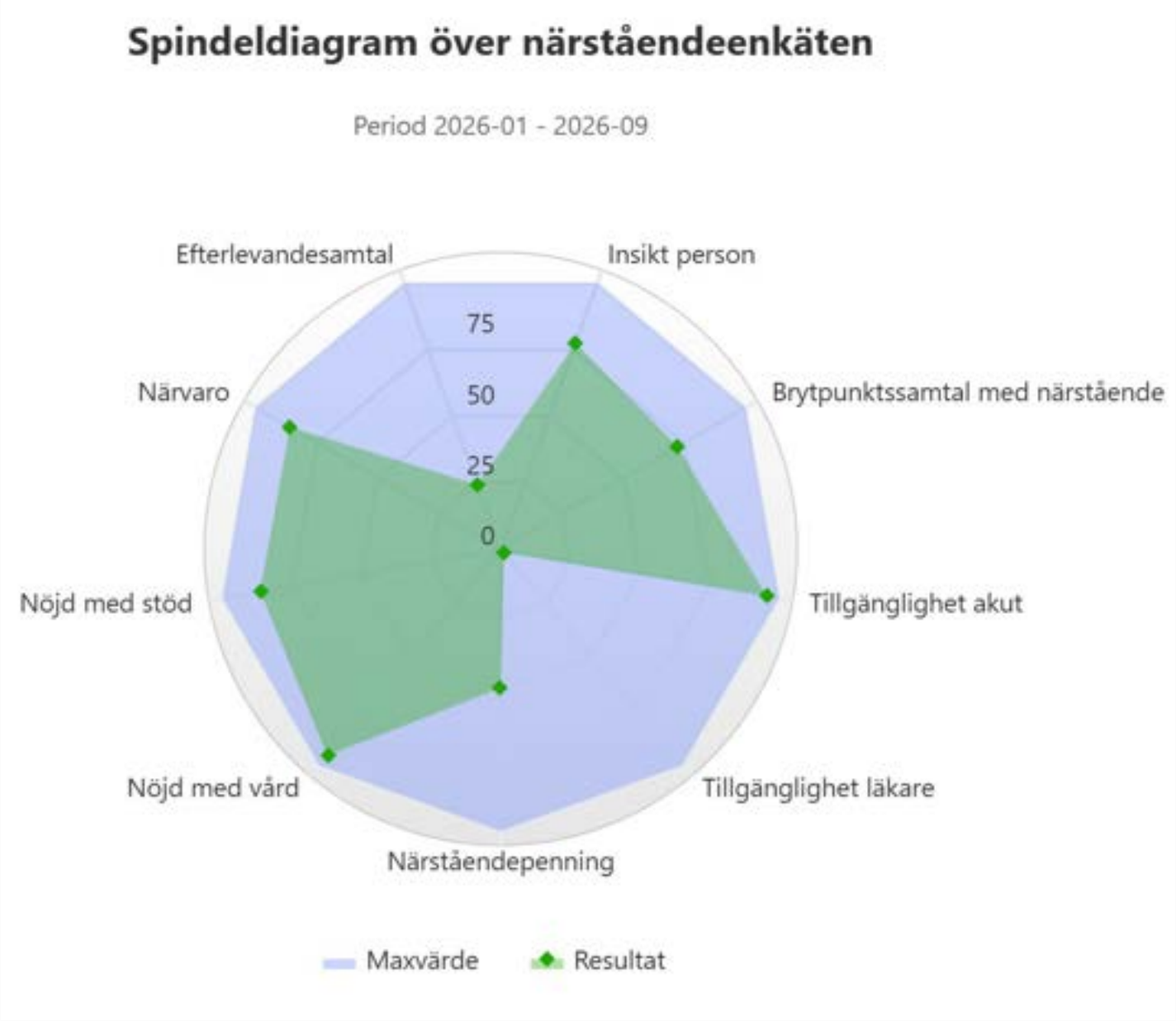
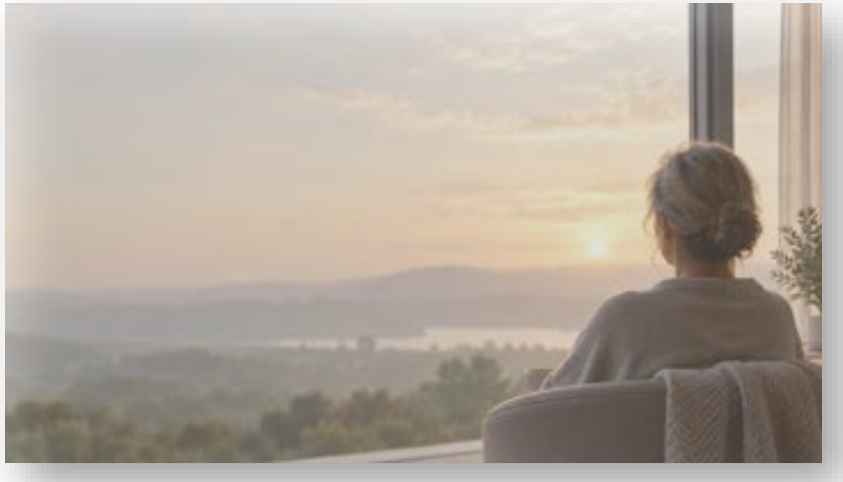
Sverige Alla

