and families, and measures of end-of-life care implementation, to assess aspects of end-of-life care currently provided.

Chapter 7 explores the perspectives and experiences of emergency department healthcare professionals about end-of-life care for patients with dementia in the emergency department through a qualitative study based on semi-structured focus groups interviews on emergency department healthcare professionals of a single-center.

Chapter 8 presents the reflection and discussion on the findings, implications for practice, policy measures and future research and the conclusions of this thesis.

Finally, Chapter 9 concludes with a personal reflection on the relevance of the work presented in this thesis.

List of publications

The list presented includes the published articles that constitute the central structure of this thesis, according to the order in which they appear in the chapters. The remaining publications and activities developed alongside this work, are listed in the annex section.

I. Scoping Review (published)

Vieira Silva, S., Conceição, P., Antunes, B., & Teixeira, C. (2025). Emergency department use and responsiveness to the palliative care needs of patients with dementia at the end of life: A scoping review. *Palliative & supportive care*, 23, e51.

<https://doi.org/10.1017/S1478951524001627> **(Chapter 3)**

II. Original Research (published)

Vieira Silva, S., Teixeira, C., & Antunes, B. (2025). Unmet Palliative Care Needs Among Patients with Dementia at the End of Life and Frequent Use of the Emergency Department: One-Year Retrospective Study in a Central Hospital. *Journal of palliative medicine*, 10.1089/jpm.2024.0447. <https://doi.org/10.1089/jpm.2024.0447>

(Chapter 4)

III. Original research (submitted to publish)

Vieira Silva S, Antunes B, Teixeira C. Potentially avoidable visits to the emergency department by patients with dementia at the end of life – a longitudinal retrospective study. *BMC Palliative Care*, submitted in 26.06.2025. Researchgate 25.11.2025

<https://doi.org/10.21203/rs.3.rs-8184276/v1> **(Chapter 5)**

IV. Original research (published)

Vieira Silva S, Teixeira C, Antunes B. Reflexive thematic analysis of emergency department medical records of dementia patients regarding the identification of last days of life. *Palliative and Supportive Care*. 2025;23:e182. doi:10.1017/S1478951525100527

<https://doi.org/10.1017/S1478951525100527> **(Chapter 6)**

V. Original research (published)

Vieira Silva S, Bertão M, Teixeira C, Antunes B. End-of-Life Care for Patients with Dementia in the Emergency Department-Reflexive Thematic Analysis of the Perspective of Health Care Professionals. *J Palliat Med.* 2026 Apr 9;10966218261441207. doi: 10.1177/10966218261441207. Epub ahead of print. PMID: 41954017. **(Chapter 7)**

Resumo

Introdução:

A abordagem no serviço de urgência centra-se numa resposta urgente a uma necessidade de cuidados agudos, e baseia-se numa atuação com necessidade de tomada de decisão rápida e terapêutica agressiva modificadora da evolução da doença. Tal facto pode ser um desafio para populações vulneráveis em cuidados de fim de vida. À medida que a prevalência de doentes com demência aumenta em todo o mundo, também as visitas destes doentes ao serviço de urgência aumentam. O compromisso cognitivo e funcional, com capacidade limitada de expressar necessidades, com imobilidade progressiva e disfagia, são sintomas comuns e podem estar presentes no fim de vida dos doentes com demência e relacionam-se com necessidades relevantes de cuidados paliativos. Estes cuidados têm sido recomendados para os doentes com demência no fim da vida. A sua integração no serviço de urgência para esta população, embora desejada, ainda é maioritariamente insuficiente. Os profissionais de saúde do serviço de urgência estão na linha da frente a atender estes doentes e a responder às suas necessidades, e a sua atuação é determinante nos cuidados prestados. No entanto, dada a escassa evidência, é necessária maior compreensão das necessidades que os doentes com demência em fim de vida apresentam no serviço de urgência, assim como a capacidade de lhes responder. É urgente perceber o que precisa de ser melhorado para ter uma resposta mais apropriada nos cuidados prestados em fim de vida.

Objectivos:

- (1) sistematizar a literatura existente sobre o recurso ao serviço de urgência e sua capacidade de resposta às necessidades de cuidados paliativos dos doentes com demência em fim de vida, com foco principal nas visitas ao serviço de urgência, oportunidades e barreiras à prestação de cuidados paliativos, e determinar o conhecimento atual sobre os cuidados prestados a essa população no ambiente do serviço de urgência;
- (2) determinar a prevalência de necessidades não atendidas de cuidados paliativos dos doentes com demência que utilizam o serviço de urgência no fim da vida e os motivos dessas visitas;
- (3) avaliar as visitas potencialmente evitáveis ao serviço de urgência por doentes com demência em fim de vida e a prevalência de medidas diagnósticas e terapêuticas potencialmente inapropriadas

realizadas nos seus últimos dias de vida no serviço de urgência, para ajudar a identificar lacunas nos cuidados de saúde;

(4) explorar a identificação da situação de últimos dias de vida dos doentes com demência no serviço de urgência, avaliando também as medidas implementadas de cuidados de fim da vida e identificar os aspetos da comunicação entre profissionais de saúde, doentes e familiares;

(5) explorar as perspetivas e experiências dos profissionais de saúde do serviço de urgência sobre os cuidados em fim de vida dos doentes com demência no serviço de urgência, incluindo como respondem às necessidades de cuidados paliativos e o que pensam e sentem sobre essa resposta.

Métodos:

Primeiro, realizámos uma revisão da literatura (*scoping review*). A estratégia de busca baseou-se na pesquisa de estudos publicados que abordavam as necessidades de cuidados paliativos de doentes com demência que visitavam o serviço de urgência. As bases *Medline*, *Web of Science*, *Scopus*, *Scielo* e *APA PsycInfo* foram pesquisadas sistematicamente a partir de 1990, utilizando palavras-chave e vocabulário controlado que representavam os termos “necessidades de cuidados paliativos”, “doentes com demência” e “serviço de urgência”. A literatura cinzenta foi considerada e consistiu na pesquisa no *Google Scholar* e em resumos de conferências sobre saúde. A pesquisa manual foi realizada com base em bibliografias de revisões anteriores. A pesquisa foi atualizada pela última vez a 19 de fevereiro de 2024. Para serem elegíveis, os estudos tinham de incluir doentes com demência em fim de vida, definidos como aqueles que estavam presumivelmente nos últimos 12 meses de vida. Todos os tipos de demência foram considerados. A deficiência intelectual não foi considerada. Seguimos as recomendações metodológicas do *Joanna Briggs Institute* para *scoping reviews* e o Protocolo de Itens Preferenciais para Relatórios de Revisões Sistemáticas e Metanálises ou Protocolo de *scoping reviews*. Dois revisores independentes realizaram a triagem preliminar dos títulos e resumos. Os artigos elegíveis foram identificados e a leitura do texto completo foi realizada pelos mesmos revisores. Os dados foram então recolhidos, compilados e resumidos. Realizámos uma análise de conteúdo dos estudos seguindo a abordagem de 7 etapas: 1. Edição do material, 2. Leituras livres, 3. Construção das unidades de análise, 4. Identificação do núcleo de significados, 5. Consolidação de categorias, 6. Discussão de tópicos e 7. Validade. A avaliação crítica dos estudos incluídos foi realizada de acordo com o *Gough Weight of Evidence*.

Os restantes estudos e análises desta tese basearam-se na realidade dos cuidados de saúde em Portugal, onde existe uma cobertura universal de cuidados de saúde a nível nacional (incluindo tanto o continente como as ilhas). Os cuidados paliativos especializados são organizados em hospitais e em contextos de cuidados comunitários. A maioria dos hospitais públicos oferece algum tipo de cuidados paliativos especializados, mais frequentemente sob a forma de uma equipa intrahospitalar de consultores em cuidados paliativos. Também existem equipas comunitárias especializadas de cuidados paliativos, mas a cobertura varia a nível nacional. Os cuidados paliativos básicos são assegurados pelos cuidados de saúde primários; não existem *hospices* públicos. A formação em cuidados paliativos não é obrigatória para os profissionais de saúde, mas tem-se tornado cada vez mais comum nos currículos pré e pós-graduados dos diferentes grupos profissionais.

Em segundo lugar, realizámos um estudo retrospectivo unicêntrico, num hospital universitário português com um serviço de urgência polivalente com atividade 24 horas por dia, 7 dias por semana, para avaliar a prevalência das necessidades não satisfeitas de cuidados paliativos em doentes com demência em fim de vida. Foram considerados os doentes com diagnóstico confirmado de demência que faleceram neste hospital entre 1 de janeiro e 31 de dezembro de 2021. As suas visitas ao serviço de urgência nos 12 meses anteriores à morte foram analisadas; mais de quatro visitas neste período foram classificadas como utilização frequente do serviço de urgência. A ferramenta *Palliative Care and Rapid Emergency Screening* foi utilizada para rastrear as necessidades não satisfeitas de cuidados paliativos. Como *outcomes* secundários, identificámos e avaliámos a frequência e as principais razões para as visitas ao serviço de urgência no fim da vida e avaliámos a associação entre as necessidades não satisfeitas de cuidados paliativos e a pertença ao subgrupo de utilização frequente do serviço de urgência.

Em terceiro lugar, estudámos as visitas potencialmente evitáveis ao serviço de urgência por doentes com demência em fim de vida, através de um estudo retrospectivo realizado no referido serviço de urgência português. Incluímos doentes com diagnóstico confirmado de demência que faleceram entre 1 de janeiro e 31 de dezembro de 2021 neste hospital e que visitaram o serviço de urgência nos 12 meses anteriores à sua morte. A prevalência de visitas potencialmente evitáveis ao serviço de urgência por estes doentes foi avaliada através da aplicação dos critérios de *Cornillion*, bem como, as suas principais razões e fatores associados. As necessidades de cuidados paliativos foram avaliadas através da ferramenta *Palliative Care and Rapid Emergency Screening*. O teste qui-quadrado foi utilizado para analisar as possíveis relações entre variáveis independentes e as visitas potencialmente evitáveis ao serviço de urgência.

Em continuidade, estudámos o uso de medidas potencialmente inapropriadas em doentes com demência que recorrem ao serviço de urgência nos seus últimos dias de vida. Para isso, realizámos um estudo retrospectivo no mesmo hospital português. Foram incluídos todos os pacientes com demência avançada (*functional assessment staging tool* ≥ 6) que faleceram nesse hospital em 2021, até 72 horas após recorrerem ao serviço de urgência. Foram analisados os registos médicos do serviço de urgência. Foram consideradas medidas potencialmente inapropriadas diagnósticas e terapêuticas. As medidas de controlo sintomático foram definidas pela prescrição de opióides, butilescopolamina ou medicamentos psicotrópicos. A análise foi realizada utilizando o teste exato de Fisher para explorar os fatores associados.

De seguida, realizámos uma revisão qualitativa retrospectiva dos registos médicos do serviço de urgência para explorar as notas clínicas relativas ao doente com demência nos últimos dias de vida que recorre ao serviço de urgência e que faleceu no hospital. Seguiram-se os seis passos propostos por Braun & Clarke: 1) familiarização com os dados, 2) geração de códigos iniciais, 3) pesquisa de temas, 4) revisão de temas, 5) definição e nomeação de temas e 6) elaboração do relatório. O estudo foi realizado no serviço de urgência português mencionado anteriormente. Os doentes com diagnóstico confirmado de demência que faleceram entre 1 de janeiro e 31 de dezembro de 2021 foram elegíveis, desde que tivessem recorrido ao serviço de urgência nos seus últimos 7 dias de vida. Todos os registos médicos eletrónicos do serviço de urgência foram analisados cronologicamente, desde a data da morte até aos últimos 7 dias de vida. Revimos o registo médico do doente, elaborámos os resumos descritivos e selecionámos excertos anonimizados relevantes para o objetivo por um investigador, com verificação pelos outros autores. A análise temática reflexiva foi utilizada para explorar qualitativamente as questões e eventos-chave em torno dos cuidados de fim de vida prestados no serviço de urgência a pacientes com demência. Desenvolvemos as seguintes perguntas como ponto de partida para a análise: Os médicos conseguem identificar os últimos dias de vida? De que forma é que os médicos comunicam a outros profissionais de saúde, pacientes e familiares quanto aos últimos dias de vida e questões relacionadas, e registam isso no processo clínico do doente? Que medidas de cuidados – nos últimos dias de vida – são registadas pelos médicos? A análise foi realizada manualmente por dois investigadores que reviram os códigos e os temas de forma colaborativa.

Por fim, explorámos as perspetivas dos profissionais de saúde do serviço de urgência sobre os cuidados em fim de vida dos doentes com demência no serviço de urgência. Realizámos um estudo

qualitativo utilizando entrevistas semiestruturadas com grupos focais (n = 23), um de médicos, um de enfermeiros e um de auxiliares de saúde, todos eles a trabalhar regularmente no referido serviço de urgência. A versão final do guia temático compreendeu três tópicos principais: 1) doentes com demência em fim de vida e respetivas necessidades de cuidados paliativos, 2) cuidados atuais para estes doentes no serviço de urgência e 3) oportunidades e barreiras para abordar as necessidades de cuidados paliativos de doentes com demência em fim de vida no serviço de urgência. As entrevistas foram realizadas por duas investigadoras até ao ponto em que não surgiram novos temas e decorreram presencialmente após o recrutamento através de uma pessoa de contacto. A análise dos dados seguiu as *Reflexive Thematic Analysis Reporting Guidelines* utilizando o NVivo® versão 15, considerando as seis etapas propostas por *Braun & Clarke*: 1) familiarização com os dados, 2) geração de códigos iniciais, 3) pesquisa de temas, 4) revisão de temas, 5) definição e nomeação de temas e 6) produção do relatório. Dois membros da equipa de investigação reviram independentemente as transcrições e derivaram temas a partir dos dados, detalhando códigos descritivos indutivos ao marcar frases ou palavras semelhantes das narrativas dos profissionais. O consenso sobre a codificação foi desenvolvido com ambas as investigadoras a codificar as mesmas transcrições e a compará-las durante reuniões regulares.

Resultados:

Em relação à revisão da literatura, um total de 1441 artigos foram selecionados. Vinte e quatro estudos foram incluídos. Os dados extraídos confirmaram que doentes com demência no último ano de vida recorrem frequentemente ao serviço de urgência, representando um dos principais diagnósticos dos doentes que procuram esse serviço. Além disso, os doentes com demência parecem frequentemente apresentar-se no serviço de urgência perto do fim da vida, muitas vezes mais de uma vez no último ano de vida. Oito estudos abordaram diretamente as necessidades de cuidados paliativos e foram utilizadas várias ferramentas de medição. Os doentes com demência que visitam o serviço de urgência no fim da vida apresentam níveis significativos de necessidades de cuidados paliativos em comparação com outras condições oncológicas e não oncológicas. Algumas das principais razões para a admissão no serviço de urgência são as infeções e os sintomas neuropsiquiátricos. Embora o acesso a cuidados paliativos comunitários pareça reduzir a utilização do serviço de urgência, as evidências que sustentam esta afirmação continuam a ser escassas.

Quanto à avaliação das necessidades não atendidas de cuidados paliativos dos doentes com demência que procuram o serviço de urgência no fim da vida, os nossos resultados mostraram que estas necessidades são altamente prevalentes (78,2%). A dispneia (30,9%) foi a razão predominante para

as visitas ao serviço de urgência, seguida pelas alterações do comportamento ($n = 184$, 22,6%) e quedas ($n = 78$, 9,6%). Em média, os doentes com demência visitaram o serviço de urgência $2,9 \pm 0,8$ vezes nos últimos 12 meses de vida, a maioria das visitas ($n = 602$, 57,8%) ocorreu nos últimos três meses de vida. 29,5% ($n = 106$) dos doentes foram considerados utilizadores frequentes do serviço de urgência. Não houve associação entre o estado *P-Cares* e o uso frequente do serviço de urgência ($p = 0,47$).

A avaliação das visitas potencialmente evitáveis ao serviço de urgência por doentes com demência em fim de vida revelou uma prevalência de 24,2%. Infecções (26,2%), alterações comportamentais relacionadas com a demência (16,7%) e obstipação (7,9%) destacam-se como as principais razões para estas visitas potencialmente evitáveis. Por outro lado, infeções (39,2%), problemas respiratórios associados à aspiração ($n = 86$, 10,9%) e traumatismos ($n = 84$, 10,6%) foram as principais razões para visitas potencialmente não evitáveis. A prevalência de necessidades não atendidas de cuidados paliativos em doentes com demência com visitas potencialmente evitáveis ao serviço de urgência (85,3%) não só foi alta, como também significativamente maior do que em doentes com visitas não evitáveis ($p < 0,05$). Não encontramos nenhuma associação entre a presença de comorbidades significativas e visitas potencialmente evitáveis ao serviço de urgência ($p = 0,12$).

Em relação ao uso de medidas presumivelmente inapropriadas, diagnósticas ou terapêuticas, em doentes com demência atendidos no serviço de urgência nos seus últimos dias de vida, observámos uma prevalência de 83,5%. Análises de sangue foram a medida diagnóstica presumidamente inapropriada mais utilizada em 77,2% dos doentes, enquanto a hidratação artificial foi o tratamento mais frequente em 29,1% dos doentes. A definição de limites terapêuticos ($p < 0,05$), a adoção de medidas de controlo sintomático ($p < 0,05$) e a identificação de mau prognóstico ($p < 0,05$) associaram-se a uma menor probabilidade de medidas diagnósticas e terapêuticas presumivelmente inapropriadas.

A análise temática reflexiva do registo médico do serviço de urgência dos doentes com demência nos seus últimos sete dias de vida revelou que mais do que 1 em cada 4 registos médicos de doentes ($n = 55$, 27,4%) não fazia referência explícita à identificação dos últimos dias de vida. Os aspetos mais relevantes identificados apresentaram-se sob três temas. (I) *O diagnóstico e o prognóstico dos últimos dias ou horas de vida*. O diagnóstico relativo à condição clínica crítica do doente apresentou-se genericamente registado. A terminologia utilizada para descrever o prognóstico associado foi diversa. A partilha multidisciplinar da identificação dos últimos dias de vida e a sua comunicação a

outros membros da equipa de cuidados de saúde não foram registadas nas notas, enquanto a comunicação à família e aos cuidadores estava geralmente presente, em estreita relação com o prognóstico. (II) *Objetivos dos cuidados, tomada de decisão e comunicação sobre os cuidados nos últimos dias ou horas de vida.* O envolvimento de médicos seniores nessas discussões foi habitualmente registado, mas não o da enfermagem. A comunicação/discussão específica com a família sobre os objetivos dos cuidados e as decisões médicas estava ausente em todos os registos médicos. A análise do registo médico sugere que a comunicação com a família se concentrou na comunicação do prognóstico e promoção da sua presença neste momento crítico do doente. Termos com significado provavelmente equivalente estavam presentes, como por exemplo, «cuidados paliativos», «cuidados de conforto», «tratamento exclusivamente sintomático», «cuidados de suporte» e «tratamento conservador». A suspensão e a retirada de tratamentos de suporte à vida foram as principais decisões de tratamento presentes no registo médico. (III) *Avaliação do conforto e das necessidades nos últimos dias de vida dos doentes.* Foram observadas poucas referências ao estado de conforto dos doentes. A avaliação das necessidades de cuidados paliativos e o apoio dos cuidados paliativos para a tomada de decisões foram registados apenas esporadicamente. A ênfase da necessidade de cuidados paliativos no registo médico centrou-se na necessidade de apoio à organização de cuidados adicionais de fim da vida.

Por fim, a nossa análise reflexiva sobre as perspetivas dos profissionais de saúde do serviço de urgência relativamente aos cuidados em fim de vida dos doentes com demência no serviço de urgência produziu cinco temas principais. (I) *O contexto cultural e o lugar percebido dos doentes com demência no serviço de urgência e na sociedade,* sendo a sua realidade entendida como amplamente desconhecida e que os doentes com demência em fim de vida não têm um lugar no serviço de urgência ou mesmo na sociedade. (II) *A pessoa com demência, a sua dignidade e necessidades multidimensionais,* os profissionais de saúde apresentam grande preocupação com a dignidade, concretizando-a através das relações interpessoais e do tratamento, ao mesmo tempo que reconhecem o sofrimento como uma realidade multidimensional. (III) *Cuidados em fim de vida no serviço de urgência,* em que os profissionais de saúde destacam a gestão da incerteza, a definição dos objetivos dos cuidados e a resposta a necessidades específicas de cuidados como aspetos centrais dos cuidados. (IV) *Condições para responder às necessidades de cuidados paliativos dos doentes com demência em fim de vida no serviço de urgência,* os profissionais alternam numa perspetiva dupla, reconhecendo tanto as limitações do próprio serviço de urgência em salvaguardar a dignidade como as condições que reconhecem como necessárias para a possibilitar. (V) *O sofrimento ético e moral dos profissionais de*

saúde no cuidado dos doentes com demência em fim de vida no serviço de urgência surge com as restrições institucionais que existem e impedem a prestação de cuidados adequados.

Discussão:

De acordo com o nosso conhecimento, atualmente não existem estudos que abordem diretamente os doentes com demência em fim de vida no serviço de urgência e a resposta às suas necessidades. Contudo, confirmámos que, com maior frequência, os doentes com demência visitam o serviço de urgência nos últimos meses de vida (57,8% das visitas ocorrem nos últimos três meses de vida) e, de acordo com os nossos resultados, com uma elevada prevalência de necessidades de cuidados paliativos não atendidas. Embora não tenhamos encontrado uma associação clara entre necessidades não atendidas de cuidados paliativos e visitas frequentes ao serviço de urgência ($p = 0,47$), a análise das principais razões para recorrer ao serviço de urgência reafirma os sintomas não controlados e o declínio funcional recente como as razões mais frequentes. Além disso, os doentes com demência em fim de vida que utilizaram recursos potencialmente evitáveis do serviço de urgência apresentaram uma prevalência de 85,3% de necessidades não atendidas de cuidados paliativos. No geral, estes resultados sugerem que avaliar e responder adequadamente às necessidades não atendidas de cuidados paliativos pode contribuir para reduzir as visitas evitáveis ao serviço de urgência. Também pode ajudar a prevenir alguns dos danos potenciais decorrentes de medidas diagnósticas e terapêuticas presumivelmente inapropriadas.

Para além destes achados, a análise das perspetivas dos profissionais de saúde do serviço de urgência aponta para algumas das respostas às necessidades paliativas destes doentes já existentes e outras que ainda estão por desenvolver. A limitada identificação da situação de últimas horas a dias de vida no registo médico do serviço de urgência sugere um baixo reconhecimento desta situação clínica e/ou reflete a cultura do serviço de urgência, onde tudo é feito em ritmo acelerado, o que pode comprometer a implementação imediata de medidas adequadas de qualidade de cuidados em fim de vida. No estudo realizado, os registos médicos sobre a comunicação com a família centraram-se em comunicar o prognóstico e promover a sua presença neste momento crítico, raramente em discutir os objetivos dos cuidados. O registo frequente observado sobre a decisão de não iniciação ou suspensão de tratamentos de suporte de órgão parece útil e provavelmente promove uma melhor comunicação entre a equipa do serviço de urgência. A avaliação das necessidades de cuidados paliativos raramente é registada, e a ênfase nos cuidados paliativos está quase sempre relacionada com o apoio na organização de cuidados adicionais de fim da vida. Por fim, as perspetivas dos profissionais de saúde do serviço de urgência indicam que eles percebem uma consciência global limitada sobre a demência, ao mesmo tempo que reconhecem que os recursos ao serviço de urgência

podem desempenhar um papel fundamental na satisfação de algumas necessidades dos doentes com demência no seu fim da vida. Eles navegam numa perspetiva dupla, reconhecendo tanto as limitações do serviço de urgência em salvaguardar a dignidade quanto as condições necessárias para possibilitá-la. Os profissionais reforçam estar expostos a importantes dilemas éticos e sofrimento moral indicando como áreas prioritárias para intervenção: aumentar o conhecimento sobre a demência, implementar programas de treino clínico estruturado e melhorar o ambiente físico e os modelos de atendimento dentro do serviço de urgência.

Os nossos resultados devem ser integrados na perspetiva específica dos profissionais de saúde, através dos seus registos e de uma avaliação qualitativa utilizando a análise temática das suas opiniões. Consideramos a sua perspetiva essencial na abordagem dos doentes com demência no serviço de urgência, mas compreendemos que ela é, obviamente, apenas complementar à perspetiva dos próprios doentes, das suas famílias e dos cuidadores. Além disso, a análise dos registos médicos, considerando a sua natureza num contexto de urgência e o facto de ter sido feita retrospectivamente, foi particularmente desafiante e pode omitir vários aspetos que são considerados na prática clínica, mas que não ficam sistematicamente registados.

A integração destes vários aspetos de análise dos recursos ao serviço de urgência e perspetivas dos profissionais e reflexão sobre os mesmos sugere algumas implicações para a prática clínica, educação e políticas de saúde. Devem ser consideradas campanhas de literacia a diferentes níveis para melhorar o conhecimento global sobre a demência. Uma melhor coordenação dos cuidados que otimize a resposta às necessidades paliativas desta população, quando possível e apropriado, em casa e na comunidade, e quando necessário e potencialmente benéfico, de uma forma mais harmoniosa, nas suas visitas ao serviço de urgência. Neste mesmo serviço, será importante ter informações relevantes prontamente disponíveis sobre o estado de saúde do doente com demência e as suas principais circunstâncias de cuidados, relevantes para facilitar a identificação da sua situação de fim de vida, as suas preferências e decisões antecipadas. Os profissionais de saúde do serviço de urgência provavelmente beneficiarão de ter, pelo menos, alguma formação em cuidados paliativos e de se coordenarem com cuidados paliativos especializados para doentes com necessidades mais complexas. São identificadas como particularmente relevantes melhores condições no próprio serviço de urgência, que permitam maior disponibilidade de tempo para cuidar e assegurem um maior conforto físico. Destaca-se igualmente a importância de possibilitar a partilha dos cuidados com a família e os cuidadores. Em paralelo, o sofrimento ético e moral reconhecido pelos

profissionais de saúde deve ser explicitamente valorizado, sendo necessária a organização de respostas estruturadas que lhes proporcionem suporte adequado.

Como áreas de estudo futuro prioritárias, destacamos a relevância da investigação sobre as melhores estratégias para acesso rápido à informação clínica mais relevante do doente com demência no serviço de urgência; os melhores modelos para identificar o doente com demência em fim de vida neste contexto; os potenciais benefícios em organizar uma abordagem específica para este doente neste ambiente; e a investigação sobre os melhores modelos de cuidados paliativos para doentes com demência em fim de vida no serviço de urgência.

Conclusões:

As perspetivas dos profissionais de saúde do serviço de urgência refletem que é importante reforçar uma resposta adequada aos doentes com demência em fim de vida que recorrem ao serviço de urgência e que estes podem realmente beneficiar dos cuidados também neste contexto. Destaca-se a necessidade de um modelo abrangente para lidar com o doente com demência em fim de vida, desde a identificação da situação de fim de vida e das necessidades não satisfeitas de cuidados paliativos até à organização dos próprios cuidados, nos quais os cuidados paliativos se afiguram com um papel central.

Abstract

Introduction:

The emergency department approach focuses on an urgent response to an acute care need and is prompt to respond with rapid decision-making and aggressive disease-modifying therapy, which can be challenging for vulnerable populations in end-of-life care. As the prevalence of patients with dementia rises worldwide, visits to the emergency department by these patients also increase. Cognitive and functional impairment, with limited ability to express needs, progressive immobility and dysphagia are common symptoms that patients with dementia can present at the end-of-life and relate to relevant palliative care needs. Palliative care has been recommended for patients with dementia at the end-of-life. Palliative care integration into the emergency department for patients with dementia at the end-of-life, although desirable, is still insufficient. Emergency department healthcare professionals are on the front line, treating these patients and responding to their needs. Their actions are crucial to the care provided. Better understanding on the needs that patients with dementia at the end-of-life present in the emergency department, on the capacity to respond to them and what needs to improve in order to have a better response is relevant to improve their end-of-life care.

Objectives:

- (1) to be acquainted with the literature regarding the emergency department use and responsiveness to palliative care needs of patients with dementia in the end-of-life, focusing primarily on emergency department visits, opportunities, and barriers to palliative care, and determine current knowledge about care for this population in the emergency department setting;
- (2) to assess the prevalence of unmet palliative care needs among patients with dementia who use the emergency department at their end-of-life and reasons for those visits;
- (3) to evaluate potentially avoidable emergency department visits by patients with dementia at the end-of-life and the prevalence of potentially inappropriate diagnostic and therapeutic measures performed in their last days of life in the emergency department, to help identify gaps in healthcare;
- (4) to explore the identification of the last days of life of patients with dementia in the emergency department, assess aspects of end-of-life care currently provided and measures of end-of-life care

implementation used, and, to identify aspects of communication between healthcare professionals, patients and families;

(5) to explore the perspectives and experiences of emergency department healthcare professionals about end-of-life care for patients with dementia in the emergency department, including how they respond to those palliative care needs and what do they think and feel about that response.

Methods:

First, we conducted a scoping review of the literature. The search strategy was based on a search of published studies addressing palliative care needs of patients with dementia who visit the emergency department. Medline, Web of Science, Scopus, Scielo and APAPsycInfo were systematically searched from 1990, using keywords and controlled vocabulary representing the terms “palliative care needs”, “patients with dementia” and “emergency department”. Gray literature was considered and consisted of searching Google Scholar and abstracts from health conferences. Hand search was conducted based on bibliographies from previous reviews. The search was last updated on 19 February 2024. To be eligible, studies had to include patients with dementia at the end of life, defined as been presumably in the last 12 months of life. All types of dementia were considered. Intellectual disability was not considered. We followed the Joanna Briggs Institute methodology recommendations for scoping reviews and the Preferred Reporting Items for Systematic Reviews and Metaanalysis Protocol or Scoping Reviews protocol. Two independent reviewers performed a preliminary screening of titles and abstracts. Eligible articles were identified, and full-text reading was performed by the same reviewers. Data was then collected, collated, and summarized. We conducted a content analysis of the studies following the 7 steps approach: 1. Editing material, 2. Free-floating readings, 3. Construction of the units of analysis, 4. Identification of core of meanings, 5. Consolidation of categories, 6. Discussion of topics, and 7. Validity. Critical appraisal of the included studies was assessed according to Gough Weight of Evidence.

The remaining studies and analyses in this thesis are based on the reality of healthcare in Portugal, where there is a universal healthcare coverage nationwide (including both the mainland and islands). Specialized palliative care is organized in hospitals and community care settings. Most public hospitals offer some form of specialized palliative care, more frequently in the form of an internal palliative care consultant team. Specialized community palliative care teams have also been developed, but coverage varies nationwide. Basic palliative care is ensured by primary care

institutions; there are no public hospices. Palliative care training is not mandatory for healthcare professionals but has become increasingly common in undergraduate curriculums.

