Masterproef: de palliatieve attitude van een arts, een conceptanalyse

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Geachte lezer,

Met trots presenteren wij u deze thesis over het belang van een goede palliatieve attitude bij zorgverleners en wat deze juist inhoudt. Deze masterproef is het resultaat van intensieve studie, analyse en reflectie, en markeert het einde van een boeiende en leerzame periode in ons academische traject.

Palliatieve zorg is een essentieel onderdeel van het medische landschap, en de rol van zorgverleners in het bieden van hoogwaardige en compassievolle zorg aan patiënten met levensbeperkende aandoeningen kan niet worden overschat. In deze thesis hebben we ons gericht op het begrijpen van de attitude die nodig is voor effectieve palliatieve zorgverlening, en hebben we de antecedenten, attributen en consequenties van deze attitude onderzocht aan de hand van uitgebreide literatuurstudie.

Het schrijven van deze thesis was een uitdagende, maar uiterst verrijkende ervaring. We hebben veel geleerd over palliatieve zorg, attitudevorming, en het belang van educatie en bewustwording in de gezondheidszorg. We willen dan ook graag onze dank uitspreken aan onze begeleiders, vrienden en familie die ons hebben gesteund tijdens dit proces.

We hopen dat deze thesis niet alleen een waardevolle bijdrage levert aan het bestaande onderzoek naar palliatieve zorg, maar ook een bron van inspiratie en inzicht vormt voor toekomstige zorgverleners en onderzoekers. Het is onze oprechte wens dat de bevindingen en inzichten die we hebben opgedaan in dit onderzoek bijdragen aan de verbetering van de kwaliteit van palliatieve zorg wereldwijd.

Nogmaals dank aan iedereen die heeft bijgedragen aan dit project, en we hopen dat u geniet van het lezen van deze thesis en de inzichten die het biedt.

Met vriendelijke groet,

Anneleen Weyns en Justin Depauw

Abstract

Inleiding: Palliatieve zorg is van cruciaal belang in het hedendaagse zorglandschap, gericht op het verbeteren van de levenskwaliteit van patiënten met levensbeperkende ziekten. Hierbij is een palliatieve attitude een kernbegrip in het huidige landschap. Toch bestaat hier weinig tot geen literatuur over op heden. Deze masterproef verkent de palliatieve attitude van artsen, met als doel een werkbare definitie te formuleren en de bijbehorende attributen, antecedenten en consequenties te identificeren van een goede palliatieve attitude.

Methodologie: De methodologie van Avant & Walker's conceptanalyse werd toegepast in vijf stappen. Allereerst werd het concept "palliatieve attitude" gedefinieerd als "een geheel van opvattingen, gevoelens en genegenheden van een arts tot handelen t.o.v. een patiënt in een levenseinde situatie bij volwassenen". Vervolgens werden relevante literatuurbronnen geselecteerd met behulp van MESH-termen in databanken zoals PubMed en Google Scholar. Literatuur werd geanalyseerd en geëxtraheerd om antecedenten, consequenties en attributen te identificeren, passend bij een goede en universele palliatieve attitude van een arts. Dit werd gedaan aan de hand van een extractietabel. Vervolgens werden de begrippen geklasseerd onder overkoepelende termen, die nadien gecondenseerd werden tot een finale lijst met attributen, antecedenten, consequenten.

Resultaten: De bevindingen onthulden cruciale attributen van een positieve palliatieve attitude, waaronder effectieve communicatie, multidisciplinaire zorg, respect voor patiënt autonomie en een holistische benadering. Ook de persoonlijke overtuiging van de arts was een belangrijk attribuut. Antecedenten, zoals end-of-life educatie en cultureel begrip, overtuigingen van zowel zorgverlener als patiënt en ervaring van de zorgverlener werden geïdentificeerd als essentieel voor de ontwikkeling van een dergelijke houding. Consequenties omvatten adequate zorg, verrijkte ervaringen rondom de dood, verbeterde levenskwaliteit, kosteneffectiviteit en open communicatie.

Conclusie: Deze conceptanalyse biedt inzicht in de palliatieve attitude van artsen en benadrukt het belang van gerichte educatie en interventies. De resultaten wijzen op de noodzaak van het ontwikkelen van communicatieve vaardigheden, culturele competenties en multidisciplinaire samenwerking in de opleiding van artsen. De bevindingen dienen als basis voor verdere strategieën ter verbetering van de palliatieve zorg, met als uiteindelijk doel een respectvolle en holistische benadering voor patiënten in hun laatste levensfase te waarborgen.

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Bijlage ..... ***Fout! Bladwijzer niet gedefinieerd.***

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Introductie

Palliatieve zorg is volgens de *World Health Organisation* (WHO) een benadering van medische zorg die zich richt op het verbeteren van de kwaliteit van leven voor patiënten met een levensbeperkende of langdurige chronische ziekte zonder uitzicht op beterschap. Het heeft als doel om lijden te lenigen door vroege identificatie, correcte beoordeling en behandeling van pijn en andere problemen. Er wordt hiervoor aandacht besteed aan zowel fysieke, emotionele als spirituele behoeften. Hiermee behoort palliatieve zorg dan ook tot een cruciaal aspect van geïntegreerde, mensgerichte voorzieningen. (1)

Door vergrijzing van de bevolking treden niet-overdraagbare chronische aandoeningen meer op de voorgrond. Palliatieve zorg krijgt hierdoor een steeds groter belang binnen het huidige zorglandschap. Elk jaar hebben naar schatting 56.8 miljoen mensen nood aan palliatieve zorg, waarvan 25.7 miljoen mensen reeds het eindstadium van het leven bereikt hebben (1). Er krijgt slecht 14% van de patiënten die nood hebben aan palliatieve zorg deze toegediend (1).

Barrières tot palliatieve zorg

Er zijn enkele cruciale barrières bekend die ervoor zorgen dat er een discrepantie is tussen zorgnood en zorgverstrekking als het gaat om palliatieve zorg. Een voorbeeld hiervan situeert zich op het niveau van legislatuur: slechts 8 Europese landen hebben nationale wetten die palliatieve zorg betreffen (1). Ook in de Verenigde Staten wordt een gebrek aan nationale strategie beschreven als het gaat over palliatieve zorg (2). Daarnaast zijn er gebreken op vlak van beleidsvoering, accreditatie en toegang tot opioïde substanties voor pijncontrole (1,2).

Daarnaast is er onvoldoende inzicht bij beleidsmakers, zorgverleners en de algemene bevolking over welke voordelen palliatieve zorg zou kunnen hebben voor zowel de patiënt als de gezondheidszorg (1,2). Er zijn misconcepties op verschillende gebieden: sociaal, cultureel, de situering van palliatieve zorg in het leven,... (1). Om inzicht te verhogen en misconcepties aan te pakken, zou educatie een belangrijke rol kunnen spelen (1,3).

Het samengaan van kennis met attitude en vaardigheden heeft reeds een bewezen effect op het vergaren van competentie in een bepaald medisch veld (9). Eerdere studies met nadruk op educatie bespreken attitudes in het kader van het bekomen van professionele en persoonlijke groei bij zorgverleners (1,8-10). Er worden hierbij thema's aangehaald zoals autonomie van de patiënt, het ondersteunen van zowel patiënt als zorgverlener, het accepteren van een ongewenst verloop,... (1,8,9). Het valt hier echter op dat een duidelijke definitie van wat een attitude juist inhoudt niet duidelijk gestipuleerd wordt.

Attitude: wat is dat nu juist?

Het begrip attitude op zich wordt in de literatuur besproken als een concept dat gedefinieerd wordt door drie hoofdattributen (10,11). Er is een cognitieve, een affectieve en een gedragsmatige component die bijdragen tot een geheel van opvattingen, gevoelens en genegenheden tot handelen ten opzichte van iets of iemand in een bepaalde situatie (10,11). Persoonskenmerken, normen, waarden, gevoelens en ideeën gaan hierin een bepalende rol spelen (11). Deze studie toont reeds de complexiteit van het concept attitude aan: een attitude strekt zich uit over alle aspecten van gedrag en intellect, en kan ook op een onbewust niveau aanwezig zijn bij een individu (10). Echter, een veralgemening naar andere attitudes is niet onmiddellijk te maken. Er is weinig literatuur over het begrip attitude.

Wanneer we kijken naar een attitude in functie van palliatieve zorgverlening, komen er geen duidelijke definities in de literatuur naar voor. Nochtans is het een begrip dat regelmatig naar voren komt in de alledaagse praktijk. Het wordt erkend dat een attitude in zijn hoedanigheid een belangrijk onderdeel is in het integraal functioneren van een arts (11). Aangezien een palliatieve attitude een belangrijk

aandeel heeft in palliatieve zorgverlening, dient een goede definitie gesteld te worden van wat deze attitude nu juist inhoudt. Het gebrek aan een duidelijke definiëring zou ertoe kunnen leiden dat de operationalisering van competenties en de evaluatie hiervan niet eenvoudig uitvoerbaar is.

Op basis van een conceptanalyse van de literatuur wordt in deze masterproef getracht een heldere definitie te formuleren van het begrip 'palliatieve attitude'. Een conceptanalyse laat toe om een veelvuldig gebruikt begrip eenduidig te definiëren. De literatuur wordt gescreend om alle mogelijke gebruiken van het begrip na te gaan. Een belangrijk aspect hierbij is het bepalen van de definiërende attributen van het concept: dit zijn karakteristieken die essentieel zijn voor het concept, die eveneens de uiteindelijke definitie grotendeels zullen vormen. Vervolgens is het belangrijk om antecedenten te gaan beschrijven: dit zijn factoren, afgeleid uit de literatuur, die het concept voorafgaan. Daarnaast worden consequenten beschreven: deze zijn het resultaat of de gevolgen van het concept.

Met deze conceptanalyse wordt getracht een eenduidige definitie voorop te stellen om toekomstig onderzoek naar wat juist een goede attitude inhoudt en hoe deze bekomen wordt. Dit eindwerk heeft ook als doel toekomstig onderzoek meer uniform te doen verlopen.

Methodologie

Voor deze masterproef werd gekozen een conceptanalyse uit te voeren over het begrip 'palliatieve attitude' volgens de methode van Avant & Walker. Hier werd als doel vooropgesteld een werkbare definitie te bekomen.

Stap 1: keuze concept

Als concept werd voor palliatieve attitude volgende definitie naar voor geschoven:

"*Een geheel van opvattingen, gevoelens en genegenheden van een arts tot handelen t.o.v. een volwassen patiënt in een levenseinde situatie".*

Er wordt hierbij gekozen om een palliatieve attitude toe te lichten naar volwassen patiënten toe. Palliatieve zorg bij pediatrische patiënten gaat gepaard met andere ethische dilemma's, de familie is veel meer betrokken en er zijn nog meer discussies omtrent wilsbekwaamheid.