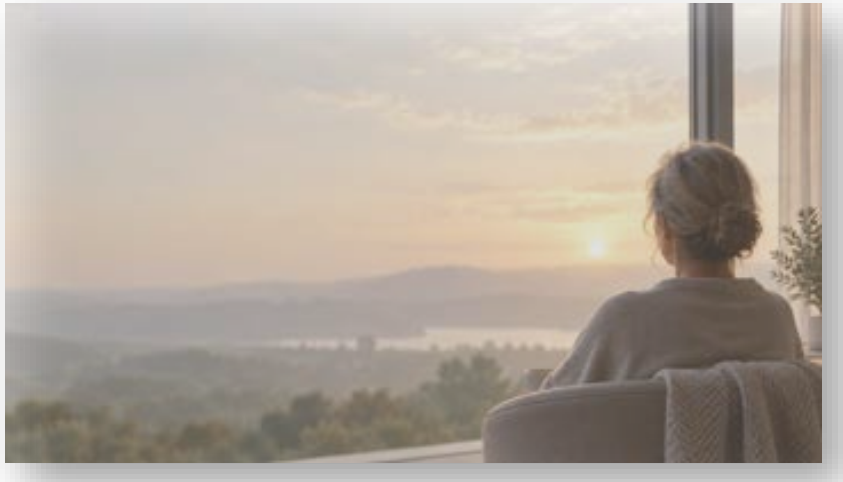


”Brist på näringsintag tror jag påskyndar förloppet och upplevs av anhöriga som en sorts passiv dödshjälp.”

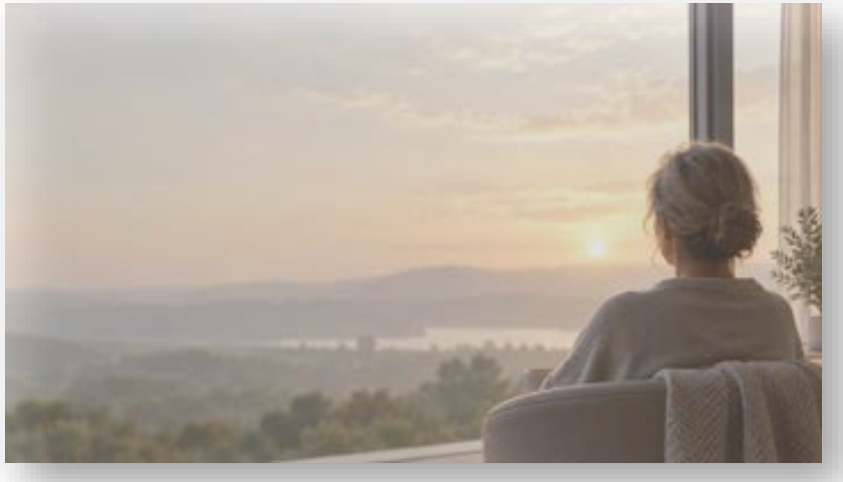
”Bättre info om olika sätt att hantera det praktiska efter ett dödsfall, inte bara en reklamfolder från begravningsbyråerna.”