Second, we conducted a single-center retrospective study in a large university portuguese hospital with a 24 hours/7-day polyvalent emergency department to assess the prevalence of unmet palliative care needs of patients with dementia at the end-of-life. Patients with an established diagnosis of dementia who died in this hospital between 1 January and 31 December 2021 were considered. Their emergency department visits in the 12 months before death were analyzed; more than four visits in this period were classified as frequent emergency department use. The Palliative Care and Rapid Emergency Screening tool was used to screen for unmet palliative care needs. As secondary endpoints we identified and assessed the frequency of and main reasons for emergency department visits at the end-of-life and evaluated the association between unmet palliative care needs and membership of the frequent emergency department use subgroup.

Thirdly, we studied the use of potentially inappropriate measures in patients with dementia who attend the emergency department in their final days of life. To do this, we conducted a retrospective study at the same portuguese hospital. All patients with advanced dementia (functional assessment tool ≥ 6) who died in that hospital in 2021, up to 72 hours after seeking emergency care, were included. Emergency department medical records were analyzed. Potentially diagnostic and therapeutic measures were considered. Symptomatic control measures were defined by the use of opioid therapy, butylscopolamine, or psychotropic drugs. The analysis was performed using Fisher's exact test to explore the associated factors.

Next, we conducted a retrospective qualitative review of the emergency department medical record to explore the clinical notes regarding the last days of life of patients with dementia who died in the hospital. The six steps approach proposed by Braun & Clarke were followed: 1) familiarisation with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes and 6) producing the report. The study took place at the previously mentioned portuguese emergency department. Patients with an established diagnosis of dementia who died between January 1 and December 31 2021 were eligible if they resourced to the emergency department in the last 7 days of life. All electronic medical records in the emergency department were approached chronologically from date of death to the last 7 days of life. We reviewed patient's medical record, collected descriptive summaries and selected deidentified extracts relevant to the aim and objectives by one researcher, with verification by the other authors.

Reflexive thematic analysis was used to qualitatively explore key issues and events surrounding emergency department-based end-of-life care for patients with dementia. We inductively engaged with the following questions as a starting point for the analysis: Do the physicians identify the last days of life? How do physicians communicate to other healthcare professionals, patients and families about last days of life and related issues and do they record that in the patient medical record? Which measures of care— in the last days of life— are recorded by physicians? Analysis was conducted manually by two researchers who collaboratively reviewed codes and revised the themes.

We then moved on to studying potentially avoidable visits to the emergency department by patients with dementia at the end of life, through a retrospective study conducted in the aforementioned portuguese emergency department. We included patients with an established diagnosis of dementia who died between January 1 and December 31 2021 in this hospital and that visited the emergency department in the 12 months before their death. Prevalence of potentially emergency department visits by these patients was assessed by applying Cornillion criteria and also their main reasons and associated factors. Palliative care needs were assessed by the Palliative Care and Rapid Emergency Screening tool. The chi-square test was used to analyse the possible relationships between independent variables and potentially avoidable emergency department visits.

Finally, we explored the perspectives of emergency department healthcare professionals about end-of-life care for patients with dementia in the emergency department. We conducted a qualitative study using semi-structured focus groups interviews ($n = 23$), one of physicians, one of nurses and one of healthcare assistants, all of whom worked regularly at the aforementioned portuguese emergency department. The final topic guide version comprised three main topics: 1) patients with dementia at the end-of-life and respective palliative care needs, 2) current care for these patients in the emergency department and 3) opportunities and barriers to address the palliative care needs of patients with dementia at the end-of-life in the emergency department. Interviews were conducted by two researchers until no new themes emerged and took place in person after recruitment through a contact person. Data analysis followed the Reflexive Thematic Analysis Reporting Guidelines utilizing NVivo® version 15, considering the six steps approach proposed by Braun & Clarke: 1) familiarisation with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes and 6) producing the report. Two members of the research team independently reviewed the transcripts and derived themes from the data, detailing inductive descriptive codes by marking similar phrases or words from the professional's

narratives. Consensus coding was developed with both researchers coding the same transcripts and comparing them during regular meetings.

Results:

Regarding the scoping review, a total of 1441 articles were screened. Twenty-four studies were included. The extracted data confirmed that patients with dementia in the last year of life frequently resort to the emergency department, representing one of the main diagnosis of patients attending this service. Moreover, patients with dementia often seem to present to the emergency department near the end-of-life, frequently more than once in their last year of life. Eight studies directly addressed palliative care needs and a plethora of measurement tools were used. Patients with dementia who visit the emergency department in the end-of-life have significant rates of palliative care needs compared to other oncological or non-oncological conditions. Some of the main reasons of admission to the emergency department are infections and neuropsychiatric symptoms. Although access to community palliative care seems to reduce emergency department use, evidence to support this remains scarce.

In relation to the assessment of unmet palliative care needs in patients with dementia that visit the emergency department at the end-of-life, our results showed that these needs were highly prevalent (78.2%). Dyspnea (30.9%) was the prevailing reason for visits to the emergency department, followed by behavioural changes (n=184, 22.6%) and falls (n=78, 9.6%). On average, patients with dementia visited the emergency department 2.9+– 0.8 times in the last 12 months of life, with most visits (n = 602, 57.8%) occurring in the last three months of life. 29.5% (n=106) of patients were considered frequent users of the emergency department. There was no association between P-Cares status and frequent use of the emergency department ($p = 0.47$).

The prevalence of potentially avoidable visits to the emergency department by patients with dementia at the end-of-life was 24.2%. Infection (26.2%), dementia-related behavioural changes (16.7%) and constipation (7.9%) stand out as the main reasons for these potentially avoidable visits to the emergency department. On the other hand, infection (39.2%), respiratory problems associated with aspiration (10.9%) and trauma (10.6%) were the main reasons for potentially unavoidable visits. The prevalence of unmet palliative care needs in patients with dementia with avoidable visits to the emergency department (85.3%) was not only high but also significantly higher than in patients with unavoidable visits to the emergency department ($p<0.05$). We found no

association between the presence of significant comorbidity and potentially avoidable emergency department visits ($p=0.12$).

Regarding the use of presumably inappropriate diagnostic or therapeutic measures in patients with dementia assisted in the emergency department in their last days of life, we observed a prevalence of 83.5%. Blood testing was the most used inappropriate diagnostic measure in 77.2% of patients, while artificial hydration was the most frequent treatment in 29.1% of patients. Defining therapeutic limits ($p < 0.05$), adopting symptomatic control measures ($p < 0.05$) and identifying poor prognosis ($p < 0.05$) were associated with a lower probability of diagnostic and therapeutic inappropriate measures.

Reflexive thematic analysis of emergency department records of patients with dementia in their last seven days of life revealed that more than 1 in 4 patient medical records ($n = 55, 27, 4\%$) made no explicit reference to the identification of last days of life. The most relevant issues presented under three broader themes. (I) *Diagnosis and prognosis concerning the last days or hours of life* Diagnoses relating to the patient's critical condition were generally recorded. The terminology used to describe the associated prognosis was diverse. Multidisciplinary clinical identification of the last days of life and its communication to other members of the healthcare team were not recorded in patients notes, while communication to family and caregivers was generally present, in strait relation to prognosis. (II) *Goals of care, medical decisions and communication about care in the last days or hours of life*. The involvement of senior physicians in these discussions was recorded, but it was not the case for nurses. Specific communication/discussion about goals of care and medical decisions with family members was absent for all medical records. Analysis of the medical records suggested that communication with the family focuses on communicating the prognosis and promoting their presence at this critical moment. Terms with probable equivalent meaning were present, e.g., "palliative care," "comfort care," "exclusively symptomatic treatment," "supportive care" and "conservative treatment." Withhold and withdrawal of life sustaining treatments were the main treatment decisions present in the medical record. (III) *Comfort and needs assessment in the last days of life of patients with dementia in the emergency department*. Few references to the patient's Comfort status were observed. The assessment of palliative care needs and palliative care support for decision making were recorded only sporadically. The emphasis on palliative care in the medical record was mainly related to the support and organization of additional end-of-life care.

Finally, our reflexive analysis of the perspectives of emergency department healthcare professionals about end-of-life care for patients with dementia in the emergency department produced five main themes. *The cultural context and perceived place of patients with dementia in the emergency department and in society*, with their reality understood as largely unknown and that patients with dementia at the end-of-life have no clear place in the emergency department or even in society. *The person with dementia, their dignity, and multidimensional needs*: healthcare professionals are very concerned with dignity, achieving it through interpersonal relationships and treatment, while recognizing suffering as a multidimensional reality. *End-of-life care in the emergency department* in which healthcare professionals highlight uncertainty management, goals of care definition and addressing specific care needs as central aspects of care. *Conditions for supporting the palliative care needs of patients with dementia at the end of life in the emergency department*: professionals navigate a dual perspective, recognizing both the emergency department's limitations in safeguarding dignity and the conditions required to enable it. *Ethics and moral distress of healthcare professionals caring for patients with dementia at the end of life in the emergency department*, arises from institutional constraints that exist and present the provision of appropriate care.

Discussion:

To our knowledge, there are currently no studies that directly address patients with end-of-life dementia in the emergency department and the response to their needs, although we have confirmed that more frequently, patients with dementia visit the emergency department in the last months of their life (57.8% of the visits occurring in the last three months of life) and, according to our findings, with a high prevalence of unmet palliative care needs (78.2%). Although we did not find a clear association between unmet palliative care needs and frequent visits to the emergency department ($p = 0.47$), analysis of the main reasons for using the emergency department reaffirms uncontrolled symptoms and recent functional decline as the most frequent reasons. In addition, patients with end-of-life dementia who used potentially avoidable emergency department resources had a prevalence of 85.3% of unmet palliative care needs. Overall, these findings suggest that assessing and responding appropriately to unmet palliative care needs may contribute to reduce avoidable emergency department visits. It may also help prevent some of the potential harm arising from presumably inappropriate diagnostic and therapeutic measures.

In addition to these findings, the analysis of the perspectives of emergency department healthcare professionals' points to some of the already existing responses to the needs of these patients and others that are yet to be developed. The lack of identification of the last days of life in the emergency

medical record suggests a low recognition of this clinical situation and/or reflects the culture of the emergency department, where everything is done at a fast pace, which can compromise the immediate implementation of appropriate quality care measures for end-of-life care. For now, medical records on communication with the family focus on communicating the prognosis and promoting their presence at this critical time, rather than discussing goals of care. The frequent recording observed in relation to withhold and withdrawal of life-sustaining treatments seems useful and probably promotes better communication among the team. The assessment of palliative care needs is rarely mentioned, and the emphasis on palliative care is almost always related to support and the organization of additional care at the end of life. Finally, the perspectives of emergency department healthcare professionals indicate that they perceive limited awareness of dementia, while recognizing that emergency department resources can play a critical role in meeting some end-of-life needs. They navigate a dual perspective, recognizing both the limitations of the emergency department in safeguarding dignity and the conditions necessary to enable it. They point to being exposed to important ethical considerations and moral distress and as priority areas for intervention: raising awareness about dementia, implementing structured training programs, and improving the physical environment and models of care within the emergency department.

Our findings should be viewed from the specific perspective of healthcare professionals, through their records and a qualitative assessment using thematic analysis of their opinions. We consider their perspective essential when dealing with patients with dementia in the emergency department, but we understand that it is, of course, only complementary to the perspective of the patients themselves, their families, and caregivers. Furthermore, the analysis of medical records, considering their nature in an emergency context and the fact that it was done retrospectively, was particularly challenging and may omit several aspects that are considered in clinical practice but are not systematically recorded.

The integration of these various aspects of analysis of the emergency department visits and professionals' perspectives and reflection on them suggest some implications for clinical practice, education and health policies. Literacy campaigns at different levels should be considered to overcome the general unawareness about dementia. Better coordination of care that improves the response to the palliative needs of this population, when possible and appropriate, at home and in the community, and when necessary and potentially beneficial, in a more harmonious manner, in their visits to the emergency department. In the emergency department, it will be important to have relevant information readily available about the patient with dementia health status and key

care circumstances, relevant to facilitating the identification of end-of-life status, patient preferences, and advance decisions. Emergency department healthcare professionals are likely to benefit from having at least some training in palliative care and to have adequate coordination with specialized palliative care for patients with more complex needs. Better conditions in the emergency department itself, with more time for care and greater physical comfort, with the possibility of sharing care with family and caregivers, are identified as relevant. At the same time, the ethical and moral distress recognized by professionals must be acknowledged, and responses to support them must be organized.

As priority areas for future studies, we highlight research into the best strategies for rapid access to the most relevant information in the emergency department; the best models for identifying patients with end-of-life dementia in this context; the potential benefits of organizing a specific approach for these patients in this setting; and research into the best models of palliative care for patients with end-of-life dementia in the emergency department.

Conclusions

The perspectives of emergency department healthcare professionals suggest the need to strengthen appropriate responses to patients with dementia at the end of life who present to the emergency department and who may genuinely benefit from care in this setting. These perspectives highlight the importance of a comprehensive model of care within the emergency department, encompassing the timely identification of end-of-life status and unmet palliative care needs, as well as the organization and delivery of care, in which palliative care is likely to play a central role.

CHAPTER 1

Rationale

The emergency department approach focuses on an urgent response to an acute care need (1), critical or not, either for symptomatic care or for prevention or treatment of severe injuries that can lead to instability or imminent death. Patients with advanced diseases or at the end-of-life frequently resort to the emergency department (2, 3). The emergency department reality includes rapid decision-making, aggressive disease-modifying therapy(4), long waiting times, lack of communication(5), bright lights, and constant noise, all of which can constraint the care provided, specially to vulnerable populations. Emergency department visits can be distressing for patients, families and challenging for staff(6-8).

Previous studies suggest that 32 to 35% of patients that present to the emergency department have palliative care needs(9). Worsening symptoms, new symptoms, limitation of oral intake, prostration, inability to tolerate medication or inability of the caregiver constitute the main reasons of emergency department resources(10). Up to 1/3 of oncologic patients resort to emergency department in the last two weeks of their lives for symptomatic control(11, 12). Emergency department use at end-of-life is considered a poor quality of life indicator(13). Integration of palliative care in the emergency department have been demonstrated (14, 15) to promote improvement of quality of life, lesser costs, and even, improvement of some clinical outcomes, patients and caregiver satisfaction, and reduce intensive care resource and hospital length of stay(15, 16). Considering emergency department circumstances, its physical conditions and human resources, the diverse nature of situations that attends, including patients in all stages of their lives, it can be quite challenging to provide a good care regarding quality of life, which is the main purpose of palliative care. Moreover, palliative care needs assessment and response can be compromised in this context since it can require specific professional skills and time, namely in terms of communication and in the nature of doctor-patient relationship itself(17).

Some studies indicate that patients with palliative care needs are often considered as low priority in the emergency department(10). They are at risk of delay in assessment, of being neglected and submitted to tests that do not prioritize quality of life and sometimes even to be under or over treated. The decision-making process can be quite challenging in this context(17). Furthermore, palliative care support might not be readily available, physical conditions are usually adverse with noise, confusion and lack of privacy, contrary to a desired compassionate environment(18).

Healthcare professionals with regular activity in the emergency department frequently attend to patients with palliative care needs. The vast majority don't have a palliative care training(19). In Portugal this is also common, despite the recommendation to include palliative care training in the overall pre-graduated medical training and in some specific medical specialities(20). This reality can compromise the possibility to identify palliative care in the emergency department patients and the

appropriate response to them. Healthcare professionals with regular activity in the emergency department are also in great risk of emotional distress and even burnout(18).

In the global context, dementia prevalence has significantly increased, side by side to population aging(21), which is also observed in Portugal(22). Up to more than 50% of patients with dementia visit the emergency department each year(23) and as the population over 65 years old continues to grow, estimates suggest that from 57.4 million cases worldwide in 2019 this number will increase up to 152.8 million cases in 2050(21) and consequently increase emergency department use. Defining end-of-life in this population is difficult due to the disease's long and unpredictable trajectory(24). At the end-of-life, most patients with dementia can present common symptoms associated with cognitive and functional impairment, including progressive immobility, dysphagia, and limited ability to express needs(25), with relevant palliative care needs (26, 27). Previous studies have identified potential benefits of palliative care for patients with dementia such as increase advance care planning(28), improvement of symptom burden, prevention of under or overtreatment, and enhance care giver quality of life(29, 30). The official position paper of the European Association for Palliative Care(31) recommends 11 core domains of palliative care for patients with dementia as optimal care:

1. Applicability of palliative care
2. Person-centred care, communication and shared decision-making
3. Setting care goals and advance planning
4. Continuity of care
5. Prognostication and timely recognition of dying
6. Avoiding overly aggressive, burdensome or futile treatment
7. Optimal treatment of symptoms and providing comfort
8. Psychosocial and spiritual support
9. Family care and involvement
10. Education of the health-care team
11. Societal and ethical issues

Palliative care for older patients with dementia aims to improve quality of life, maintain function, and maximize comfort(31). Person-centred care, with communication and shared decision-making and advanced care planning are strongly recommended and essential to define goals of care and plan future interventions(31). Even so, studies confirm that usually these patients have less access to palliative care compared to cancer patients (32, 33). Thus, it can be expected that emergency department responsiveness to patients with dementia palliative care needs is probably insufficient.

On the other hand, each year, more than 50% of patients with dementia visit the emergency department (23). For the population in general, it is known from previous studies that many emergency department visits are potentially avoidable (34-36). At the end-of-life, for the vulnerable population of patients with dementia it may be particularly important to prevent these visits, reduce the associated harm and also improve care itself with better treatment in other setting, possibly at lower cost (36). Community-based palliative care is associated with greater satisfaction with care among patients and families and a reduction of emergency department visits(37, 38). In the emergency department, palliative care integration debates with important barriers, ranging from space constraints to human and technical constraints, since few healthcare professionals have palliative care training and access to direct support from specialized teams is limited(19). Strategies to promote palliative care integration include healthcare professionals training in palliative care, regular assessment of palliative care needs and specialized palliative care consultation(16, 19). To our knowledge, there are no portuguese or international studies specifically about the emergency department responsiveness to palliative care needs of patients with dementia at the end-of-life. This thesis intends to deepen knowledge about the current response of the emergency department in end-of-life care for patients with dementia, from the needs that these patients present, to the capacity to respond to them and what needs to improve in order to have a better response, from the perspective of the emergency department healthcare professionals.

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CHAPTER 2

Aim and objectives

The aim of this work is to explore and improve knowledge on how care can be provided in the emergency department to better respond to the palliative care needs of patients with dementia at the end-of-life from the emergency department healthcare professional's perspective.

For this, we propose to achieve the following objectives:

1. to conduct a scoping literature review on the emergency department use and responsiveness to palliative care needs of patients with dementia in the end-of-life, focusing primarily on emergency department visits, opportunities, and barriers to palliative care, and determine current knowledge about care for this population in the emergency department setting;
2. to assess the prevalence of unmet palliative care needs among patients with dementia who use the emergency department at their end-of-life and reasons for those visits;
3. to evaluate potentially avoidable emergency department visits by patients with dementia at the end-of-life and the prevalence of potentially inappropriate diagnostic and therapeutic measures performed in their last days of life in the emergency department, to help identify gaps in healthcare;
4. to explore the identification of the last days of life of patients with dementia in the emergency department, assess aspects of end-of-life care currently provided and measures of end-of-life care implementation used, and, to identify aspects of communication between healthcare professionals, patients and families;
5. to explore the perspectives and experiences of emergency department healthcare professionals about end-of-life care for patients with dementia in the emergency department, including how they respond to those palliative care needs and what do they think and feel about that response.

CHAPTER 3

Emergency department use and responsiveness to the palliative care needs of patients with dementia at the end of life: A scoping review

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This chapter provides a scoping review of the literature on the emergency department use and response to palliative care needs of end-of-life patients with dementia. Recognizing the state of knowledge about these needs provides insights into emergency department use. The circumstances and needs of patients with dementia are among the important elements to consider in an integrated analysis of healthcare professionals' perspectives on how emergency department care responds to the palliative care needs of end-of-life patients with dementia.

Review Article

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Corresponding author: Sara Vieira Silva;
Email: nevesvp@gmail.com

Emergency department use and responsiveness to the palliative care needs of patients with dementia at the end of life: A scoping review

Sara Vieira Silva, ¹M.S.,¹ Paulo Conceição, ²B.S.,² Bárbara Antunes, ³Ph.D.,³ and Carla Teixeira, ⁴Ph.D.⁴

¹Palliative Care Service, Unidade Local de Saúde de Santo António, Porto, Portugal; ²Internal Medicine Service, Unidade Local de Saúde de Santo António, Porto, Portugal; ³Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK and ⁴Unidade Local de Saúde de Santo António, ICBAS Universidade do Porto, Porto, Portugal

Abstract

Objectives. More than 50% of patients with dementia visit the emergency department (ED) each year. Patients with dementia experience frequently unrelieved symptoms that can benefit from palliative care. Response to palliative care needs in the ED can be quite challenging and access to palliative care is generally scarce. The aim of this scoping review is to assess ED use and responsiveness to palliative care needs of patients with dementia in their last year of life.

Methods. A scoping literature review following the Joanna Briggs Institute methodology. Electronic search of the literature was undertaken in Medline (PubMed), Web of Science, Scopus, Scielo, and APA PsycInfo, last updated on 19 February 2024.

Results. Twenty-four studies were identified and confirmed that patients with dementia frequently resort to the ED near the end of life, frequently more than once in their last year of life. Eight studies directly addressed palliative care needs, suggesting significant rates of palliative care needs among patients with dementia and in comparison, to other oncological or non-oncological conditions. Infections and neuropsychiatric symptoms were the main reasons of admission to the ED. Access to palliative care was confirmed to be low.

Significance of results. This scoping review indicates that patients with dementia frequently resource to the ED in their last year of life with unmet palliative care needs. Although scarce access to palliative care and the existence of important barriers in the ED, palliative care intervention in this setting can be seen as an opportunity to attend palliative care needs and referral to palliative care services.

Introduction

Emergency departments (EDs) are generally designed to respond to acute and life-threatening conditions, so visits to the ED by people who are approaching end of life frequently can be distressing for patients, families and challenging for staff (Antunes 2020; Briggs et al. 2013). Up to more than 50% of patients with dementia visit the ED each year (Hunt et al. 2018a) and as the population over 65 years old continues to grow, estimates suggest that from 57.4 million cases worldwide in 2019 this number will increase up to 152.8 million cases in 2050 (Nichols et al. 2022) and consequently increase ED use. Patients with dementia experience frequently unrelieved pain (Reynolds et al. 2008) and other significant needs (Black et al. 2006; Hendriks et al. 2014; Kverno et al. 2008; Shega et al. 2006) that can benefit from palliative care interventions. A 2021 Cochrane review (Walsh et al. 2021) showed that advance care planning interventions for people with advanced dementia increased the documentation of advance directives and the number of discussions regarding goals of care with family decision-makers and may increase concordance with goals of care. Although not with the same grade of evidence, previous studies have identified other potential benefits of palliative care such as improvement of symptom burden, prevention of under or overtreatment, and enhance caregiver quality of life (Mitchell et al. 2009; van Soest-poortvliet et al. 2015). Also, community-based palliative care has been associated with a reduction of ED visits (Godard-Sebillotte et al. 2019; Williamson et al. 2021), resulting in lower health-care costs and greater satisfaction with care among patients and families.

In general, at the end of life, several studies have shown poor quality of care for patients with dementia, including low levels of symptom control (Davies et al. 2014; Martinsson et al. 2018). The ED reality includes rapid decision-making, aggressive disease-modifying therapy (Lafond et al. 2016), long waiting times, lack of communication (Smith et al. 2010), bright lights, and constant noise, all of which can constraint the care provided, specially to vulnerable populations.

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In a recent systematic review, Williamson et al. (2021) identified significant factors that are associated with ED attendance to patients with dementia at the end of life, namely, number of comorbidities, neuropsychiatric symptoms, previous hospital transfers, and rural living. These were positively associated, while higher socioeconomic status, being unmarried and living in a care home were negatively associated, among other factors that were also identified. Although these factors might constitute relevant criteria to help identify patients at risk of ED attendance, there is a lack of knowledge about ED assistance to patients with dementia with palliative care needs at the end of life. This scoping review aimed to assess ED use and responsiveness to palliative care needs of these patients in their last year of life, focusing mainly on ED resource, the opportunities, and barriers to palliative care.

Methods

This scoping review follows the Joanna Briggs Institute methodology recommendations for scoping reviews (Peters 2015) and the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocol (PRISMA-P) for Scoping Reviews protocol (Tricco et al. 2018). The final protocol is available from the corresponding author upon request. The PRISMA for Scoping Reviews checklist is attached in Appendix 1.

Selection criteria

Studies addressing palliative care needs of patients with dementia who attended the ED were considered. To be eligible, studies had to include patients with dementia at the end of life, defined as been presumably in the last 12 months of life (Fisher et al. 2015). All types of dementia were considered. Intellectual disability was not considered. Studies did not need to present a control group. Peer-reviewed studies – either quantitative, qualitative, or mixed-methods – were eligible. Editorials, letters to the editor, and case studies were ineligible. Only studies written in English, Portuguese, or Spanish were included.

Only studies authorized by an ethics committee, respecting the principles of Helsinki Declaration, were considered.

Search strategy

The search strategy was defined using PRISMA-P (Tricco et al. 2018) which was revised by the research team. Studies were retrieved from Medline (PubMed), Web of Science, Scopus, Scielo, and APA PsycInfo using keywords and controlled vocabulary representing the terms “Palliative Care needs,” “Patients with dementia,” and “ED,” with adjustment to the different databases (Table 1). As an example, detailed search strategy for Medline is available in Supplementary Table S1. Gray literature was considered and consisted of searching Google Scholar and abstracts from health conferences. Hand search was conducted based on bibliographies from previous reviews. The search was last updated on 19 February

2024, and final search results were exported to EndNote, where duplicates were removed.

Screening and data extraction

Two independent reviewers (S.S. and P.C.) performed a preliminary screening of titles and abstracts. Eligible articles were identified, and full-text reading was performed by the same reviewers who further excluded articles if they did not meet the inclusion criteria. Discrepancies were resolved by discussion and consensus.

According to Joanna Briggs Institute methodology recommendations for scoping reviews, data were collected, collated, and summarized (Peters 2015). A data extraction form was developed by the research team, available in Appendix 2, and included main characteristics of the studies (identification of first author, date of publication, country, objective, design, population, sample size, recruitment, date of data collection, interventions, comparators, outcomes, and statistical analysis), the prevalence of patients with dementia at the end of life who presented palliative care needs, the reasons for resorting to the ED, the benefits, barriers, and lack of responsiveness to these needs. The 2 independent reviewers performed the data extraction with subsequent joint discussion and validation of the collected data by a third independent reviewer.

Analysis, synthesis, and reporting

A content analysis of the articles was conducted following the 7-step approach (Faria-Schützer et al. 2021): 1. Editing material, 2. Free-floating readings, 3. Construction of the units of analysis, 4. Identification of core of meanings, 5. Consolidation of categories, 6. Discussion of topics, and 7. Validity. Content is presented in tables with summarized items and with a complementary narrative format. Critical appraisal of the included studies was assessed according to Gough (2007) Weight of Evidence (WoE) (Gough 2007), a tool that measures overall quality as low, medium, or high.

Results

From 1441 initial records, 78 papers were screened for eligibility and 24 were included in the full review (Fig. 1).

An overview of the characteristics of the 24 included studies is provided in Table 2. Only 2 studies took place in developing countries (Amado-Tineo et al. 2020a, 2020b), the majority occurred in Europe (Afonso-Argilés et al. 2020; Antunes et al. 2021; De Matteis et al. 2022; Fürst et al. 2022; Leniz et al. 2021; Nordt et al. 2023; Reeves et al. 2023; Sleeman et al. 2018; Willert et al. 2021; Williamson et al. 2023) or North America (Glajchen et al. 2011; Hanson et al. 2019; Hill et al. 2022; Hunt et al. 2018b; Kirkland et al. 2022a; Kruhlak et al. 2021; Lamantia et al. 2016; Shah et al. 2022). Quantitative methods were used for all of the studies ($n = 24$), 2 were randomized controlled trials (Hanson et al. 2019; Shah et al. 2022); from the remaining, 6 of the observational were prospective studies (Afonso-Argilés et al. 2020; Amado-Tineo et al. 2020a; Kirkland et al. 2022a; Kruhlak et al. 2021; Sleeman et al. 2018;

Table 1. Search terms used for scoping literature review

Population	"Dementia" OR "Alzheimer's Disease" OR "Dementia Multi Infarct" OR "Vascular Dementia" OR "Frontotemporal Dementia" OR "Lewy Body Dementia" OR "Korsakoff's Dementia" OR "HIV Dementia" OR "Creutzfeldt-Jakob's Dementia" OR "Cognitive Impairment" OR "Senile" terms AND
Intervention	"Emergency Department" OR "Emergency Care" OR "Emergency Service" OR "Emergency room" OR "Emergency Medicine" OR "Acute Care" terms AND
Outcomes	"Palliative Care" OR "Palliative Medicine" OR "Terminal care" OR "Dying" OR "End of life Care" OR "Supportive care" OR "Hospice care" terms

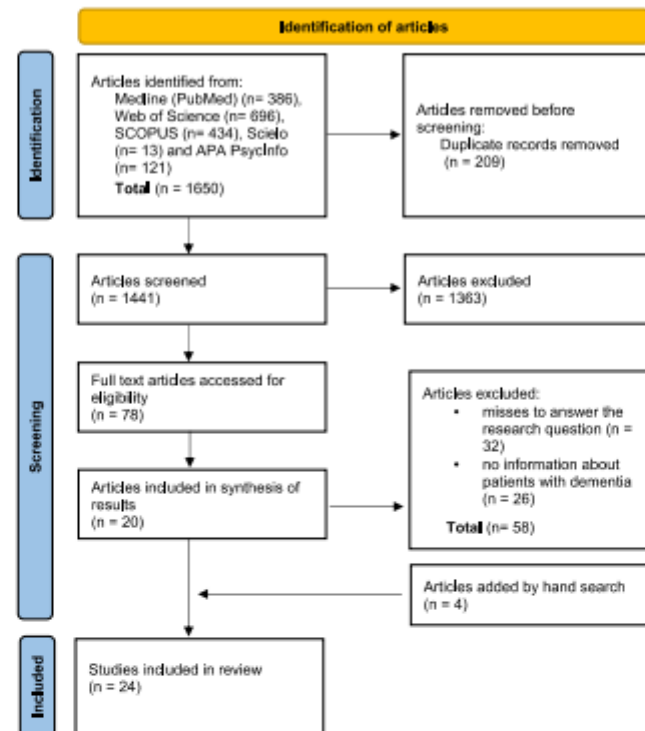


Figure 1. PRISMA flow-diagram of selection of source of evidence.