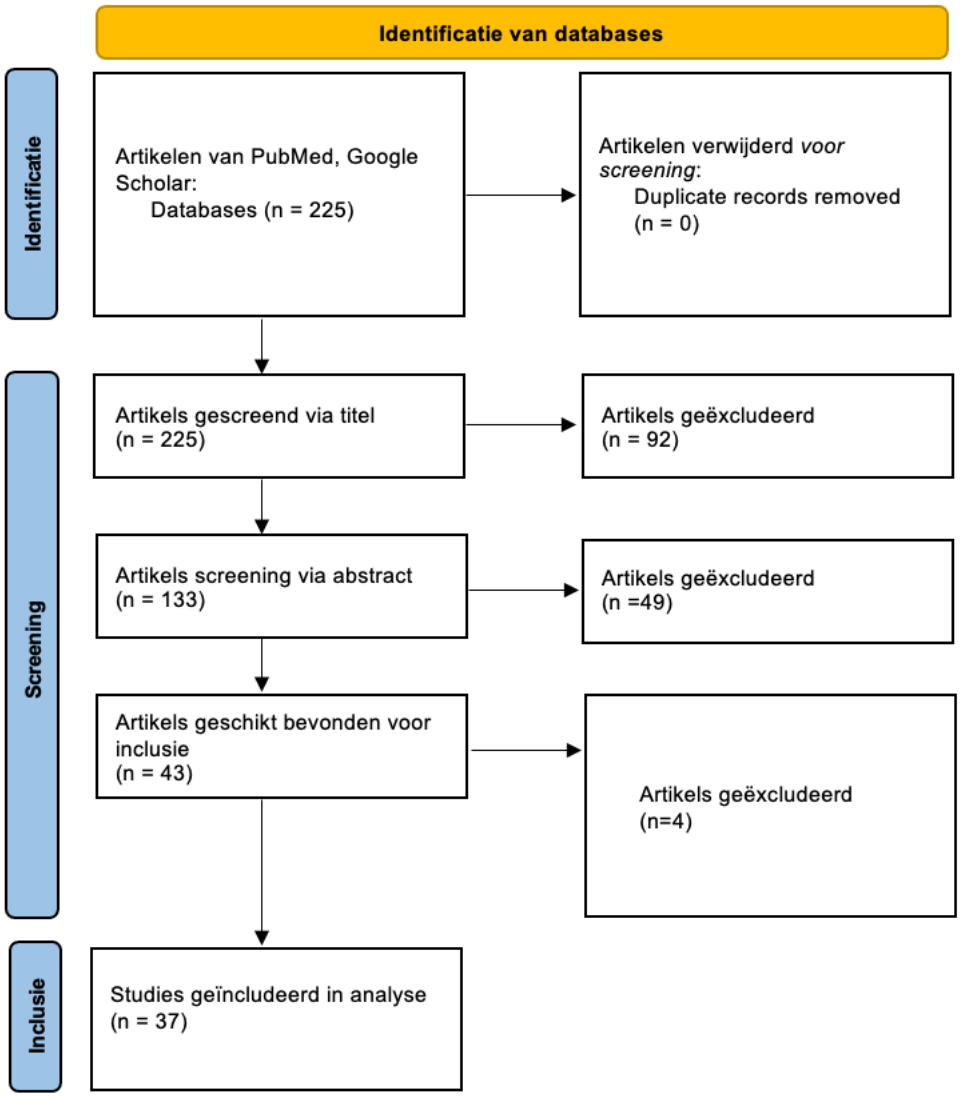
Stap 2: Selectie literatuur

Literatuur werd geselecteerd op basis van de volgende MESH termen: 'palliative *care', 'palliative medicine', 'physicians', 'attitude', 'nurses', 'end of life care*'. Hierbij werden databanken PubMed en Google Scholar gebruikt. Dit leverde 225 zoekresultaten op.

Er werden exclusiecriteria vooropgesteld. Zo werden artikels met een publicatiejaar voor 2000 niet weerhouden, daar in België bv. pas een wet werd afgekondigd rond palliatieve zorg in 2002. Hierna is er nog een grote evolutie in het landschap geweest. Artikels betreffende pediatrische palliatieve zorg werden niet weerhouden wegens hierboven vermelde redenering. Daarnaast werden artikels uitgefilterd die een bepaalde skill bespraken in de palliatieve zorg: wanneer er medicamenteuze behandelingen of technische uitvoeringen in de palliatieve zorg werden besproken, week dit af van het doel om een attitude te gaan beschrijven. Focus op beleidsvoering, symptoomcontrole, implementatie van guidelines waren wegens gelijkaardige redenering niet includeerbaar in deze conceptanalyse. Artikels die het uitvoeren van euthanasie of physician assisted suicide bespraken, werden niet geïncludeerd omdat dit slechts een zeer nauw aspect van palliatieve zorg is met eveneens een ander ethisch kader dan het toepassen van palliatieve zorg.

De concrete inclusiecriteria waren als volgt. De artikels die barrières in de palliatieve zorg bespraken waren belangrijk wegens het vooropstellen van attitudes als barrière in het bovenvermelde artikel van het *European Association of Palliative Care.* Artikels moesten attitude aanhalen of percepties bespreken die aanwezig zijn bij artsen en/of verpleegkundigen.

Bij de screening van de titels werden 133 artikelen weerhouden. Vervolgens werd gescreend op abstract. Hierbij werden volgens de vooropgestelde criteria 92 artikelen weerhouden. Na een uitgebreide full tekst screening werden 43 studies opgenomen in de analyse, waarvan 37 artikelen gebruikt werden in het opstellen van de conceptuele analyse.



Figuur 1: PRISMA flowchart literatuurstudie

Stap 3: extraheren van literatuur

De onderzoeksvraag was gebaseerd op het vooropstellen van een definitie van 'palliatieve attitude'.

Om overzichtelijk data te krijgen werd een extractietabel opgesteld. Hierbij werd door beide thesisstudenten meermaals de artikels doorgenomen en gescreend naar informatie in de artikels die

aan zouden kunnen sluiten bij het bekomen van een definitie voor palliatieve attitude. Stelselmatig werden zo excerpten uit de artikels gehaald en verbatum overgenomen in de initiële tabel.

Nadien werd de tabel gecondenseerd. Er werd in overleg tussen de twee studenten getracht de kern van de boodschap in een beknopte samenvatting te distilleren. Deze werd vervolgens in een nieuwe tabel gegoten: de tabel met 'hoofdpunten' in.

Stap 4: onderverdeling in antecedenten, consequenten en karakteristieken

Volgens de methode van Walker & Avant dient bij een concept gekeken te worden naar antecedenten, consequenten en karakteristieken van een bepaald concept.

De hoofdpunten in de tabel werden gesorteerd volgens deze definities. Een attribuut werd beoordeeld als een karakteristiek voor het concept. Een antecedent was een factor voorafgaand aan het concept. Een consequent was een factor die als gevolg kon gezien worden van het concept. Zo bekwamen we 3 lijsten met verschillende termen die zouden passen bij een antecedent, consequent of karakteristiek van het concept 'palliatieve attitude'.

Deze termen werden vervolgens zo veel mogelijk samengebracht onder overkoepelende termen die een verband legden tussen verschillende hoofdpunten. Hiermee werden de uiteindelijke lijsten bekomen van termen die binnen het kader van een palliatieve attitude zouden kunnen passen.

Stap 5: verwerking van de data.

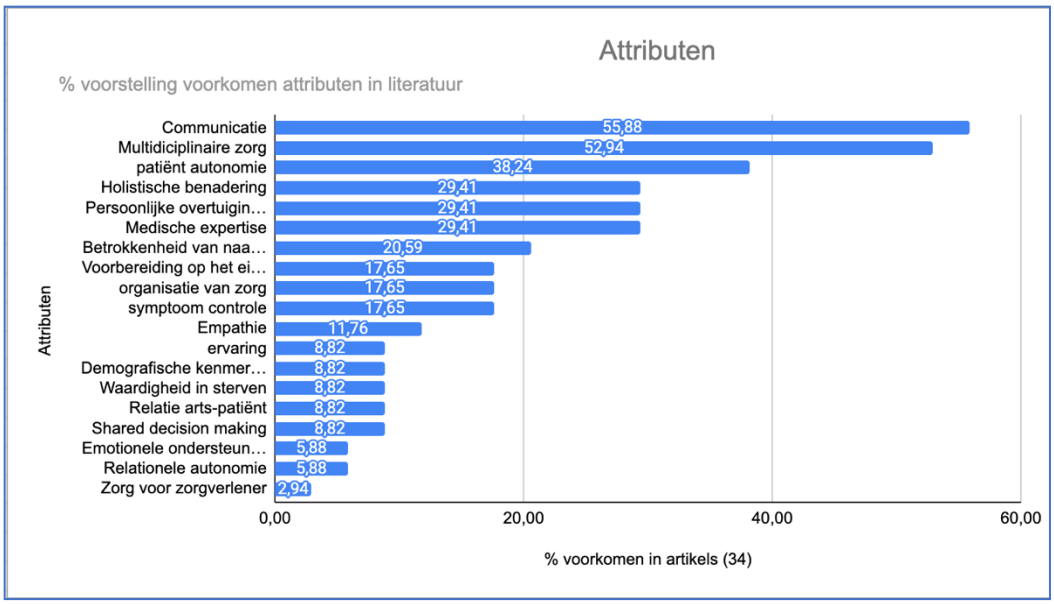
Per categorie (antecedenten, consequenten of attributen) worden verschillende eindtermen bekomen. Deze eindtermen werd een gewicht toegekend door na te gaan in de literatuur in hoeveel van de geselecteerde artikels dit voorkwam. Een totaaloverzicht van alle antecedenten, attributen en consequenten werd grafisch weergegeven en opgelijst in tabellen. Hierbij werd arbitrair besloten de 5 meest beschreven termen te weerhouden als hoofdkenmerken in de literatuur ter beschrijving voor een palliatieve attitude. Een totaaloverzicht van alle antecedenten, attributen en consequenten werd grafisch weergegeven en opgelijst in tabellen. Vervolgens werd vanuit de literatuur geciteerd om aan te tonen welke termen juist verbonden worden aan de termen die vooropgesteld werden.

Er werd gekozen om gewicht toe te kennen op basis van voorkomen in geselecteerde literatuur. Dit om eerder aan te geven hoe frequent in literatuur deze eindterm reeds aan bod kwam. Een andere optie was om te bekijken hoeveel van de geselecteerde termen samen te vatten waren onder de eindterm. Gezien het samenvatten nog een zekere subjectieve component heeft, ondanks dat deze zoveel mogelijk geminimaliseerd werd door het samenwerken tussen de studenten, kan zo een overkoepeling een verkeerd beeld geven van het belang van een bepaalde eindterm.

Resultaten:

Attributen

De attributen van een goede palliatieve attitude worden in deze sectie behandeld, gebaseerd op de literatuuranalyse. Figuur 2 geeft grafisch weer welke attributen in welke mate voorkomen in de literatuur. Verder toont tabel 1 een overzicht van de diverse kenmerken en vaardigheden die nodig zijn voor het ontwikkelen van een effectieve palliatieve attitude bij zorgverleners. Elke eigenschap wordt kort toegelicht om de lezer een beter begrip te geven van wat de betekenis is van de belangrijkste attributen.



***Figuur 2**: Overzicht attributen: hoofdeigenschappen van het concept. Percentage geeft weer hoe frequent genoemde attributen voorkomen in de geselecteerde artikels. In 34 van de 37 artikels werden attributen weerhouden.*

1. **Communicatie (55,88%)**: Binnen het kader van dit onderzoek wordt communicatie gedefinieerd als het proces van informatie uitwisseling tussen zorgverleners, patiënten en hun familieleden. Hierbij werden verschillende aspecten geïncludeerd waaronder de frequentie van gebruik van communicatieve termen in de literatuur, het verstrekken van eerlijke prognostische informatie, de wijze waarop communicatie over het levenseinde plaatsvindt, de communicatie over het stervensproces en de voorkeuren van patiënten met betrekking tot therapieën en de interactie tussen zorgverleners en patiënten of hun familie.
2. **Multidisciplinaire Zorg (52,94%):** Het begrip multidisciplinaire zorg omvat diverse aspecten van samenwerking en coördinatie tussen verschillende disciplines binnen de gezondheidszorg. Dit omvat niet alleen de theoretische concepten van multidisciplinaire zorg, maar ook de praktische aspecten zoals teamwerk, samenwerking, interdisciplinaire communicatie en coördinatie tussen de zorgverleners.
3. **Patiënt autonomie (38,24):** Patiënt autonomie wordt gedefinieerd als het vermogen van de patiënt om zelfbeschikking uit te oefenen over zijn of haar medische behandelingen en beslissingen. Dit omvat het respecteren van de wensen van de patiënt, het ondersteunen van de besluitvorming van de patiënt, het betrekken van de patiënt en zijn of haar familie bij beslissingen en het bevorderen van de capaciteit vand e patiënt om actief deel te nemen aan zijn of haar zorgproces.
4. **Holistische benadering (29,41%):** De holistische benadering van palliatieve zorg erkent de complexe en multidimensionele aard van het menselijke leven en sterven. Dit omvat niet alleen medische zorg, maar ook aandacht voor de culturele, ethische, religieuze en spirituele behoeften van de patiënt. Een holistische benadering streeft naar patiëntgerichte zorg die het individu in zijn totaliteit behandelt.
5. **Persoonlijke Overtuigingen van de Zorgverlener (29,41%):** De persoonlijke overtuigingen van de zorgverlener omvatten de persoonlijke interesses en emoties van de zorgverlener, hun zelfvertrouwen in het omgaan met palliatieve situaties, bewustzijn van persoonlijke angsten met betrekking tot dood en sterven, perceptie van hun rol in de zorg, en de manier waarop zij omgaan met ethische en professionele dilemma's in de palliatieve zorg.