”Ingen omvårdnad såsom lägesändringar, erbjuda vätska eller fukta mun samt inga byten av inkontinensskydd skedde under tiden vi var där vilket var större delen av dagarna.
Fick sedan veta att personalen inte gick in för att vi anhöriga var sjukvårdskunniga. Vilket absolut inte är okej.”



”Efter dödsfallet. Låt de anhöriga vara ensamma med den avlidna. Nu sprang personalen ut och in på rummet vilket inte kändes bra. Man kan samordna den information som ska lämnas till anhöriga och göra det i efterhand innan man lämnar sjukhuset.”



Varför Närståendeenkäten?

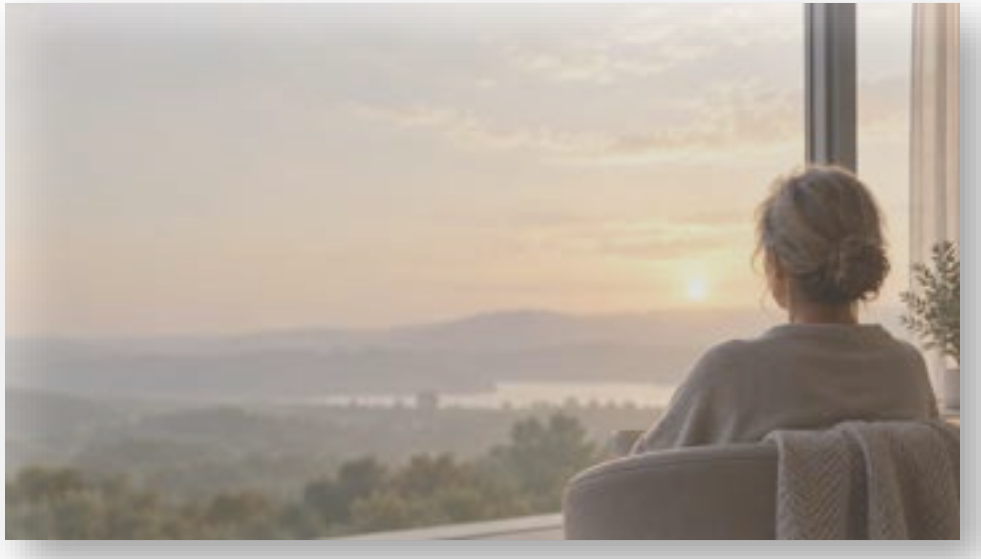
Återkoppling till personal

Jämföra era upplevelser av vård i livets slut

Förbättringsarbete

Jämföra med er själva och hela riket

VI sammanställer resultat ☺



Forskning

Kostnadsfritt för forskare

68 publicerade artiklar

Hemsidan

Publikationslista

2026

2025

2024

RESEARCH

Quality of end-of-life care among ir with and without dementia: a Swec registry-based study

Lisa Kastbom[1,2*], Johan Lyth[1], Johanna Simmons[1,3], Lisa Martinsson[4], Ma Staffan Lundström[7,8], Katarina Nägga[1,3†] and Anna Segernäs[1,2†]

Abstract

Background Despite dementia being a leading cause of death and clinical guide substantial gaps in care quality for this population have previously been shown. T compare the quality of end-of-life (EOL) care provided to individuals with and wit

Methods In this registry-based study, patients registered in the Swedish Register 2011 and 2020 were cross-referenced with patients in the Swedish registry for cog (SveDem). For each patient with dementia registered in SveDem ($n = 39\,712$), two matched by year of birth and gender were selected from the SRPC ($n = 79\,336$). Qu analyzed by group (dementia/controls) and by place of death, separately, using th logistic regression analyses were conducted to examine the association between diagnosis of dementia or not, overall and in different settings.