Straeuli et al. 2022). Kirkland's study (Kirkland et al. 2022a) is a secondary analysis of the Kruhlak (Kruhlak et al. 2021). Most of the studies were conducted in more than 1 centre (Afonso-Argilés et al. 2020; Amado-Tineo et al. 2020a; Chen et al. 2017; Fürst et al. 2022; Hill et al. 2022; Hunt et al. 2018b; Kirkland et al. 2022a; Kruhlak et al. 2021; Leniz et al. 2021; Reeves et al. 2023; Rosenwax et al. 2015; Shah et al. 2022; Sleeman et al. 2018; Williamson et al. 2023; Wong et al. 2017). Sample sizes ranged from 7 patients with dementia (Amado-Tineo et al. 2020a; Willert et al. 2021) to 918,341 patients (Reeves et al. 2023).

Outcomes and measures

Identification of patient's characteristics, including reason for admission, treatment received, and destination were the most frequent outcomes (Amado-Tineo et al. 2020a; Chen et al. 2017; De Matteis et al. 2022; Glajchen et al. 2011; Hanson et al. 2019; Hunt et al. 2018b; Kruhlak et al. 2021; Lamantia et al. 2016; Leniz et al. 2021; Nordt et al. 2023; Reeves et al. 2023; Rosenwax et al. 2015; Straeuli et al. 2022; Willert et al. 2021; Williamson et al. 2023; Wong et al. 2017), followed by frequency of ED visits (Afonso-Argilés et al. 2020; Antunes et al. 2021; Chen et al. 2017; Fürst et al. 2022; Hill

et al. 2022; Hunt et al. 2018b; Lamantia et al. 2016; Leniz et al. 2021; Nordt et al. 2023; Reeves et al. 2023; Straeuli et al. 2022; Williamson et al. 2023). Factors associated with ED use were assessed in 5 studies (Afonso-Argilés et al. 2020; Hunt et al. 2018b; Rosenwax et al. 2015; Sleeman et al. 2018; Williamson et al. 2023).

Palliative care needs of patients attending the ED, including patients with dementia, were evaluated in 8 studies (Amado-Tineo et al. 2020a, 2020b; Glajchen et al. 2011; Kirkland et al. 2022a; Kruhlak et al. 2021; Leniz et al. 2021; Straeuli et al. 2022; Wong et al. 2017), using different tools, namely GSF-PIG1 (Straeuli et al. 2022; Wong et al. 2017), P-cares (Kirkland et al. 2022a; Kruhlak et al. 2021), BriefPal (Glajchen et al. 2011), NECPAL (Amado-Tineo et al. 2020a), SPICT-ESTM (Amado-Tineo et al. 2020b), and Palliative Care Quality and Outcomes Framework (Leniz et al. 2021). Access to palliative care was evaluated in 7 studies (Amado-Tineo et al. 2020a; Fürst et al. 2022; Kirkland et al. 2022a; Kruhlak et al. 2021; Leniz et al. 2021; Rosenwax et al. 2015; Willert et al. 2021).

The 3 clinical trials included evaluated the feasibility of BriefPal as a screening tool (Glajchen et al. 2011), the development of a best practice model for patients with dementia (Fürst et al. 2022), and a care transition intervention (Shah et al. 2022).

Table 2. Main characteristics of the 24 included studies

Author, year of publication	Study design/intervention (country)	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality WoE D
I. Glajchen KDB, 2011	Prospective, intervention study ED 1 university hospital (USA)	139/36	Address the needs of elderly patients presenting to ED and explore the feasibility of rapid screening and referral	7.9% (18.3% of patients with dementia attended at ED)	BriefPal	>> Primary diagnosis of patients with PC needs: cancer 43%, dementia 22%, and heart failure 16%. >> Pain was the most common symptom - 14%, dyspnea - 12%, nausea/diarrhea/anorexia/weight loss - 8%. >> Caregivers of patients in the referral group tended to show significantly higher levels of burden. >> Patients that received PC reported symptom reduction, 80% died - 25 in hospital, 5 at hospice, 5 at home, and 3 at nursing home. >> Rate of referral to PC and hospice rose during the implementation phase, with referral peaks at the midpoint, after staff education and during the months when the project social worker was in the ED full time, with a marked decline when she was away. >> Main barrier to referral was reluctance by the primary care physician, included fear of involving PC, misunderstanding PC and hospice, and belief that they were already "doing" PC. >> System barriers included lack of understanding about PC and hospice and hesitation from ED - staff about involving another medical specialty. The PC service itself was in a state of flux, with a gap in attendings for the duration of the project. >> Patient and family barriers included uncertainty about the patient's prognosis and the symbolic meaning of PC and hospice. >> The BriefPal project showed the feasibility of successful screening, the value of staff education, and the importance of trained champions.	Medium

(Continued)

Table 2. (Continued.)

Author, year of publication	Study design/sampling/location	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality of evidence
2. Rosemaux, 2015	Retrospective, observational study Data from WA Linkage System (ED of Western Australian state) (Australia)	8126/5261	Describe patterns in the use of ED by patients with dementia in their last year of life and determine whether this is modified by the use of community-based PC service	Not directly evaluated	-	>> 6% of the dementia cohort used community-based palliative care in the last year of life compared to 26% of the comparative cohort >> > 70% of decedents in both the dementia and comparative cohorts attended an ED at least once in the last year of life >> Visits to the ED by the dementia cohort tended toward being triaged as less urgent >> The dementia cohort had a higher proportion of neurological and mental disorder presenting symptoms and a higher proportion of fall- and injury-related symptoms at presentation to ED. In contrast, the comparative cohort had more cardiac and abdominal pain-related presentations to ED >> At the time of death, decedents with dementia in their last year attended ED on average of 2.7 (95% confidence interval [CI]: 2.4–3.0) days compared to 2.7 (95% CI: 2.6–2.8) days for the comparative cohort. >> For the first 130 days of the last year of life, those receiving regular care in a private residence visited ED almost twice as often as those receiving palliative care (hazard ratio 1.9; 95% CI 1.4–2.5). Decedents with dementia who received regular care in a care facility visited the ED 1.4 times more often than those receiving community-based palliative care (95% CI 1.1–1.9). In the last month of life, the relative rate of ED visits for those receiving regular care jumped markedly compared to those receiving palliative care reaching a maximum rate around day 340 or 25 days before death. Those receiving regular care in private residences visited EDs 6.7 (95% CI 4.7–9.6) times more frequently and those receiving regular care in a care facility visited EDs 3.1 (95% CI 2.2–4.2) times more frequently than those of dementia cohort who were receiving palliative care at that time. >> Other factors associated with increased ED use in the dementia cohort were being male, being younger and living with dementia with other diseases rather than Alzheimer's or vascular dementia, living in outer regional or remote areas, and having certain types of comorbid conditions	High

(Continued)

Table 2. (Continued)

Author, year of publication	Study design/setting/country	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality WOE D
3. Laktania 37, 2016	Retrospective, observational study ED of 1 university hospital and database from 10 federally qualified health centers (USA)	32697/11069	Describe the clinical characteristics, care patterns, associated medical costs, and health outcomes for older adults with and without dementia who seek care in the ED	Not directly evaluated	-	>> 37.54% of patients with dementia visited ED vs 20–31% of patients without dementia >> Patients with dementia were admitted to the hospital at higher rates (39.7%) than patients without dementia (29.06%) ($p < 0.001$) >> 58% of patients with dementia had at least 1 ED visit within 30 days after an Index ED visit as compared to 38% of patients without dementia ($p < 0.001$) >> Mean of comorbid conditions of patients with dementia were 8.0 vs without 5.0 ($p < 0.001$) >> Most frequent ED primary diagnosis: urinary tract infections, chest pain and abdominal pain; those not discharged, pneumonia, congestive heart failure, and urinary tract infections >> Mortality of dementia patients at >ED 1.3% vs 1.0% >> Mean Medicaid payment was increased (\$199 vs \$134, $p < 0.001$) for patients with dementia as compared to those without dementia. Mean Medicare ED payments for patients with dementia at any time during the study period were 75% higher for patients without dementia [\$6628 vs \$3454, $p < 0.001$]	Medium
4. Wong 46, 2017	Retrospective, observational study ED of 2 general hospitals (New Zealand)	1024/50	Estimate the incidence of patients presenting to ED with PC needs	1.2% (24.0% of patients with dementia attended at the ED)	GSF FIG	>> Cancer, chronic obstructive pulmonary disease, and heart failure were the most common disease presentations (75.1%), dementia (4.9%) >> Most common symptoms: pain (23.4%), dyspnea (19.1%), and "unwell" (16.0%) (Fig. 5). >> 18.4% of the overall patients presented PC unmet needs vs 24.0% patients with dementia	Medium

(Continued)

Table 2. (Continued.)

Author, year of publication	Study design/setting/country	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality of evidence
5. Sleeman 2018	Retrospective, observational study SLAM Biomedical Research Centre Case Register (United Kingdom)	4867/4867	Examine the frequency, and identify the predictors, of ED attendance among people with dementia in their last year of life	Not directly evaluated	-	>> Factors associated with increased number of ED attendances during the last year of life: male gender, depression severity, higher cognitive function, and diagnosis of vascular dementia. >> Being resident in a care home and living in the most affluent areas were associated with fewer ED attendances.	Medium
6. Chen YH et al. 2017	Retrospective, observational study Data from the Taiwan National Health Insurance Research Database (Taiwan)	2724/908	Comparison of the utilization of health-care services and life-sustaining interventions by patients with dementia and cancer patients in their last year before death	Not directly evaluated	-	>> Number of patients with dementia with <3 ED visits/year 287 (62.9%) vs with cancer 613 (62.7%). Number of patients with dementia with ≥3 ED visits/year 169 (37.1%) vs with cancer 364 (37.3%) >> Most common causes of hospitalization and ED visits by dementia and cancer groups were infectious diseases	High
7. Hanson LC et al. 2019	Randomized controlled trial ED of 1 university	62/62	Develop a best-practice model of specialty PC for late-stage dementia, and conduct a pilot randomized trial of specialty PC for late-stage dementia triggered by	Not directly evaluated	-	>> The primary outcome of 60-day hospital or emergency department visits did not differ significantly between intervention and control arms (0.68 vs 0.53 visits, $p = 0.415$) >> The most common admitting diagnoses were infections and neuropsychiatric symptoms >> Two-thirds of patients had advance directives. Baseline characteristics did not differ significantly between	High

(Continued)

Table 2. (Continued.)

Author, year of publication	Study design/setting/country	Sample size/patients with dementia	Arm	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality WoE D
	hospital (USA)		hospitalization for acute illness			study arms >> Family decision-makers had an average age of 59.7 years, 75% were female, and more than half were daughters. At enrollment, 92% of caregivers felt they were very involved in treatment decisions for the person with dementia, and 60% expected that person to get worse or possibly die in the next 6 months. >> One of 3 enrolled patients with late-stage dementia visited an emergency department or was hospitalized in the 60 days after discharge >> Family caregivers' ratings of comfort for the person with dementia and of distress for themselves did not differ between arms at 60 days >> Dementia patients in the intervention arm had more elements of clinical palliative care addressed in their hospital treatment plan, as measured on the 10-point Palliative Care Domain score (7.6 vs 2.7, $p < 0.001$) >> Patients with the intervention group were more likely to have assessment and treatment for physical symptoms of dyspnea, constipation, and nausea, and for neuropsychiatric symptoms. >> Spiritual needs were addressed for 47% of patient-family dyads in the intervention arm, and for 0% of those in the control arm >> Specialty PC during hospitalization also resulted in increased communication and decision-making about treatments relevant to late-stage dementia and in increased hospice use	

(Continued)

Table 2. (Continued)

Author, year of publication	Study design(setting/country)	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality of evidence
8. Hunt LJ38, 2018b	Retrospective, observational study Data from The	281/281	Assess prevalence of pain and unmet need for pain management in the last month of life in older adults dying with dementia; describe ED use in the last month of life	Not directly evaluated	-	>> The most frequent diagnoses for ED visit were septicemia, cardiac arrest and pneumonia and other respiratory disease. >> Almost 3/4 of respondents reported that the decedent had pain in the last month of life (73.1%) and approximately 10% had an unmet need for pain management	Medium
	National Health and Aging Trends Study (USA)		among older adults with dementia; and examine whether pain was associated with increased ED use in the last month of life in older adults with dementia			>> More than half (56.6%) of decedents with dementia visited the ED in the last month of life. The mean number of ED visits was 0.75. >> There was no association between pain in the last month of life and ED visits. However, unmet need for pain management increased ED visit rate by almost 50%. A higher percentage of participants with unmet need for	
						pain management had 1. (46% vs 35%) or multiple ED visits (26% vs 16%) compared to those without	
						unmet need for pain management	(Continued)

Table 2. (Continued)

Author, year of publication	Study design/setting/(country)	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality WOE D
9. Monza-Argüelles (13), 2020	Prospective, cross-sectional observational study Home Care and Nursing Care (Estonia, Finland, France, Germany, Netherlands, Spain, Sweden, United Kingdom)	1700/284	Assess frequency of hospital admissions (including ED), among people with dementia from 8 European countries living in the community and those living in nursing homes; examine the factors associated with hospital admissions among people with dementia living in the community and those living in nursing homes separately; and to evaluate the costs associated with hospital admissions according to the different living situations	Not directly evaluated	-	>> 16.7% patients with dementia had ED visit >> Estimated rate of ED per person with dementia/year of 0.26 among persons living in nursing home and 0.43 among those living in home care >> Factors associated with ED visit: people with dementia living in nursing home polypharmacy (OR 1.96, CI 1.03–3.75), people with dementia living in home care, presence of falls in the preceding 3 months (OR 1.64, CI 1.12–2.41), polypharmacy (OR 2.48, CI 1.70–3.62), weight loss (OR 1.73, CI 1.17–2.56), caregiver burden (OR 1.76, CI 1.04–2.98). >> The estimated average expenditure per person with dementia/year for ED admission was 67.30€ in the nursing home group and 117.48€ in the home care group	High
10. Amado-Tinoco JA23, 2020a	Prospective, cross-sectional, observational study ED of 3 tertiary hospitals (Peru)	66/7	Estimate the prevalence of advance disease among patients admitted to ED and identify among them the need of PC in patients admitted to ED	83.3% of the overall patients (not specifically patients with dementia)	NECPAL	>> Surprised question: "no" answer in n=26 (43.3%) of overall patients >> ED professional considered that the patient needed PC in n = 50 (83.3%), requested PC for the patient in n = 12 (20.0%), the patient used PC in n = 13 (21.6%) >> Symptoms were controlled in n = 8 (13.3%) of patients >> Reason for admission was uncontrolled symptoms in 52 (86.7%) patients, with the most frequent being dyspnea (42%), somnolence (22%), and pain (18%)	Medium

(Continued)

Table 2. (Continued)

Author, year of publication	Study design/sample size/country	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality of evidence
11. Aradino-Tineo JA25, 2020b	Retrospective, observational study ED of 1 university hospital (Peru)	233/36	Identify the frequency and characteristics of patients with chronic terminal disease admitted to the ED of a national hospital and identify the reason for admission, treatment received and destination, comparing oncological and non-oncological pathology	4.8% of the overall patients (not specifically patients with dementia)	SPECT-ESTM	>> ED resource cause: non-oncological - infection 80 (59.7%), pain 3 (2.2%), encephalopathy 17 (12.7%), bleeding 7 (5.2%), dyspnea 8 (6.0%) vs cancer infection 31 (31.3%), pain 17 (17.2%), encephalopathy 2 (2.0%), bleeding 10 (10.1%), dyspnea 7 (7.1%) >> Invasive procedures: non-oncological - nasogastric tube 66 (69.3%), orotracheal tube 15 (11.2%), vasopressors 7 (5.2%), invasive ventilation 12 (9.0%), hemodialysis 4 (3.0%), blood transfusion 3 (6.7%) vs cancer nasogastric tube 13 (13.1%), orotracheal tube 4 (4.0%), vasopressors 11 (11.1%), invasive ventilation 3 (3.0%), hemodialysis 1 (1.0%), blood transfusion 15 (15.2%) >> Treatment: Non-oncological - antibiotics 80 (59.7%), opioids 2 (1.5%), metformin 11 (8.2%), haloperidol 10 (7.5%) vs antibiotics 31 (31.3%), opioids 10 (10.1%), metformin 5 (5.1%), haloperidol 1 (1.0%) >> 27% ED mortality of 234 patients with PC criteria (not specifically dementia patients).	Medium
12. Antunes A26, 2021	Retrospective, observational study ED of 1 general hospital (Portugal)	484/45	Examine the influence of chronic diseases in ED and inpatient hospital utilization and expenditures in the 12 months before death	Not directly evaluated	-	>> Median of 3 ED admissions/year for patients with dementia vs 2 in overall patients during the last year of life	High

(Continued)

Table 2. (Continued.)

Author, year of publication	Study design/setting/country	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality WoE D
13. Krulhjak M40, 2021	Prospective, cross-sectional observational study ED of 2 hospitals, 1 tertiary (Canada)	664/151	Identify presentations for end of life conditions to ED and describe the characteristics of the patients and their management	2.5% of the overall patients, 78.0% of patients at the end of life (neither specifically patients with dementia)	P-care	>> Most common EOL condition cancer (41%), followed by dementia (23%) >> 74% of the presentations for EOL conditions met the criteria for unmet PC needs. Most common risk factors: a positive response to the SQ (68%), followed by uncontrolled symptoms (55%), and frequent ED visits/hospitalizations in the previous 6 months (54%). >> Goals of care were documented in two-thirds of patients (62%) and considered appropriate by physicians in 59% (23%). >> Physicians reported challenges in providing care for 24% of the presentations, most commonly due to a language barrier (34%) or cognitive impairment (34%). >> Reason for admission: Dyspnea 21% (121), general weakness 12% (76), abdominal pain 9% (59), altered level consciousness (4%, 28) >> 84% of presentations involved medical treatment, with antibiotics being the most common medication prescribed (35%), followed by opioids (34%). Almost all the presentations involved at least 1 investigation during their ED visit (97%) with blood work (97%), imaging (92%), and electrocardiogram (58%) being the most common investigations. An estimated 11% of presentations involved various medical procedures, with noninvasive positive pressure ventilation (43%) and intubation (10%) being the most common >> 0.9% of presentations included admission to a PC unit. Nearly 30% of presentations included a postdischarge referral, which included home care (32%), specialists (30%), and palliative services (26%). >> A total of 16% of the patients died during their index presentation either in the ED or in hospital, most of whom presented with advanced cancer (48%), dementia (19%), or chronic pulmonary disease (16%) >> Patients with dementia (OR: 0.32; 95% CI 0.22–0.48) were less likely to have presented to the ED in the previous 6 months	Medium

(Continued)

Table 2. (Continued.)

Author, year of publication	Study design/source (country)	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality of evidence
14. Lenz JDS, 2021	Retrospective, observational study. Data from the Discover dataset (United Kingdom)	5604/5904	Explore the proportion and characteristics of people with a diagnosis of dementia who are identified as having PC needs during the last year of life; examine the association between identification of PC needs before the last 90 days and multiple non-elective hospital admissions, primary and community care contacts during the last 90 days of life	33.6%	Palliative Care Quality and Outcomes Framework	>> 2576 (44.4%) with 3 or more comorbidities, hypertension was the most common (64.5%) >> 12.7% (737) experienced multiple non-elective hospital admission in the last 90 days of life >> 13.7% (839) dementia patients without PC identification had multiple hospital admissions in the last 90 days of life VS 8.6% (38) from those who had PC identification (OR 0.70) >> Among the 5804 decedents with dementia, 1132 (19.5%) and 2658 (45.8%) had at least 1 face-to-face or telephone contact with the primary care practice in the last 90 days of life, 2702 (47.9%) people in the cohort had at least 1 contact with community nurses in the last 90 days >> A total of 403 (6.9%) patients had at least 1 contact with community PC teams, 589 (10.3%) with physiotherapists and 638 (11.0%) with rehabilitation teams	Medium

(Continued)

Table 2. (Continued)

Author, year of publication	Study design(s)/setting/(country)	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality WoE D
15. Willert AC30, 2021	Retrospective, observational study ED of 1 university hospital (Germany)	130/7	Identification of causes for ED hospitalization of patients with neurological disorders or neurological symptoms requiring PC	All patients included had PC needs	Not specified	>> Primary diagnoses: neoplastic disorders (49%), neurodegenerative disorders (30%) (dementia [5.4%]), cerebrovascular diseases (18%) >> Reasons for admission: epileptic seizures (22%), gait disorders/falls (22%), disturbances of consciousness (20%), pain (17%), nutritional problems (17%), and paresis (16%), difficulties with organization of care or overburdening of family (8%) >> Symptom assessment: assistance with Activities of Daily Living (ADL, 83%), weakness (71%), difficulties with organization of care (61%), tiredness (59%), or overburdening of family caregivers (53%), pain (31%), difficulties in communication (30%) aphasia, 38% dysarthria, nutritional problems for solids (42%) or fluids (38%), and paresis (47%). >> Diagnostic and therapy: at least 1 mode of acute diagnostic imaging (88%), cranial imaging was most frequently performed (60%). In 55% of cases, a medication was administered in the ED, antiseizure medication (19%) and benzodiazepines (14%), analgesics (26%), antibiotics (17%) >> Documentation of Healthcare Proxy or Legal Guardians, Patient Decree, and Therapy Limitations in 31%. >> In 63% of patients, it took at least 2 days until specialist PC consultation was initiated >> Forty percent of patients were discharged with further inpatient (PC unit or hospice, 12%) or outpatient (home/nursery home with outpatient PC supply, 28%) specialized PC	Medium
16. Furst 31, 2022	Retrospective, observational study Data from the Stockholm Region's central data warehouse (Sweden)	12667/695	Compare 2 groups of > 65 years old deceased patients with cancer and patients with concomitant cancer and dementia at end of life regarding their access to specialized PC; study their ED visits, hospital admissions, and place of death	Not directly evaluated	.	>> Concomitant dementia diagnosis with cancer did not affect the likelihood of ED visits [255 (43%) vs 4758 (40%) p value 0.11] >> During the last 3 months of life, 76% of patients with cancer and 42% of patients with cancer and concomitant dementia had access to specialist PC ($p < .0001$) >> Specialist PC for patients with concomitant cancer and dementia did not influence ED visits during the last month of life but affected place of death: 3% and 21%, among those with and without access to PC, respectively of hospital deaths ($p < 0.001$)	High

(Continued)

Table 2. (Continued)

Author, year of publication	Study design (setting/country)	Sample size (patients with dementia)	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality of evidence
17. Hill JD41, 2022	Retrospective, observational study Data from Medicare claim referring to 34 ED (USA)	25626/25626	Identify a large sample of community-dwelling people living with dementia from a diverse cohort of EDs and compare post-ED outcomes to patients with chronic conditions without dementia	Not directly evaluated	-	>> Patients with dementia had a higher percentage of ED visits (5.2% vs. 4.1%). >> Patients with dementia had a greater number of chronic conditions (mean 4.8 ± 2.8 vs 3.3, SD: 2.1) >> Disposition to home was lower for patients with dementia (37.9% vs 53.6%) and to hospice slightly higher (0.4% vs. 0.2%). >> Patients with dementia had higher health-care utilization, including 1 or more ED visits post-index visit (43.1% vs 35.4%), greater number of inpatient stays post-index visit (mean 0.8 visits vs 0.5 visits) and ED visits post index (mean 0.9 visits vs. 0.1 visits), 1 or more inpatient stays post-index visit (43.4% of patients vs 28.0%), and longer length of inpatient stays (mean 6.5 days vs 5.9). >> Patients with dementia who died within the 12 months following their index visit were nearly double (31.9% vs 15.3%)	High
18. Kirkland S42a, 2022a	Prospective, cross-sectional study ED of 2 hospitals, 1 university hospital (Canada)	663/106	Identify and compare the characteristics and management of ED presentations for advanced cancer to other end of life conditions	76.3% of patients with non-cancer conditions that included patients with dementia	P-cases	>> No difference between presentations by patients with unmet PC needs, 81% cancer vs 77% other conditions. Emergency physicians were more likely to report a positive response to the surprise question for patients with cancer (76% vs 61%) >> Goals of care documentation was lower among patients with cancer (53% vs 79%) >> Patients with cancer were more likely to be referred to PC services (41% vs 10%, $p < 0.001$) at discharge. >> PC consultations in the ED were requested in only 7 (11%) presentations, all for patients with cancer. >> There were no significant differences in proportion of patients with a return to ED within 30 days or a previous ED visit 6 months before	High

(Continued)

Table 2. (Continued)

Author, year of publication	Study design (setting/country)	Sample size (patients with dementia)	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality of evidence
19. Shah MM3, 2022	Randomized controlled trial ED of 3 university hospitals (USA)	81/81	Evaluate if care transition intervention improves ED to home transitions for cognitively impaired community-dwelling older adults	Not directly evaluated	-	>> No significant difference in the primary outcome of ED revisits within 30 days. Among secondary outcomes, no significant differences in ED revisits within 14 days or outpatient follow-up at 14 or 30 days >> Multivariate regression analysis for ED revisits, adjusted for presence of moderate-to-severe depression and health literacy, showed that intervention participants had 75% decrease odds of an ED revisit within 30 days (OR 0.25, 95% CI 0.07–0.90) >> Forty-three of the 80 participants had specified red flags on their ED discharge instructions. Seven (15.3%) of these participants correctly reported at least 1 specific red flag from their ED discharge instructions, with no significant difference between groups. >> Specific medication changes were present in 21 participants. >> ED patients randomized to the intervention group had a 26% increase odds of obtaining follow-up.	High
20. Stræuli C44, 2022	Prospective, cross-sectional observational study ED of 1 general hospital (South Africa)	426/62	Estimate the prevalence of patients with potential PC needs attending the ED; describe the patient demographics and diagnoses of these patients; to understand the reasons for ED attendance and describe their disposition from the ED	0.6%	Palliative Care Identification tool-based GSF-PIG	>> 4.24% (426) of the total patient visits to the ED ($N = 10\,040$) presented PC needs >> The top 3 diagnoses were cancer (25.8%), neurological disease (13.1%) and HIV (17.4%) >> Reasons for ED admission: physical symptoms ($n = 379$ (87%)), of which pain and dyspnea were most frequently reported, followed by social (46 (11%)) and health systems (43 (10%)) needs >> Most of the patients with social reasons for attending had caregiver fatigue or absent support structures, needing placement. Health system reasons included caregiver changes or running out of medication at home	Medium

(Continued)

Table 2. (Continued.)

Author, year of publication	Study design/setting/country	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality WoE D
21. De Mattos 632, 2022	Retrospective, observational study ED of 1 university hospital (Italy)	27355/4896	Describe the clinical characteristics of older patients affected by dementia and hospitalized; investigate the impact of dementia on in-hospital mortality; and identify the predictors of in-hospital mortality in these patients	Not directly evaluated	-	>> Reasons for ED admission (patients without dementia vs with dementia): dyspnea 9056 (20.0) vs 729 (20.5); Fever 8520 (18.8) vs 784 (22.0); chest pain 5817 (12.8) vs 161 (4.5); syncope 3420 (7.5) vs 355 (10.0); abdominal pain 5324 (11.7) vs 207 (5.8); diarrhea 1553 (3.4) vs 134 (3.8); vomit 3752 (8.3) vs 226 (7.2); malaise/fatigue 5411 (11.9) vs 374 (10.5) >> Acute medical conditions (patients without dementia vs with dementia): respiratory failure 5904 (13.0) vs 681 (19.1); COPD exacerbation 1651 (3.6) vs 347 (9.7); acute heart failure 5172 (11.4) vs 619 (17.4); acute myocardial infarction 2798 (6.2) vs 83 (2.3); acute pulmonary embolism 702 (1.5) vs 51 (1.4); ischemic stroke 4549 (10.0) vs 482 (13.5); hemorrhagic stroke 1947 (4.3) vs 225 (6.3); <0.001, bloodstream infections 3084 (6.8) vs 372 (10.5); pneumonia 4386 (9.7) vs 733 (20.6); abdominal infection 1743 (3.8) vs 102 (2.9); urinary tract infection 3729 (7.2) vs 477 (13.4); <0.001, acute kidney injury 2561 (6.5) vs 376 (10.8) >> Death during hospitalization (patients without dementia vs with dementia): 4865 (10.7) vs 666 (18.7)	High
22. Nordt SP33, 2023	Retrospective, observational study ED of 1 university hospital (Ireland)	499/29	Identify and assess the frequency of presenting complaints, diagnosis, triage acuity, and admission, in ED patients previously evaluated by a university-hospital-based palliative medicine service	Not directly evaluated	-	>> 499 ED visits, of which, 92 (18.44%) patients being seen more than once in the ED >> 29 (5.81%) patients with dementia, second non-oncological most common cause. 3.1 mean number of repeat ED visits of these patients, median of 3, and a range of 2–9 visits >> 358 (71.7%) patients admitted and 141 (28.3%) discharged home >> 373 visits on weekdays (74.75%) compared to 126 visits on weekends (25.25%), as weekends account for 28% of a week >> 40% presented low emergency scores >> 64 (12.8%) admitted patients died during their hospital admission	Medium

(Continued)

Table 2. (Continued)

Author, year of publication	Study design/setting/country	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality WoE D
33. Reeves 034_2023	Retrospective, observational study ED of 178 general hospitals (United Kingdom)	256507/918341	Describe the epidemiology of ED admissions for patients with dementia and how this compares to people without across the period 2010–2016; examine the trends in hospital outcomes for patients with dementia and without across the period and the extent to which differences in outcomes might be accounted for by differences in patient characteristics	Not directly evaluated	-	>> Patients with dementia were more likely to have experienced 1 or more ED visits in the previous year >> Mean numbers of comorbidities were similar for both groups, though patients with dementia were more likely to have fluid and electrolyte disorders, additional neurodegenerative disorders and depression, but less likely to have cancer or be obese. >> Reasons for ED admission: patients with dementia presented higher rates of orthopaedic trauma and renal procedures disorders, but lower rates of cardiac disorders and digestive system disorders. >> Length of stay was longer for patients with dementia, ED revisits were more frequent, and mortality was higher	High

(Continued)

Table 2. (Continued)

Author, year of publication	Study design/setting/country	Sample size/patients with dementia	Aim	Prevalence of patients with dementia with PC needs	PC assessment tool	Other main findings	Quality WOE D
24. Williamson LEIS, 2023	Retrospective, observational study of public hospitals (United Kingdom)	74486/74486	Examine individual and service-level factors associated with ED visits by people with dementia in the last year of life	Not directly evaluated	-	>> In the last year of life, 82.6% ($n = 61,491$) of patients with dementia visited the ED, 53.2% ($n = 39,586$) attending at least twice. >> For 58.1% ($n = 89,778$) of all visits in the last year of life, the ED outcome was hospital admission. For 0.5% ($n = 840$), the ED outcome was death in the department. >> The proportion of visits that were in the month before death was 23.9% ($n = 36,849$), and for 66.3% ($n = 24,560$) of these, the ED outcome was hospital admission. >> Reasons for ED admission: mostly respiratory conditions and urological conditions, including cystitis >> Factors associated with higher end-of-life ED visits included: South Asian ethnicity [RR 1.07, 95% CI 1.02–1.13, $p < 0.01$], diagnosis of vascular dementia [RR 1.14, 95% CI 1.13–1.16, $p < 0.01$] or unspecified dementia [RR 1.12, 95% CI 1.10–1.14, $p < 0.01$], underlying cause of death as chronic respiratory [RR 1.31, 95% CI 1.28–1.34, $p < 0.01$], cardiovascular [RR 1.17, 95% CI 1.14–1.20, $p < 0.01$], or cerebrovascular disease [RR 1.14, 95% CI 1.11–1.18, $p < 0.01$], other underlying causes of death [RR 1.22, 95% CI 1.19–1.25, $p < 0.01$], being a resident in an urban settlement [RR 1.06, 95% CI 1.04–1.08, $p < 0.01$] and selected regions >> There was a negative dose–response association between ED visits and increasing socioeconomic position [RR 0.92, 95% CI 0.90–0.94, $p < 0.01$]. Being a resident in a local authority with more nursing home beds was statistically significantly associated with fewer ED visits [RR 0.87, 95% CI 0.80–0.95, $p < 0.01$]	Medium

ED = emergency department; PC = palliative care; WOE D = Weight of Evidence D.15
 *Secondary analysis of KeirNak.27

ED use and reasons for admission

Dementia represented 1 of the most frequent non-oncological primary diagnoses for patients admitted to the ED with palliative care needs (Glajchen et al. 2011; Kruhlak et al. 2021; Nordt et al. 2023; Straeuli et al. 2022). Infections (Chen et al. 2017; De Matteis et al. 2022; Hanson et al. 2019; Hunt et al. 2018b; Lamantia et al. 2016; Williamson et al. 2023), mostly respiratory or urinary, and neuropsychiatric symptoms (De Matteis et al. 2022; Hanson et al. 2019) were the most prevalent reasons for admission.