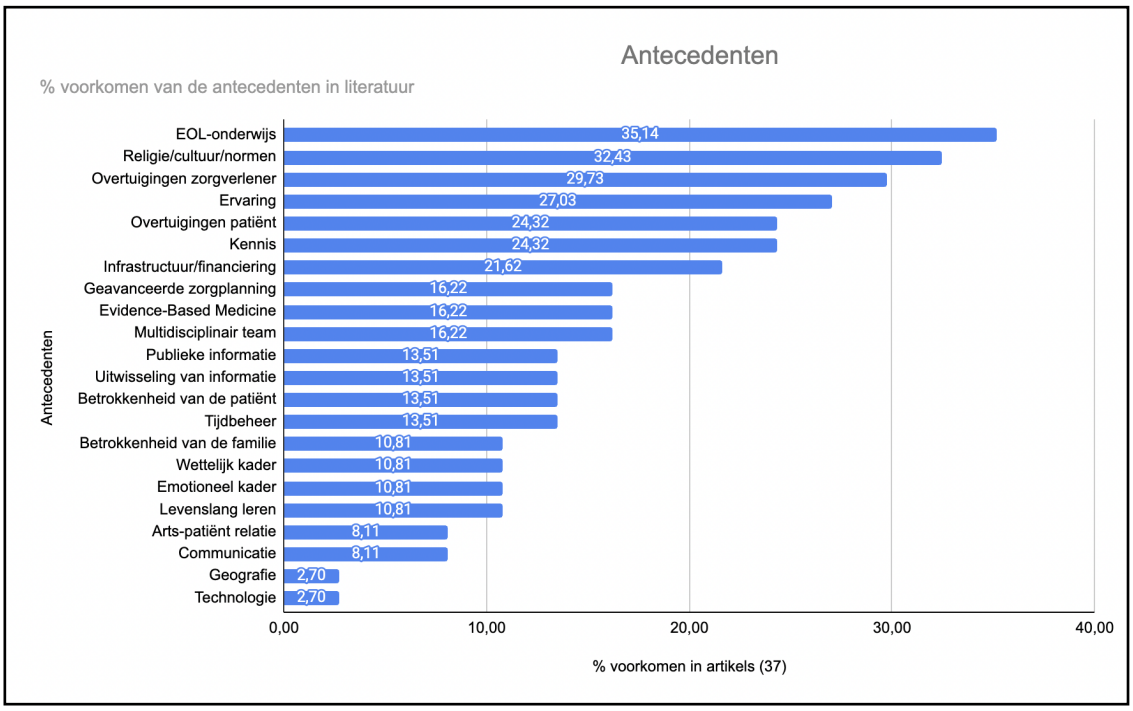
ATTRIBUTEN	VOORKOMEN IN LITERATUUR (%)	BESCHRIJVING IN LITERATUUR
Communicatie	55,88	Honest prognostic information, answering informational needs, communication, prognostication, communication at the end of life, communication with patient and family, communication between personnel and family, informing family and patient about diagnosis and prognosis, need for appropriate communication, patients want informed decision, asking patient about wanting information, communication of treatment preferences.
Multidisciplinaire zorg	52,94	Interaction with interdisciplinary members, multidisciplinary care, teamwork, collaboration among disciplines, collaborator, communication between personnel, cooperation between health care personnel, interdisciplinary communication
Patiënt autonomie	38,24	Patient autonomy, wishes of the patient, autonomy, empowerment, support of patients' decision making, patients' wishes and goals of care, involvement of patient, respect for the patient, respect for the patients' wishes, patients' participation in EOL decision making, patient preference
Holistische benadering	29,41	Holistic approach, holistic support, psychosocial issues, spiritual aspect, respecting culture, patient centered care, holistic EOL care, cultural context, ethics, spiritual and psychological support, spirituality considered as integral part of care, addressing spiritual and emotional needs
Persoonlijke overtuigingen van de zorgverlener	29,41	Interest, emotions physician, attitudes of health care providers, self confidence, sense of justice, ability to accept medical limits and death, levels of spirituality or religiosity of the physician, recognition of own emotions by physician, cultural background caregiver, physicians' perception of role, enthusiastic faculty who find palliative medicine professional rewarding
Medische expertise	29,41	Great global knowledge in palliative care, duty of the physician to assess if treatment is medical futile, difference in viewpoint according to specialty, competence, knowledge, responsibility of physician, expertise of the physician, profession
Betrokkenheid van naasten	20,59	Involvement of family members, involvement of family, wishes of the family of the patient, communication with family, involvement of significant others .
Voorbereiding op het einde van het leven	17,65	Prepare for bereavement, giving family time to cope, responsibility of the physician to help patient face EOL, hope of the patient, dealing with emotions of the patient regarding EOL, normalization of death experience
Organisatie van zorg	17,65	Compliance of the law, legal framework, longitudinal support, lack of attainable goals of care, need to optimize profit, accessibility

Symptoombestrijding	17,65	Painmanagement, symptom management, management of symptoms, management pain
Empathie	11,76	Empathy, type of approach, emphatic patient centered style of the physician
Ervaring	8,82	Attending physicians older than 35 years were more comfortable than their younger colleagues, participants' confidence in explaining the role of palliative care to patients, senior vs junior physicians, lifetime learner in EOL competence
Demografische kenmerken van de zorgverlener	8,82	Sex, demographics, ethnicity, age
Waardigheid in sterven	8,82	Dignity, respect, sense of dignity in death
Relatie arts-patiënt	8,82	Relationship between physician and patient and/or family, a long term patient-doctor relationship, relationship between healthcare personnel and patient, knowledge of the situation of the patient
Shared decision making	8,82	Shared decision making
Emotionele ondersteuning	5,88	Spiritual support for patients and families, emotional support
Relationele autonomie	5,88	Relational autonomy, relational understanding of autonomy .
Zorg voor zorgverlener	2,94	Emotional and organizational support of the staff

***Tabel 1**: Oplijsting alle overkoepelende termen attributen, percentage van voorkomen in de literatuur en betrokken termen.*

Antecedenten:

In deze sectie worden de antecedenten van een goede palliatieve attitude besproken, zoals geïdentificeerd in de literatuur. De figuur (figuur 3) geeft een overzicht van de verschillende factoren die van invloed kunnen zijn op de ontwikkeling van een palliatieve attitude bij zorgverleners. De belangrijkste antecedenten worden vervolgens besproken. Aansluitend toont tabel 2 alle gevonden attributen in de literatuur. Elk item wordt kort beschreven om de lezer een duidelijk beeld te geven welke belangrijkste antecedenten die zijn geïdentificeerd in de studie.



Figuur 3: *Overzicht antecedenten: voorafgaand aan concept. Percentage geeft weer hoe frequent genoemde antecedenten voorkomen in de geselecteerde artikels. In 37 van de 37 artikels werden antecedenten weerhouden.*

1. **Levenseinde-educatie (35,14%)**: Binnen dit onderzoek wordt de term 'levenseinde educatie' gebruikt om verschillende aspecten van educatie met betrekking tot het levenseinde te benadrukken. Dit omvat niet alleen algemene educatie maar ook specifieke trainingen en programma's gericht op palliatieve zorg, zoals de integratie van palliatieve zorg in medische curricula, de behoefte aan training en educatie voor zorgverleners, training in levenseindezorg, educatieve initiatieven voor personeel en educatie die gecombineerd wordt met klinische praktijkervaring.
2. **Religie/cultuur/normen (32,43%):** De complexe dynamiek van religie, cultuur en normen binnen de context van palliatieve zorg komt naar voor binnen deze analyse. Dit omvat een breed scala aan aspecten, zoals de religieuze en culturele achtergrond van patiënten en zorgverleners, de invloed van socio-culturele normen op de acceptatie van de dood en de rol van religieuze en culturele overtuigingen bij besluitvorming rond het levenseinde. Ook worden ethische bezorgdheden en sociale attitudes ten opzicht van leven en dood, evenals de psychologische en spirituele ondersteuning binnen deze context, geïncludeerd.
3. **Overtuigingen van de zorgverlener (29,73%)**: Overtuigingen van de zorgverlener belichten de persoonlijke overtuigingen en attitudes van de zorgverleners t.o.v. levenseinde en palliatieve zorg. Dit omvat onder andere de religieuze achtergrond van zorgverleners, bestaande misconcepties over palliatieve interventies, de waarde die zorgverleners hechten aan het leven, en hun gedrag en zelfevaluatie van competenties in de palliatieve zorg. Daarnaast wordt ook gekeken naar hoe zorgverleners omgaan met de dood, hun visie op het bespreken van levenseindekeuzes met patiënten en hun emotionele betrokkenheid bij palliatieve zorg.
4. **Ervaring (27,03%)**: De verschillende aspecten van ervaring die relevant zijn voor een palliatieve attitude worden hier besproken. Dit omvat de werkervaring van zorgverleners, hun expertise in palliatieve zorg, en hoe zij leren en zich ontwikkelen door klinische ervaring. Ook wordt de tijd die zorgverleners besteden aan palliatieve zorg en de frequentie van zorg voor terminale patiënten mee in rekening genomen.
5. **Overtuigingen van de patiënt (24,32%):** De verwachtingen en percepties van patiënten, hun religieuze en spirituele overtuigingen en hun openheid voor discussies over het levenseinde worden hier besproken. Ook wordt gekeken naar hoe deze overtuigingen en voorkeuren

kunnen variëren over de tijd. De behandelingsvoorkeur van een patiënt dient hier ook mee in gedachte genomen te worden.

ANTECEDENTEN	VOORKOMEN IN LITERATUUR (%)	BESCHRIJVING IN LITERATUUR
Educatie	35,14	Preparation for EOL care, education in palliative care, educational activities, palliative care in medical curriculum, educated stakeholders, education and training for healthcare personnel, physician training in communication, education, training in EOL care, communication skill training, staff education, residency training, education combined with clinical provision
Religie/cultuur/normen	32,43	Cultural background, socio-cultural acceptance of death, spiritual support for patients and families, cultural and socio-economic factors, norms in society, psycho-socio-economic environment, social attitudes and norms, an individuals' personal-cultural-social and spiritual constructs, anticipation of the need of ethical decision making, ethical concerns, cultural and spiritual context
Overtuigingen zorgverlener	29,73	Religious affiliation physician, misconceptions on palliative care interventions, validation of life by physician, behavior of physician in palliative care, self assessment level of competence, dealing with death perceived as dealing with failure, DNR perceived as a right, similar religious beliefs between caretakers, physicians' religious beliefs and attitudes to life and death, physicians feeling of preparedness, religion of the physician, concerns regarding patients hopes, current state of the patient, emotional involvement of the physician, perception of advance directives
Ervaring	27,03	Work experience in palliative care, experience in palliative care, experience in EOL care, practice level, experience EOL, job, frequent care for terminal patients, time spent in hospice care
Overtuigingen van de patiënt	24,32	Perceptions of patients and their families, patient/family expectations, patients wishes and goals of care, patients' personal religious and spiritual beliefs, readiness of the patient to discuss EOL, religion of the patient, variability in patients wishes over time, patients preferential type treatment, patients' expectations
Kennis	24,32	Knowledge, knowledge of palliative care interventions, medical knowledge, medical expertise, knowledge of diagnosis, knowledge of EOL