Results Individuals with dementia were more likely to have staff or family memb documented decisions to shift to EOL care, have symptom assessments made the of injectables. However, they were less likely to express preferences for place of de care transitions, especially in hospitals without specialized palliative care.

Conclusions In this study, individuals with dementia received higher quality EOL with those without dementia. However, they were less likely to have expressed pr These findings highlight the need for early, proactive care planning to align care w potentially non-beneficial actions.

Keywords End-of-life care, Palliative care, Dementia, Place of death, Advance care Quality registry

†Katarina Nägga and Anna Segernäs contributed equally to this work.

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BM

RESEARCH ARTICLE

Better quality of end-of-life care for p with advanced dementia in nursing compared to hospitals: a Swedish na register study

Lisa Martinsson[1*], Staffan Lundström[2,3] and Johan Sundelöf[4]

Abstract

Background: Hospitalisation of patients with advanced dementia is generally regarde to care at home or in a nursing home. For patients with other diagnoses, young age better end-of-life care. However, studies comparing the quality of palliative care for p dementia in hospitals and nursing homes are scarce. The aim of this study was to inv end-of-life care for patients with dementia depends on age, gender and place of dea

Methods: The Swedish Register of Palliative Care (SRPC) was used to identify patient hospitals or nursing homes during a three-year period. The likelihood of death occur age and gender differences, was calculated. Associations between 13 end-of-life care from the SRPC and age, gender and place of care were examined in a logistic regres

Results: Death at a hospital was associated with poorer quality of end-of-life care for outcomes when compared to death at a nursing home, and with better quality acco Death at a hospital was more common for men compared to women and for young Receiving fluids intravenously or via enteral tube in the last 24 h of life was strongly a hospital. Women were more likely to have their oral health assessed and less likely to Eight of 12 end-of-life care outcomes showed better results for the age group 65 to years or older.

Conclusions: Death in hospitals was associated with poorer quality of end-of-life car nursing homes. Our data support the importance of advance care planning and indiv homes to avoid referral to hospitals during end of life. Despite established recommer hospitalisation if possible, there were strong associations between younger age, male the end of life. Further studies are needed to investigate the role of socioeconomic fa this patient group.

Keywords: Dementia, Advanced dementia, Palliative care, End-of-life care, Hospitalisa Place of care

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PLOS ONE

RESEARCH ARTICLE

Quality of end-of-life care in patients with dementia compared to patients with cancer: A population-based register study

Lisa Martinsson[1]*, Staffan Lundström[2,3], Johan Sundelöf[4]

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Data Availability Statement: The data contain personally-identifying information, such as personal identity numbers, and potentially identifying information, such as date of death, and therefore are subject to ethical and legal restrictions on public sharing. We cannot share the data set, which is on individual level, because it is not permitted according to the laws that apply in Sweden. The permission we obtained for this study from the Regional Ethics Board at Umeå University, Sweden, only allowed public sharing on group level. Questions about register data availability can

Abstract

Introduction

Globally, dementia is one of the leading causes of death. Given the growing elderly population in the world, the yearly number of deaths by dementia is expected to increase. Patients dying from dementia are reported to suffer from a burden of symptoms similar to that of patients with cancer, but receive less medication against symptoms, have a lower probability of palliative care planning and seldom have access to specialised palliative care. Studies investigating the quality of palliative care in dementia are scarce. The aim of this Swedish national study was to compare the quality of end-of-life care between patients with dementia and patients with cancer regardless of place of care.

Methods

Thirteen end-of-life care quality indicators collected by the Swedish Register of Palliative Care (SRPC) were compared between patients dying from dementia and patients dying from cancer. Data were collected from deaths occurring in nursing homes, hospitals, specialised and general palliative home care, and palliative in-patient units during a three-year period (during March 2012 to February 2015). Analyses were performed using a multivariable logistic regression model, adjusted for age and gender. A subgroup of patients with Alzheimer's disease was identified and compared to patients with other and unspecified types of dementia.