Emergency use by patients with dementia were consistently high (Afonso-Argilés et al. 2020; Antunes et al. 2021; Chen et al. 2017; Fürst et al. 2022; Hill et al. 2022; Hunt et al. 2018b; Lamantia et al. 2016; Leniz et al. 2021; Nordt et al. 2023; Reeves et al. 2023; Rosenwax et al. 2015; Williamson et al. 2023), mostly at the end of life (Chen et al. 2017; Hunt et al. 2018b; Leniz et al. 2021; Rosenwax et al. 2015; Williamson et al. 2023) and often with more than 1 visit in the last year of life (Antunes et al. 2021; Nordt et al. 2023; Rosenwax et al. 2015; Williamson et al. 2023). Analysis of factors associated with ED use suggested that being male (Rosenwax et al. 2015; Sleeman et al. 2018), younger (Rosenwax et al. 2015), and having depression (Sleeman et al. 2018), pain (Hunt et al. 2018b), polypharmacy, falls, weight loss, caregiver burden (Afonso-Argilés et al. 2020), type of dementia (Rosenwax et al. 2015; Williamson et al. 2023), and place of residency (Rosenwax et al. 2015; Williamson et al. 2023) might be associated with increased ED use. In contrast, access to community palliative care was associated with reduced use of ED (Straeuli et al. 2022).

Palliative care needs and access to palliative care

Prevalence of palliative care needs of patients with dementia assisted at the ED ranged from 0.6% (Straeuli et al. 2022) to 7.9% (Glajchen et al. 2011). When comparing to patients with other comorbidities also assisted at the ED, prevalence of palliative care needs of patients with dementia was non-inferior to that of cancer patients (Kirkland et al. 2022a). Considering total dementia patients attending the ED, palliative care needs ranged from 18.3% (Glajchen et al. 2011) to 33.6% (Leniz et al. 2021). Access to palliative care was low in general (Amado-Tineo et al. 2020a; Kirkland et al. 2022a; Kruhlak et al. 2021; Leniz et al. 2021; Rosenwax et al. 2015; Willert et al. 2021), only 3 studies presented rates pertaining to patients with dementia, ranging from 6.0% (Rosenwax et al. 2015) to 42% (Willert et al. 2021). The latter study considered patients with dementia associated with cancer, inferior to the 76% of patients who only had cancer.

Studies included presented a WOE D quality score of medium (Afonso-Argilés et al. 2020; Amado-Tineo et al. 2020b; Glajchen et al. 2011; Hunt et al. 2018b; Kruhlak et al. 2021; Lamantia et al. 2016; Leniz et al. 2021; Nordt et al. 2023; Rosenwax et al. 2015; Sleeman et al. 2018; Straeuli et al. 2022; Willert et al. 2021; Williamson et al. 2023) or high (Afonso-Argilés et al. 2020; Amado-Tineo et al. 2020a; Antunes et al. 2021; Chen et al. 2017; De Matteis et al. 2022; Fürst et al. 2022; Hanson et al. 2019; Hill et al. 2022; Kirkland et al. 2022a; Reeves et al. 2023; Rosenwax et al. 2015; Shah et al. 2022).

Discussion

To our knowledge, this is the first review directly addressing palliative care needs of patients with dementia at the ED at the end of life.

Our findings reveal that the evidence is scarce, limited to 24 studies. Patients with dementia in the last year of life frequently resort to the ED, representing 1 of the main diagnosis of patients attending this service. Moreover, patients with dementia often seem to present to the ED near the end of life, frequently more than once in their last year of life. Only 8 studies directly addressed palliative care needs and a plethora of measurement tools were used, suggesting significant rates of palliative care needs among patients with dementia and in comparison, to other oncological or non-oncological conditions. Some of the main reasons of admission to the ED are infections and neuropsychiatric symptoms. Although access to community palliative care seems to reduce ED use, evidence to support this remains scarce.

Previous studies estimate that 32–35% of patients attending the ED present unmet palliative care needs (Kirkland et al. 2022b), presenting a wide range in prevalence, from 0.6% (Straeuli et al. 2022) to 7.9% (Glajchen et al. 2011), and these needs are probably non-inferior to the ones present in cancer patients (Kirkland et al. 2022a). These results are in accordance with studies describing similar levels of distressing symptoms and palliative care needs in patients with dementia and patients with cancer and other chronic diseases, outside the ED setting (Chaudhry et al. 2013; Eisenmann et al. 2020; Moens et al. 2014; Sampson et al. 2018).

ED use is usually considered a low-quality indicator of end-of-life care, including patients with dementia, especially in the last 90 days of life (Gozalo et al. 2011; Leniz et al. 2019). In fact, ED attendance of patients with dementia has been associated with an increased risk of delirium, falls, cognitive and functional decline, readmission, and death (Godard-Sebillotte et al. 2019; Travers et al. 2014; Volicser and Simard 2015). Evidence shows that significant avoidable ED use occurs (Lamba et al. 2012; Nuñez et al. 2006). This is in line with our scoping review, given that this population presented high rates of ED use (Afonso-Argilés et al. 2020; Antunes et al. 2021; Fürst et al. 2022; Hill et al. 2022; Hunt et al. 2018b; Lamantia et al. 2016; Leniz et al. 2021; Nordt et al. 2023; Reeves et al. 2023; Rosenwax et al. 2015; Williamson et al. 2023), specially at the end of life (Hunt et al. 2018b; Leniz et al. 2021; Rosenwax et al. 2015; Williamson et al. 2023) and frequently more than once in the last year of life (Antunes et al. 2021; Nordt et al. 2023; Rosenwax et al. 2015; Williamson et al. 2023).

Frequent ED resource suggests frequent unmet needs, including palliative care needs. None of the studies included in this review specifically addressed which palliative care needs are more commonly present. Reasons to resorting to the ED may represent some of these needs and in the present review infections (De Matteis et al. 2022; Hanson et al. 2019; Hunt et al. 2018b; Lamantia et al. 2016; Williamson et al. 2023) and dominated neuropsychiatric symptoms (De Matteis et al. 2022; Hanson et al. 2019). Other reasons of resorting to the ED have also been proposed (Vasquez et al. 2019), such as reduced oral intake and inability to tolerate medication. Williamson et al. (2021) previously identified several individual, clinical, and environmental factors that can influence ED attendance by patients with dementia at the end of life, including palliative care that was associated with reduced ED use. In our study, depression (Sleeman et al. 2018), pain (Hunt et al. 2018b), polypharmacy, falls, weight loss, and caregiver burden (Afonso-Argilés et al. 2020) were identified as factors that can be associated with ED use when addressing palliative care needs.

This scoping review confirms that palliative care needs of patients with dementia attending the ED are frequent and access to palliative care remains scarce (Amado-Tineo et al. 2020a; Fürst et al. 2022; Kirkland et al. 2022a; Kruhlak et al. 2021; Leniz et al.

2021; Rosenwax et al. 2015; Willert et al. 2021). Evidence shows that the main barriers contributing to the latter include time constraints, lack of privacy and other space limitations, staff with low confidence in palliative care skills, and difficulties in relationship building with patients and families. Barriers related to limited community service provision and to particular aspects of patients with dementia that complicate palliative care recognition such as cognitive changes, communication difficulties, and the pattern of slow incremental decline have also been identified (Jamieson et al. 2016; Jurgens et al. 2012; Lillyman and Bruce 2016; Mataqi and Aslanpour 2020; Ryan et al. 2012; Verhoef et al. 2020). Additionally, health-care professionals tend to underestimate the potential role of palliative care for life-limiting conditions other than cancer (Shearer et al. 2014), and patients with life limiting conditions are frequently triaged as low priority patients (Hjermstad et al. 2013) at the ED, and can consume resources like over investigations and inappropriate treatment that fail to address their needs and goals of care (Lawson et al. 2008).

Considering that ED use by patients with dementia with palliative care needs is frequent, some authors have proposed to assume ED use as an opportunity to identify gaps in care, offer timely interventions, initiate end-of-life discussions, and refer to palliative care services (Elsayem et al. 2016; George et al. 2015; Grudzen et al. 2016, 2011; Ouchi et al. 2017, 2014). Lamba et al. (2013) suggest training of emergency staff in palliative care principles encouraging them as primary providers to seek the multi-professional palliative care service as means to improve access to palliative care. Our results are in line with these views (Glajchen et al. 2011; Hanson et al. 2019; Shah et al. 2022). The BriefPal project (Glajchen et al. 2011) showed feasibility of successful screening of palliative care needs and the value of staff education, reporting patient symptom reduction and improvement in referral to palliative care services. Hanson LC et al. (2019) conducted a trial of best-practice model of specialty palliative care triggered by ED use, and results show that the intervention group presented more elements of palliative care needs addressed; more frequent assessment and treatment of physical, neuropsychiatric, and spiritual symptoms; and increased communication and decision-making concerning end-of-life issues. The Shah et al. (2022) trial reported that a care transition intervention can improve transition of patients with dementia, specially of those with depression, reducing ED revisits, and increase odds of obtaining follow-up.

Strengths and limitations

This scoping review complied with an established systematic method and examined the available evidence on experience and needs of a particularly frail subgroup of patients, in the challenging setting of ED. Our search included studies from a diverse range of countries and hence presents wide-ranging relevance. However, there are some limitations. Search was limited regarding number of databases, and no hand search of key journals was conducted, besides those based on references from previous reviews. We only considered English-, Portuguese-, and Spanish-language publications. The main focus was in studies addressing palliative care needs directly with specific tools but studies with indirect assessment of palliative care needs were also considered. Studies included in this review presented very diverse methodologies and frequently samples were not exclusively of dementia patients, limiting analysis of the results.

Conclusions

Current evidence indicates that patients with dementia frequently resource to the ED in their last year of life with unmet palliative care needs. Scarce access to palliative care seems to pose an even greater challenge to care for these patients in the ED setting. Results from palliative care intervention studies (Elsayem et al. 2016; George et al. 2015; Glajchen et al. 2011; Grudzen et al. 2016, 2011; Hanson et al. 2019; Lamba 2009; Ouchi et al. 2017, 2014; Shah et al. 2022) at the ED are encouraging and suggest that ED can and probably should be seen as an opportunity to attend to palliative care needs and refer to palliative care services.

Future research regarding models of identification of palliative care needs and development of best practice approach along with palliative care principles at the ED might shed light in improving the response to palliative care needs of patients with dementia. Referral to palliative care services, advance discussion of goals of care and reinforcement of community palliative care services seems to be key to guarantee better access to palliative care.

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Data availability statement. Further information about the search strategies and other supplemental material are available from the corresponding author on reasonable request.

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CHAPTER 4

Unmet Palliative Care Needs Among Patients with Dementia at the End
of Life and Frequent Use of the Emergency Department: One-Year
Retrospective Study in a Central Hospital

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39.88

This chapter provides a real-world assessment of the prevalence of unmet palliative care needs among patients with dementia who use the emergency department at their end-of-life and why they resort to visiting the emergency department. Greater knowledge and understanding of the palliative care needs of these patients is essential. These needs can also be seen as potential intervention targets to improve emergency department care for this vulnerable population and should be integrated into healthcare professionals' perspectives on how emergency departments respond to the palliative care needs of end-of-life patients with dementia



Unmet Palliative Care Needs Among Patients with Dementia at the End of Life and Frequent Use of the Emergency Department: One-Year Retrospective Study in a Central Hospital

Sara Vieira Silva, MD,^{1,2} Carla Teixeira, PhD,²⁻⁶ and Bárbara Antunes, PhD⁶

Abstract

Background: The use of emergency departments (ED) by patients with dementia at the end-of-life (EOL) presents various challenges.

Objective: To evaluate the prevalence of unmet palliative care (PC) needs among patients with dementia who use the ED at their EOL.

Methods: A single-center, retrospective study analyzing ED visits in the last 12 months of life among patients with dementia who died in 2021 (359 patients, 1042 ED visits) in Portugal. Unmet PC needs were assessed using the Palliative Care and Rapid Emergency Screening tool (P-CaRES).

Results: Unmet PC needs were highly prevalent (78.2%). Dyspnea (30.9%) was the prevailing reason for ED visits; 29.5% of patients were considered frequent ED users. The association between P-CaRES status and frequent ED use was nonsignificant ($p = 0.47$).

Discussion: The high prevalence of unmet PC needs and frequent ED use highlights the need for better responding to these needs.

Keywords: dementia; end-of-life care; emergency medicine; palliative care needs

Background

The prevalence of Alzheimer's disease and associated types of dementia continues to increase.¹ Concurrently, emergency department (ED) use by affected patients is growing, particularly at the end-of-life (EOL).^{2,3} Defining EOL in this population is difficult due to the disease's long and unpredictable trajectory.⁴ Most patients present common symptoms associated with cognitive and functional impairment, including progressive immobility, dysphagia, and limited ability to express needs.⁵ Accordingly, providing adequate care for this population in EDs is a growing problem.

In an expert consensus white paper, the optimal aims of palliative care (PC) for older patients with dementia were defined as improving quality of life, maintaining function, and maximizing comfort.⁶ Notably, at the EOL, these patients experience distressing symptoms at a similar rate to patients with other chronic illnesses.⁷⁻¹⁰

Against this background, we aimed to evaluate the prevalence of unmet PC needs among patients with dementia who use the ED at their EOL and assess why they resort to visiting the ED. Understanding their PC needs may help identify potential intervention targets to improve ED care for this vulnerable population.

¹Palliative Care Service, Centro Hospitalar Universitário de Santo António, Porto, Portugal.

²Faculdade de Medicina da Universidade do Porto, Universidade do Porto, Porto, Portugal.

³Centro Hospitalar Universitário de Santo António, Porto, Portugal.

⁴Instituto de Ciências Biomédicas Abel Salazar, Universidade do Porto, Porto, Portugal.

⁵CINTESIS RISE, Porto, Portugal.

⁶Department of Public Health and Primary Care, University of Cambridge, Cambridge, United Kingdom.

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Methods

Context

Portugal has universal health care coverage nationwide (including both the mainland and islands); specialized PC is organized in hospitals and community care settings.^{11,12} Most public hospitals offer some form of specialized PC, more frequently in the form of an internal PC consultant team. Specialized community PC teams have also been developed, but coverage varies nationwide. Basic PC is ensured by primary care institutions; there are no public hospices. PC training is not mandatory for health care professionals but has become increasingly common in undergraduate curriculums.^{11,12}

Study design and population

This is a single-center, retrospective study conducted in a large university hospital (Centro Hospitalar Universitário de Santo António in Porto) serving 650,000 inhabitants with a 24 hours/7-day polyvalent ED. We enrolled patients with an established diagnosis of Alzheimer's disease or related dementias (ICD10—F00* to F03) who died in this hospital between 1 January and 31 December, 2021. ED visits in the 12 months before death were analyzed; more than four visits in this period were classified as frequent ED use.¹³ The study was approved by the Unidade Local de Saúde de Santo António Ethics Commission and Review Board.

Study variables

Data were obtained through electronic medical records. Sociodemographic and clinical characteristics were collected. Sex, age, place of care, major comorbidities (organ insufficiency and malignancy), number of ED visits, and reasons for ED visits were extracted and assessed.

Outcome measures

The primary endpoint was assessing the prevalence of unmet PC needs based on the Palliative Care and Rapid Emergency Screening tool (P-CaRES).^{14,15} This is a validated five-item instrument used in EDs to assess the PC needs of patients with potential EOL conditions, including dementia. The five items are frequent visits, uncontrolled symptoms, functional decline, uncertainty about goals of care and/or caregiver distress, and surprise question. Patients are identified as having unmet needs if they present at least one EOL condition and two or more risk factors. The surprise question item was not considered due to the retrospective nature of the study. The secondary endpoints involved identifying the frequency of and main reasons for ED visits at the EOL and evaluating the association between unmet PC needs and membership of the frequent ED use subgroup.

Statistical analysis

Patients' characteristics were described using summary statistics. For categorical data, frequencies and percentages were compared using the chi-square test. All analyses were

conducted using SPSS v26® (IBM, Armonk, NY, USA). *p*-values of 0.05 or less were considered significant.

Results

During 2021, 359 patients with dementia died at the hospital, among whom 68.0% (*n* = 244) were female (mean age: 85.9 ± 7.7 years); 93.3% (*n* = 335) presented with a Functional Assessment Staging Tool¹⁶ score of 6 or more (Table 1). Most patients (*n* = 316, 88.0%) received care at home. Regarding major comorbidities, 126 patients (35.1%) presented established cardiac, respiratory, hepatic, or renal failure; 29 patients (8.1%) presented active malignancy; and 14 patients (3.9%) presented both (Table 2).

ED visits

During 2021, the hospital had 112,275 ED visits in total. Our sample presented 1042 ED visits in the 12 months before their deaths (0.9% of total ED visits; mean: 2.9 ± 0.8 visits). Among the 1042 visits, 57.8% (*n* = 602) occurred in the last three months of life (Table 2).

Prevalence of unmet PC needs

Prevalence of unmet PC needs in all ED visits was 78.2% (*n* = 815). Among these, 98.9% (*n* = 806) involved uncontrolled symptoms, 75.8% (*n* = 618) involved patients who had recurred twice or more to the ED in the previous six months, 55.6% (*n* = 453) were due to recent functional decline, 4.8% (*n* = 39) related to caregivers being unable to meet long-term needs, and 1.2% (*n* = 10) involved caregivers who presented with uncertainty/distress about goals of care. Among patients who were subsequently hospitalized (*n* = 539), 53.3% (*n* = 435) had unmet needs, while 45.8% (*n* = 104) did not.

TABLE 1. OVERALL DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF PATIENTS WITH DEMENTIA DIED AT CENTRO HOSPITALAR UNIVERSITÁRIO DE SANTO ANTÓNIO IN 2021

Characteristic	Total (N = 359), n (%)
Sex	
Female	244 (68.0)
Male	115 (32.0)
Age (mean ± SD)	85.9 ± 7.7 years
FAST	
Stage <6	24 (6.7)
Stage ≥6	335 (93.3)
Previous place of care	
Home care	315 (87.7)
Nursing care	40 (11.1)
Other	4 (1.1)
Major comorbidities	
Organ insufficiency (cardiac, respiratory, renal and/or hepatic)	126 (35.1)
Malignancy	29 (8.1)
Organ insufficiency and Malignancy	14 (3.9)
Frequent users of the ED	106 (29.5)

ED, emergency department; FAST, functional assessment staging tool; SD, standard deviation.

TABLE 2. ED VISITS, REASONS OF RESOURCE AND FINAL DIAGNOSIS

	All visits (n = 1042)	Visits from patients with unmet PC needs (n = 815)	Visits from patients without unmet PC needs (n = 227)
ED visits			
in the last 12 months of life	1042 (100%)	815 (100%)	227 (100%)
in the last six months of life	758 (72.7%)	610 (74.8%)	148 (65.2%)
in the last three months of life	602 (57.8%)	548 (60.7%)	107 (47.1%)
Mean $\pm$ SD of ED visits per patient	2.9 $\pm$ 0.8		
Minimum of ED visits per patient	1		
Maximum of ED visits per patient	14		
Reasons of resource			
Dyspnea	322 (30.9%)	252 (30.9%)	70 (30.8%)
Behavioural changes	219 (21.7%)	184 (22.6%)	35 (15.4%)
Fall	92 (8.8%)	78 (9.6%)	14 (6.2%)
Pain	58 (5.6%)	39 (4.8%)	19 (8.4%)
Fever	51 (4.9%)	37 (4.5%)	14 (6.2%)
Major aspiration	29 (2.8%)	28 (3.4%)	1 (0.4%)
Urinary complaints	25 (2.4%)	23 (2.8%)	2 (0.9%)
Eating related difficulties	19 (1.8%)	19 (2.3%)	0 (0%)
Diarrhea	22 (2.1%)	18 (2.2%)	4 (1.8%)
Bleeding	24 (2.3%)	18 (2.2%)	6 (2.6%)
Other	181 (17.4%)	119 (14.6%)	62 (27.3%)
Final diagnosis			
Infection	376 (36.1%)	274 (33.6%)	102 (44.9%)
Aspiration	100 (9.6%)	98 (12.0%)	2 (0.9%)
Trauma	87 (8.3%)	73 (9.0%)	14 (6.2%)
Cardiac failure	59 (5.7%)	43 (5.3%)	16 (7.0%)
Dementia	54 (5.2%)	41 (5.0%)	13 (5.7%)
Dehydration	28 (2.7%)	28 (3.4%)	0 (0%)
Constipation	25 (2.4%)	21 (2.6%)	4 (1.8%)
Stroke	23 (2.2%)	17 (2.1%)	6 (2.6%)
Malignancy	14 (1.3%)	13 (1.6%)	1 (0.4%)
Urinary changes	10 (1.0%)	10 (1.2%)	0 (0%)
Other	266 (25.5%)	197 (24.2%)	69 (30.4%)
Inpatient	539 (51.7%)	435 (53.3%)	104 (45.8%)

ED, emergency department; SD, standard deviation.

Reasons for ED visits

Dyspnea ($n = 252$, 30.9%), behavioral changes ($n = 184$, 22.6%), falls ($n = 78$, 9.6%), pain ($n = 39$, 4.8%), and fever ($n = 37$, 4.5%) were the five most frequent reasons for ED visits among patients with unmet PC needs (Table 2). The five most common final diagnoses were infection ($n = 274$, 33.6%), aspiration ($n = 98$, 12.0%), trauma ($n = 73$, 9.0%), congestive heart failure ($n = 43$, 5.3%), and behavioral and psychological dementia symptoms ($n = 41$, 5.0%) (Table 2).

Unmet PC needs and frequent ED users

Among all 359 patients considered, 29.5% ($n = 106$) were considered frequent ED users (Table 1). We found no significant association between P-CaRES status and membership of the frequent ED users subgroup ($p = 0.47$, chi-squared test).

Discussion

Unmet PC needs among patients with dementia at the EOL presenting to the ED were highly prevalent, at 78.2%; this is higher than published studies, where this figure ranged from 18.3%¹⁷ to 33.6%.⁵ This difference may be explained by our inclusion of patients who later died in hospital, implying

greater complexity of needs and care. Furthermore, the P-CaRES assessment tool, which has a high sensitivity (over 90%) but a specificity of around 70%,¹⁸ may have contributed to the high prevalence. Most ED visits (57.8%) occurred in the last 90 days of life.

Our results highlight the importance of assessing PC needs in EDs and responding adequately. Some authors have proposed ED use as an opportunity to identify gaps in care, offer timely interventions, initiate EOL discussions, and provide referrals to PC services.^{14,19–23} To our knowledge, no previous studies have specifically addressed which unmet PC needs are more common. In our study, uncontrolled symptoms were by far the most frequent unmet PC need ($n = 806$, 98.9%). Besides recurrent ED visits, functional decline was also identified in 55.6% of ED visits ($n = 453$). Disabled patients often need the support of a third person, which may not be immediately available. However, the impact of caregivers' inability to continue providing care or uncertainty/distress about goals of care was quite low in our study, though this may have been under-recorded and even underestimated.

Although we found no association between unmet PC needs and ED use frequency, patients with dementia at the EOL presented frequent visits to the ED, especially in the last three months of life. Recurrent ED visits are an indicator of

low care quality,^{2,3} since it has been associated with an increased risk of delirium, falls, cognitive and functional decline, readmission, and death.^{29–30} As for the reasons for ED visits, we confirmed infection^{37–38} as the most frequent, followed by aspiration, trauma, congestive heart failure, and behavioral and psychological dementia symptoms. Thus, education and prevention of associated nutritional problems, falls, and symptom control might be fertile areas for intervention. In addition, better response and access to community PC was previously associated with reduced ED use.³³ Help with managing symptom burden, prevention of under or overtreatment, and enhanced caregiver quality of life are other of the identified benefits of PC.^{34,35} Disease-specific approach programs targeted to other frequent comorbidities, such as heart failure, might also address some unmet PC needs.

In the future, it will be important to define which ED approach works best in terms of systematically identifying unmet PC needs and amplifying PC skills among ED professionals. Development of community PC care might anticipate some unmet PC needs among these patients and facilitate post-ED discharge care.

Strengths and limitations

Our use of retrospective analysis facilitated real-world assessment of some of the specific circumstances concerning ED use among patients with dementia at the EOL. Notably, data collection depended on the quality of available medical records, which were brief (as expected in the ED) and not always uniform or available. Thus, relevant actions or conversations that were not recorded may have been missed in our analysis.

Conclusion

ED use by patients with dementia at the EOL presents various challenges. The high prevalence of unmet PC needs and frequent ED use, particularly in the last months of life, highlights the need to develop better responses to these needs. Investing in training of ED health care professionals for adequate clinical identification of PC needs at the EOL, improving symptom control strategies in inpatient and outpatient settings, and facilitating access to assisted care might contribute to solving some of those challenges.

Author Disclosure Statement

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Address correspondence to:

Sara Vieira Silva, MD

Palliative Care Service

Centro Hospitalar Universitário de Santo António

Rua João Pedro Ribeiro

788, 2nd floor left

4000-306 Porto

Portugal

E-mail: nevensp@gmail.com

CHAPTER 5

Potentially avoidable visits to the emergency department by patients with dementia at the end of life – a longitudinal retrospective study

OPEN ACCESS

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AND

Prevalence of inappropriate diagnostic and therapeutic measures in patients with advanced dementia in the last days of life in the emergency department – a retrospective study in a tertiary hospital

https://cnmi.spmi.pt/wp-content/uploads/2016/05/LIVRO-DE-RESUMOS_31CNMI_2025_V08.pdf (page 1135)

This chapter concerns the potential avoidable emergency department visits by patients with dementia at the end-of-life. The real-world assessment of the prevalence of these visits, its main causes and associated factors can provide useful knowledge about patients with dementia at the end-of-life and possible gaps in healthcare services. At the same time, it is important to consider, when reflecting on the secondary harm caused by potentially avoidable visits, the disproportionate diagnostic and therapeutic measures carried out in the emergency department for patients with dementia at the end-of-life. Together this knowledge is relevant to integrate with the perspectives that healthcare professionals have on how emergency department care responds to the palliative care needs of end-of-life patients with dementia.

1 **Title page**

2 **Title:** Potentially avoidable Emergency Department Visits Among Patients with Dementia
3 at the End of Life: A Retrospective Cohort Study

4

5 **Authors**

6 Sara Vieira Silva, Palliative Care Service, Centro Hospitalar Universitário de Santo António,
7 Porto, Portugal; Faculdade de Medicina da Universidade do Porto, Universidade do Porto,
8 Porto, Portugal

9

10 Bárbara Antunes, Department of Public Health and Primary Care, University of Cambridge,
11 Cambridge, United Kingdom

12

13 Carla Teixeira, Centro Hospitalar Universitário de Santo António, Porto, Portugal; Faculdade
14 de Medicina da Universidade do Porto, Universidade do Porto, Porto, Portugal; Instituto de
15 Ciências Biomédicas Abel Salazar, Universidade do Porto, Porto, Portugal; CINTESIS.RISE,
16 Porto, Portugal

17

18 **Corresponding author**

19 Sara Vieira Silva

20 Largo Abel Salazar, 4099-001 Porto, Portugal

21 Email: nevesp@gmail.com

22 Phone: +351 963102086

23 ABSTRACT

24 Background

25 Preventing avoidable visits to the Emergency department (ED) by patients with dementia at
26 the end of life may reduce harm and improve the quality of care. This study aimed to
27 determine the prevalence of potentially avoidable ED visits among patients with dementia
28 at the end of life, identify the main reasons for these visits, and explore factors associated
29 with their occurrence.

30 Methods

31 This retrospective study was conducted in the 24-hour ED of a tertiary university hospital in
32 northern Portugal. Adult patients with a diagnosis of Alzheimer's disease or related
33 dementias who died between January 1 and December 31, 2021, and had at least one ED
34 visit in the 12 months before death were included. Sociodemographic, clinical and ED
35 related variables were extracted from the patients' electronic medical record. Potentially
36 avoidable ED visits were classified by *Cornillon et al* criteria and palliative care needs were
37 assessed using the Palliative Care and Rapid Emergency Screening (P-Cares) tool.
38 Bivariable analyses were performed using chi-square tests, and multivariable logistic
39 regression was used to identify factors independently associated with potentially avoidable
40 ED visits.

41 Results

42 Among 359 patients with dementia who visited the ED during the last year of life, a total of
43 1052 ED visits were recorded. Of these, 24.0% (n = 252) were classified as potentially
44 avoidable, and 35.7% of patients (n = 128) experienced at least one potentially avoidable
45 ED visit. The most frequent reasons for potentially avoidable visits were infection (26.2%),
46 behavioural changes related to dementia (16.7%), and constipation (7.9%). In multivariable

47 logistic regression analysis, the presence of unmet palliative care needs was independently
48 associated with potentially avoidable ED visits (OR 2.01, 95% CI 1.34–3.02, $p = 0.001$).

49 Conclusions

50 Potentially avoidable ED visits among patients with dementia at the end of life were
51 frequent and independently associated with unmet palliative care needs. Improved
52 identification and management of palliative care needs may contribute to reducing
53 avoidable ED use in this population.