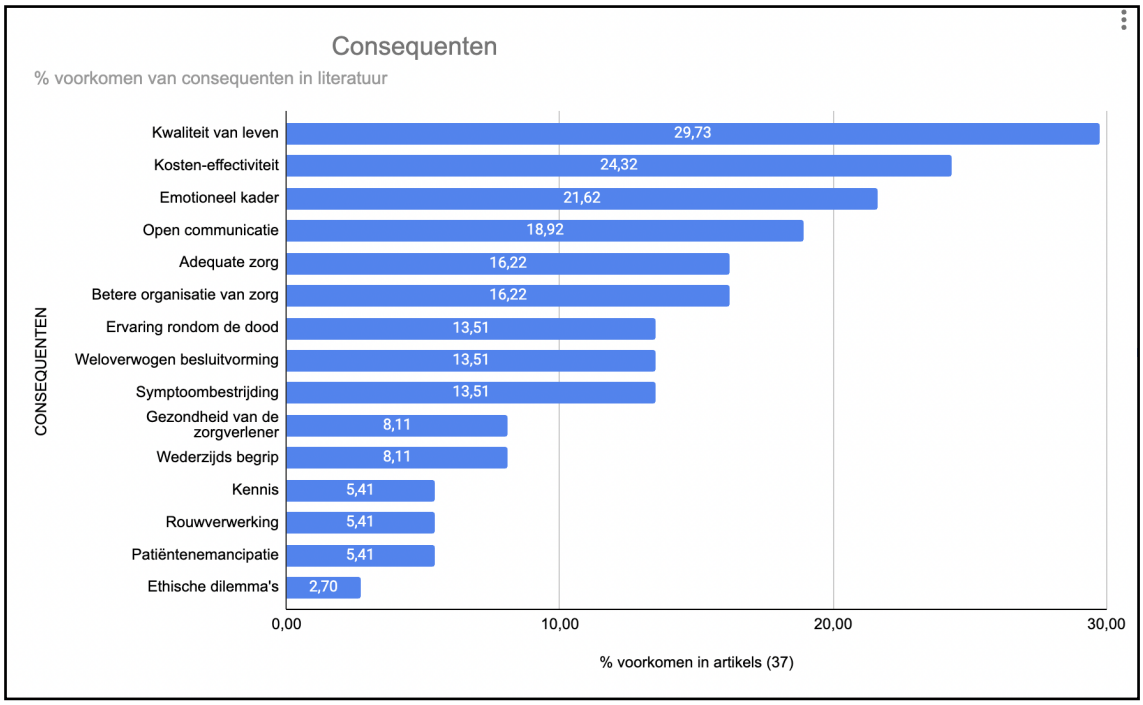
Middelen	21,62	Institutional barriers, need to optimize profit, staff management, distribution of palliative care facilities and funds, institutional factors such as budget and infrastructure, budget, resources, timely access to palliative or hospice care
Vroegtijdige zorgplanning	16,22	Presence of advance directives, EOL care planning, providing advance care planning, early palliative discussions, physicians' understanding of directives
EBM (Evidence-Based Medicine)	16,22	Decision making process, symptom management, presence of palliative care programs, medical evidence, aggressiveness of treatment, determination of onset of dying process
Publieke informatie	16,22	Population level interventions, raising awareness in palliative care, public awareness, public education
Multidisciplinair team	13,51	Inclusion of nurses in EOL conversations, personalization of care, bereavement programs, differences between specialties, good interdisciplinary communication, role of specialized nurse in assessing the need of dying patient, nurses as primary communication link to physicians, involvement of a team
Uitwisseling van informatie	13,51	Prognosis of diagnosis, information delivery, uncertainty about prognosis, the patient being asked about wanting information, information delivery, prognosis of the last phase of life, assessment of life expectancy
Betrokkenheid van de patiënt	13,51	Empowerment of patients, participation in decision making of the patient,evaluation of the decision making ability of the patient, informed patients' preferences
Tijdbeheer	13,51	Time to listen, make enough time, competing demands on physicians' time, determination of the right time to initiate PC, protocols existing for EOL
Betrokkenheid van de familie	10,81	family demands, vision of the family, role of the family
Wettelijk kader	10,81	Follow up of the law, respecting human rights, law, interpretation of legislation
Emotioneel kader	10,81	Prediction of reaction family or patient, moral distress personnel, emotional and organizational support for staff, spiritual and psychological support, spirituality as an integral part of care
Levenslang leren	10,81	Continuous training, learning through clinical practice,

		continuous training courses in palliative care
Arts-patiëntrelatie	8,11	An established relationship, continuum of patient-physician communication, trust relationship with caregiver
Communicatie	8,11	Quality of EOL discussions, engaging in EOL communication, using open ended questions with emotional content, communication with patients about transition in care
Geografie	2,70	Geography
Technologie	2,70	New tools and technology

Tabel 2: *Oplijsting alle overkoepelende termen antecedenten, percentage van voorkomen in de literatuur en betrokken termen*

Consequenten

Deze sectie bespreekt de consequenties van een goede palliatieve attitude, zoals geïdentificeerd in de literatuur. De figuur (figuur 4) geeft grafisch een overzicht van de verschillende resultaten die voortvloeien uit het hebben van een effectieve palliatieve attitude bij zorgverleners. Een volledige lijst met korte beschrijving van de consequenten op basis van weerhouden literatuur wordt kort beschreven in tabel 3 om de lezer inzicht te geven in de mogelijke uitkomsten die worden geassocieerd met een goede palliatieve attitude.



***Figuur 4**: Overzicht consequenten: gevolgen van het concept. Percentage geeft weer hoe frequent genoemde consequenten voorkomen in de geselecteerde artikels. In 37 van de 37 artikels werden consequenten weerhouden.*

1. **Kwaliteit van Leven (29,73%):** Als consequent treedt kwaliteit van leven op de voorgrond. Niet alleen het algemene concept 'kwaliteit van leven' wordt hierbij vermeld, maar ook specifieke indicatoren zoals verbetering van de levensduur, de bevordering van een betere kwaliteit van zorg, het handhaven van de optimale kwaliteit van leven en het streven naar verbetering van de kwaliteit van het levenseinde.
2. **Kosteneffectiviteit (24,32%):** Een gevolg van een palliatieve attitude kan zich bevinden op het vlak van kosteneffectiviteit. Hierbij noteren we verlagen van de gezondheidskost, reductie van hospitalisatiekost en andere financiële aspecten.
3. **Emotioneel kader (21,62%):** Hierbij worden volgende kenmerken in beschouwing genomen als gevolg van een palliatieve attitude: positieve emotionele reacties van patiënten, de emotionele ondersteuning van zowel patiënten als hun families, de invloed van palliatieve zorg op de mentale gezondheids van terminaal zieken en hun naasten. Hierbij worden copingsmechanismes, vertrouwen, angst en de kwaliteit van de zorgrelatie tussen zorgverlener en patiënt in beschouwing genomen.
4. **Open Communicatie (18,92%)**: Volgende kenmerken worden onder de overkoepelende term 'open communicatie' besproken. Samenvattend onder open communicatie werd eerlijke volledige openheid, minimaliseren van onrealistische verwachtingen, vertrouwen, uiting van gevoelens, verbetering van arts-patiënt communicatie, eerlijke prognostische informatie en kwaliteitsvolle levenseinde discussies geïncludeerd.
5. **Adequate Zorg (16,22%)**: Onder adequate palliatieve zorg als consequent wordt het volgende verstaan. Enerzijds dat attitude zou kunnen leiden tot minder agressieve behandeling, een gebrek aan palliatieve zorg die zou leiden tot meer ernstige bijwerkingen met marginale winst, het durven vertrouwen in zorgverlener met angsten en spirituele bezorgdheden, geruststelling van de familie door een medische autoriteit, het gebrek aan een vroegtijdige zorgplanning die zorgt voor stresserende discussies rond levenseinde en reanimatie, futiele behandeling, continuïteit van de zorg, psychologische en spirituele ondersteuning, reductie van lijden van de patiënt en betere zorg aan het einde van het leven.

CONSEQUENTEN	VOORKOMEN IN LITERATUUR (%)	BESCHRIJVING IN LITERATUUR
Kwaliteit van leven	29,73	Improved quality of life, better quality of care, better quality of EOL care, quality in EOL, quality in EOL care, maintaining the best possible quality of life, improve quality of (end of) life and the family
Kosten-effectiviteit	24,32	Reduction of cost, reduction of hospitalization cost, effective utilization of palliative care services, financial aspects, save costs, beneficence, reduce cost of care, lower health care cost, lower total health care cost
Emotioneel kader	21,62	Positive emotional response of patients, emotional support for patients and families, influence on mental health for dying person and families, good coping mechanisms for patient, care tenor, patient satisfaction, trust, less anxiety
Open communicatie	18,92	Honest prognostic information, good quality of end of life discussions, reduction in misunderstanding by patients, having an own advance care planning, improvement in patient-physician communication, greater expression of feelings, confiding negative feelings and concerns to specialized caregiver, reassurance of family, honest disclosure, minimization of unrealistic expectations

Adequate zorg	16,22	Futile treatment, continuity of care, patients' comfort, quality of care, less aggressive treatment, earlier hospice referral, gain of lifetime, appearance of side effects
Betere organisatie van zorg	16,22	Relieve tension in team, reduced stay in ICU, interdisciplinary conflict and tension, less ICU deaths, more use of hospice, earlier hospice referrals
Ervaring rondom de dood	13,51	Dignity, best possible death, experience of and response to illness including dying by patient, provide a dignified death; sense of dignity and dignified deaths, normalization of the death experience
Weloverwogen besluitvorming	13,51	Educated decisions by patients and their family members, better decision making process, good decision making, decision making at the end of life, patient receiving unwanted treatment .
Symptoombestrijding	13,51	Psychological and spiritual support are provided by physician, symptom relief, reduce the patients' suffering, relieving physical symptoms, dying in pain
Gezondheid van de zorgverlener	8,11	Prevention of burnout, professional burnout caregivers, poorer caregiver bereavement adjustment
Wederzijds begrip	8,11	Understanding and accepting concepts of palliative medicine, perception of emotional reaction patient/family by physician, manner of discussion on resuscitation
Kennis	5,41	Greater global knowledge of palliative care, better knowledge
Rouwverwerking	5,41	Prepared for bereavement, family psychological outcomes
Patiëntenemancipatie	5,41	Empowerment of the patient, decision of treatment preference
Ethische dilemma's	2,70	Lower frequency of ethical dilemma's

***Tabel 3**: Oplijsting alle overkoepelende termen consequenten, percentage van voorkomen in de literatuur en betrokken termen*

Modelcase: een goede palliatieve attitude

Fictieve Model Case: Dr. X

Dr. X, een ervaren huisarts met een passie voor palliatieve zorg, staat bekend om haar holistische benadering en uitgebreide medische kennis. Haar benadering van palliatieve zorg wordt vaak gezien als een voorbeeld van een goede palliatieve attitude.

In een recente situatie werd Dr. X benaderd door de familie van een terminaal zieke patiënt, meneer Smith, die leed aan vergevorderde kanker. Het gezin was radeloos en worstelde met de emotionele en fysieke belasting van het zorgen voor hun geliefde.

Dr. X nam de tijd om naar de zorgen en behoeften van het gezin te luisteren. Ze creëerde een veilige ruimte waarin ze openlijk konden praten over hun angsten, verdriet en hoop. Door attent te luisteren,

kon ze de specifieke behoeften van het gezin identificeren en een zorgplan opstellen dat niet alleen gericht was op de medische aspecten van de ziekte, maar ook op het bevorderen van comfort en kwaliteit van leven voor meneer Smith en zijn familie.

Dr. X werkte nauw samen met het multidisciplinaire palliatieve zorgteam, waaronder verpleegkundigen, maatschappelijk werkers en geestelijke verzorgers, om een uitgebreide en holistische benadering van zorg te bieden. Ze zorgde ervoor dat het zorgplan regelmatig werd geëvalueerd en aangepast aan de veranderende behoeften van de patiënt en zijn familie.

Naast het bieden van medische expertise en symptoombestrijding, stond Dr. X erop dat meneer Smith en zijn familie volledig geïnformeerd waren over hun opties en betrokken waren bij besluitvormingsprocessen. Ze respecteert de autonomie van de patiënt en zijn familie en moedigde hen aan om actief deel te nemen aan beslissingen over hun zorg.

Gedurende het hele proces bleef Dr. X steun en empathie tonen, waardoor het gezin zich gehoord en ondersteund voelde tijdens deze moeilijke tijd. Haar waardigheid en respectvolle benadering van de dood werden gewaardeerd door meneer Smith en zijn familie. Dit had ook voor het betrokken zorgpersoneel een positieve impact. Er werd ook na de dood van de patiënt aandacht gegeven, het algemene verloop van de casus en feedback werd gevraagd aan alle betrokkenen.