Results

A total of 4624 deaths from Alzheimer's disease, 11 804deaths from other dementia diagnoses and 51 609 deaths from cancer were included. For six of the 13 quality indicators examined (prescription of PRN drugs against nausea and anxiety, information and bereavement support offered to next of kin, pain assessment and specialised palliative care consultations), poorer outcomes were shown for the dementia group in comparison to the cancer group. Two outcomes (prevalence of pressure ulcers and fluid therapy during the last 24

Kvartalets fråga

Ny fråga varje kvartal

Valfri

10-15 000 svar!

Q4 Samtal vid allvarlig sjukdom
- När?
- Vem?
- Innehåll?

Kunskapsstöd
Barn
Symtom
Skriftliga rutiner
Styrande dokument
Beställ material
Samtal vid allvarlig sjukdom

Publicerad: 2025-12-23

Samtal vid allvarlig sjukdom

Här hittar du fördjupningsfilm om samtal vid allvarlig sjukdom där du får möta patienter och personal och ta del av deras erfarenheter och reflektioner. Filmen är indelad i korta avsnitt. Ett eller flera avsnitt kan användas som utgångspunkt för reflektion, till exempel på en arbetsplatsträff eller under utbildning. Här finns även själva frågan i dödsfallsenkätem om samtal vid allvarlig sjukdom, Termer och Begrepp från Socialstyrelsen.

Filmserien som består av fyra delar:

- Samtal vid allvarlig sjukdom – En introduktion till begreppet Samtal vid allvarlig sjukdom.
- Samtal vid allvarlig sjukdom – Att komma igång med samtalen på er arbetsplats.
- Samtal vid allvarlig sjukdom – Att hålla samtal vid allvarlig sjukdom
- Samtal vid allvarlig sjukdom – Fördjupning med erfarenheter och reflektioner

Länk till filmer om samtal vid allvarlig sjukdom - Regionala cancercentrum i samverkan

Länkar till dokument gällande samtal vid allvarlig sjukdom.

Termer och begrepp från Socialstyrelsen

Frågan i dödsfallsenkäten inkl hjälptext.

Checklista vid misstanke om palliativa vårdbehov

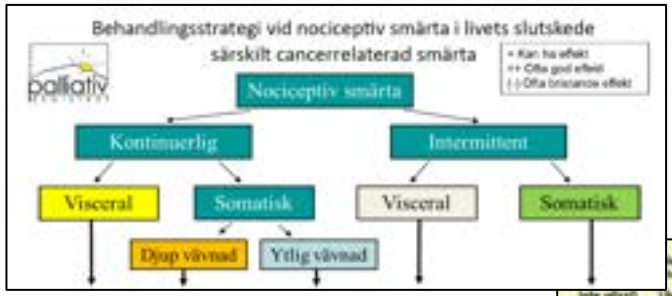
Vid ett eller flera **ja** bör en fördjupad bedömning av patientens palliativa vårdbehov utföras.

För patienter med en eller flera livshotande sjukdomar
Successivt försämrat allmäntillstånd trots fortsatt sjukdomsinriktad behandling.
WHO performance status 3–4 (I behov av vila mer än 50 procent av vaken tid).
Upprepade oplanerade vårdtillfällen på sjukhus utan klinisk förbättring.
Ofrivillig viktnedgång.
Otillräcklig symtomlindring.
Påtaglig oro, ångest eller stress hos patienten eller närstående.
Täta infektionsepisoder som kräver behandling.
Förväntad snabb utveckling av besvärande symtom.

Fundera även tillsammans i teamet kring förvåningsfrågan:
Skulle jag bli förvånad om personen dör inom det närmaste året?

Palliativt Centrum

Gratis kunskapsmaterial



Varför Svenska palliativregistret?

Identifiera förbättringsområden

Underlag för beslutsfattare

Bidra till forskning

Finns ingen motsvarighet i världen!

Förbättra palliativ vård för patient och närstående!

Att mäta för att veta!

Tack!

www.palliativregistret.se