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55 **KEYWORDS:** Avoidable visits, Emergency department, Dementia, End of Life

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68 **Background**

69 Each year, more than 50% of patients with dementia (PwD) visit the Emergency Department
 70 (ED)(1), more frequently than patients without dementia(2) and more often at the end of life
 71 (EOL)(1, 3). ED attendance is distressing for PwD (4) and their caregivers (5) and is
 72 associated with an increased risk of delirium, falls, cognitive and functional decline,
 73 readmissions and death (6-8). Additionally, in our recent study we found a 78.2%
 74 prevalence of unmet palliative care needs among patients with dementia who visit the ED
 75 at the end of life, and, uncontrolled symptoms were by far the most frequent unmet
 76 palliative care need(3).

77 Many ED visits are potentially avoidable (9-11). Considering the care for PwD at the end of
 78 life, it is important to prevent their avoidable visits to the ED, not only to reduce the harm
 79 associated with it but also to improve care itself, with better treatment elsewhere,
 80 eventually at lower costs, as already suggested by *Hsia and Niedzwiecki* (11) for patients in
 81 general. There is no standard definition for “avoidable visits”, and often, terms such as
 82 “inappropriate”, “non-urgent” or “unnecessary” ED visits, are used interchangeably and/or
 83 as equivalents (12-14). In this study we use a restrictive definition suggested by *Cornillon et*
 84 *al* (15), based on the need for specialized medical/clinical evaluation or for complex
 85 diagnostic approaches. Specific criteria for potentially avoidable ED visits are defined in the
 86 methods section.

87 A more in-depth understanding of potentially avoidable ED visits by PwD at the end of life
 88 might provide useful knowledge about these patients’ needs and eventually help identify
 89 gaps in healthcare services. Based on previous literature on ED use among PwD and on the
 90 potential role of unmet palliative care needs at the end of life, we hypothesized that
 91 potentially avoidable ED visits would be associated with unmet palliative care needs and
 92 with clinical conditions that could potentially be managed outside the hospital setting. We

also expected that potentially avoidable visits would be characterized by less complex diagnostic or therapeutic interventions. This study aimed to determine the prevalence of potentially avoidable ED visits among PwD at the end of life, identify the main reasons for these visits, and explore patient characteristics associated with potentially avoidable ED use.

Methods

Contextualization

Portugal presents national universal healthcare coverage similar to that of the United Kingdom National Health System. Emergency care is provided at the level of primary care, basic emergency services and, at the hospital level, medical-surgical EDs and polyvalent EDs. There is a national telephone referral system for emergency care, but referral before resorting to the ED is not mandatory (16). Only hospital-based EDs provide a 24h/7d response. Specialized Palliative Care (PC), at the public hospital level, more frequently includes an internal consultant PC team, while some hospitals also have external consultation and only some have specific inpatient PC units. There are no public hospices. Primary care ensures important basic PC care. Community specialized PC teams have been developed but still without global coverage of the territory. Many areas do not have home-based PC available. No preparation or training is mandatory for carers, particularly informal ones. PC training is also not mandatory, but it has become increasingly common in health courses (16, 17).

Design and population

This is a retrospective study performed at the ED of Centro Hospitalar Universitário de Santo António/Unidade Local de Saúde de Santo António, a university hospital. It is a 24h/7day

polyvalent ED serving a population of 650000 inhabitants in northern of Portugal (Porto). This tertiary hospital has an internal consultant PC team that also provides limited access to external consultation. We included adult patients with an established diagnosis of Alzheimer's disease or other related dementias (ICD10 – F00* to F03) who died between January 1 and December 31 2021 in this hospital and that visited the ED in the 12 months before their death.

The study was approved by the Unidade Local de Saúde de Santo António Ethics Commission and Review Board [reference number 2023.094(083-DEFI/075-CE)].

Data source and collected variables

Selected variables were collected from the patients' medical records, including sociodemographic variables (sex, age and place of care), major comorbidities, number of ED visits, reasons for ED visits and the presence of PC unmet needs. Dementia staging was classified by the Fast assessment staging tool (FAST) (18), that considers 7 stages of cognitive decline (ranging from stage 1 to 7f), where higher FAST score indicates a more advanced stage of cognitive decline. Stage 6 or higher corresponds to states of severe functional impairment up to total dependence (18). We have published these data in a recent study and we include them in this present study for context(3). ED length of stay and destination were also collected, as well as potentially avoidable ED visits that were assessed by Cornillon *et al* (15) criteria defined as visits without explicit medical intervention or with basic investigations such as X-rays, electrocardiograms or simple biological analysis, whereas nonavoidable ED visits were considered when there was an explicit intervention by a specialist doctor and the need to resort to complex means of investigation or procedures. PC needs were assessed by the Palliative Care and Rapid Emergency Screening tool (P-cares) (19, 20). This is a 5-item validated instrument (1- Frequent visits, 2- Uncontrolled symptoms, 3 – Functional decline, 4 – Uncertainty about

goals of care and/or Caregiver distress and 5 – Surprise question) used to assess PC needs in the ED of patients with potential end of life conditions, including dementia. Patients are identified as having unmet needs if they present with at least one end of life condition and two or more risk factors. Surprise question was not considered due to the retrospective nature of the study.

Statistical analysis

A descriptive analysis was performed to establish the main population characteristics. Reference data were summarized as numerical data (mean, standard deviation and range) for quantitative variables and as frequencies for qualitative variables. The chi-square and t-student tests were used to analyse the possible relationships between independent variables and potentially avoidable ED visits. These independent variables were based on previous studies(11, 12) and on hypotheses considered to be plausible to the research team, such as comorbidities and place of care. A multivariable logistic regression analysis was performed to identify factors independently associated with potentially avoidable ED visits. Variables included in the model were sex, presence of caregiver, comorbidity, palliative care needs (P-Cares), and ED length of stay (>12h). Odds ratios (OR) with 95% confidence intervals (CI) were calculated. All analyses were conducted using SPSS v26® (IBM, Armonk, NY, USA). *P*-value of 0.05 or less was considered significant.

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Results

Patient-level characteristics

During 2021, 359 patients with dementia died at Centro Hospitalar Universitário de Santo António and had visited the Emergency Department (ED) during the last 12 months of life. Among these patients, 57.1% (n=205) were female and the mean age was 85.9 ± 7.7 years.

Most patients presented with advanced dementia (FAST ≥ 6 , n=335, 93.3%) and were primarily cared for at home (n=323, 90.0%).

Overall, 35.7% of patients (n=128) experienced at least one potentially avoidable ED visit in the last year of life (Table 1).

Table 1. General characteristics of patients with dementia that died at the hospital in 2021 and visited the ED in their last 12 months of life

	PwD (total n=359)	
Age	85.9+-7.7years	
Sex	Female	n=205 (57,1%)
FAST	<6	n=24 (6.7%)
	≥ 6	n=335 (93.3%)
Place of care	Home	n=323 (90.0%)
	Care home	n=36 (10.0%)
Comorbidity	Organ insufficiency	n=126 (35.1%)
	Malignancy	n=29 (8.1%)
	Organ insufficiency and Malignancy	n=14 (3.9%)
Patients with avoidable visits in the last 12 months of life	Yes	n=128 (35.7%)
	No	n=231 (64.3%)

PwD Patients with dementia, ED Emergency department, FAST Functional assessment staging tool

Visit-level analysis

In total, these 359 patients accounted for 1052 ED visits during the last 12 months of life. Of these visits, 24.0% (n=252) were classified as potentially avoidable according to Cornillon *et al.* criteria, while 76.0% (n=800) were considered non-avoidable (Table 2). Almost all patients with potentially avoidable ED visits (n=125, 97,7%) visited the ED more than once in the last year of their lives (Table 2). The prevalence of unmet PC needs in total ED visits

was 79.6% (n=837), 84.9% (n=214) when considering only potentially avoidable visits (Table 2).

Table 2. Potentially avoidable and non-avoidable ED visits

	ED VISITS of PwD (total n=1052)			
	Potentially avoidable visits n=252 (24.0%)		Potentially non-avoidable visits n=800 (76.0%)	
Age	84.5+-7.8 years		85.4 +- 6.0 years	
Sex	Female	n=147 (58.3%)	Female	n=406 (50.1%)
FAST	<6	n=4 (1.6%)	<6	n=37 (4.6%)
	>=6	n=248 (98.4%)	>= 6	n=763 (95.4%)
Place of care	Home	n=213 (84.5%)	Home	n=649 (81.1%)
	Care home	n=39 (15.5%)	Care home	n=151 (18.9%)
Comorbidity	None	n=122 (48.4%)	None	n=413 (51.6%)
	Organ insufficiency	n=111 (44.0%)	Organ insufficiency	n=300 (37.5%)
	Malignancy	n=15 (6.0%)	Malignancy	n=60 (7.5%)
	Organ insufficiency and Malignancy	n=4 (1.6%)	Organ insufficiency and Malignancy	n=27 (3.4%)
Unmet PC needs	Yes	n=214 (84.9%)	Yes	n=623 (77.9%)
	No	n=38 (15.1%)	No	n=177 (22.1%)
ED length of stay	<12h	n=160 (63.5%)	<12h	n=275 (34.4%)
	>= 12h	n=92 (36.5%)	>=12h	n=525 (65.6%)
Patients with 1 or > ED visits	125 (97.7%)		110 (47.6%)	
Days between ED visit and death	Mean+-SD	133.8+-7.2 days	Mean+-SD	69.3 days+-5.2 days
	Median	100 days	Median	25 days
Destination	Discharged	n=238 (94.4%)	Discharged	n=497 (62.1%)
	Hospital admission	n=14 (5.6%)	Hospital admission	n=303 (37.9%)

ED Emergency department, PwD Patients with dementia, FAST Functional assessment staging tool, PC Palliative care, SD

Standard Deviation

The most frequent reasons for potentially avoidable ED visits were infection (26.2%), behavioural changes related to dementia (16.7%), and constipation (7.9%). In contrast, the most frequent reasons for non-avoidable visits were infection (38.8%), respiratory problems associated with aspiration (10.8%), and trauma (10.5%) (Table 3).

191 **Table 3. Reasons for Emergency Department visits by avoidable status among patients**
 192 **with dementia at the end of life (n=1052 visits)**

Reasons	Potentially avoidable visits (n=252)	Potentially non-avoidable visits (n=800)
Infection	66 (26.2%)	310 (38.8%)
Behavioural changes	42 (16.7%)	--
Constipation	20 (7.9%)	--
Respiratory aspiration	14 (5.6%)	86 (10.8%)
Trauma	--	84 (10.5%)
Acute heart failure	--	33 (4.1%)
Dehydration	--	23 (2.9%)

193

194 Despite the potentially avoidable nature of the ED visit, the length of stay in the ED was
 195 longer than 12h in 36.5% (n=92) of these patients but was still generally shorter than that in
 196 patients with potentially nonavoidable admissions (63.5% vs 34.4%). Additionally, 14 (5,6%)
 197 potentially avoidable visits resulted in further hospital admission, all in patients with PC
 198 needs (Table 2). Time between the ED visit and death was shorter in the group of patients
 199 with potentially non-avoidable visits (69.3+-5.2 days vs 133.8+-7.2 days) (Table 2).

200

201 *Comparison between avoidable ED visits status, patients' characteristics and other*
 202 *factors*

203 There was no association between age, sex, place of care or the presence of a significant
 204 comorbidity and potentially avoidable ED visits (p>0.05) (Table 4).

205

Table 4. Comparison of PwD with potentially avoidable and PwD with potentially non avoidable ED visits

Variable	Patients with potentially avoidable visits (n=128)	Patients with potentially non avoidable visits (n=231)	p-value
Age (mean±SD)	85.4±7.5	86.2±7.7	0.92
Female	77 (60.2%)	167 (72.3%)	0.38
Place of care			
Home	110 (85.9%)	213 (92.2%)	0.11
Comorbidity			0.16
Without	63 (49.2%)	127 (55.0%)	
With	65 (50.8%)	104 (45.0%)	
Organ insufficiency	52	74	
Malignancy	11	18	
Both	2	12	

SD Standard deviation

In multivariable logistic regression analysis, the presence of unmet PC needs was independently associated with potentially avoidable ED visits (OR 2.01, 95% CI 1.34–3.02, $p=0.001$) (table 4). ED visits lasting more than 12 hours were significantly less likely to be classified as avoidable (OR 0.33, 95% CI 0.24–0.44, $p<0.001$) (Table 5). No significant associations were found for sex or comorbidities (Table 5).

219 **Table 5. Multivariable logistic regression results**

Variable	Odds ratio (OR)	95% CI	p-value
Sex	1.11	0.82-1.50	0.50
Caregiver present	1.34	0.98-1.84	0.065
PC needs (P-cares positive)	2.01	1.34-3.02	0.001
ED stay >12h	0.33	0.24-0.44	<0.001
Comorbidity	0.98	0.80-1.20	0.85

220 ED Emergency department, PC Palliative care

221

222 **Discussion**

223 Despite not having found association between unmet PC needs and ED use frequency in
 224 our previous study(3), in the present study, the prevalence of unmet PC needs in PwD with
 225 potentially avoidable ED visits was not only high but the presence of unmet PC needs was
 226 independently associated with potentially avoidable ED visits. These current findings
 227 reinforce the importance of assessing PC needs in both outpatients and EDs and
 228 responding appropriately to them, not only to ensure support but also because they may
 229 contribute to reducing avoidable ED visits. Appropriate daily assessment of symptoms,
 230 timely responses to clinical changes, and prompt access to primary care may help improve
 231 the management of these situations (21). This can be particularly important since we also
 232 found that 5,6% of the potentially avoidable visits resulted in further hospital admission, all
 233 in patients with PC needs. Different strategies such as advance care planning, access to
 234 specialist medical advice and a mobile emergency response have been suggested to help
 235 prevent potentially inappropriate ED visits(21-23).

236 With a 24.0% prevalence of potentially avoidable visits to the ED by PwD at the end of life
 237 reported in this study, infection, behavioural changes related to dementia, and constipation

238 were the most frequent reasons for potentially avoidable ED visits. Understanding the
 239 causes of avoidable ED use may help improve healthcare organization and prevent
 240 unnecessary hospital visits. According to its definition, the prevalence of avoidable ED visits
 241 reported in previous studies ranged from as low as 4.8% (9) to as high as 90% (10). Our study
 242 revealed that almost one out of four visits to the ED were potentially avoidable. This finding
 243 is particularly relevant because we used restrictive criteria to define avoidable ED visits,
 244 based on the need for specialized clinical assessment or complex clinical resources, and
 245 not based on simple triage scores, self-report, physician reports or discharge diagnoses
 246 (11). Patients were predominantly female, elderly and cared at home, such as the general
 247 population with dementia seen in the ED. The scarcity of available home-based PC and
 248 qualified carers may contribute to this. Home care can also be provided by primary health
 249 care services for these patients. There are no official data, but it is common practice that its
 250 availability is lower than demand. Private healthcare services response, both at home and
 251 in emergency services, is also not officially known. Given the universal nature of the public
 252 Portuguese healthcare system, we expect that private response represents only a small part
 253 of care requested and provided. Patients in care homes were previously associated with
 254 frequent visits to the ED, hospital admissions and readmissions (2, 21) and it has been
 255 suggested to be related to the presence of comorbidities, complex care needs (2),
 256 uncertainty about services available to care homes and a lack of anticipatory care planning
 257 (24). Some of these factors are also related to avoidable ED visits (25, 26). In our study we
 258 found no association between PwD in care homes and avoidable visits to the ED (15,5% vs
 259 18,9%). Infections are well known to be the most frequent reason for ED visits for patients
 260 with dementia (27), which was also found in this study, and its occurrence is similar in
 261 patients without and with avoidable ED visits. The diagnostic approach and, more
 262 frequently, the necessary means of treating infections can range from simple to more
 263 complex means, which explains why they were responsible for avoidable and non-

264 avoidable visits to the ER. On the other hand, behavioural changes related to dementia and
 265 constipation were more frequent in the subgroup of patients with avoidable visits, which
 266 may represent needs that are not currently met by outpatient treatment. In fact, these were
 267 two of the most frequent reasons for PwD to visit the ED at the end of life with unmet PC
 268 needs that we found in our previous study(3). Together, these findings suggest that
 269 improved identification and management of PC needs may represent an important
 270 opportunity to reduce potentially avoidable ED visits among PwD at the end of life

271

272 *Strengths and limitations*

273 This study has several strengths. To our knowledge, it is among the first real-world studies
 274 to evaluate the prevalence and reasons for potentially avoidable ED visits among PwD at
 275 the end of life. The study included a relatively large number of ED visits and used routinely
 276 collected clinical data from a tertiary hospital serving a large population. Additionally, the
 277 use of previously published criteria to classify potentially avoidable ED visits and the
 278 systematic assessment of PC needs using the P-Cares screening tool allowed a structured
 279 evaluation of the relationship between avoidable ED use and unmet PC needs.

280 However, several limitations should also be considered. First, the study was conducted in
 281 a single tertiary hospital, which may limit the generalizability of the findings to other
 282 healthcare settings with different PC resources or emergency care organization. Second,
 283 the retrospective design relies on information recorded in electronic medical records and
 284 may therefore be affected by incomplete or inconsistently documented data. Third,
 285 although we used previously published criteria to classify ED visits as potentially avoidable,
 286 there is no universally accepted definition of avoidable ED visits, and some degree of
 287 interpretation is inevitable. Fourth, the study period (2021) coincided with the COVID-19
 288 pandemic, which may have influenced healthcare-seeking behaviour and access to

community services, potentially affecting patterns of ED use. Finally, some potentially relevant contextual factors, such as caregiver support, advance care planning, or access to community-based PC services, could not be evaluated in this retrospective dataset.

Conclusions

In this study, potentially avoidable ED visits among PwD at the end of life were frequent and independently associated with the presence of unmet PC needs. These findings highlight the importance of early identification and appropriate management of PC needs, both in community settings and in the ED, as a potential strategy to reduce avoidable ED use in this population.

List of abbreviations

ED Emergency department

FAST Fast assessment staging tool

PC Palliative care

PwD Patients with dementia

P-cares Palliative Care and Rapid Emergency Screening tool

Declarations

Ethics approval and consent to participate

The authors declare that the study participants were not subjected to any experiments.

Need for consent was waived by the Unidade Local de Saúde de Santo António Ethics

311 Commission and Review Board [reference number 2023.094(083-DEFI/075-CE)]. This study
312 was conducted in accordance with the European Council Regulation (536/2014) and was
313 approved on March 31, 2023, by the Unidade Local de Saúde de Santo António Ethics
314 Commission and Review Board [reference number 2023.094(083-DEFI/075-CE)].

315

316 *Consent for publication*

317 Not applicable.

318

319 *Availability of data and materials*

320 The dataset generated and analysed during the current study is not publicly available to
321 safeguard individual privacy.

322

323 *Competing interests*

324 Not applicable.

325

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327 Not applicable.

328

329 *Authors' contributions*

330 VS, AB and TC made substantial contributions to the conception of the work. VS design the
331 work. VS and AB collected, analyzed and interpreted data. VS wrote the main manuscript
332 text and prepared tables 1 and 2. All authors reviewed the manuscript. All authors have
333 approved the submitted version and have agreed both to be personally accountable for the

author's own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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Authors' information (optional)

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Obstinação no doente com demência avançada no Serviço de Urgência – estudo em hospital terciário

Margarida Ribeiro¹; Joana Cabral²; Bárbara A.³; Teixeira, C⁴; Vieira Silva, S⁴

¹ UNIDADE LOCAL DE SAÚDE DE LISBOA OCIDENTAL

² UNIDADE LOCAL DE SAÚDE DE GAIA/ESPINHO

³ DEPARTMENT OF PUBLIC HEALTH AND PRIMARY CARE, UNIVERSITY OF CAMBRIDGE

⁴ UNIDADE LOCAL DE SAÚDE DE SANTO ANTÓNIO

Tema: Cuidados paliativos/ Hospitalização Domiciliária

Introdução

A demência avançada é uma doença terminal caracterizada pela deterioração cognitiva e funcional grave, com complicações que motivam o recurso frequente ao serviço de urgência (SU). Este ambiente, de alta pressão e decisões rápidas, nem sempre é adequado para atender às necessidades destes doentes. A identificação precoce do doente em fase terminal e a respetiva tomada de decisão podem ser desafiadoras, resultando em práticas médicas agressivas e de obstinação, como a realização de exames invasivos e terapêuticas desproporcionais, não considerando a alternativa de uma abordagem focada no conforto e dignidade.

Objetivo

Avaliar a prevalência da obstinação diagnóstica e terapêutica em doentes com demência avançada no SU e explorar fatores associados.

Material e Métodos

Estudo longitudinal retrospectivo, realizado num SU polivalente de um hospital terciário universitário. Foram incluídos doentes com demência avançada (FAST ≥ 6), falecidos nesse hospital em 2021, até 72h após terem recorrido ao SU. Avaliação da obstinação diagnóstica e terapêutica, definida pela realização de meios complementares de diagnóstico e intervenções como: colocação de dispositivos, administração de fluidoterapia, antibióterapia e outros, através da análise do registo clínico. Medidas de controlo sintomático foram definidas pelo uso de terapêutica opióide, butilescopolamina ou psicofármacos. Foi realizada análise bivariável com teste de Fisher para explorar fatores associados como comorbilidades, identificação de mau prognóstico, definição de limite terapêutico e estratégia de controlo sintomático. O valor de p considerado estatisticamente significativo foi $<0,05$. Foi utilizado software R.

Resultados

Foram incluídos 79 doentes com idade média de 86,5 anos (mínima 69, máxima 101 anos), predomínio do sexo feminino, 53,2% ($n=42$) e 32,9% ($n=37$) com doença oncológica ou insuficiência de órgão. Verificou-se obstinação diagnóstica e terapêutica em 83,5% ($n=66$) dos doentes. A colheita de estudo analítico foi o meio complementar de diagnóstico mais utilizado, em 77,2% dos doentes ($n=61$), enquanto que a fluidoterapia foi a terapêutica mais frequente, em 29,1% dos doentes ($n=23$), seguida da antibióterapia, em 24% dos doentes ($n=19$).

Em 63,3% ($n=50$) doentes foi registado mau prognóstico e em 68,4% ($n=54$) foi decidida a ordem para não reanimar. Observou-se que o estabelecimento de limite terapêutico ($p < 0,05$), a adoção de medidas de controlo sintomático ($p < 0,05$) e a identificação de mau prognóstico ($p < 0,05$) estão associados a menor probabilidade de obstinação diagnóstica e terapêutica. Não foi encontrada relação entre presença de comorbilidades e obstinação diagnóstica e terapêutica.

Conclusões

A prevalência de obstinação diagnóstica e terapêutica foi elevada nos doentes com demência avançada que recorreram ao SU nos seus últimos dias de vida. A identificação precoce de situações de mau prognóstico e o estabelecimento de limite terapêutico, parecem relacionar-se e poder contribuir para menor probabilidade de ocorrência de obstinação diagnóstica e terapêutica.

CHAPTER 6

Reflexive thematic analysis of emergency department medical records of dementia patients regarding the identification of last days of life

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<https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/reflexive-thematic-analysis-of-emergency-department-medical-records-of-dementia-patients-regarding-the-identification-of-last-days-of-life/AFD4EBCF97498E38ADCFA09685350C6C>

This chapter addresses aspects of the medical record related to end-of-life care for patients with dementia in the emergency department. Medical records were considered regarding the identification of the last days of life of these patients, communication with other healthcare professionals, patients, and family members, and end-of-life care implementation measures. The analysis of the clinical notes in the medical record are relevant to integrate what is commonly valued in the medical record and the perspective that healthcare professionals have on how emergency department care responds to the palliative care needs of end-of-life patients with dementia.

Original Article

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Corresponding author: Sara Vieira Silva,
Email: nevesp@gmail.com

Reflexive thematic analysis of emergency department medical records of dementia patients regarding the identification of last days of life

Sara Vieira Silva, ^{1,2}, Carla Teixeira, ^{1,3,4} and Bárbara Antunes, ^{1,5}

¹Palliative Care Service, Centro Hospitalar Universitário de Santo António, Porto, Portugal; ²Faculdade de Medicina da Universidade do Porto, Universidade do Porto, Porto, Portugal; ³Intensive Care Unit, Centro Hospitalar Universitário de Santo António, Porto, Portugal; ⁴University of Porto Institute of Biomedical Sciences Abel Salazar, Porto, Portugal and ⁵Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK

Abstract

Objectives. End-of-life care in the Emergency Department (ED) can be a challenge. Defining goals of care in dementia patients may be more complex. The quality of ED medical records is relevant for better care in the last hours or days of life. In this article, we explore the identification of last days of life recognition in ED records of dementia patients.

Methods. Retrospective qualitative review of ED medical records of patients with dementia in the last 7 days of life using reflexive thematic analysis. This study was conducted at a university tertiary hospital, with a 24 h/7 days polyvalent ED. All 2021 ED medical records of dementia patients who presented to the ED within the last 7 days of their lives were included.

Results. More than 1 in 4 patient's medical records ($n = 55, 27.4\%$) made no explicit reference to the identification of last days of life and only 2 medical records contained this specific designation. Most relevant issues presented under three broader themes: (I) diagnosis and prognosis concerning the last days or hours of life; (II) goals of care, medical decisions and communication about care in the last days or hours of life; and (III) comfort and needs assessment in the last days of life of patients with dementia in the ED.

Significance of results. There is limited identification of the last days or hours of life in ED medical records and clinical notes are of poor-quality regarding communication and shared decision making.

Introduction

The nature of the Emergency Department (ED) is to respond to very diverse acute and life-threatening conditions. Its response frequently includes rapid decision making and aggressive disease modifying therapy (Lafond et al. 2016). Patients with dementia often present to the ED, specially near the end-of-life (Vieira Silva et al. 2025). Appropriate end-of-life care in dementia has been proposed (van der Steen et al. 2014). It is recommended that care be person-centred, with communication and shared decision-making. It is essential to define goals of care and plan future interventions, to avoid overly aggressive, costly or non-proportional treatments, to provide optimal symptom management and comfort, with family care and involvement. Providing quality end-of-life care in the ED is likely to be a challenge. Although early preparation of Advance Care Planning is recommended, most patients with dementia don't engage in these discussions early on (Donnelly et al. 2019; Karnieli-Miller et al. 2012; Yates et al. 2021). Cognitive impairment imposes greater complexity in defining goals of care (van der Steen et al. 2014), and, in fact, most patients with advanced dementia have significant limitations in their decision-making ability. As recommended, prioritizing of explicit global care goals helps guide care and evaluate its appropriateness. Advance Care Planning should start soon, when the patient can still be actively involved and patient preferences, values, needs and beliefs can be elicited. This plan should be regularly updated (Anantapong and Davies 2021) and the diminished capacity for a specific decision should not be assumed to compromise the person's ability in other decisions (Hegde and Ellajosyula 2016). In advanced dementia and when death approaches, the patient's best interest may be safeguarded with the primary goal of maximization of comfort and shared decision-making should involve the surrogate or family decision-makers. (van der Steen et al. 2014).

Failure to properly record patient preferences and decisions may lead to medical care incongruence, with patient's wishes, as well as stress for patients and surrogate decision makers

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(Detering et al. 2010; Houben et al. 2014). Previous interventions to improve advance care planning documentation led to a significant increase in accessible electronic medical records (Kantor et al. 2021; Turley et al. 2016). However, Medical records (MR) in the ED are often of poor quality regarding patient preferences and decisions, which is a setting where professionals may have a greater need for access to this type information (Mashoufi et al. 2019, 2023; Sulmasy et al. 1996). Advanced care planning, as a continuous process of patient preferences, can help define the therapeutic plan and increase congruence with the patient's wishes (Brinkman-Stoppelenburg et al. 2014). Medical records in the ED can benefit from this information but are not limited to it. They correspond to the medical notes, which can also include medical proposals of benefit to the patient, multidisciplinary and family discussion and decision-making in addition to documentation of clinical and comfort assessment (Brinkman-Stoppelenburg et al. 2014; Marck et al. 2014; Yash Pal et al. 2017). The MR in the ED is not limited to the aspects considered in the advance care planning, when this is available, but considers other aspects that may also be relevant to the quality of end-of-life care in this context. Therefore, good quality MR notes in the ED is important not only for patient care, but also to the efficiency and effectiveness of healthcare professionals and services (Marck et al. 2014; Yash Pal et al. 2017).

The present study aims to explore the quality of clinical notes regarding level of identification of the last days of life of patients with dementia in the ED MR. More specifically, our objectives are to identify aspects of communication to other healthcare professionals, patients and families, and measures of end-of-life care implementation.

Methods

Study design

We conducted a retrospective qualitative review of ED MR to explore clinical notes regarding the last days of life of patients with dementia who died in the hospital. The six steps approach proposed by Braun & Clarke (Braun and Clarke 2006) were followed: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report.

Ethics approval [reference number 2023.094/083-DEFI/075-CE] was provided by Unidade Local de Saúde de Santo António Ethics Commission and Review Board.

Setting

Our study was conducted at a university tertiary hospital in Porto, Portugal, which serves a population of 650000 inhabitants with a polyvalent emergency service, 24 hours a day, 7 days a week.

Participants

Patients with an established diagnosis of Alzheimer's disease or other related dementias (ICD10 – F00* to F03) who died between January 1 and December 31, 2021 were eligible. Patients who resourced to the ED in the last 7 days of life were included. A total of 359 dementia patients died in hospital during this period. Of these, 201 patients presented to the ED in their last 7 days of life. We used descriptive statistical measures to explore quantitative clinical and service use details.

Data generation

All electronic MR in the ED were approached chronologically from date of death to the last 7 days of life. We reviewed patient's MR, including the entire period of hospitalization in the ED and the records of the different doctors, from different specialties, who followed the patient during that period. Descriptive summaries and de-identified extracts relevant to the aim and objectives were collected and extracted by one author (VSS), with verification by authors TC and AB (VSS researcher; TC clinical and academic professor of emergency and intensive care and AB academic researcher of palliative care). Quotes were extracted *verbatim*, translated into English and are presented in italics.

Data analysis

Reflexive thematic analysis was used to qualitatively explore key issues and events surrounding ED-based end-of-life care for people with dementia (Braun and Clarke 2006, 2024). This methodology, considering our clinical and research experience, allowed us to better explore the subjectivity of the records. In line with existing literature, we inductively engaged with the following questions as a starting point for the analysis: Do the physicians identify the last days of life? How do physicians communicate to other healthcare professionals, patients and families about last days of life and related issues and do they record that in the patient MR? Which measures of care – in the last days of life – are recorded by physicians?

Analysis was conducted manually by two researchers (VSS and MP) who collaboratively reviewed codes and revised the themes, detailing inductive descriptive codes by marking similar phrases or words from the professionals' narratives. Consensus coding was developed with both researchers coding the same transcripts and comparing them during regular meetings. Manual coding was chosen to facilitate familiarizing ourselves with details that automated tools may overlook. Themes were then generated by their shared meaning, around a central concept, while subthemes were considered as essential facets of these themes. Differences in coding and development of themes were further analysed with the wider research team until consensus was reached.

We adhere to the Reflexive Thematic Analysis Reporting Guidelines (Braun and Clarke 2024).

Results

More than 1 in 4 patient's MR ($n = 55$, 27.4%) had no explicit reference to the identification of the last days of life. Only 2 medical records contained this specific designation, specifically "terminal" and "end of life."