Dr. X vertegenwoordigt het ideale scenario van een arts met een goede palliatieve attitude, waarbij compassie, deskundigheid en betrokkenheid samenkomen om het levenseinde van patiënten en hun families te verbeteren.

Discussie:

De resultaten van deze studie bieden waardevolle inzichten in de antecedenten, attributen en consequenties die verband houden met een goede palliatieve attitude bij zorgverleners. Door de complexiteit van palliatieve zorgverlening te onderzoeken, kunnen we beter begrijpen welke factoren en kenmerken essentieel zijn voor het leveren van kwalitatief hoogwaardige zorg aan patiënten in hun laatste levensfase.

In deze conceptanalyse werd als doel vooropgesteld om voor het concept ‘palliatieve attitude’ een eenduidige definitie te vinden. Als concept werd hierbij het volgende vooropgesteld: “*Een geheel van opvattingen, gevoelens en genegenheden van een arts tot handelen t.o.v. een volwassen patiënt in een levenseinde situatie”.* Na grondige selectie uit de literatuur kwamen er 37 artikels in aanmerking. Hieruit werden uiteindelijk de 5 meest voorkomende attributen, antecedenten en consequenten weerhouden en verder beschreven. De 5 meest voorkomende attributen waren communicatie, multidisciplinaire zorg, autonomie, holistische benadering en persoonlijke overtuigingen van de zorgverleners. De 5 meest voorkomende antecedenten waren levenseinde-educatie, religie/cultuur/normen, overtuigingen van de zorgverlener, ervaring van de zorgverlener en overtuigingen van de patiënt. De 5 meest voorkomende consequenten waren kwaliteit van leven, kosten-effectiviteit, emotioneel kader, open communicatie en adequate zorg.

Attributen

In de analyse van de literatuur emergeert communicatie als het meest voorkomende hoofdattribuut, waarbij het aanwezig was in 55,88% van de onderzochte bronnen. De integratie van diverse terminologieën onder deze noemer impliceert dat adequaat ontwikkelde communicatie centraal staat bij het cultiveren van een goede palliatieve attitude bij zorgverleners. Het belang van openhartige

dialogen over prognoses, behandelopties, palliatieve interventies en naderende levenseinde kwesties staan hierbij op de voorgrond.

Als tweede belangrijke hoofdattribuut wordt multidisciplinaire zorg naar voren gebracht. Dit was aanwezig in 52,94% van de onderzochte bronnen. Hierbij speelt de samenwerking tussen verschillende disciplines binnen de gezondheidszorg een integrale rol bij het verzekeren van een alomvattende en gecoördineerde benadering van palliatieve zorg. Een arts met een goede palliatieve attitude zorgt via deze benadering voor het adresseren van diverse behoeften van de patiënt, met het oog op maximaliseren van de kwaliteit van leven tijdens de palliatieve fase.

Het derde hoofdattribuut omvat patiënt autonomie, waarbij een essentieel onderdeel van een goede palliatieve attitude het respecteren van de voorkeuren en beslissingen van patiënten is. Dit geeft patiënten de nodige controle over hun eigen besluitvormingsproces in de context van hun zorgtraject. Autonomie was aanwezig in 38,24 % van de weerhouden literatuur.

Een andere belangrijke pijler is de holistische benadering van patiënten, waarbij het erkennen van de veelzijdige aard van het individu, inclusief fysieke, emotionele en spirituele dimensies, cruciaal is voor een gedegen palliatieve attitude. Deze benadering streeft naar een integrale zorgaanpak die recht doet aan de complexe behoeften van patiënten. Dit attribuut was aanwezig in 29,41% van de gebruikte literatuur.

Ten slotte is er aandacht voor de persoonlijke overtuigingen van de zorgverleners binnen een palliatieve attitude. Hierbij spelen de individuele interesse van de arts en emoties en zelfvertrouwen in een palliatieve context een belangrijke rol binnen de bredere palliatieve attitude. Het bewustzijn van persoonlijke overtuigingen en hun impact op de zorgverlening is van groot belang voor een goede palliatieve attitude en de plaats hiervan binnen effectieve en compassievolle zorgverlening. Dit attribuut was aanwezig in 29,41% van de gebruikte literatuur.

Antecedenten

Voorafgaand aan de identificatie van de kernattributen, identificeren we de vijf belangrijkste antecedenten die een significante invloed hebben op de ontwikkeling van een palliatieve attitude bij zorgverleners. Zoals eerder onderzocht in de literatuur, is er een prominente rol voor levenseinde-educatie binnen medische curricula (1,3). Dit resultaat is consistent met de richtlijnen van de Wereldgezondheidsorganisatie (WHO), die de cruciale rol van dergelijke educatie in de context van palliatieve zorg benadrukken. Een degelijke educatieve achtergrond draagt bij aan het zelfvertrouwen van artsen en hun competentie op het gebied van palliatieve zorg, waarbij zij beschikken over de vereiste kennis en vaardigheden om patiënten op een empathische en effectieve wijze te ondersteunen. Door educatie kan ingegrepen worden op hoofdattributen zoals bv. communicatie. Communicatie werd aangehaald in 35,14% van de gevonden artikels.

De religieuze, culturele en normatieve context van zowel de patiënt als de zorgverlener en de bredere samenleving spelen eveneens een cruciale rol bij het vormgeven van een palliatieve attitude. De waarden en normen van een patiënt of van een arts zullen bijdragen aan de perceptie van leven en dood en dus als gevolg hiervan ook aan de visie op palliatieve zorg. De palliatieve attitude kan in lijn liggen met de diverse achtergronden die aanwezig zijn bij zowel patiënten als artsen. Dit antecedent werd teruggevonden in 32,43% van de artikels.

De individuele overtuigingen van zorgverleners zijn van essentieel belang voorafgaand aan een palliatieve attitude. In 29,73% van de artikels wordt dit antecedent teruggevonden. De concepties over

palliatieve zorg zullen bijdragen aan het beoefenen van palliatieve zorg. De visie van zorgverleners op het bespreken van levenseindekeuzes met patiënten kan de zorgpraktijk gaan beïnvloeden.

De ervaring van zorgverleners, opgedaan door directe zorgverlening aan terminaal zieke patiënten en klinische praktijkervaring, speelt eveneens een aanzienlijke rol bij het ontwikkelen van een palliatieve attitude. Ervaring draagt bij aan de competentie van zorgverleners en stelt hen in staat om complexe situaties beter te begrijpen en op een sensitieve wijze met diverse uitdagingen om te gaan. In 27,03% van de artikels wordt dit antecedent aangehaald als relevant voor een palliatieve attitude.

De overtuigingen van de patiënt zelf zijn tot slot ook bepalend voor een palliatieve attitude bij een arts. De perceptie van de arts kan beïnvloed worden, en daarmee ook de besluitvorming en de attitude van een arts. In 24,32% van de artikels komt dit antecedent aan bod.

Consequenties

De ramificaties van deze attributen werden geanalyseerd en gecategoriseerd in 5 hoofdthema's. Het meest bediscussieerde onderwerp betreft de kwaliteit van leven. Men zou kunnen stellen dat een goede palliatieve attitude zorgt voor een verbetering van de kwaliteit van leven tijdens de laatste levensfase, doordat de kwaliteit van palliatieve zorg op zichzelf verbetert. Kwaliteit van leven was een onderwerp in 29,73% van de studies. Bovendien heeft dit een impact op de kosteneffectiviteit: een optimaler gebruik van palliatieve zorg kan onnodige ziekenhuisopnames en behandelingen vermijden. In 24,32% van de geïncludeerde literatuur werd kosteneffectiviteit besproken. Er is een toename in het gebruik van instellingen die effectief palliatieve zorg bieden. Daarnaast kan men vermoeden dat emotionele ondersteuning van zowel de arts als de patiënt beter geïntegreerd en omgeven wordt, wat ook besproken wordt in 21,62% van de studies.. Er is een groter begrip voor diverse emoties bij goede palliatieve zorg, waardoor open communicatie vlotter verloopt (18,92% van de literatuur) en er meer adequate zorg wordt verleend (16,22% van de literatuur).

Bespreking resultaten

Wanneer we de initiële definitie van Altmann bekijken, komt naar voren dat er een cognitief, affectief en gedragsmatige component is aan het concept 'attitude' an sich (10). Wanneer we echter de resultaten van deze conceptanalyse proberen onderverdelen naargelang deze componenten, lijkt dit absoluut niet zo eenduidig te lukken.

Wanneer we kijken naar de hoofdattributen, zal bijvoorbeeld communicatie zowel als gedragsmatig als affectief kunnen beschreven worden. Dit geldt eveneens voor patiënt autonomie, holistische benadering, multidisciplinaire aanpak en de overtuigingen van de zorgverlener. Ook binnen de antecedenten is het niet steeds eenduidig: bij levenseinde-educatie kan bijvoorbeeld de cognitieve component wel meer aangehaald worden, maar de overtuigingen van de zorgverlener of patiënt zijn zowel als affectief als cognitief te beschrijven. Hetzelfde geldt voor de consequenten.

Beperkingen

Er dienen enkele belangrijke observaties bij deze analyse die in acht genomen dienen te worden. Eerst en vooral is het belangrijk om de breedte van het concept te erkennen. Bij een conceptuele analyse van het concept 'attitude' door Tanya K Altmann, wordt reeds aangegeven dat het een uitdagend begrip is om een vaste definitie te geven van dit concept (10). Hier werd reeds een complexe interactie tussen zowel de intellectuele als gedragsmatige aspecten van een individu beschreven. Bovendien kan een attitude op een onbewust niveau worden ervaren, waardoor het een

uiterst complex concept is om te onderzoeken of te kwantificeren (10,11). Dit wordt ook in deze analyse opgemerkt. In totaal worden 19 attributen bekomen voor het concept ‘palliatieve attitude’.

De complexe interactie komt ook terug in de verschillende attributen, antecedenten en consequenten. We merken overlap: zo is communicatie een gegeven zowel als attribuut, maar ook als antecedent. Dit lijkt een circulaire interactie weer te geven tussen de verschillende aspecten die een palliatieve attitude zullen opmaken. Daarnaast blijven de overkoepelende termen ook eerder breed en moeilijk te vernauwen. Als attribuut zal persoonlijke overtuiging van de arts of patiënt ook een gevoelsmatige component bevatten.

We dienen ook op te merken dat het baseren op de huidige literatuur zijn limieten stelt. Er is namelijk weinig tot geen literatuur die specifiek een palliatieve attitude gaat beschrijven. Dit zorgt ervoor dat conclusies getrokken worden op basis van wat reeds onderzocht is. De huidige studies benoemen voornamelijk zaken die gemakkelijker te kwantificeren of onderzoeken zijn. Zo zal als consequent kosteneffectiviteit veel gemakkelijker na te gaan zijn dan de emotionele beleving van de patiënt.

Dit zou ook kunnen verklaren waarom ‘empathie’ als attribuut eerder laag landt in de lijst, ondanks dat dit in huidige opleidingen en geneeskundige praktijken algemeen een veel grotere plaats zou verwacht worden om in te nemen. Echter, empathie is niet gemakkelijk te onderzoeken: empathie gaat uit van subjectieve beleving van de persoon in kwestie. Een systematische review van Ernancion Perez-Bet raakte dit onderwerp reeds aan: er zou meer specificiteit voor de term moeten bestaan (12). Hierdoor kan het dat in een extensieve literatuurstudie een scheef beeld weergegeven wordt wat belangrijk kan zijn voor de huidige definitie: vooral de iets makkelijker te onderzoeken onderwerpen komen naar voor. In dit opzicht is het logisch dat kosteneffectiviteit een prominentere rol krijgt toebedeeld.

Wanneer we de literatuur gaan naslaan, merken we algemeen dat er zeer weinig literatuur gegeven wordt rond palliatieve attitude. Een totaal van 37 artikels om uit te analyseren kan onvoldoende zijn om dergelijk ruim en veelgebruikt concept te gaan definiëren.

Toekomstperspectieven

Het blijkt dus moeilijk om een volledig eenduidige definitie van het concept ‘palliatieve attitude’ te geven. Echter, een mogelijkheid bestaat om bijvoorbeeld mits interviewstudies hier een toekomstig onderzoeksonderwerp voor voorop te stellen.

Conclusie

Deze conceptanalyse heeft een werkbare definitie van een palliatieve attitude geformuleerd als "een geheel van opvattingen, gevoelens en genegenheden van een arts tot handelen t.o.v. een patiënt in een levenseinde situatie bij volwassenen". De identificatie van attributen, antecedenten en consequenties biedt een diepgaand begrip van de elementen die bijdragen aan een positieve palliatieve houding.

De bevindingen benadrukken de noodzaak van gerichte educatie, met name op het gebied van communicatie, multidisciplinaire samenwerking en culturele competenties. Medische opleidingen moeten aandacht besteden aan deze aspecten om artsen adequaat voor te bereiden op de complexiteit van palliatieve zorgsituaties.

Een positieve palliatieve houding is niet alleen van belang voor de patiënt, maar heeft ook brede consequenties voor de kwaliteit van zorg, de ervaring rondom de dood, de levenskwaliteit van

patiënten en kosteneffectiviteit. Het benadrukt het belang van het integreren van palliatieve zorgprincipes in de medische praktijk om de algehele zorg ervaring te verbeteren.

Deze bevindingen benadrukken het belang van een holistische benadering van palliatieve zorg, waarbij rekening wordt gehouden met diverse factoren zoals de persoonlijke overtuigingen van zorgverleners, de behoeften en voorkeuren van patiënten, en de culturele achtergrond van individuen. Bovendien onderstrepen de attributen het belang van het ontwikkelen van vaardigheden zoals communicatie en empathie bij zorgverleners, om een ondersteunende en respectvolle omgeving te creëren voor patiënten in hun laatste levensfase.

Het is echter belangrijk op te merken dat deze studie enkele beperkingen heeft. Ten eerste is de data-analyse gebaseerd op een literatuuronderzoek, wat kan leiden tot een zekere mate van subjectiviteit en selectieve rapportage van resultaten. Bovendien kan de beschikbaarheid en kwaliteit van de geselecteerde literatuur van invloed zijn op de betrouwbaarheid van de bevindingen. Een andere beperking is dat de resultaten mogelijk niet generaliseerbaar zijn voor alle zorgcontexten en culturele achtergronden.

Om deze beperkingen aan te pakken en verder inzicht te krijgen in de rol van een goede palliatieve attitude, zijn er verschillende opties voor verder onderzoek mogelijk. Dit omvat longitudinale studies om de langetermijneffecten van een palliatieve attitude te onderzoeken, interventiestudies om de effectiviteit van training en educatieprogramma's te evalueren, en kwalitatieve onderzoeken om een dieper inzicht te krijgen in de ervaringen en perspectieven van zowel zorgverleners als patiënten. Door deze benaderingen te combineren, kunnen we streven naar een verbetering van de palliatieve zorgpraktijk en een betere kwaliteit van leven bieden aan patiënten in hun laatste levensfase.

Deze conceptanalyse vormt een basis voor verdere discussie en onderzoek naar palliatieve attitudes, waarbij de focus moet liggen op het ontwikkelen van interventies en educatieve strategieën om deze essentiële aspecten van zorg te bevorderen. Het uiteindelijke doel is het verbeteren van de kwaliteit van palliatieve zorg en het waarborgen van een respectvolle en holistische benadering voor patiënten in hun laatste levensfase.

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Bijlagen

Artikel	Link met vraag					
	Introductie	Methodologie	Resultaten	Discussie	Extra opmerking	
1. Physicians' and Nurses' Knowledge in Palliative Care: Multidimensional Regression Models	**Knowledge** of palliative care is essential in ensuring the delivery of professional care.	The first section included demographic information- age, sex, training (nurse or physician), years of work experience, training received in palliative care in the degree, **continuing training** received in the last 5 years, and **work experience** in palliative care.	No significant differences were shown **between men (11.24 ± 3.58) and women** (10.48 ± 3.16) in palliative care global knowledge.	This study showed that physicians have a greater knowledge of palliative care than nurses, with no significant differences between **sexes**.		
	However, most studies suggest that recently graduated physicians and nurses are **poorly prepared** for end-of-life care	The second part was the PCKT-SVB [23], adapted and validated from the Palliative Care Knowledge Test	The professionals who carried out **continuous training** in palliative care in the last five years showed a significantly higher level of knowledge than those who did not	Both **continuous training and professional experience** proved to be important values to determine significantly greater knowledge in palliative care in physicians		
	Furthermore, students and Furthermore, students and health professionals identify a **lack of education in palliative care,** both in theory and in practice, and do not feel capable of managing patients who need this care.		professionals with **experience in palliative care** showed a significantly higher **level of knowledge** than those who did not have professional experience in palliative care			
			Continuous training (BE) 1.68 (0.35) t = 4.73 p < 0.001) and **work experience** (BE) 1.81 (0.41) t = 4.46 p < 0.001) were the best predictors to determine a significantly **greater global knowledge of physicians in palliative care**, also being significant in relation to the dimensions of **philosophy, pain**, respiratory disorders, and gastrointestinal disorders. Work experience also showed a significant influence on global knowledge and on the dimensions of pain, and respiratory and neuropsychiatric disorders			
2. Perception of palliative medicine by health care professionals at a teaching community hospital: what is the key to a "palliative attitude"?	**Population-level interventions** are needed to **reduce cost** and, at t he same time, **improve patients' quality of life.**		The attendance of these educational activities increased from 14% to 48% (p<0.05). In our opinion, this reflects a growing **interest** of health care professionals in palliative care	Attendance of **educational** activities increased and confidence in pal- liative care was higher in the follow-up study.		
	The interaction involves **educational** activities such as lectures, seminars, grand rounds, and **direct involvement in patients' care.**		Physicians who have **an established relationship** with their elderly functional patients experience positive **emotional** responses after discussion of advance directives in the outpatient setting.7	**Inter- action with palliative care** teams and learning through **clinical practice** was the key factor in understanding and accepting concepts of palliative medicine and development of a "palliative attitude" by health care professionals. We could not associate perception of palliative medicine with **educational activities in the form of lectures**, seminars, and workshops, but we remain committed to these forms of education.		
	In order for our interaction with **interdisciplinary team** members to be most effective, we had to learn their attitudes toward issues and concepts of palliative medicine.		It is possible that compliance with **the law** contributed to better performance in the inpatient setting.			
	learned factors influencing attitudes of health care professionals.		Attending physicians older than 35 years were more comfortable than their younger colleagues			
			The awareness of this progress in palliative care has increased through **educational** activities and from clinical experience of interdisciplinary teams.			
			While obtaining the DNR/DNI **consent, goals and a plan of care** need to be established			
			Of note, physicians **younger** than 35 years had a better understanding and acceptance of this concept than their colleagues older than 60			
			It has been acknowl- edged that these patients need evaluation by a palliative care team with expertise in managing symptoms and defin- ing **goals of care.**			
			A majority of health care professionals (79%) in our study were not influenced by their **religious** affiliation.			
			Most of the health care professionals (91%) agreed that medical **futility should be discussed** with terminally ill patients and their caregivers.			
3. Care at the end of life in critically ill patients: the European perspective	First, maintaining life-sustaining treatments in the absence of clinical improvement robs patients of **their dignity and families** of their right to receive honest prognostic information and to prepare for bereavement.			These patients must be offered the **best possible death**. We must remain at their side and on their side, keeping them comfortable at all times, while encouraging families to take part in decisions and care, if they so wish, welcom- ing family members in the ICU as partners rather than as visitors, alleviating their guilt, and helping them to prepare for the bereavement process. Clearly, information needs to be improved before family involvement can be promoted.		
	Second, the concept of a transition from **curative care to comfort care** is emerging worldwide, and considerable attention is being given to the development of palliative and patient–family-centered care aimed at meeting specific needs near the end of life			major improvements in EOL management of ICU patients, most notably regarding our **skill in communicating,** imparting information, and organizing and implementing treatment withholding and withdrawal. Serving the principle of autonomy requires not only that a patient's wishes be honored, but also that the family be able to proceed through the bereavement process with the least possible guilt, remorse, and regret. Thus, our end-of- life practice should be tailored to the specific characteris- tics of each region and culture, each clinical situation, each patient, each family, and each ICU professional.		
	A growing number of **family** members is being **involved** in DFLSTs [9–3•], and specific efforts are being made to answer their **informational needs**					
	European physicians working in ICUs report that they regularly withdraw and withhold life-sustaining treatments from patients near the end-of-life, and there are **important differences in attitudes between northern and southern countries**, where fewer physicians report using or DFLSTs					
	After years of heated debate opposing **autonomy and paternalism**, a model in which decision-making is shared with family members is gaining ground. This model upholds **patient autonomy** [23] without forcing family members to participate in decisions they do not want to make					
	The **legal framework** for end-of-life care is being reworked in European countries, in some cases in the wake of legal action taken against intensivists					
	Perhaps even more importantly, limita- tions of **advance care planning** have been recognized. Advance care planning generally failed to **improve quality of life** or care or to r**educe hospitalization costs and ICU use**					
	Another explanation may be greater paternalism among **European** physicians, compared with their colleagues in North **America**					
	Furthermore, although European intensive care medicine societies promote respect of **patient autonomy** and recommend taking into account the patient's wishes and the family's opinion, most of them consider that DFLSTs remain the responsibility of the clinician					
	Patient–physician relations are far more complex, and variations exist across ICUs in a given country [9] and across physicians in a given ICU					
	changes in habits and attitudes are leading to gradual acceptance of the **shared decision-making** model among ICU staff members					
	two recent single-center studies from Belgium and France, families were **'fully informed'** in 91% of cases and shared in decision-making in 100% of cases					
	paternalistic' attitude of Euro- pean physicians ignores the fact that the underlying force is the **ethical principle of non-malfeasance**, which seeks to avoid causing pain					
	Family needs may vary across cultures, and a balance may need to be found between physician–patient–family relation models that exist on either side of the Atlantic.					
	Tai- loring the decision-making process to the wishes of family members is not contradictory with the principle of **patient autonomy.**					
	Instead, **communication** with families must receive close attention as a means of empowering families to **share in decisions**					
	A strong focus on the patient and family, on meeting their needs and **respecting their wishes,** is probably the best way to reconcile disagreements based on ethical theory					
	Third, we advocate a shared decision-making process as a good tool for providing **culturally** appropriate and **multi- disciplinary** care.					
	The need for developing palliative care in the ICU has been pointed out, with special **emphasis** on the need for a **holistic** approach taking into account the **emotional, social, spiritual, and physical needs of dying patients and their families**					
	palliative care teams have invalu- able experience with symptom and **pain management near the EOL, multidisciplinary management**, and family com- munication and support.					