During 2021, 359 patients with dementia who resourced to the ED, died in hospital. Of these, 201 patients (56.0%) were admitted to the ED in the last 7 days of life. The median age was 86.0 $\pm$ 8.1 year and the majority of patients were female (58.7%, $n = 118$) (see Table 1), 94.0% ($n = 189$) with moderately severe/severe dementia (Functional Assessment Staging Tool ≥ 6). Almost half (49.8%, $n = 100$) presented at least one comorbidity, 79 (39.3%) had organ insufficiency, 16 (8.0%) malignancy and 4 (2.0%) had both. Most patients ($n = 138$) had two or more ED visits in the final 12 months of life, mean of 3.1 visits in that period. Most ($n = 129$) of the patients' last ED visits occurred 3 to 4 days before their death, mean of 3.7 days.



Figure 1. Themes and sub-themes which emerged from reflexive thematic analysis.

Table 1. Codes, Themes and Subthemes

CODES	References (n =)	Themes	Subthemes
End-of-life Terminal situation Last days or hours of life Agony Advanced disease Critical state Bad prognosis Imminent failure Surrogate and family communication	105	Diagnosis and prognosis concerning the last days or hours of life	Aspects concerning Diagnosis and Terminology Prognosis and Communication of Prognosis
Age Comorbidities Performance status Senior discussion/Other Surrogate and family discussion Response to treatment Do not resuscitate decision Diagnosis withhold Treatment withdraw Treatment withhold Comfort care Conservative care	158	Goals of care, medical decisions and communication about care in the last days or hours of life	Discussion of Goals of Care and Decision making Factors of decision making Specific life sustaining treatment decisions – withhold and withdraw
Comfort measures Specialized palliative care Signs of physical discomfort	121	Comfort and needs assessment in the last days of life	Comfort assessment Referral to a specialized Palliative Care team

Key themes

The MR reveal, in part, how physicians approach patients with dementia in the last days of life in the ED. Most relevant issues are presented under three main themes (Fig. 1). More details on coding are presented in Table 1.

Diagnosis and prognosis concerning the last days or hours of life

Aspects concerning diagnosis and terminology Identification of the clinical situation covered elements related to the acute clinical presentation (symptoms and signs) and the presence of advanced disease criteria. Mention to respiratory and circulatory symptoms and signs were preponderant.

“respiratory and cardiovascular severe dysfunctions” (MR 26) and “with Cheyne-Stokes respiratory pattern, interspersing periods of tachypnea with periods of apnea” (MR 191).
“Terminal cachexia. Rigid position characteristic of advanced dementia.” (MR 108)

Despite a high Functional Assessment Staging Tool score this was rarely explicitly mentioned. Specific criteria of advanced dementia were only rarely indicated, while *“terminal heart failure”* (MR 146) and *“terminal renal failure”* (MR 4) represented some of the identified criteria of other associated advanced comorbidities.

Diagnosis concerning the critical state of the patient and its associate terminology were diverse. Terms like *“terminal”* and *“end of life”* were found in the majority of MR, while the specific designation of last days or hours of life were only twice mentioned as *“terminal patient, probable in the last hours of life”* (MR 200) and *“patient in an agonizing state”* (MR 30).

Prognosis and communication of prognosis Prognostic registry disclosed the expected clinical deterioration and high risk of proximity to death. Most MR referred only *“prognosis”* integrated in the context of signs of clinical deterioration, reinforced by short expressions as *“bad prognosis”* (MR 69, MR 93, MR 118, MR 168, MR 190), *“bad evolution”* (MR 45, MR 113), *“reserved prognosis”* (MR 17, MR 30, MR 42, MR 94, MR 113, MR 124, MR 133, MR 135, MR 139, MR 150, MR 168, MR 172, MR 181, MR 186, MR 192, MR 193), *“probable fatal outcome”* (MR 53, MR 71, MR 93). Longer expressions were present, for example *“very reserved prognosis, with a high risk of unfavorable evolution and short-term cardiac arrest”* (MR 166).

Explicit prognosis communication to other members of the healthcare team was absent while communication to family and

caregivers was usually present, in strait relation to prognosis. This communication addressed those who were contacted

"the patient's clinical situation and reserved prognosis were discussed with the family present (son and grandson) who understood" (MR 165);

or attempted to be contacted "an attempt was made to contact the daughter by telephone to inform her of the patient's condition, without success" (MR 158);

and often mentioned the degree of understanding by family member of the gravity of the clinical situation perceived by the clinician "I communicated a very reserved prognosis to the family, who understood" (MR 113);

and that family visits were facilitated "I will contact the daughter, explain the cautious prognosis and plan a visit for this morning" (MR 94).

Goals of care, medical decisions and communication about care in the last days or hours of life

Discussion of goals of care and decision making References about goals of care were diverse. None directly mentioned the patients' underlying values or priorities. Implicit information was present:

"background data, functional status and decision on the last hospitalization already discussed with family/were considered" (MR 154);

"after discussing therapeutic objectives with the patient's daughter, exclusive symptomatic treatment was decided" (MR 40).

There was no information about previous advanced care planning. Decision making was frequently referred to as "team discussed," in relation to discussion of goals of care and treatment decisions,

"We decided as a team to prioritize the best supportive care" (MR 158).

More specifically, peer and/or multidisciplinary discussions often included internal medicine senior physicians, "After discussion with a senior physician, given the multiple advanced organic dysfunctions, we decided to suspend NIV" (MR 125)

and intensive care colleagues "Discussion with a colleague from the Intensive Care Unit, agreeing that, given the comorbidities of the patient with high functional fragility, there is no benefit on invasive support" (MR 86).

The inclusion of Nursing professionals in these discussions was never explicit.

Different designations concerning goals of care of the last days or hours of life were present, namely: "palliative care," "comfort care," "exclusively symptomatic treatment," "supportive care" and less frequent "conservative treatment" (MR 33, MR 34, MR 65, MR 74). These designations were frequently applied to decision-making, often followed by a lack of improvement with the treatment of potentially reversible causes. The attitudes they were associated with were essentially those of withdrawal or withholding. Designations were presented as equivalent terms and focused exclusively on symptom control.

Factors of decision making Old age, global health status and performance measures were considered, "Given that this is a patient with low functional reserve and a high degree of dependence, it was decided to prioritize comfort care" (MR 200);

as well as potential benefit of the clinical intervention, like diagnostic testing, invasive measures and treatments, "the benefit of being invasive, doing blood tests and medicating with antibiotics is very dubious" (MR 54).

Also, reversibility or lack of clinical response to treatment of the cause of clinical deterioration was frequently mentioned, "There

was no improvement in the general condition [of the patient], with the measures instituted. Exclusively symptomatic treatment was decided" (MR 7).

Specific life sustaining treatment decisions – Withhold and withdraw

Life sustaining measures were present regarding treatment limitation, "no indication for escalating care" (MR 10, MR 39, MR 111, MR 120) and the benefit of withholding or withdrawing specific measures. Diagnosis investigation, clinical procedures, invasive life support, resuscitation and use of some drugs were some of the mentioned measures. Most MR included "do not resuscitate (DNR)" and "no indication for non-invasive ventilation" (MR 107, MR 110, MR 155, MR 181), "no indication for thrombolysis" (MR 93), "no indication for starting antibiotics" (MR 67), "haemodialysis discontinuation" (MR 77) or "non-invasive ventilation suspension" (MR 86, MR 125).

Comfort and needs assessment in the last days of life

Comfort assessment

Comfort assessment was shortly recorded as the patient's state, described as "comfortable" (MR 2, MR 15, MR 23, MR 48, MR 54, MR 56, MR 71, MR 75, MR 109, MR 110, MR 131, MR 177, MR 191), "calm" (MR 56, MR 75, MR 95), with "no signs of discomfort" (MR 97, MR 105), "denies pain, dyspnoea or respiratory discomfort" (MR 23) or, when with compromised comfort, as "groans and localizes pain" (MR 27), "very complaining, uncomfortable groans" (MR 66), "PAINAD 8 = severe pain" (MR 33) and "polypneic with signs of suffering" (MR 53). These descriptions were recorded sporadically by doctors at different times during the visit to the ED. References to comfort assessment rarely came up during the first observation, would sometimes come up before the application of symptom control measures and never systematically after their application.

Referral to a specialized palliative care team

Referral to a specialized palliative care team was found occasionally. Reasons recorded included the assessment of palliative care needs, support for decision making and, most frequently, support for care management, "admitted for organizing care together with the palliative care team" (MR 76, MR 116). Notes on the need for palliative care occurred during the initial assessment in the ED, or after an unfavourable evolution and/or multidisciplinary discussion. The outcome of the referral for PC was not specified in the MRs and no patient was assessed by a specialized team in the ED, or no notes were taken if that occurred.

Discussion

Key findings

Most of the patient's MR (n = 146, 72.6%) had no explicit reference to the identification of the last days of life. This suggests either low recognition of this clinical situation, which might compromise prompt implementation of adequate quality care measures for end-of-life, or, reflects ED culture where everything is fast paced, including clinical notes taking, especially regarding end-of-life care, which calls for a more descriptive, and hence, longer text.

Diagnosis and prognosis concerning the last days or hours of life

Diagnoses relating to the patient's critical condition were generally recorded, which probably indicated the doctor's concern to do so. The terminology used to describe the associated prognosis

were diverse. Terms such as "terminal" and "end of life" were frequently mentioned and seem to be used somehow as equivalents to the situation of the last days or hours of life. This inconsistency of terms is not desirable. An active attitude to diagnose and do so correctly is recommended (Diez-Mangano et al. 2021). The use of validated instruments for this purpose can be an added value (Cardona-Morrell and Hillman 2015; Walter et al. 2001).

In addition, the frequent use of verbal communication in the context of ED, as demonstrated by Currie et al (Currie et al. 2003), may contribute to and partly explain the limited recording of this situation. Prognostic registry disclosed the expected clinical deterioration. Contrary to recommendations (van der Steen et al. 2014), multidisciplinary clinical identification of the last days of life and its communication to other members of the healthcare team were not registered in the patients' notes. However, communication to family and caregivers was usually present, in strait relation to prognosis.

Goals of care, medical decisions and communication about care in the last days or hours of life

Rather than the discussion of goals of care with the patient and the family, the analysis of the MR suggests that family communication focuses on communicating the prognosis and promoting their presence at this critical moment, which are only two of the important measures in end-of-life care (van der Steen et al. 2014). Patient information, including demographic, clinical and social data, was previously identified as the most needed information in the ED (Ayatollahi et al. 2013; Reddy and Spence 2008) and this is normally obtained by asking patients and/or their relatives (McKnight et al. 2001; Reddy and Spence 2008). Furthermore, even if there is information recorded in the MR regarding ACP and patient's decisions, often those notes can be overlooked by other professionals, which may reflect the realities of data fragmentation in EDs and hospital wards. Information and registration breakdowns can increase the risk of communication failures with potential adverse effects on patients (Hertzum 2010).

And even when there has been some advanced discussion about patients' decisions, it turns out that MR of the advanced or end-of-life stages of dementia can be overlooked by other professionals, which may reflect the fragmentation of data sharing in emergency departments and hospital wards.

Also, involvement of senior physicians in these discussions was recorded, however, that was not the case for nurses, as recommended in the literature (van der Steen et al. 2014).

Specific communication/discussion about goals of care and medical decisions with family members was absent in all MR. This is noteworthy because, not only, most of the patients didn't present with an advanced care plan, but also, because the recommended model of shared-decision making implies active and ongoing discussion with surrogate and family decision makers about goals of care (McGlinchey et al. 2023; van der Steen et al. 2014). In fact, it is a process that should always be reviewed when there is a significant change in health status (McGlinchey et al. 2023; van der Steen et al. 2014). MR are likely to be of better quality if including information about preferences of end of life care (Sulmasy et al. 1996) since this can facilitate better access to the patient's perspective, greater congruence in care and reduce the burden on the caregivers (Houben et al. 2014).

Our findings suggest that decision making notes reflect the global health status and performance of the patient as well as the potential benefit of the clinical intervention. The reversibility or lack of clinical response to treatment were also considered.

These criteria are in line with the recommended focus being on the patient's best interest achieved with a primary goal of maximization of comfort (van der Steen et al. 2014). Communication about PC and end-of-life care that can provide comfort care would reassure and comfort families, prevent their misunderstanding and guilty feeling of "giving up" on the patients.

Terms with probable equivalent meaning were present, e.g., "palliative care," "comfort care," "exclusively symptomatic treatment," "supportive care" and "conservative treatment." This is relevant because specific features of the ED care, such as task complexity, high speed healthcare delivery, frequent transfer of care between providers, multiple interruptions, high turnover of patients, and sometimes dealing with unknown or complex cases, makes this type of care prone to errors (Fattahi et al. 2023). Incorrect use of medical terms might increase this risk of mistakes. Use of standard terminology can improve clarity of record and eventually continuity of care. Also considering in the ED a specific set of essential outcomes for the best care of the dying person, as recently proposed by iLIVE (Zambrano et al. 2025), could improve care through standardization of clinical aspects of care, improving patient, family and healthcare professional's experiences. This international Delphi study and consensus meeting composed a 14-item core outcome set: to address pain, to address anxiety, to address respiratory symptoms, to ensure that family and friends have unrestricted access to the patient, to address the fear of death, to give the possibility to say goodbye, to recognize and discuss the dying phase, to reduce suffering, to ensure dignity and respect, to ensure access to competent health professionals and to their continuous support, to provide compassionate care, to make the patient and the family feel heard and understood, to respect the patient's autonomy, preferences and wishes and to provide quality of death and dying.

Withhold and withdrawal of life sustaining treatments were the main treatment decisions present in the MR. Recording these decisions seems useful and probably promotes better team communication and care since access to high quality data at the ED can be extremely important to improve quality and promptness of care (Ayatollahi et al. 2013; Hakimzada et al. 2008).

Comfort and needs assessment in the last days of life

Few references to the patient's state of comfort were noted. Palliative care needs assessment and palliative care support for decision making were also only sporadically recorded. Emphasis on palliative care in the MR were almost always related to help support and organize further end-of-life care, and not so much in facilitating decision making or anticipating suffering, as proposed in the literature (McGlinchey et al. 2023; van der Steen et al. 2014). In fact, support for decision-making should focus on how the patient can be supported to make their own decisions and, if this is not possible, support families in their role as proxy decision-makers (Scholten and Gather 2018).

Study strengths and limitations

The main strength is that this is a real-world study based on ED MR. It includes clinical notes related to the identification of last days or hours of life, goals of care definition, communication and caring at the end-of-life of patients with dementia in the ED.

A limitation is that this is a single-centre study, but the biggest limitation is that the analysis is restricted to information recorded in the MR which reflects formally documented interactions and discussions. There is no possibility of knowing what else, if anything, was ever discussed and with whom. The MR does not fully

represent actual practice. The limited time and facilitating conditions of registration in the ED can prevent the proper recording of clinical assessment, discussion and decision-making, as well as the application of palliative measures. This does not exclude that all the steps were not carried out, nor does recording them confirm that they were. Future research into the quality of care could involve complementing the analysis of the quality of the records with other indicators, both clinical and of the satisfaction of those involved, using qualitative research methods, such as interviews and focus groups. Ultimately it would be desirable to develop a systematic tool with common nomenclature to be used widely, and even internationally, with proper translation and validation.

Final considerations

To our knowledge, this is the first qualitative study on end-of-life care provided in the ED to patients with dementia in the last days of life. Caring for patients with dementia at the end-of-life in the ED is challenging (Vieira Silva et al. 2025). Prompt and adequate clinical identification of the last days or hours of life is mandatory to provide the best care during this period (McGlinchey et al. 2023). MR should reflect this in the ED. Our analysis of the MR of the dying patients with dementia in the ED emerged with limited identification of this clinical situation and poor registration of aspects of communication and shared decision making. Just because this type of note taking is not prioritised, does not mean that conversations and discussions do not take place with all who should be involved in patient care. Family involvement and multidisciplinary team discussions are considered key measures and are in line with the patient's best interest, especially when there is significant cognitive impairment (van der Steen et al. 2014). The dynamic nature of the ED care might benefit from more complete and accurate documentation of the care processes (Liaw et al. 2012). Additionally, appropriate use of medical terms and accurate record of goals of care and treatment might benefit end-of-life care. Consideration may be given to using a specific set of essential outcomes to better care for the dying person in the ED.

Further studies focusing on understanding which specific themes concerning best care in the last days or hours of life of patients with dementia, and how those should be recorded in the ED MR should be of great use to add to the evidence.

Competing interests. All authors have no interests to disclose.

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CHAPTER 7

End-of-life care for patients with dementia in the emergency department
– Reflexive Thematic Analysis of the perspective of healthcare
professionals

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This chapter describes a qualitative study using semi-structured focus groups and reflexive thematic analysis aiming to explore what are the perspectives and experiences of emergency department healthcare professionals about end-of-life care for patients with dementia in the emergency department. Five main themes were produced 1) the cultural context and perceived place of patients with dementia in the emergency department and in society; 2) the person with dementia—their dignity and multidimensional needs; 3) end-of-life care in the emergency department - managing uncertainty, setting goals, and meeting specific care needs; 4) conditions for supporting the palliative care needs of patients with dementia at the end-of-life in the emergency department; and 5) ethics and moral distress of health professionals in caring for patients with dementia at the end-of-life in the emergency department. These perspectives help clarify on how emergency department care responds to the palliative care needs of end-of-life patients with dementia. Healthcare professionals indicate that they perceive limited awareness of dementia in the emergency department, but still recognize that the emergency department's response is essential to meeting some of the needs of patients with dementia at the end-of-life. They simultaneously find it difficult to recognize the limitations of the emergency department in safeguarding dignity and point out the conditions necessary to enable it, emphasizing the ethical and moral suffering they face when institutional constraints prevent the provision of adequate care.

End-of-Life Care for Patients with Dementia in the Emergency Department—Reflexive Thematic Analysis of the Perspective of Health Care Professionals

Sara Vieira Silva, MD,^{1,2} Manuela Bertão, MD,¹ Carla Teixeira, PhD,²⁻⁵ and Bárbara Antunes, PhD⁶

Abstract

Background: Patients with dementia at the end-of-life frequently visit the emergency department. These visits can be distressing for patients and families and challenging for staff.

Aim: To explore the perspectives of emergency department health care professionals about end-of-life care for patients with dementia in the emergency department.

Design: Qualitative study using semi-structured focus groups interviews ($n = 23$). Interviews took place in-person after recruitment via a contact person and were transcribed verbatim. Reflexive thematic analysis was used.

Setting/Participants: Physicians, nurses, and health care assistants who regularly work at the emergency department of a tertiary hospital.

Results: Participants' views on end-of-life care for patients with dementia in the emergency department produced five main themes: (1) the cultural context and perceived place of patients with dementia in the emergency department and in society; (2) the person with dementia—their dignity and multidimensional needs; (3) end-of-life care in the emergency department—managing uncertainty, setting goals, and meeting specific care needs; (4) conditions for supporting the palliative care needs of patients with dementia at the end of life in the emergency department; and (5) ethics and moral distress of health professionals in caring for patients with dementia at the end of life in the emergency department.

Conclusions: Health care professionals identify strengthening dementia awareness, implementing structured training programs, and improving the physical environment and care models within emergency departments as key priorities for practice.

Keywords: dementia; end-of-life care; emergency department; health care professionals

Key Message

Emergency department health care professionals identified key priorities for improving end-of-life care for patients with dementia. These include raising awareness of dementia among both the public and health care staff, providing structured training, and improving the emergency department environment and care models.

Introduction

Over 55 million people worldwide live with dementia at present¹ and by 2050, this number is expected to reach 139 million.¹ Attendance of end-of-life patients in the

emergency department can be distressing for patients and families and challenging for staff.^{2,3} Care in this setting, frequently includes rapid decision-making, aggressive disease-modifying therapy,⁴ long waiting times, lack of communication,⁵ bright lights, and constant noise, all which constrain the care provided, specially to vulnerable populations. Specifically, patients with dementia present an increased risk of delirium, falls, cognitive and functional decline, readmission, and death in emergency department visits.⁶⁻⁸ This suggests that the emergency department may not be the best place to properly care for these patients and attend to their specific needs. However, the literature shows that visits to this setting by patients with dementia are high^{2,9-19} and tends to increase at the end-of-life.^{13,15,18,19} Furthermore, patients

¹Palliative Care Service, Centro Hospitalar Universitário de Santo António, Porto, Portugal.

²Faculdade de Medicina da Universidade do Porto, Universidade do Porto, Porto, Portugal.

³Centro Hospitalar Universitário de Santo António, Porto, Portugal.

⁴Instituto de Ciências Biomédicas Abel Salazar, Universidade do Porto, Porto, Portugal.

⁵CINTESIS.RISE, Porto, Portugal.

⁶Department of Public Health and Primary Care, University of Cambridge, Cambridge, United Kingdom.

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with dementia at the end-of-life have a high prevalence of palliative care needs during emergency department visits,^{9,20} with uncontrolled symptoms and recent functional decline being some of the most frequently identified needs.²¹ While the presence of comorbidities, neuropsychiatric symptoms, previous hospital transfers, and rural living are factors associated to ED visits of patients with dementia at the end-of-life,²² infections and neuropsychiatric symptoms are the most frequent reasons of ED admissions.⁹ Still, despite the complications mentioned, some authors point out that ED can be considered as an opportunity to identify gaps in care of patients with dementia at the end-of-life.^{23–26} In this setting, access to palliative care seems to be scarce, and the barriers are identified at different levels,⁹ including among professionals themselves.^{27,28} Nevertheless, intervention studies in ED have shown positive results,^{23–26,29–33} but it remains to be established which methodologies for integrating CP can work best. Overall, the needs of these patients can generate high expectations in patients and families regarding ED care and its professionals. It is unclear whether the response to these needs is already secured or can be provided in the context of the ED. The present study aimed to explore the perspectives and experiences of emergency department health care professionals about end-of-life care for patients with dementia in the emergency department.

Methodology

Design

We drew on an interpretivist/constructivist paradigm³⁴ to explore what the perspectives on and experiences of health care professionals with end-of-life care for patients with dementia in the emergency department, while recognizing the importance of researcher experience and background in such interpretations. We conducted semi-structured focus groups interviews and followed the six-step approach proposed by Braun & Clarke.^{35,36} We present this article in accordance with the RTARG checklist³⁶ (see Supplementary Appendix SA1).

Setting

We proceed to an exploratory study focused on a single center at a university tertiary hospital in Porto, Portugal, which serves a population of 650,000 inhabitants with a polyvalent emergency department, 24 hours a day, 7 days a week. Care is provided by a medical team organized in rotating units—most physicians work in the emergency department once a week, and nurses, and health care assistants' teams work on a daily basis.

Participants

Inclusion criteria were working in the medical area of the emergency department for at least once/week, providing frequent care for patients with dementia (more than one patient with dementia in each emergency shift) and having more than two years of work experience in the emergency department. The characteristics identified for sampling included profession and experience and, to the extent possible, age and gender, resulting in a predetermined sample size of 6–10 participants per group. To recruit participants from each one of the three professional groups, one staff member (a

physician, a nurse, and a health care assistant in leading or management positions) was a "contact person," informing colleagues about the study and identifying possible candidates. Eligible professionals who showed interest in participating were contacted by the principal researcher (S.V.S.).

Data collection

We conducted semi-structured interviews following a topic guide developed by the principal researcher (S.V.S.), a specialized physician in internal medicine with expertise in palliative care and emergency care. It was then discussed with the other members of the research team and reviewed by another experienced qualitative researcher (JR) at the Unidade Local de Saúde Entre Douro e Vouga. Regarding the research question, the final topic guide version comprised three main topics:

- i. patients with dementia at the end of life and respective palliative care needs,
- ii. current care for these patients in the emergency department,
- iii. opportunities and barriers to address the palliative care needs of patients with dementia at the end of life in the emergency department.

Two researchers (S.V.S., JR) piloted the topic guide in two interviews, leading to slight amendments (see Supplementary Appendix SA2). The same two researchers conducted the three focus groups at the point to which no new themes emerged. Interviews were undertaken at the participants' workplace between June and July 2024 and lasted between 60 and 90 min. Additionally, each interviewee was asked to complete an anonymized and standardized form to collect socio-demographic and professional data.

Focus groups were digitally voice recorded, transcribed verbatim, and anonymized, with field notes taken.

Data analysis

Data analysis followed the Reflexive Thematic Analysis Reporting Guidelines,³⁶ utilizing NVivo® version 15, to qualitatively explore the perspectives of health care professionals. Considering our clinical and research experience, this allowed us to better explore the complex perspective of health care professionals, from their knowledge to their experiences.

Two members of the research team (S.V.S. and M.B.) independently reviewed the transcripts and derived themes from the data. Consensus coding was developed with both researchers coding the same transcripts and comparing them during regular meetings. Themes were then generated by their shared meaning around a central concept. During the whole analysis process, we gathered feedback from the other members of the research team, and differences in coding and development of themes were further analyzed until consensus was reached.

Ethical issues and approvals

All participants provided written informed consent. The study received approval from the Unidade Local de Saúde de Santo António Ethics Commission and Review Board [reference number 2023.094 (083-DEFI/075-CE)].

Results

We conducted three focus groups: one with physicians ($n = 8$), one with nurses ($n = 8$), and one with health care assistants ($n = 7$), for a total of 23 emergency department professionals. The majority were female ($n = 18$, 78.3%) with a mean age of 37.0 years. They presented a mean of 9.8 years of emergency department work experience, and the majority had no training in palliative care ($n = 13$, 56.5%) (Table 1). Although all professionals had significant emergency department work experience and acknowledged frequently working with patients with advanced dementia in the emergency department, none of the assistants had any palliative care training, unlike all the physicians, who had, mostly, basic training, as did 25% of nurses. Five main themes emerged: (1) Cultural context—place of the person with dementia in society and in the emergency department; (2) The person with dementia; (3) Care of the person with dementia at the end of life in the emergency department; (4). Conditions to support the palliative care needs of the person with dementia at the end of life in the emergency department; and (5). Moral distress in the care of the person with dementia at the end-of-life in the emergency department. The themes, subthemes, and categories derived are presented in the Supplementary Appendix SA3. Illustrative references to themes and subthemes are presented in Table 2.

Theme 1: Cultural Context—Place of the Person with Dementia in Society and in the Emergency Department

The prevailing perspective of health care professionals is that society in general, and the emergency department in particular, are largely unaware of the reality of patients with dementia. The natural history of dementia, the needs of these patients, and care demands are generally unknown.

“This often comes as a surprise to the family. In other words, it’s the first time they’ve heard that dementia can be a terminal illness” (P1)

Caregiving experiences, whether by family or professionals, shape caregivers’ knowledge and capacity. Health care assistants note that the (mis)treatment of patients with dementia at the end-of-life in the emergency department reflects broader societal attitudes, including assumptions of impaired relational capacity and loss of identity.

“Well, because dementia is considered: “Oh, he has dementia...put him aside.” It’s true: “He doesn’t know what he’s saying, he’s put to the side a bit.” “We waste time with someone who doesn’t know where they are, don’t know what they want?” It’s true, it’s a reality we live in today in the emergency department.” (H1)

Most respondents noted that the fast pace of life limits caregiving and drives patients with dementia to the emergency department, with hospital, remaining the dominant perceived place of death.

“It’s a cultural issue, nobody has time. . .lately we have never seen so many patients with dementia as end-of-life social cases that stay in the ED” (N1)

Respondents viewed the emergency department as unsuitable for end-of-life care of patients with dementia due to its curative focus, linking this to risks of overtreatment and displacement from the community, while nurses stressed that care is overly hospital-centered and patients with dementia are routinely deprioritized.

“I think these patients don’t get the priority they deserve because “they’re at the end of their lives and destined to die, so let’s treat others that are for investment.” (N1)

Physicians noted that dementia is often not recognized as terminal, affecting end-of-life care. Respondents from all groups reported that cognitive changes and memory limitations may protect the patient from the suffering they experience. On the contrary, severe psychomotor agitation often leads to the almost normalized use of physical restraints.

“Unfortunately, society still can’t fully grasp the need to restrain someone.” (H2)

These perspectives reflect a broader unawareness, and at times invisibility, of patients with dementia in the emergency department, reinforcing the sense of non-belonging and the belief that the emergency department is ill-suited to their care, potentially causing more harm than good. Community-based care is considered the most appropriate form of assistance for these patients.

“I think it will never be the right place for these patients.” (N2)

Surprisingly, all professional groups acknowledged that the emergency department offers opportunities to identify advanced disease and palliative needs, facilitate communication with families and caregivers, and establish goals of care for patients with dementia.

“But (in the emergency department) you have the opportunity to identify a patient and their symptoms.” (P2)

Finally, not only is the emergency department often the patient’s gateway into the health care system, but all professional categories recognize that the emergency department is a place for direct care, especially for comfort during the management of physical symptoms and to address some of the caregivers’ needs.

TABLE 1. SOCIO-DEMOGRAPHIC OVERVIEW OF THE INTERVIEWEES

Characteristics	Physicians ($n = 8$)	Nurses ($n = 8$)	Healthcare assistants ($n = 7$)
Female (%)	5 (62.5)	7 (87.5)	6 (85.7)
Age, mean (range)	39.5 (33–48)	32.6 (32–42)	34.0 (25–44)
ED work experience in years, mean (range)	14.1 (9–22)	9.5 (4–20)	5.1 (4–10)
Training in Palliative care (%)	8 (100)	2 (25.0)	0 (0)
Basic level	6 (80)	2 (100)	—
Advanced level	2 (20)	—	—

TABLE 2. ILLUSTRATIVE REFERENCES OF THEMES AND SUBTHEMES

Themes and subthemes	Illustrative references
Cultural context—place of the person with dementia in society and in the emergency department	"This often comes as a surprise to the family. In other words, it's the first time they've heard that dementia can be a terminal illness" "I think it will never be the right place for these patients"
The person with dementia, their essence and needs Dignity and identity	"(The mistreatment) verbal, sometimes it's not just verbal, it's physical. Being naked, wearing those transparent robes on women, who are sometimes nuns and have their breasts exposed because they're semi-transparent, those transparent green robes... It's dehumanization. Dehumanization exists a lot in emergency rooms" "even if they are not aware of what is happening, they hear, respond, see..."
Multidimensional suffering and needs	
Care of the person with dementia at the end-of-life in the emergency department Dealing with uncertainty and defining goals of care	"I wonder if this is really the end-of-life episode, because they are very similar... and we all put the label of totally dependent... we are always looking for (reversible causes)... And I think we all have this anguish "Is this really the last trip and should I take care of this as end-of-life care... or not?"
Providing end-of-life care	"To these patients we have to give double the attention, double the calm and double the patience"
Conditions to support the palliative care needs of the person with dementia at the end-of-life in the emergency department	"Having the family there and having someone who could... and that's where I think we failed a lot... go to the person, saying a word, understanding if the patient and the family need anything. Communication."
Moral distress among health care professionals caring for the person with dementia at the end-of-life	"But what worries us all, I think, and I at least always have this worry, is whether I'm really making the right choice? There are times when I'm sure I'm the most correct person in the world, but there's always that moment when I wonder if this is really the last episode, and if I'm doing everything right and saying it's over here."