	Based on our experience, we believe that partnership between an ICU team and a palliative care team must rest on close, trusting **interactions** among open-minded nurses and physicians interested in a two-way learning process. This process could **include academic exchanges, training** of nurses and residents (most notably in the field of commu- nication), and multidisciplinary care at the bedside for espe- cially difficult DFLSTs, protracted dying, or conflicts			
	Multidisciplinary management, one of the key concepts of palliative medicine			
	lack of communication between nurses and physicians in the ICU can lead to mis-understandings, divergent practices, and conflicts regard- ing EOL management, which may translate into a worse prognosis for the patients			
	In Europe, ethics consultations are generally viewed favorably by intensiv- ists but rarely used in practice [4,21], despite evidence of improved decision-making and communication and decreased conflicts and length of ICU stay for dying patients [54,55].			
	One of the main explanations to variations not only across countries, but also within the same country or team, seems to lie in differences among physicians. **Age and experience, spe- cialty and training, as well as cultural background and reli- gious beliefs** influence physicians' choices			
	By improving their **communication skills**, ICU staff mem- bers create important opportunities to improve the quality of EOL care			
	The recent **introduction of palliative med- icine** into the medical school curriculum of most European countries can be expected to improve the ability ofphysicians to provide EOL care and to use the shared decision-making model			
	Moreover, **new technologies and new teaching tools** offer opportunities that could be developed in the future			
4. Perceptions of healthcare professionals towards palliative care in internal medicine wards: a cross-sectional survey	These **gaps in understanding and misconceptions on the role of palliative care interventions** have been identified as significant **barriers** to referrals and the utilisation of palliative care services	To design the survey, the research team reviewed recent studies on perceptions of palliative care amongst health- care professionals	Nearly 11% of physicians would defer to the pal- liative care team to discuss these issues whilst 89% of physicians would **include the family** in these discussions.	However, effective utilisation of palliative care services continues to be undermined by gaps in **knowledge, prog-nostication and communication**.
		Participant **demographics** relating to clinical and palliative care experience.	There was strong agreement that **more stakeholders involved should** be **educated** or trained in palliative care.	Indeed, this study reveals that misconceptions on **the role of prognosis** as an entry criteria inhibit up to 60% of physician initiated referrals to palliative care.
		Perceptions of palliative care with a focus on perceived benefits,1 roles and indications of consultation referrals	High mean scores ranging from 4 to 4.6 were observed for statements such as "**Nurses should be included** more in end of life conversations", "There should be more **palliative training** to healthcare workers" and "The general public does not know enough about palliative care"	Given such wide ranging knowledge and skill gaps and misconceptions, we opine that there is a need for a concerted national **education program** to target these barriers to palliative care's effective use as they likely persist across clinical settings.
		Self-reported behaviours so as to identify potential obstacles in initiating palliative care – these include **participants' confidence in explaining the role of palliative care to patients,3** confusion with palliative terminologies4 and views on palliative care training and utilisation	**Senior** physicians re- ported being more confident in explaining the role of palliative care to their patients as compared to **junior** physicians	
			Nurses in this study, on the other hand, appreciated pal-liative care's **holistic** and longitudinal support even after hospital discharge.	
5. Medical futility at the end of life: the perspectives ofintensive care and palliative care clinicians	A growing concern is how clinicians should react if patients or **family members demand futile treatment**, such as ineffective chemotherapy for end-stage cancer.		When asked to define medical futility at the end of life, interviewees **displayed unease**, demonstrated by a longer latency before the response and an increase of filler words by 17%.	Although 9 of the 17 case consultations clarified that LSTwas futile, this treatment had been provided up until the consultation meeting in all of these cases, and in four cases futile treatment was continued even after the consultation, **mainly in order to give families more time to cope with the situation**.
			Most frequently, participants associated futility with the **lack of attainable goals of care.**	Interestingly, **demands of family members was not the most frequently mentioned reason**, in contrast to a survey among Canadian intensivists.
			Many healthcare professionals also regarded a treatment as futile if the **benefit conferred to the patient by the goal of care was surmounted by the burden with all associated risks, harms and expenses**	A plethora of emotional difficulties surfaced in our interviews, in addition to well-known problems such as delay due to prognostication and consensus-seeking, communication problems and lack of legal or medical knowledge
				Based on these results and the literature, it appears necessary to improve end-of-life decision making on intensive care units by various interventions: regular and proactive family meetings, effective ethics consultation, conducive organisational structures and applicable hospital policies, integration of palliative care expertise in intensive care, improved legal education, emotional support (eg, by supervision), and specific training of end-of-life communication skills
			Some participants included **financial aspects** into their benefitburden-assessment	
			Participants stated that it is the **primary duty of the physician to assess whether the treatment is medically futile, yet only after consulting** specialists of other medical disciplines (eg, neurologists) and the nursing team. Some also emphasised that the patient should be involved in this assessment:	It has been shown that German physicians tend not to disclose their unilateral decisions about the futility of treatment at the end of life, **especially if they predict that the patient or family will not agree with this decision.**
			Clinicians were asked about the reasons why LST is sometimes continued despite being considered futile. They came up with several reasons (figure 2), **most notably personal reasons like concerns, fears and emotions**	It has also been documented that intensive care clinicians in Germany are dissatisfied with end-of-life communication, in particular nurses who run into moral distress when having to provide futile care despite their moral convictions.
			Other reasons seem to be treatment **wishes of patients or relatives, ignorance of law and of palliative treatment options, hope for a miracle, and institutional barriers**	Of note, in our interviews, we heard that nurses sometimes team up with the patient's family and try to get the physicians to stop LST by supporting the futility judgement with the assertion of a presumed treatment-opposing will of the patientbe it true or not
			While nurses and physicians did not differ in their statements, we found that **participants from intensive care and those from palliative care focus on different aspects** when they communicate futility to patients and their families	While intensive care clinicians use a more cautious, indirect and matter-of-fact approach, palliative care clinicians favour a rather swift, direct and personal approach.
				In order to develop and train the best communicative approaches, it is imperative to understand more about the needs of families
				The algorithm visualises that the patient's autonomous consent rests on two critical questions: (1) what is the patient's preferred goal of treatment; and (2) how does the patient evaluate the benefits versus risks and burdens of the intervention needed to achieve this goal?
6. Exploring Health Care Providers' Views About Initiating End-of-Life Care Communication	Having good quality EOL discussions requires **time to listen** to patients' needs and explore their options.	participants' experiences with **barriers** that limit EOL care communication, factors that **hinder transitions** at the EOL, and explored the overall **importance of engaging in EOL** care communication with vulnerable populations.	most providers said it was **partially their role** to initiate discussions (64.5%), whereas some said it was completely their role (27.8%) or not their role at all (7.6%).	Providers specify physicians as **leaders** of EOL care com- munication and are responsible for **initiating** discussions with patients and families; however, nonphysician providers also hold important roles in moving EOL care dialogue forward, especially because gaps in communication exist
	Another aspect of the problem is that some physicians feel pressured to move quickly to see as many patients as possible, **optimizing profits** in patient care.	participants' experiences with barriers that limit EOL care communication, factors that hinder transitions at the EOL, and explored the overall importance of engaging in EOL care com- munication with vulnerable populations.	he social worker, I'm here to provide the **support counseling..., active listening, grief counseling,** because of the implications of what the terminal diagnosis means.	teams working together to address complex patient care; however, not all teams have nonmedical providers as members, possibly intended to **save costs**.
	it is often unclear **who should begin** the discussion as well as when and how the issues should be discussed by various members of the health care team.		For physicians, this meant **taking the primary responsibility** for the discussions because, "it's intricately tied with issues of treatment'	
			Physicians emphasized **stating the obvious,** for example, describing what can be expected, exploring the out- comes of patients' life-limiting medical condition, and making recommendations for health care **decision making,** turning to palliative and hospice care when appropriate.	
			who should be the **most responsible for initiating the discus- sion,** a majority (87%) of providers said that the physician is most responsible for beginning discussions with patients and their families.	
			Physicians should have the main responsibility for initi-ating EOL discussions "because they're the one who can best discuss the patient's **prognosis [and] the different options**	
			it was difficult for physicians to discontinue curative medical treat- ment and to focus on comfortEOL care: "A lot of physicians have a **hard time accepting the fact of when to stop**	
			Limitaties: **focus op medische opties, te weinig tijd,**	
			Most participants reported that physicians should lead the medical team, be the central provider of the team, delivering bad news, and involve other providers to manage the various aspects of patient care. It was reported that **working as a team was an essential part of communication** because it encourages dialogue across disciplines.	
			When working as a team, more can be accomplished in less time because each provider is in contact with other providers to confirm information about patients' needs and develop a coor- dinated patient care plan. help **reduce misunderstanding and help patients and their family members to make educated decisions** about their EOL care choices.	

			Collaborating on a team is also important because it helps to **relieve the tension** that sometimes exists between providers as a result of the **hierarchy** and the conflicts that can arise across disciplines, which can hinder EOL care discussions.			
7. Defining dignity in end-of-life care in the emergency department	Having **dignity** is some- thing which is **valued** above anything else,12 giving us satisfaction without the need for any other end.	**Definitie: Dignity** is primarily understood as a human quality, as the meaning of dignity is rooted in recognising a valuable person in a human being, an attribute which is inherent and unconditional for him or her. It is there- fore a human condition, as only a human being is aware of possessing, demanding and, where relevant, los- ing it	Dignity refers to an intrinsic value in every human being, m**ore than the preservation of one's own life.**			
	Dignity exists in human beings,22 reflecting the individuals' choices, values, ideals and lifestyle. Dignity should mean having cognitive ability, feeling comfortable with oneself and having control over one's behaviours and surroundings.23 **Respect, autonomy, empowerment and communication** have also been identified as being the defining attributes of dignity.	It is human nature to treat people according to their dignity, a duty to which, in Kantian terms, even **life itself would have to submit.**	dying person's dignity in the ED is associated with **self-esteem and respect; safety, autonomy and integrity are all inviolable attributes.**			
	Dying with **dignity** is important for patients, their families and healthcare providers23 and is a fundamental objective of quality end-of-life care.	**Overvaluing life** may be linked to a lack of self-esteem, stopping the patient from facing death peacefully.	**care environment, professional actions and socio-family** context as attributes of dignity. For the nurses, a good death in the ED implies the **control of symptoms, relief from suffering and help to substitute and satisfy the dying person's basic needs.**41 As in other studies, the participants identified a threat to the patient's dignity in the socio-environmental cond- tions			
		respecting the dignity of the terminally ill patient in the ED means reflecting on the **socio-cultural acceptance** of death and the finitude of the human condition	**Social non-acceptance of death**, together with the lack of advanced directives, generates distress, suffering, rage and helplessness.45 Helping the family to **start the grieving process**, **respecting** individual differences, may contribute to the dying person's dignity in the ED. As seen with the older people,46 the **presence of the family** with the dying person can dignify care			
		human dignity is founded on autonomy, in the capacity of each human being to give themselves rules and make decisions. Autonomy is an unconditional value, incomparable and independent of status and circumstances.	**Autonomy and empowerment** have been identified as attributes of dignity;			
		Humanizing care lit tichnicificeren. ED. Prepared to preserve life, here care is focused on monitoring vital signs and carrying out invasive procedures. However, these patients do not require saving-life procedures, but would **benefit from palliative care** instead. For this reason, they feel helpless, in a **depersonalised** environment which infringes upon their dignity	According to the physicians and nurses who participated in our study, dignity in the care of a dying person in the ED is defined by **acknowledging the inherent value** in each person in these circumstances, an intrinsic value of a human being, linked to **self-esteem and respect.**			
		Facilitating **accompaniment.** Our participants recognised an attribute of dignity for terminally ill patients in the ED in this accompaniment	Social and individual acceptance of **death, autonomy in decision-making**, humanisation and accompaniment constitute attributes of dignity and may help in confronting and coping with the situation.			
		Coping with decorum. Being concerned about the person's integrity forms part of dignity in end- of-life care in the ED.				
		Respecting human rights.				
8. Self-Perceived End-of-Life Care Competencies of Health-Care Providers at a Large Academic Medical Center	Common barriers to quality EOL care include physicians' and nurses' lack of **formal education** and experience in EOL care.	patient and family decision-making; communication within the team and with patients and families; continuity of care; emotional support for patients and families; symptom management; spiritual support for patients and families; and emotional and organizational support for staff.		It also confirms the notion that **EOL care education is needed** in the hospital setting and iden- tifies areas of greater needs for education.	OPMERKINGEN Appendix A End-of-Life Care Questionnaire (EOL-Q)	
	Many studies have documented gaps in EOL care competencies among intensive care unit (ICU) staff including **communication, continuity of care, decision-making process, and collaboration** among disciplines	The greatest self-perceived competency was in **attitudes related to the provision of EOL care**, and the least perceived competency was in providing **continuity of care.**		We found that the highest levels of self-perceived competencies among participants were in attitudes related to the **provision of EOL care**, providing **emotional support for patients and families**, **symptom** management, **communication**, and **spiritual** support		
		Participants with **more than 10 years** of practice had higher total scores than participants with 0 to 1 year		The least perceived competencies were in **decision-making, staff support, and continuity of care**		
9. Family physicians' role in palliative care throughout the care continuum: stakeholder perspectives	FP as (i) available **medical expert**, (ii) **communicator**, (iii) **collaborator** and (iv) **life-long learner** committed to improving their palliative care competencies by training.	According to FPs, nurses and patients it is important to **make enough time** for contact and **communication** between the FP and the patient				
		life-limiting illness not only affects the patient but also their family and FPs should therefore be able to **communicate effectively with the family;**			Opmerking: studie in vlaanderen.	
		FP does not have to take care of every care need personally, but is expected to advise the patient on or **refer** to alternative options **multidisciplinair**.				
		FPs and nurses thought that it was the FP' s responsibility to stay informed about the latest developments in diagnosis and treat- ment of chronic life-limiting diseases and palliative care for example by following **training courses.**				
		that use of the term 'palliative care' may be a deterrent to the adoption of early palliative care and that 'supportive care' may be better				
		However, patients also might benefit from 'training' or **'awareness-raising'** as they still tend to view their FP mainly as the person to turn to in acute situations and often do not see them during treatment phases				
10. Treatment and Communication-That Is What Matters: An Analysis of Complaints Regarding End-of-Life Care	medical intervention to meeting the **subjective needs of patients and families.**	70 relatives of deceased persons	most complaints fell into one of two broad thematic categories: **"provision of service" and "communication."**	82.9% reported **problems with quality of care.** These quantitative results reveal a disturbing picture of EoL care, whe Israel		
	serious consequences, such as **decreased mental health**, for both the dying persons and their families	**Is there something in the health system or the behavior of the doctors/nurses that you would recommend changing?**	In addition, three "distal" thematic categories were identified: **"system," "institution," and "staff.**"	most urgent intervention are lack of services and **lack or poor quality** of **communication**		
	needs of patients and family members concerning palliative and EoL care can be grouped into **eight key domains** of satisfaction with the care system, namely **accessibility, coordination, competence, communication and relationships, education, emotional support, personalization of care, and support of patients' decision making.**		**Provision of service.** "Provision of service" included **all medical, nursing, and custodial interventions,** subdivided into domains of quantity and quality. Quantity included responses that reported necessary treatments that **were unavailable** to the patient, services that **were available,** but were only **partially provided** to the patient, and cases of **over- treatment.**	'justice," which includes several types of complaints: **patients receiving different quality of treatment based on connections or money,** conflicts between staff and patient values, and systemic corruption		
			Staff This general category includes training of staff, staff competence, and staff burnout.	question of **cause and effect:** to what extent are the distal factors actually causing the proximal ones, such as **understaffing resulting in poor care?** These causal rela- tionships are crucial in terms of planning interventions to improve quality of care.		
			Emotional valence of responses. The classification system does not allow for the expression of the intensity and emotional quality—anguish, despair, and helplessness—of the complaints.	answer appears to involve distal systemic root causes, which include **institutional structure, staff management, and resources**		
			FIG. 2. A nomenclature for classifying quality of care: distal factor impacting proximal factors and their dimensions.	proximal issues of standards of care as well as **attitudes and communication** need to be addressed simultaneously.		
			not providing needed services (27.1%), lack of compassion (22.9%), staff not focusing on the patient (21.4%), staff not manifesting respect and dignity (20.0%), insufficient health insurance coverage (18.6%), health services unavailable (18.6%), lack of information regarding prognosis (12.9%), and lack of justice (11.4%).			
11. Implementation of palliative care for patients with terminal diseases from the viewpoint of healthcare personnel	**Cultural and socioeconomic factors, perceptions of patients and their families, attitudes of healthcare providers, lack of education and training for healthcare personnel, uneven distribution of pallia- tive care facilities, lack of coordination, and limited funds serve as barriers to implementation**	12 physicians and five nurses from December 2017 to June 2018. In-depth interviews	**family and environmental** context identified issues that could hinder or enable implementation. These included (1) **empowerment, (2) perceptions and preferences, (3) norms, (4) coping mechanisms, and (5) health-seeking behavior.**	**support from the family** is an important aspect for improving the quality of life of patients with terminal disease.	Indonesia	
	Support for implementing palliative care requires **competent healthcare providers, adequate facilities, and good public awareness**.	Five themes and 24 categories were identified from the interviews	Needed skills emerging from the interviews were (1) **empathy, (2) communication, (3) decision-making, and (4) self-confidence.**	Ideally, healthcare professionals should have **good communication skills and empathy** to build good relationships with patients and families		
	It will require **collaboration** between healthcare personnel in hospitals and primary care.		Factors important in effectively managing patients are **(1) case notification, (2) comprehensive care, (3) inter-disciplinary collaboration, (4) integration of care, and (5) follow-up.**	physicians are reluctant to provide palliative care because they are not **confident** in their ability to do so.		
	patients **and families** need staff who can provide **psychological and spiritual support**, assist in **decision making, manage symptoms, and communicate** well		Issues related to the healthcare system explored in the interviews consisted of (1) **policy, (2) standard and guideline, (3) availability of drugs, (4) networking, (5) financing, (6) quality assurance, and (7) legal aspects.**	This requires involvement of **multidisciplinary teams.**		
				Accecibility of pain medication, policy, finance		