"(emergency department) It's the entry point (to the healthcare system)." (H3)

"Yes. (In the emergency department we provide) Comfort, hydration and hygiene. Body care." (H4)
"Yes, symptom control, despite everything... it may not be in the most effective time, but we eventually get there. We control the agitation; we control the pain... we manage to involve the family" (N2)

Theme 2: The Person with Dementia, Their Essence and Needs

Dignity and Identity

In both nurses and health care assistants' groups, the perspective on dignity is based on each person's ability to relate to others. For patients with dementia at the end-of-life, who frequently experience communication and relationship limitations, their dignity is embodied in the human presence and care, by the health care professionals and family—by not being alone.

"Because [as family members complain] "my father died alone, my mother died alone, I couldn't be with her". That's inhumane." (H2)

These two professional groups demonstrate ambivalence regarding their understanding of dignity in patients with dementia, specifically, whether living can be considered the

same as existing. They attribute dignity as external to the person and not as intrinsic to the patients with dementia at the end of life.

"They (patients with dementia) can't communicate, they no longer recognize themselves, they often don't even speak to their family members, and from then on, they can also become more dependent on self-care in daily life. And we end up wondering what are the benefits" (N2)

Physicians seem to incorporate the idea of dignity as stemming from how patients with dementia are treated—the language used, how their body is cared for. They suggest that dehumanization is the antithesis of dignity and that the dignity of life of patients with dementia at the end of life depends on their ability to relate to others, to communicate and of self-care.

"(The mistreatment) verbal, sometimes it's not just verbal, it's physical. Being naked, wearing those transparent robes on women, who are sometimes nuns and have their breasts exposed because they're semi-transparent, those transparent green robes... It's dehumanization. Dehumanization exists a lot in emergency rooms" (P3)

Multidimensional suffering and needs

All three groups identify suffering of patients with dementia at the end of life as multidimensional. At a physical level,

eating-related problems stand out due to their frequency and complexity of approach.

"Eating is always everyone's biggest problem." (P1)

Aspiration, weight loss, and pressure ulcers are highlighted, and all groups recognize the total dependency of these patients. Health care assistants focus on behavioral issues, nurses and physicians on fragile interpersonal relationships, while all value family involvement—assistants for managing agitation and feeding; nurses for supporting the patient-family relationship; and physicians for addressing complex family communication and representing the voice of the patients with dementia.

"I often ask family members if they've ever talked about what they want? And the answer is always a surprise. 'No, but why would anyone ever ask?'" (P4)

Recognition of spiritual needs appears to be almost exclusively centered on the importance of religion and its disregard in the emergency department, particularly among physicians.

"The other issue has to do with religion, because I think we are also there to facilitate religious support, but we often end up ignoring it." (P5)

The health care assistants emphasize the importance of continuing to see the patient as a person and acknowledging gratitude. Nurses stress the importance of adapting the measures instituted to the condition of advanced disease—quality of life as the priority.

"even if they are not aware of what is happening, they hear, respond, see..." (H4)

"Most of the time, they're affectionate because we turn them around and they put their hands on our waist, grab our arms. I think it's a way of showing gratitude." (H7)

Theme 3: Care of the Person with Dementia at the End-of-Life in the Emergency Department

Dealing with uncertainty and defining goals of care

Physicians explicitly acknowledge uncertainty, linking it to prognosis and decision-making. Emergency department constraints—time pressure, limited patient communication, scarce information, and lack of advance care planning—exacerbate this, while family expectations to "do everything" increase pressure, often leading to defensive decisions to "do more."

"I wonder if this is really the end-of-life episode, because they are very similar... and we all put the label of totally dependent... we are always looking for (reversible causes)... And I think we all have this anguish 'Is this really the last trip and should I take care of this as end-of-life care... or not?'" (P2)

Nurses believe that uncertainty is amplified by the lack of clear decisions from physicians. They emphasize the need to define goals of care to adapt and avoid disproportionate care.

"Sometimes completely unnecessary procedures are performed. Blood cultures, for example. It's a struggle... (Physicians need to) Decide once and for all whether to invest or not... because if not, I'll stick a catheter in, and, and..." (N3)

They suggest the implementation of identification protocols, some even decision-making protocols. However, they

do not propose a method of person-centered care and shared decision-making. For health care assistants, uncertainty is directly related to the interpretation of the behavior of patients with dementia.

Providing end-of-life care

All groups agree that patients with end-of-life dementia have profound communication limitations, total dependence, positioning needs, and frequent feeding difficulties. At the same time, they consider that recognition of these needs is low and that responses from the ED are inadequate; they emphasize the importance of sufficient professional time and availability to meet these needs.

"To these patients we have to give double the attention, double the calm and double the patience" (H4)

Physicians emphasize that to effectively manage these patients, they must be proficient in identifying the often-challenging end-of-life situation. This group, along with nurses, highlights the importance of having a more dedicated area of the emergency department for caring for patients with dementia—calm environment, privacy, and trained professionals are key features.

"Area dedicated to optimizing the care provided to patients with terminal dementia. And the dedicated team assigned to this area should have minimum training for this." (P4)

Nurses stress that it is beneficial to review unnecessary therapeutic proposals, especially invasive procedures, and that adequate treatment of agitation must be ensured, minimizing situations of physical constrain.

"There must be a review of treatments and there must be no unnecessary and invasive nursing procedures." (N4)

All professional groups recognize that patients with dementia at the end of life in the emergency department benefit from family support. Health care assistants add that human contact from professionals is as important as comfort and body care.

Theme 4: Conditions to Support the Palliative Needs of the Person with Dementia at the End-of-Life in the Emergency Department

Professionals simultaneously present the perspective that patients with dementia at the end of life in the emergency department cannot see their dignity respected, and the conditions that the emergency department should have to safeguard their dignity.

"Dying in the emergency department is not dignified...but there are situations that are not avoidable and that we cannot offer more..." (P3)

Whether for decision-making or communicating and caring, extra time is considered essential. Greater awareness among families and better conditions to allow family presence, and especially greater knowledge among emergency department professionals about these patients and their needs, is highlighted.

"Having the family there and having someone who could...and that's where I think we failed a lot...go to the

person, saying a word, understanding if the patient and the family need anything. Communication." (N1)

More competent professionals are needed, with appropriate attitudes and communication skills.

"In-hospital palliative care teams will likely have to consider the need for increased emergency room response." (P1)

Finally, a greater response from community care, before or after the use of the emergency department, is highlighted by physicians and nurses.

"And maybe if this home support in the community worked... because I know that in some places it exists... maybe those patients wouldn't need to go to the emergency room as much. Maybe they wouldn't end up here." (N4)

Theme 5: Moral Distress Among Emergency Department Health Care Professionals Caring for the Person with Dementia at the End-of-Life

The need for ethical consideration and the moral distress of professionals that arises "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action,"³⁷ emerged across practically all topics covered in all focus groups. Because the human experience cannot—and should not—be separated from the professional role, society's understanding of end-of-life and death, and the suffering it evokes in those who accompany it, appears to be a key, cross-cutting factor contributing to professionals' moral distress.

"I think it's a lot, not just because of the work, but because of fear of getting involved or because of... all of us who face death..." (N4)

The awareness that it is impossible to respond to every situation with the same quality, combined with the understanding that empathy fluctuates, reinforces concerns that patients with dementia may not always be treated with full dignity. The arising process of dehumanization is seen as inevitable, even defensive, by some, while others say it must necessarily be countered.

"Dehumanization exists—there's the ignoring, the looking ahead, we go down the hallway and don't want to see what's going on because there's a patient there screaming... Absolutely, but what I mean is that sometimes we have to realize that there's a man there pulling on the IV line... it's up to us to intervene" (P2)

More specifically, decision-making is the most challenging aspect listed by the group of physicians. Managing uncertainty, fear of harm, limited alternatives, and the need to monitor progress, compounded by the emergency department's limited response time, are the main causes of distress identified.

"But what worries us all, I think, and I at least always have this worry, is whether I'm really making the right choice? There are times when I'm sure I'm the most correct person in the world, but there's always that moment when I wonder if this is really the last episode, and if I'm doing everything right and saying it's over here." (P3)

Health care assistants report distress when using physical restraints despite protective intentions, frustration at feeling

undervalued by other professionals, and the ongoing psychological burden of working under such conditions.

"It breaks my heart to have to restrain them." (H5)

"Because there's a certain lack of credibility among nurses and assistants, because I speak for myself; I'm not there just to help patients urinate... we're the ones who have to call the nurses because that person isn't well or..." (H5)

"So, where's the psychological support for us?" (H6)

Discussion

This exploratory analysis of the emergency professionals' perspectives on dementia end-of-life care revealed five key themes. The way society views dementia suggests that people living with it are often misunderstood and do not clearly fit into places like emergency departments or even wider society; this emerged in one theme named "Cultural context—place of the person with dementia in society and in the emergency department." Dignity is understood through interpersonal relationships and treatment, while suffering is recognized as multidimensional. End-of-life care in the emergency department poses challenges in managing uncertainty, defining goals, and addressing specific care needs. Professionals navigate a dual perspective, recognizing both the emergency department's limitations in safeguarding dignity and the conditions required to enable it. Across all groups, ethical considerations and moral distress emerge when institutional constraints hinder provision of appropriate care.³⁷

While the emergency department is often seen as unsuitable for patients with dementia at end-of-life, professionals acknowledge that these patients frequently present with significant needs. This perspective is aligned with the reality that the hospital is the main place of death in many developed countries³⁸ and emergency department visits by patients with dementia at the end of life have increased.^{13,15,18,19} Raising awareness and fostering environments that promote positive behaviors toward patients with dementia have been identified as important strategies.³⁹ Furthermore, the transfer of end-of-life care for patients with dementia to community settings, as suggested by respondents, is already recommended for this population.⁴⁰ Regardless, the emergency department can play a fundamental role in determining the goals of care of patients with dementia, in discussing prognosis and initiating palliative care,^{41,42} all of which are central aspects of end-of-life care.

The understanding of dignified treatment for patients with dementia in the emergency department appears diverse, encompassing both intrinsic and extrinsic aspects. Lindwall et al⁴³ reviewed perspectives on dignity in clinical practice and emphasized its recognition through respect, acknowledgment, and supportive community contexts. In the emergency department, health care professionals perceive the needs of patients with dementia as multidimensional, with feeding and eating difficulties posing challenges, consistent with findings by Sharma et al⁴⁴ linking dementia severity to caregiver distress during mealtimes. The family emerges as a key partner in end-of-life care for patients with dementia in the emergency department, requiring special attention in communication. This is consistent with previous evidence³¹ that insufficient support for families may compromise the quality of end-of-life care.

Interestingly, uncertainty was acknowledged by all groups of health care professionals and as a multidimensional reality

in end-of-life care for patients with dementia in the emergency department. Uncertainty was assumed in the establishment of prognosis by physicians, in how to care according to goals of care by nurses, and the understanding of what patients feel and think by health care assistants. This perspective seems quite in line with the concept of *total uncertainty* previously described by Etkind *et al*, namely, the multidimensional experience of unpredictability in serious illness, encompassing disease, health care, relational, and existential domains.⁴⁵ Uncertainty has been associated with increased resource utilization and higher rates of burnout.⁴⁶ Proper identification of the often-challenging end-of-life situation and a model of person-centered care and shared decision-making are recommended.⁴⁷ Addressing better end-of-life conditions in the emergency department was also emphasized. Proposals include education and communication training as previously recommended,⁴⁸ improving physical conditions, with an emphasis on privacy, silence, and a calm environment, and improving organizational aspects as access to information, developing specific protocol for identifying and/or treatment of patients with dementia at the end of life, psychological support, and prior and early referral to palliative care. Complementary and integrative palliative care approaches in the emergency department have yielded positive results,⁴⁹ although with uncertainties about the best models. Finally, the recurring reference throughout the interviews to the moral distress of professionals deserves our attention and is known^{50–53} to benefit from an approach to support professionals in the different levels at which this suffering arises. Strategies to improve person-centered care and shared decision-making are expected to help support health care professionals.⁴⁷

Strengths and limitations

The group of professionals interviewed share extensive experience working in the emergency department and has diverse training in palliative care, which mirrors many emergency departments. The researchers, with experience in both these contexts, facilitated reflection and subjectivity analysis of their perspectives. There are also limitations, namely the fact that this is an analysis of a single center, possibly influenced by the local cultural context either in terms of the patient population and the attitudes and practices of the health care professionals. In addition, the recruitment methodology in which the contact person may have suggested certain interlocutors based on prior knowledge of some of their perspectives, and also there is a known risk of professional and social bias on the part of professionals who may tend to present a false positive image. Finally, respondents used their own definitions about patients with dementia and end-of-life.

Conclusion

The perspectives of emergency department professionals reflect a broader context of limited awareness of dementia and a perception that patients with dementia do not fully belong in the emergency department. Nevertheless, emergency department resources are essential and can provide important opportunities to address some end-of-life needs of these patients. Despite structural and organizational constraints, it is essential to ensure an appropriate place for patients with dementia

in the emergency department at the end of life. Priorities for practice include raising awareness of dementia in society through greater general knowledge about patients with this disease but also greater recognition by health care professionals of their needs at different stages, including at the end of life. At the same time, consideration should be given to implementing structured training programs for health care professionals and improving the physical environment and care models in emergency services. Applying the *Platinum Rule*⁴⁰ “doing unto patients as they would want done unto themselves” can guide more person-centered responses. Closer coordination with families, community services, and palliative care teams is also critical to ensure continuity and quality of care. Finally, systematic support mechanisms are needed to address and mitigate the moral distress experienced by emergency department professionals in providing end-of-life care for patients with dementia. We believe that these perspectives, although limited to the opinions of different professional groups within a single ED, point to possible interventions to improve the quality of care provided to patients with dementia at the end-of-life. These results highlight a potential opportunity for intervention in this particular ED while also supporting the rationale for future multicenter investigations.

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Authors' Contributions

Study concept and design: S.V.S., C.T., and B.A. Acquisition of data: S.V.S. and J.R. Analysis of data: S.V.S. and M.B. Interpretation of data: all authors. Drafting of the article: S.V.S. and M.B. Critical revision of the article for important intellectual content: all authors.

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Supplementary Material

Supplementary Appendix A1
Supplementary Appendix A2
Supplementary Appendix A3

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Address correspondence to:

Sara Vieira Silva, MD
Palliative Care Service
Centro Hospitalar Universitário de Santo António
Largo Abel Salazar
4099-001 Porto
Portugal

E-mail: nevessp@gmail.com

CHAPTER 8

Discussion: main findings, limitations, implications for practice, education, policy and future research. Conclusions.

This thesis addresses the palliative care needs that patients with end-of-life dementia present in the emergency department, the capacity of the emergency department and its professionals to respond to these needs, and what healthcare professionals consider necessary to improve in order to provide better end-of-life care. This section discusses the main findings of the overall work conducted, rather than each study (as this has been done in each individual paper), its limitations, explores the implications of our findings for practice, education and policy and ends with considerations for future research.

Discussion

The aim of this work was to assess the responsiveness of the emergency department to the palliative care needs of end-of-life patients with dementia, focusing on the perspective of emergency department healthcare professionals. For this, we proposed to achieve the following objectives:

1. to conduct a scoping literature review on the emergency department, use and responsiveness to palliative care needs of patients with dementia in the end-of-life, focusing primarily on emergency department visits, opportunities, and barriers to palliative care;
2. to assess the prevalence of unmet palliative care needs and reasons for visits to the emergency department by patients with dementia at the end-of-life;
3. to assess potentially avoidable visits to the emergency department by patients with dementia at the end-of-life and the prevalence of potentially inappropriate diagnostic and therapeutic measures performed in their last days of life in the emergency department, to help identify gaps in end-of-life care;
4. to evaluate aspects of care provided to patients with end-of-life dementia in the emergency department, specifically the identification of their last days of life, measures for implementing end-of-life care, and aspects of communication between healthcare professionals, patients, and family members;
5. to explore the perspectives and experiences of emergency department healthcare professionals about end-of-life care for patients with dementia in the emergency department, including how they respond to those palliative care needs and what do they think and feel about that response.

Main findings

To date, we have not identified any published studies that specifically address emergency care for patients with end-of-life dementia and their palliative care needs. In our scoping review(1) we only identified 8 studies(2-9) that include patients with end-of-life dementia and directly but only in general assessed palliative care needs, with a plethora of measurement tools used, suggesting

significant rates of palliative care needs among patients with dementia and in comparison, to other oncological or non-oncological conditions. Even though emergency department visits are usually considered a low-quality indicator of end-of life care(10, 11), our main findings reinforce that patients with end-of-life dementia often visit the emergency department and represent one of the main diagnosis of patients attending this service. More frequently, patients with dementia visit the emergency department in the last months of their life (57.8% of the visits occurring in the last three months of life) and, according to our findings, with a high prevalence of unmet palliative care needs (78.2%). This was higher than published studies, from 18.3%(11) to 33.6%(4). No previous studies have specifically addressed which unmet palliative care needs are more common. In our research, uncontrolled symptoms stand out as the most frequent unmet palliative care need of patients with end-of-life dementia who visit the emergency department, followed by recent functional decline, in addition to frequent visits to the emergency department itself. Although we did not find a clear association between the presence of unmet palliative care needs and frequent visits to the emergency department ($p = 0.47$), the main reasons for using the emergency setting, dyspnea, dementia-related behavioural changes, and falls, reaffirm uncontrolled symptoms and recent functional decline as the most frequent reasons for using the emergency department, while also revealing themselves as likely relevant unmet palliative care needs. Also, our analysis on the potentially avoidable emergency department visits of patients with dementia at the end-of-life revealed 85.3% of prevalence of unmet palliative care needs, significantly greater than patients with nonavoidable emergency department visits. Overall, these findings suggest that assessing and responding appropriately to unmet palliative care needs, such as constipation or dementia-related behavioural changes, may contribute to reduce avoidable emergency department visits. Strategies as advance care planning, access to specialist medical advice and a mobile emergency response have been suggested to help prevent potentially inappropriate emergency department visits (21-23). Furthermore, based on our analysis on the presumably inappropriate use of diagnostic and therapeutic measures in patients with dementia at the end-of-life that visit the emergency department, we can expect additional harm secondary to these measures. The 83.5% prevalence of presumably diagnostic and therapeutic inappropriate measures is impressive, while early identification of poor prognosis and defining therapeutic limits seem to contribute to a lower probability of these inappropriate measures. Together this knowledge is relevant to integrate with the perspectives that healthcare professionals have on how emergency department care responds and can respond to the palliative care needs of end-of-life patients with dementia.

Based on our reflexive thematic analysis of the emergency department medical records of patients with dementia in the last days of life, the scarcity of direct references to the identification of the

last days of life suggests either low recognition of this clinical situation and/or, reflects emergency department culture where everything is fast paced, including clinical notes taking, especially regarding end-of-life care, which calls for a more descriptive, and hence, longer text. Either one might compromise prompt implementation of adequate quality care measures for end-of-life(12) in the emergency department. The records reflect the medical concern with diagnosis of the patient's critical condition, poor prognosis and communicating of this to the family and caregivers. In fact, rather than the discussion of goals of care with the patient and the family, the analysis of the medical record suggests that family communication focuses on communicating the prognosis and promoting their presence at this critical moment. This is noteworthy because, not only, most of the patients didn't present with an advanced care plan, but also, because the recommended model(13) of shared-decision making implies active and ongoing discussion with surrogate and family decision makers about goals of care. Withhold and withdrawal of life sustaining treatments were the main treatment decisions present in the medical record. Recording these decisions seems useful and probably promotes better team communication. Few references to the patient's state of comfort were noted. Palliative care needs assessment and palliative care support for decision making were also only sporadically recorded. Emphasis on palliative care in the medical record were almost always related to help support and organize further end-of-life care, and not so much in facilitating decision making or anticipating suffering. Ultimately the terminology used to describe either the associated prognosis or palliative care were diverse. Terms such as "terminal" and "end of life" were frequently mentioned and seem to be used somehow as equivalents to the situation of the last days or hours of life which was also verified with "palliative care," "comfort care," "exclusively symptomatic treatment," "supportive care" and "conservative treatment". This inconsistency of terms is not desirable. Use of standard terminology can improve clarity of record(14) and eventually continuity of care.

Finally, the perspectives of emergency department healthcare professionals indicate that they perceive limited awareness of dementia, particularly in the emergency department, but also more broadly in society. They question whether these patients fully belong in this setting but recognize that the emergency department's resources can play an essential role in meeting some end-of-life needs. In addition, healthcare professionals identify families as essential partners in end-of-life care for patients with dementia in the emergency department, emphasizing the need for special attention to communication. Furthermore, emergency department healthcare professionals navigate a dual perspective, recognizing both the limitations of the emergency department in safeguarding dignity and the conditions required to enable it. Throughout the process, they point out that ethical considerations and moral distress(15) arise when institutional constraints prevent the provision of

appropriate care. As key priorities for practice, emergency department healthcare professionals indicate raising awareness of dementia, implementing structured training programmes, and improving the physical environment and care models within the emergency department.

Limitations

In addition to considering the limitations of each study in the respective chapters, it is important to consider the main limitations that may have affected the research. First, it is important to bear in mind that research aimed at the responsiveness of the emergency department to palliative care needs of patients with dementia at the end-of-life, and it included studies that indirectly assessed these patients. We choose to base this analysis on the perspective of emergency department healthcare professionals, both retrospectively, through their records, and through a qualitative assessment via thematic analysis of their opinions. We consider the perspective of healthcare professionals essential in the approach to patients with dementia in the emergency department, but we understand that it is naturally complementary to the perspective of the patients themselves, their families, and caregivers. Secondly, the assessment of palliative care needs of patients with dementia at the end-of-life, reasons for emergency department visits, and diagnostic and therapeutic approaches was based on a retrospective analysis of the medical records. The nature of the registry in medical records in the emergency department is particularly challenging, usually combining records from different professionals in a short space of time, with little time for the actual writing-up process. These records are naturally concise and, we must admit, may omit several aspects that are considered in clinical practice but are not systematically recorded. However, this methodology sought to reflect what is recorded and performed in the emergency department in the care provided to patients with end-of-life dementia. Thirdly, the analysis focused on the records of a single emergency department and the professionals who work in that same emergency department. As a polyvalent emergency department operating 24 hours a day, every day of the year, it attends to countless end-of-life patients with dementia daily. The complementarity between the registry in the emergency department medical records and the perspective of the professionals from the same department seemed relevant to us, giving prominence and substance to the data originating from a single center.

Implications for practice, education, policy

The recognition of the frequent use of the emergency department by patients with dementia at the end-of-life, with significant palliative care needs, highlights the relevance to respond to these needs.

Emergency department healthcare professionals themselves point to areas of intervention that should be considered priorities.

Firstly, the widespread unawareness in society in general and in the healthcare context specifically about the patient with dementia is something that needs to be addressed and changed. Literacy campaigns at different levels should be considered. In society in general, campaigns should raise awareness about people with this disease and demystify it. For patients and their caregivers, campaigns also should focus on their empowerment. And finally, for healthcare professionals it will be important to increase skills in recognizing patients with dementia, their needs, and the necessary responses. On the other hand, it is essential to improve the organization of healthcare for this population and respond to their palliative care needs, when possible and appropriate, at home and in the community. This must be coordinated with a more harmonious and better articulated access and response from emergency services when these patients can truly benefit from them. In this way, we can expect health gains through effectively improving the response to the palliative care needs of patients with dementia at the end-of-life and protecting them from the potential harm that avoidable emergency visits and the verified use of inappropriate diagnostic and therapeutic means represent for them.

Finally, recognizing the opportunity and responsibility that emergency department represent now and will likely continue to represent in the future, for patients with dementia at the end-of-life, the approach and care provided in these services would benefit from improvements in this same context. Thus, in the emergency department, it is important to have readily available relevant information about the patient's health status and main care circumstances, relevant to facilitating the identification of the end-of-life condition, the patient's preferences and advance decisions, their care proxy, if identified, or who best represents them(16). To correctly integrate this information, assess needs, and respond to them, emergency service healthcare professionals probably should be trained in providing palliative care, at least at a basic level, so that they can identify needs and respond promptly(17). At this level, it will be also important to have adequate coordination with specialized palliative care for patients with more complex needs(18). Shared decision-making model, widely proposed and advocated in end-of-life care(13, 19), should also be reinforced in emergency services. Aspects of quality communication with patients, family and caregivers, and among the team are essential tools for better decision-making and for providing care and support. The clinical record should, in a structured manner and with more careful use of medical terms, reveal the main aspects of identifying the clinical situation, assessing needs, decision-making, and the provision and organization of care. To improve conditions of the emergency department itself, more time for care and better conditions for physical comfort, with the possibility of sharing care

with family and caregivers, are identified as relevant. Very few studies addressed direct intervention of palliative care in end-of-life care in the emergency department(18, 20), but it may be beneficial to integrate all these aspects of palliative care into an articulated and specific approach model for end-of-life care for patients with dementia in this context.

Last but not the least, given the need to care for patients with dementia at the end-of-life in a high-pressure environment such as the emergency department, the ethical and moral distress recognized by professionals must be acknowledged, and responses to support them must be organized.

Future research

In line with the expected growth in the prevalence of dementia, alongside the increase in the population aged over 65 years old(21), and the importance of the emergency department in responding to the palliative care needs of this population, we identify areas of study and research that would benefit from further development. Advance care planning has been recommended(13), but the best strategies for development, implementation, adjustment, and access to information in the emergency department lack models for their proper establishment. Strategies that facilitate the identification of patients with end-of-life dementia in the context of the emergency department and the potential benefits of organizing a specific approach for these patients in this setting have not yet been defined and deserve to be studied in terms of their benefits and possible models. Perhaps the development of specific guidelines for the identification and management of these patients in the emergency department could benefit from a discussion with experts using the Delphi methodology, complemented by a multicenter study on possible approaches. Research on the best models of palliative care(22), such as palliative care consultation or integrated palliative care-emergency care (18, 23), in the context of the emergency department should be developed, particularly through intervention studies. Strategies should be studied that provide greater support for the ethical and moral suffering of emergency department healthcare professionals who care for patients with dementia at the end-of -life, both in terms of prevention and follow-up. Finally, all these lines of research and care development to respond to the palliative needs of patients with dementia at the end-of-life in the emergency department should include studies that incorporate the perspective of the patients themselves and their caregivers.

Conclusions

The perspectives of emergency department healthcare professionals reflect that the emergency department resources are essential and can provide important opportunities to address some palliative care needs of patients with dementia at the end-of-life. More specifically, they indicate

that it is important to strengthen an adequate response to patients with dementia at the end-of-life who use the emergency service and who can truly benefit from care in this context. They favour prioritizing care that is focused on *the right place* and the *right care*. This implies aspects of improving care for this population upstream and downstream of the emergency department and in the emergency department itself. At the emergency department, a comprehensive model for dealing with patients with dementia at the end-of-life stands out, from identification to the organization of care - from oxymoron to standard of care of the patient with dementia at the end-of-life in the emergency department. In this approach, palliative care is central, and it is essential to develop its better integration in this context for patients with dementia at the end-of-life.

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CHAPTER 9

Personal reflection

After completing this thesis, I hope to have contributed to greater clarity on the fundamental question that guided it: *how can care be provided in the emergency department to better respond to the palliative care needs of patients with dementia at the end of life?* The concern at the root of this issue accompanies me as a person and as a physician who seeks to support these patients in this context and who feels the responsibility to do so well.

My clinical experience as a physician who works weekly in the emergency department since the last 17 years is inseparable from the research produced and presented in this thesis. One could consider this a conflict of interest, I hope not. I believe and I have attempted to overcome this with a retrospective analysis model, without direct intervention, but directly to what emergency department healthcare professionals think about this question. The methodology applied sought to adopt a form of analysis based on the researcher's experience, not as a prejudice, but as an enrichment. And I believe I have experienced this enrichment in two ways. Firstly, through a relevant means of helping to clarify and, eventually, intervene in the concrete improvement of the quality of end-of-life care provided to people with dementia in the emergency department—through the perspective of its professionals. They are irreplaceable actors in this scenario, with assumed responsibility and with an unparalleled ability to recognize needs and the true essence of these patients' care. Our research confirms that these patients frequently visit the emergency department and with very significant palliative care needs. Their place in this setting must be reclaimed. Healthcare professionals recognize this and are in favour of taking advantage of the opportunity to meet their needs in the emergency department. In fact, the main entrance to the emergency department, one of the main points of access to medical care, should be open to these patients and prepared to provide them with appropriate care. I emphasize the importance that healthcare professionals recognize the need to improve conditions that favour the provision of care that respects the dignity of these patients, recognizing their special vulnerability. I also highlight the need that professionals themselves feel for support for their moral and ethical suffering, inherent in providing care in such challenging circumstances, but also often aggravated by shortcomings in the context of the emergency service. Palliative care emerges as the necessary response to be organized in the emergency department. Identification of the end-of-life situation, palliative care needs, communication, shared decision-making, impeccable symptom control, and support for the patient and family are the recognized elements. Effective models for approaching and implementing palliative care in the emergency department for patients with end-of-life dementia are yet to be defined. However, training in palliative care, even if basic, for most healthcare professionals working in emergency departments, as is already recognized as necessary in other contexts, is probably one of the priorities.

Secondly, in addition to the knowledge that I hope this research has contributed, the transformation I have experienced, both professionally and personally, is undeniable. The opportunity to reflect daily on the issues in this thesis and my daily clinical practice have influenced each other. My own awareness of the reality of these patients, which I realized was so limited in general, has grown. The identification of these patients, the recognition of their vulnerability and their needs, and the search for better ways to respond to them, I think, has also grown. Dignity as a starting point, which must be recognized as inherent to these patients, but also as a point of arrival, as a goal that must be respected. This is what I fundamentally understand to be the main objective of the response that must be sought. Palliative care, I believe, is the way forward.

Finally, having the opportunity to gather perspectives, reflect, and share clinical practice with healthcare professionals has increased the responsibility I feel in wanting to find a better response to patients' needs, but also for professionals, a response that better supports and fulfils them.

ANNEX 1

Work conducted alongside the PhD thesis

Work conducted alongside the PhD Thesis

Papers Published as first author

2026 *End-of-life care for patients with dementia in the emergency department – Reflexive Thematic Analysis of the perspective of healthcare professionals*, J Palliat Med. 2026 Apr 9;10966218261441207. doi: 10.1177/10966218261441207. Epub ahead of print. PMID: 41954017.

2025 Vieira Silva, S., Conceição, P., Antunes, B., & Teixeira, C. *Emergency department use and responsiveness to the palliative care needs of patients with dementia at the end of life: A scoping review*. Palliative & supportive care, 23, e51.
<https://doi.org/10.1017/S1478951524001627>

Vieira Silva, S., Teixeira, C., & Antunes, B. *Unmet Palliative Care Needs Among Patients with Dementia at the End of Life and Frequent Use of the Emergency Department: One-Year Retrospective Study in a Central Hospital*. Journal of palliative medicine, 28(10), 1367–1371.
<https://doi.org/10.1089/jpm.2024.0447>

Vieira Silva, S., Teixeira, C., & Antunes, B. *Reflexive thematic analysis of emergency department medical records of dementia patients regarding the identification of last days of life*. Palliative & supportive care, 23, e182. <https://doi.org/10.1017/S1478951525100527>

Papers submitted to publish

2025 *Potentially avoidable visits to the emergency department by patients with dementia at the end of life – a longitudinal retrospective study*, submitted to BMC Palliative Care, 26.06 2025
<https://doi.org/10.21203/rs.3.rs-8184276/v1>

Papers accepted to be presented in national and international conferences

2026 *Perspectives on end-of-life care in the emergency department – Reflexive thematic analysis of healthcare professionals’ views* Vieira Silva S, Teixeira C; Antunes A, 20th World Congress of the European Association for Palliative Care, May 2026, Prague, Czechia

2025 *Qualitative analysis of the emergency medical records of patients with dementia in their final days of life.* Vieira Silva S, Teixeira C; Antunes A, 31º Congresso Nacional de Medicina Interna, May 2025, Coimbra

Prevalence of inappropriate diagnostic and therapeutic measures in patients with advanced dementia at the end of life in the Emergency Department – a retrospective study in a tertiary hospital. Vieira Silva S, Teixeira C; Antunes A. II Congresso Internacional de Cuidados Paliativos de Leiria, November 2025, Leiria

2024 *Palliative care needs of patients with dementia attending the Emergency department: a scoping review.* Vieira Silva S; Conceição P; Antunes B; Teixeira C. European Association of Palliative Care. May 2024, Barcelona, Spain

Emergency department admissions by patients with dementia at the end of life – experience of a university hospital. Vieira Silva S, Teixeira C; Antunes A. XI Congresso Nacional de Cuidados Paliativos. October 2024, Aveiro

Avoidable visits to the emergency department by patients with dementia at the end of life - One year experience of a university hospital. Vieira Silva S; Antunes A; Teixeira C. XI Congresso Nacional de Cuidados Paliativos. October 2024, Aveiro

Prevalence of palliative care needs of patients with advanced dementia who resort to the emergency department – experience of a university hospital. Vieira Silva S, Teixeira C; Antunes A. XI Congresso Nacional de Cuidados Paliativos, October 2024, Aveiro

Emergency department medical records of dementia patients in the last days of life - qualitative analysis. Vieira Silva S; Moura P, Teixeira C, Antunes B. International Conference on the Best Care of the Dying Person. November 2024, Porto

Home cared dementia patients: last week of life visits to the Emergency Department a retrospective analysis. Vieira Silva S; Antunes B, Teixeira C. International Conference on the Best Care of the Dying Person. November 2024, Porto

- 2023** *Use of the emergency department by patients with dementia at the end- of-life and their palliative care needs: scoping review.* Vieira Silva, S; Conceição, P; Antunes, B; Teixeira, C. IV Jornadas de Investigação da APCP, November 2023, Viana do Castelo

Peer reviewer for

- 2024** Reviewer fo BMC Palliative care

What helps or hinders effective end-of-life care in adult intensive care units in Middle Eastern countries? A systematic review, March 2024

Awards

- 2023** *Honorable Mention Award for Best Abstract:* Use of the emergency department by patients with dementia at the end- of-life and their palliative care needs: scoping review. (oral communication) Vieira Silva, S; Conceição, P; Antunes, B; Teixeira, C. IV Jornadas de Investigação da APCP, Viana do Castelo, November 2023

- 2024** *Best Parallel Session Abstract Award:* Prevalence of palliative care needs of patients with advanced dementia who resort to the emergency department – experience of a university hospital. Vieira Silva S, Teixeira C; Antunes A. XI Congresso Nacional de Cuidados Paliativos. October 2024, Aveiro

Invited Lecturer

- 2025** *Palliative Care in the Emergency Department*, PEOLBC - Palliative, End of Life and Bereavement Care group Journal Club, University of Coimbra, as a guest moderator, October November

ANNEX 2

Curriculum Vitae

Curriculum Vitae

Personal Information

Full name: Sara Neves Vieira da Silva

E-mail: nevessp@gmail.com

Nationality: Portuguese

ORCID: <https://orcid.org/0000-0003-4463-6732>

Date of birth: 22nd February 1984

Education and Qualifications

2022-2026: PhD in Doctoral Program of Palliative Care, Faculdade de Medicina, Universidade do Porto, Portugal

2021 Consultant degree in Internal Medicine granted by Colégio de Medicina Interna of Ordem dos Médicos, Portugal

2020 Palliative Care competence granted by Colégio de Medicina Paliativa of Ordem dos Médicos, Portugal

2018-2021 Masters in “Palliative Care”, Faculdade de Medicina, Universidade do Porto, Portugal
Dissertation Title: “Palliative Care in Advanced Liver Disease – a prospective study on palliative needs and possibilities for care integration from a Portuguese university hospital and transplant center”

2016-2017 Postgraduate on Palliative Care for Non-Oncological Patients, Universidade Católica Portuguesa, Portugal

2009-2015 Internal Medicine Specialist granted by Colégio Medicina Interna of Ordem dos Médicos, Portugal

2002-2008 Medical Degree (6 years) at Faculdade de Medicina, Universidade de Lisboa, Portugal. Professional badge number 48133

Positions

January 2021 to date

Specialist attending physician of Internal Medicine and Palliative Care, with weekly clinical activity (12 to 24 hours per week, day or night) at the Emergency Department as a specialist physician, Palliative Care Department at Unidade Local de Saúde de Santo António, Porto, Portugal

January 2017 to October 2024

Training advisor in Internal Medicine, Unidade Local de Saúde de Santo António, Porto, Portugal

June 2015 to February 2020

Specialist attending physician of Internal Medicine, with weekly clinical activity at the Emergency Department as a specialist physician, Internal Medicine Department at Unidade Local de Saúde de Santo António, Porto, Portugal

October 2012 to September 2018

Emergency physician, twice a month clinical activity at the Emergency Department, Unidade Local de Saúde de Santo António, Porto, Portugal

January 2009 to May 2015

Resident physician of Internal Medicine, Internal Medicine Department, with weekly clinical activity at the Emergency Department as a resident physician, Unidade Local de Saúde de Santo António, Porto, Portugal

2021 to date

Bem Cuidar no Fim de Vida project coordinator, ULS Santo António, Porto

2021 to date

Heart Failure Studies group, as Palliative Care consultant, ULS Santo António, Porto

2021 to date

Development and Investigation group, as Palliative Care consultant, ULS Santo António, Porto

Research grants awarded
2023

Finalist for the **2023 Prémio Boas Práticas em Saúde**, Associação Portuguesa para o Desenvolvimento Hospitalar (Poster), Lisbon, October 2023

Invited lecturer

2023 to date

Care in the Last Days or Hours of Life, Sociedade Portuguesa de Medicina Interna,
Vila Nova de Gaia

2022

Palliative Care in Orgain failure, Palliative Care Intermediate Course, ARS Norte,
Porto

2022 to date

Care in the Last Days or Hours of Life, Master's Degree in Medicine, School of
Medicine and Biomedical Sciences, Universidade do Porto, Porto

2022 to date

Care in the Last Days or Hours of Life, postgraduate Basic Palliative Care Course,
Unidade Local de Saúde de Santo António, Porto

June 2020

Palliative Care in Advanced Liver Disease, Master's Degree in Medicine, Faculty of
Medicine, Universidade de Lisboa, Lisboa

May 2019

Palliative Care in Heart Failure, postgraduate Basic Course in Palliative Care,
Master's Degree in Medicine, Faculty of Medicine, Universidade de Coimbra, Coimbra

2018 to date

Introduction to Palliative Care, Master's Degree in Medicine, School of Medicine
and Biomedical Sciences, Universidade do Porto, Porto

2017 to date

Palliative Care in Heart Failure, Master's Degree in Medicine, School of Medicine
and Biomedical Sciences, Universidade do Porto, Porto

2017 to date

**Management of Respiratory Symptoms and Palliative Care in Chronic
Respiratory Diseases**, Master's Degree in Medicine, School of Medicine and
Biomedical Sciences, Universidade do Porto, Porto

2015 to date

Respiratory symptoms management and Palliative Care in Chronic Respiratory Diseases and Heart Failure, postgraduate Basic Palliative Care Course, Unidade Local de Saúde de Santo António, Porto

Student supervision

June 2025

Beatriz Almeida – Integrated MSc in Medicine, School of Medicine and Biomedical Sciences, Universidade do Porto, Porto. **Palliative care practices in an intensive care unit at the Santo António Local Health Unit – A retrospective study**,

Final mark: 20 (scale 0-20)

January 2022 to date

Training advisor in Palliative Care of Joana Pinto (Family physician resident, 2021), Marta Fonseca (Internal medicine resident, 2021), Sofia Pinheiro Torres (Family physician specialist, 2022), Tânia Lopes Palliative (Internal medicine resident, 2022), Ana Barbosa (Internal medicine resident, 2022), Paulo Conceição (Internal medicine resident, 2023), Pedro Neves (Internal medicine resident, 2023), José Magalhães (Internal medicine resident, 2023), Andreia Salgado (Internal medicine resident, 2023), Sara Barbosa (Internal medicine resident, 2023), Pedro Moura (Haematology resident, 2024), Ana Margarida Ribeiro (Internal medicine resident, 2024), Sara Abreu (Internal medicine specialist, 2025), Maria Inês Candeias (Internal medicine resident, 2025), Beatriz Ferreira (Internal medicine resident, 2025). Palliative Care Service, Unidade Local de Saúde de Santo António, Porto

January 2016 to October 2024

Training advisor in Internal Medicine of Ana Oliveira (OM 57428), Patrícia Baptista (OM 61898) and Isabel Silva (OM 64179), Internal Medicine Service, Unidade Local de Saúde de Santo António, Porto

Publications

Papers in peer reviewed journals

2026 *End-of-life care for patients with dementia in the emergency department – Reflexive Thematic Analysis of the perspective of healthcare professionals*, J Palliat Med. 2026 Apr 9:10966218261441207. doi: 10.1177/10966218261441207. Epub ahead of print. PMID: 41954017.

2025 Vieira Silva, S., Conceição, P., Antunes, B., & Teixeira, C. *Emergency department use and responsiveness to the palliative care needs of patients with dementia at the end of life: A scoping review*. Palliative & supportive care, 23, e51.
<https://doi.org/10.1017/S1478951524001627>

Vieira Silva, S., Teixeira, C., & Antunes, B. *Unmet Palliative Care Needs Among Patients with Dementia at the End of Life and Frequent Use of the Emergency Department: One-Year Retrospective Study in a Central Hospital*. Journal of palliative medicine, 28(10), 1367–1371.
<https://doi.org/10.1089/jpm.2024.0447>

Vieira Silva, S., Teixeira, C., & Antunes, B. *Reflexive thematic analysis of emergency department medical records of dementia patients regarding the identification of last days of life*. Palliative & supportive care, 23, e182. <https://doi.org/10.1017/S1478951525100527>

2023 Vieira da Silva, S. N., Baptista, P., Fonseca Silva, I., Freire, E., & Pessegueiro Miranda, H. *Palliative Care in Advanced Liver Disease: Similar or Different Palliative Care Needs in Patients with a Prospect of Transplantation? Prospective Study from a Portuguese University Hospital and Transplantation Center*. GE Portuguese journal of gastroenterology, 30(3), 204–212.
<https://doi.org/10.1159/000522172>

Vieira Silva S., Santos M, Alves J, Freire E. *Better Care in the End of Life Project*. RPMI [Internet]. 2023 Sep. 27 [cited 2025 Nov. 17];30(3):203-4. Available from:
<https://revista.spmi.pt/index.php/rpmi/article/view/1944>

- 2022** Fonseca M, Vieira Silva S, Santos M, Bertão M, Gonçalves I, Barbedo I, et al. *High-Flow Nasal Cannula Oxygen Therapy in A Palliative Care Context at Home, a New Opportunity? A Palliative Care Team Experience*. RPMI [Internet]. 2022 Dec. 19 [cited 2025 Nov. 17];29(4):261-6. Available from: <https://revista.spmi.pt/index.php/rpmi/article/view/647>
- 2020** Vieira Silva, S., Freire, E., Pessegueiro Miranda, H. *Palliative Care in End-Stage Liver Disease Patients Awaiting Liver Transplantation: Review*. GE Portuguese journal of gastroenterology, 2020, 27(6), 417–428. <https://doi.org/10.1159/000507336>
- 2019** Vieira Silva S, Oliveira A, Barbedo I, Mirra J, Santos M, Alves J, et al. *Palliative Care in Advanced Heart Failure: The Experience of an Intra-Hospital Support Palliative Care Team*. RPMI [Internet]. 2019 Mar. 15 [cited 2025 Nov. 17];26(1):33-9. Available from: <https://revista.spmi.pt/index.php/rpmi/article/view/360>

Book chapters

- 2021** *Best practices manual last hours to days of life* , Unidade Local de Saúde de Santo António, Porto
Coordinator : Dr. Sara Vieira Silva
- 2017** *Practical Guide to Symptom Control*, Núcleo Medicina Paliativa da Sociedade Portuguesa de Medicina Interna, Porto
Coordinator: Dr. Elga Freire
Chapters: Dyspnea, Cough, Suffocation and Palliative Sedation
- 2015** *Palliative Care Manual of the Unidade Local de Saúde de Santo António*, 2015 edition, Unidade Local de Saúde de Santo António, Porto
Coordinator: Dr. Elga Freire
Chapters: Respiratory Symptoms, Heart Failure

Editorials activities

2024 Moderator of the Poster Presentation session at the 30º Congresso Nacional de Medicina Interna, May 2024, Vilamoura

2024 Reviewer fo BMC Palliative care
What helps or hinders effective end-of-life care in adult intensive care units in Middle Eastern countries? A systematic review, March 2024

2022 Poster reviewer of the X Congresso Nacional APCP – I Congresso Internacional da APCP – Cuidar do nosso Legado, September 2022, Porto

2020 to date

Reviewer of Revista de Medicina Interna of the Sociedade Portuguesa de Medicina Interna

Estrongiloidose em doente transplantado renal – uma paratização catastrófica, March 2020

Disfagia orofaríngea por osteofitose cervical anterior, November 2022

Pielonefrite enfisematosa bilateral: um diagnóstico incomum, September 2022

Cisticercose intramuscular e cerebral disseminada: relato de caso, October 2024

2020 Poster reviewer of the 26º Congresso Nacional de Medicina Interna, May 2020, Vilamoura

Awards

2024 *Best Parallel Session Abstract Award*: Prevalence of palliative care needs of patients with advanced dementia who resort to the emergency department – experience of a university hospital. Vieira Silva S, Teixeira C; Antunes A. XI Congresso Nacional de Cuidados Paliativos. October 2024, Aveiro

2023 *Honorable Mention Award for Best Abstract*: Use of the emergency department by patients with dementia at the end- of-life and their palliative care needs: scoping review. (oral

communication) Vieira Silva, S; Conceição, P; Antunes, B; Teixeira, C. IV Jornadas de Investigação da APCP, Viana do Castelo, November 2023

- 2016** *Best Poster Award: Abordagem da Insuficiência Cardíaca Avançada: a experiência de uma Equipa Intra-Hospitalar de Cuidados Paliativos (poster).* Vieira Silva, S; Barbedo, I; Mirra, J ; Alves, J ; Freire, E. VIII Congresso Nacional de Cuidados Paliativos, Porto, 2016

Keynote speaker

- 2017** *Advanced Liver Disease – Challenges and lines of research.* I Jornadas do Núcleo de Estudos de Medicina Paliativa da Sociedade Portuguesa de Medicina Interna, September 2017, Porto

- 2018** *Approaches managing dyspnea in chronic respiratory disease and heart failure – the clinical experience of an intra-hospital palliative care team.* IX Congresso Nacional/8º Congresso IPO Porto Cuidados Paliativos, October 2018, Porto

- 2019** *Advanced Care Planning.* I Congresso de Cuidados Paliativos do Alto Minho, April 2019, Viana do Castelo

- 2020** *Palliative Care in Non-Cancer Patients - Addressing Dyspnea in Chronic Respiratory Disease and Advanced Heart Failure.* 26º Congresso Nacional de Medicina Interna, August 2020, Braga

- 2020** *Palliative Care in Cardiology – what are we talking about? - Palliative Care units and patients with heart disease – are we far from where we need to be?* Congresso Português de Cardiologia, October 2020

- 2023** *Caring After Cancer.* III Oporto Biomedical Summit. April 2023, Porto

2024 *Palliative Care in Vascular Surgery*, Reunião de Núcleos da Sociedade Portuguesa de Angiologia e Cirurgia Vascular. January 2024, Coimbra

End-of-Life Dilemmas – Bem Cuidar no Fim de Vida Project: the experience of a university hospital.
30º Congresso Nacional de Medicina Interna, May 2024, Vilamoura

2025 *Home hospitalization from the perspective of palliative care*, Congresso Luso-Galaico de Cuidados Paliativos, April 2025, Viana do Castelo

Bem Cuidamos no Fim de Vida?, 2º Encontro de Medicina Interna da Unidade Local de Saúde de Santo António, November 2025, Porto

Palliative Care in the Emergency Department, PEOLBC - Palliative, End of Life and Bereavement Care group Journal Club, University of Coimbra, as a guest moderator, October November

Continuous personal development

2018 *2nd Palliative Care advanced course*, Hospital da Luz, 11 and 12 October 2018, Lisbon

2019 *Intensive Course on End-of-Life Ethics*, Universidade Católica, 17 to 19 July 2019, Porto

Community Care and Dementia: Understanding the Condition course, Dementia Training Australia, October 2019 (*e-learning*)

2020 *Como Ajudar Quem está Morrendo?* course, Associação Humana Vida e Humana Palavra, Ana Cláudia Quintana Arantes, 2020 (*e-learning*)

Strategies of Effective pain management course, Pri-Med Institute, April 2020 (*e-learning*)

Chronic Complex Illness End-Of-Life Care course, End Of Life Essentials, April 2020 (*e-learning*)

Emergency Department End-Of-Life Care course, End Of Life Essentials, April 2020 (*e-learning*)

Imminent Death – How to Respond course, End Of Life Essentials, April 2020 (*e-learning*)

Planning End-Of-Life Care – Goals of Care course, End Of Life Essentials, June 2020 (*e-learning*)

Management of Antipsychotic Medications for Responsive Behaviour in Residential Aged Care course, Dementia Training Australia, June 2020 (*e-learning*)

The pain puzzle : Recognition, assessment and treatment of pain in people living with dementia course, Dementia Training Australia, June 2020 (*e-learning*)

Multimodal Analgesia Strategies for Pain Management course, AIM International, June 2020 (*e-learning*)

2022 *Basic Course in Ultrasound for Critical Care Patients*. Reanima. Winfocus, April 2022, Porto

2023 *Cuidados e acompanhamos outros...e como podemos cuidar de nós?* course – Enrico Benito. Instituto Português de Oncologia. May 2023, Porto

2023 *Biostatistics Course: Introduction to health data analysis*. Centro de Ensino e Formação da Unidade Local de Saúde de Santo António, May 2023, Porto

Language skills

Portuguese : Native

English: Fluent speech, understanding, writing and reading (B2*)

Spanish: Intermediate speech, understanding, writing and reading (B1*)

French: Basic speech, understanding, writing and reading (A2*)

*European language levels - Self Assessment Grid

<https://www.coe.int/en/web/portfolio/self-assessment-grid>

Presentations in conferences

Oral communications

2025 *Qualitative analysis of the emergency medical records of patients with dementia in their final days of life.* Vieira Silva S, Teixeira C; Antunes A, 31º Congresso Nacional de Medicina Interna, May 2025, Coimbra

Prevalence of inappropriate diagnostic and therapeutic measures in patients with advanced dementia at the end of life in the Emergency Department – a retrospective study in a tertiary hospital. Vieira Silva S, Teixeira C; Antunes A. II Congresso Internacional de Cuidados Paliativos de Leiria, November 2025, Leiria

2024 *Emergency department admissions by patients with dementia at the end of life – experience of a university hospital.* Vieira Silva S, Teixeira C; Antunes A. XI Congresso Nacional de Cuidados Paliativos. October 2024, Aveiro

Avoidable visits to the emergency department by patients with dementia at the end of life - One year experience of a university hospital. Vieira Silva S; Antunes A; Teixeira C. XI Congresso Nacional de Cuidados Paliativos. October 2024, Aveiro

Prevalence of palliative care needs of patients with advanced dementia who resort to the emergency department – experience of a university hospital. Vieira Silva S, Teixeira C; Antunes A. XI Congresso Nacional de Cuidados Paliativos, October 2024, Aveiro

2023 *Pain Assessment in Patients with Dementia in the Medical Department.* Barbosa AC, Vieira Silva S, Matos M, Freire E, Correia JA. 29º Congresso Nacional de Medicina Interna, May 2023, Porto

Use of the emergency department by patients with dementia at the end- of-life and their palliative care needs: scoping review. Vieira Silva, S; Conceição, P; Antunes, B; Teixeira, C. IV Jornadas de Investigação da APCP, November 2023, Viana do Castelo

2021 *Functional limitation in patients with advanced liver disease—a palliative need that should not be overlooked!*. Silva, IF; Baptista, P; Vieira Silva, S. 27º Congresso Nacional de Medicina Interna, October 2021, Vilamoura

Bem Cuidar no Fim de Vida project - proposal for patients in their final hours or days of life Vieira Silva S; Barbedo I, Gonçalves I; Bertão M, Santos M, Bela M, Alves J, Freire E. IV Jornadas do Núcleo de Medicina Paliativa, March 2022, Porto

2019 *Opioid use for symptom control in chronic respiratory disease and advanced heart failure*. Baptista, P; Vieira Silva, S; Freire, E. 25º Congresso Nacional de Medicina Interna, May 2019, Vilamoura

Is it possible to learn and engage with person centred care at the beginning of medical school? Teixeira, C; Strecht Almeida, M; Vieira Silva, S; Moreira, S; Reis, A; La Fuente de Carvalho, JM. Congresso Internacional de Cuidados de Saúde centrados nas Pessoas, October 2019, Porto

2018 *Impact of bronchiectasis on morbidity and mortality in patients admitted to a university hospital center*. Oliveira, T; Costa, I; Almeida, P; Pires, S; Cravo, M; Vieira Silva, S; Leuschner, P. Congresso de Pneumologia, November 2018, Porto

Retrospective analysis of morbidity and mortality in patients with chronic respiratory disease and/or lung cancer – what indicators of advanced disease in clinical practice? Vieira Silva, S; Cravo, M; Oliveira, T; Pires, S; Almeida, P; Costa, I; Leuschner, P; Freire, E. IX Congresso Nacional/8º Congresso IPO Porto Cuidados Paliativos, October 2018, Porto

Pain in an Intra-hospital Palliative Care Support Team: assessment, recording, and outcomes. Alves, J; Ferreira M; Moraes, R; Freire E; Mirra, J; Barbedo, I; Santos, M; Vieira Silva, S. 2ªs Jornadas de Investigação da APCP, March 2018, Bragança

Family conferences – the two year experience of a palliative care support team in a tertiary hospital. Alves, J; Mirra, J; Soares, RF; Santos, M; Barbedo, I; Vieira Silva, S; Freire, E. 4Th Health IP, May 2018, Leiria

Pain in an Intra-hospital Palliative Care Support Team: assessment, recording, and outcomes. Oliveira, T; Costa, I; Almeida, P; Pires, S; Cravo, M; Vieira Silva, S; Leuschner, P. Congresso de Pneumologia, November 2018, Porto

Retrospective analysis of morbidity and mortality in patients with chronic respiratory disease and/or lung cancer – what indicators of advanced disease in clinical practice? Vieira Silva, S; Cravo, M; Oliveira, T; Pires, S; Almeida, P; Costa, I; Leuschner, P; Freire, E. IX Congresso Nacional/8º Congresso IPO Porto Cuidados Paliativos, October de 2018, Porto

2017 *Approaching patients with advanced dementia – the experience of a medical service.* Rola, A; Castelo Branco, C; Ferreira, T; Vieira Silva, S; Barbedo, I; Mirra, J; Alves, J; Freire, E; Araújo Correia, J. Equipa Intra-hospitalar de Suporte em Cuidados Paliativos. ULS Santo António. 23º Congresso Nacional de Medicina Interna, May 2017, Porto

Eating disorders and management strategies in patients with dementia – the experience of a medical service. Castelo Branco, C; Ferreira, T; Rola, A; Vieira Silva, S; Barbedo, I; Mirra, J; Alves, J; Freire, E; Araújo Correia, J. Equipa Intra-hospitalar de Suporte em Cuidados Paliativos. ULS Santo António. 23º Congresso Nacional de Medicina Interna, May 2017, Porto

Posters

2026 *Perspectives on end-of-life care in the emergency department – Reflexive thematic analysis of healthcare professionals' views* Vieira Silva S, Teixeira C; Antunes B, 20th World Congress of the European Association for Palliative Care, May 2026, Prague, Czechia

2024 *Palliative care needs of patients with dementia attending the Emergency department: a scoping review.* Vieira Silva S; Conceição P; Antunes B; Teixeira C. European Association of Palliative Care. May 2024, Barcelona, Spain

Emergency department medical records of dementia patients in the last days of life - qualitative analysis. Vieira Silva S; Moura P; Teixeira C, Antunes B. International Conference on the Best Care of the Dying Person. November 2024, Porto

Home cared dementia patients: last week of life visits to the Emergency Department a retrospective analysis. Vieira Silva S; Antunes B, Teixeira C. International Conference on the Best Care of the Dying Person. November 2024, Porto

End-of-life care education hospital healthcare professional's perspectives on relevance and needs. Vieira Silva S; Bertão M; Alves J; Santos M; Barbedo I; Gonçalves I; Bela M; Faria C; Pereira R; Freire E. International Conference on the Best Care of the Dying Person. November 2024, Porto

2022 *Palliative high-flow oxygen at home - the experience of a Palliative Care Team.* Vieira Silva S; Fonseca M; Bertão M; Santos M; Barbedo I; Gonçalves I; Bela M; Alves J; Freire E. IV Jornadas do Núcleo de Medicina Paliativa, March 2022, Porto

Bem Cuidar no Fim de Vida project – initial data from a proposal for people in their final hours to days of life. Vieira Silva S; Bertão M; Santos M; Barbedo I; Gonçalves I; Alves J; Freire E. X Congresso Nacional APCP – I Congresso Internacional da APCP – Cuidar do nosso Legado. September 2022, Lisboa

2021 *Psychoemotional symptoms in patients with advanced liver disease – palliative care is essential.* Baptista, P; Silva, IF; Vieira Silva, S. 27º Congresso Nacional de Medicina Interna, October 2021, Vilamoura

2020 *Memo: Non-pharmacological treatment of dyspnea in advanced diseases.* Pereira, N; Silva, I; Bertão, M; Vieira Silva, S; Freire, E. III Jornadas do NEMPAL, February 2020, Porto

Palliative care for patients with dementia: the importance of early referral. Alves Pinto, MJ; Bertão, M; Vieira Silva, S; Barbedo, I; Mirra, J; Santos, M; Alves, J; Freire, E. III Jornadas do NEMPAL – Integração dos CP no trajeto da doença, February 2020, Porto

Family conferences as an indicator of the quality of a palliative care team: a 5-year case series. Alves, J; Rente, J; Mirra, J; Santos, M; Barbedo, I; Vieira Silva, S; Bertão, M; Freire, E. III Jornadas do NEMPAL – Integração dos CP no trajeto da doença, February 2020, Porto

Pulmonary toxicity patterns of folfox- case study. Silva, IF; Rego, R; Vieira Silva, S; Correia, JA. 26º Congresso Nacional de Medicina Interna, August 2020, Braga

2019 *Parental grief – case study.* Alves, J; Mirra, J; Santos, M ; Vieira Silva, S; Freire, E. 8ªs Jornadas Nacionales de Enfermeria en Cuidados Paliativos AECPAL, April 2019, Mérida, Spain

When different specialties make a difference in a palliative care patient: a clinical case study. Alves, J; Rente, J; Mirra, J; Santos, M; Vieira Silva, S; Freire, E. 3ªs Jornadas de Investigação da APCP, September 2019, Beja

COPD – comorbidities and their impact on the use of healthcare resources. Almeida,P; Cravo, M; Costa, I; Pires, S; Oliveira, T; Vieira Silva, S; Leuschner, P. European Respiratory Society International Congress, October 2019, Madrid, Spain

2017 *Pain in an Intra-Hospital Palliative Care Support Team: Assessment, Recording, and Outcomes.* Alves, J; Mirra, J; Santos, M; Vieira Silva, S; Barbedo,I; Freire, E.II Jornadas de Investigação APCP, March 2017, Bragança

Antibiotic use and other strategies in the treatment of infection in patients with dementia. Ferreira, T; Castelo Branco, C; Rola, A; Vieira Silva, S; Barbedo, I; Mirra, J; Alves, J; Freire, E; Araújo Correia, J. Equipa Intra-hospitalar de Suporte em Cuidados Paliativos. Centro Hospitalar e Universitário do Porto. 23º Congresso Nacional de Medicina Interna, May 2017, Porto

Experience of a palliative care team on patients with stroke. Cipriano, P; Monteiro, N; Mirra, J; Alves, J; Santos, M; Vieira Silva, S; Barbedo, I; Freire, E. 23º Congresso Nacional de Medicina Interna, May 2017, Porto

- 2016** *Lung cancer and chronic non-oncological lung disease – experience of an intra-hospital palliative care support team.* Francisco, J; Vieira Silva, S; Barbedo, I; Mirra, J; Alves, J; Elga Freire. VIII Congresso Nacional de Cuidados Paliativos, 2016, Porto

Advanced heart failure approach: the experience of an inpatient palliative care team. Vieira Silva, S; Barbedo, I; Mirra, J ; Alves, J ; Freire, E. VIII Congresso Nacional de Cuidados Paliativos, 2016, Porto

Lung cancer and chronic non-oncological lung disease – experience of an intra-hospital palliative care support team. Francisco, J; Vieira Silva, S; Barbedo, I; Mirra, J; Alves, J; Freire, E. VIII Congresso Nacional de Cuidados Paliativos. April 2016, Lisboa

- 2015** *The experience of an intra-hospital palliative care team in the treatment of advanced heart failure.* Vieira Silva, S; Alves, J; Barbedo, I; Mirra, J; Conde, L ; Freire, E. 21º Congresso Nacional de Medicina Interna, May 2015, Vilamoura

Chronic non-oncological lung disease and oncological lung disease – experience of an intra-hospital palliative care team at a hospital center. Francisco, J; Vieira Silva, S; Monteiro, M; Barbedo,

I; Alves, J; Conde, L; Freire, E. 21º Congresso Nacional de Medicina Interna, May 2015,
Vilamoura

References Available upon request.