12. Doctors' learning experiences in end-of-life care – a focus group study from nursing homes	Experiences during internship vary from valuable to nearly unbearable de- pending on the content, structure and supervision	Methods: House officers in nursing homes (n = 16) participated in three focus group interviews. + slagsirs	staff's attitudes taught them how **calmness and acceptance** could be more appropriate	There is a considerable potential for training doctors in EOL care in nursing homes, which can be developed and integrated in medical education.	Noorwegen
	Newly qualified doctors receive little formal training in end-of-life (EOL) care in hospitals and are not prepared to meet challenges regarding death and dying	how the newly qualified doctors gained knowledge of end-of-life care through participation in the nursing home's community of practice.	Shifting focus from disease treatment to symptom relief was **demanding, yet participants comprehended situations where death could even be welcomed**	studies have shown how nursing homes can offer medical students and newly qualified doctors a broad range of specific geriatric and long term care learning outcomes	
	In Norway, serving as house officers in nursing homes during primary care internship is mandatory In nursing homes, newly qualified medial doctors meet frail old people liv- ing with death in sight, making this arena relevant for developing skills and reflections about EOL care		challenging dialogues dealing with family mem- bers' hope and trust, they learnt how to adjust words and decisions according to family and patient's life story.	nursing home setting may give interns access to learning experiences through **close interaction and dialogues with patients, relatives and nurses.**	
	Medical care is provided by part-time employed GPs (60–65%), other spacialists (e.g. geriatrics, internal medicine), or full time employed nursing home doctors [7]		The nursing home setting of- fered the possibility of getting to know patients and fam- ilies over a time span longer than most hospital stays This often made **communication and decision-making easier. Built trust with family / patient**	Multidiciplinair / attitude, death is not failure. But sometimes welcomed.	
	Patients and their relatives request doctors and nurses who are confident in EOL care and in communication about death and dying				
	Furthermore, we shared the **preconception that medical education, including the maturation and development of new doctors** through internship, is a key factor ameliorating this im- portant field.				
13. Should palliative care patients' hope be truthful, helpful or valuable? An interpretative synthesis of literature describing healthcare professionals' perspectives on hope of palliative care patients		Of the 37 articles, 31 articles were of sufficient quality. The majority of these 31 articles described perspectives of nurses or physicians.	**realistic perspective** – hope as an expectation should be **truthful**, and healthcare professionals focused on **adjusting hope to truth**, (2) **functional perspective** – hope as **coping mechanism should help patients**, and professionals focused on fostering hope, and (3) **narrative perspective** – hope as meaning should be valuable for patients, and healthcare professionals focused on interpreting it.	Healthcare professionals who are able to work with three perspectives on hope may **improve their communication with their palliative care patients, which leads to a better quality of care.**	
14. End of life decision making for ICU patients with limited English proficiency: A qualitative study of healthcare team insights	VOORLOPIG SKIP WEGENS WEINIG RELEVANT				
15. End-of-life care for the critically ill: A national intensive care unit survey		**patient/family factors** (seven items), **clinician factors** (14 items rat- ing the roles of both physicians and nurses), and **institutional/ICU factors**	Important barriers to better end-of-life care included patient/family factors, including **unrealistic patient/family expectations** 2.5 (1.0), **inability of patients to participate in discussions** 2.7 (0.8), and **lack of advance directives**	rated all 14 strategies as helpful (Table 3). Almost universally endorsed were a **family bereavement program, regular pastoral care visits, role modeling and close supervision of trainees by clinicians experienced in end-of-life care, and training of ICU clinicians in relevant communication skills**	Nation wide USA
		600 ICUs represented ap- proximately 10% of the total number of ICUs in the United States.	clinician factors, which included insufficient **physician training in communication** 2.9 (1.1) and **competing demands on physicians' time**	improved communication may reduce anxiety and distress (36) and enhance satisfaction with care	
			institution/ICU factors, such as **suboptimal space for family meetings** 3.5 (1.2) and lack of a **palliative care service**	**public education** also requires greater attention.	
			improve end-of-life care, including trainee r**ole modeling** by experienced clinicians, clinician training in **communication** and **symptom management**, regular meetings of senior clinicians with families, **bereavement programs**, and end-of-life care **quality monitoring**.		
16. Respiratory practitioners' experience of end-of-life discussions in COPD	FOCUS OP COPD Voorlopig OUT				
17. Doctors' understanding of palliative care	complex path between **education** and **behavioural change** is increasingly recognized as important.	even focus groups with doctors expected to have a role in the care of patients with heart failure.	strong sense of the **holistic aspects** of palliative care throughout the groups.	Their thoughtful discussion of the **holistic** aspects of care of the dying suggests that a lack of knowledge would not prevent them from delivering good palliative care.	
			psychosocial issues, communication and spiritual aspect	the multi-disciplinary team	
			difficulties of recognizing the right time to switch to palliative care surfaced as a major challenge.	Palliative care has a place in many **undergraduate and postgraduate curricula**, albeit limited	
			'not very medical', and 'largely nursing based care for people who are terminal'	Our work certainly suggests that greater emphasis on these within **educational strategies** may be beneficial.	
18. Provision of comprehensive, culturally competent palliative care in the Qikiqtaaluk region of Nunavut: Health care providers' perspectives		Thirteen health care providers participated in in-person or telephone semistructured interviews	**respecting Inuit culture, end-of-life care planning**, and the role of **family**; recognizing the importance of the northern community (sense of home); being aware of the limited health care **resources**; recognizing the critical role of medical **interpreters**, and improving the quality of **palliative care programs** and resources, as well as health care provider **training** in palliative care	understanding of a patient's **psychosocial, cultural, and spiritual** back- ground. In addition, participants described the need for health care providers to understand a patient's **wishes and goals of care**	
			benefit greatly from additional training and education in advance care plan- ning, goals-of-care discussions, a palliative approach to care, and providing culturally sensitive end-of-life care	Participants believed that all members of the palliative care **multi- disciplinary** team would benefit greatly from **additional training and education** in palliative care and on how to provide culturally sensitive end-of-life care for Nunavut patients by understanding their sociocultural background	canada
19. Patient autonomy and participation in end-of-life decision-making: An interpretive-systemic focus group study on perspectives of Asian healthcare professionals	enhance patient autonomy and self-determination in end-of-life (EoL) care decision-making	sixty-three physicians, nurses, medical social workers Twelve interpretive-systemic focus groups were conducted.	collusion over truth-telling to patient, (ii) deferment of autonomy by patients, (iii) negotiating patient self-determination, (iv) relational autonomy as the gold standard and (v) barriers to realization of patient choices	Healthcare practitioners in Asian communities must align themselves with the **values and needs of patients and their family** and **jointly** make **decisions** that are consistent and congruent with the **values of patients and their families**	singapore
	Derived from the Greek word autos, that is, the **self**, and nomos, that is, **laws**, the term "autonomy" is commonly understood as related to **self-governance and self-determination**		Particularly, physicians tended to be governed by the belief of their roles to **determine the extent to which patients are given the choice to decide on their own health** care and EoL decisions.	decisions regarding healthcare are the product of a dialog between the patient, their family, and healthcare professionals.	
	Advance care planning (ACP) is increasingly recognized as a **core component** of patient-centered care in medically advanced nations		he best possible outcome of an ACP facilitation session was described by participants as one in which patients could exercise their **relational autonomy.**	A relational understanding of autonomy, which recognizes the social dimensions of an individual patient's agency was found to be fitting in the Asian setting.	
	holistic EoL care service delivery and promote quality of life for patients at EoL by empowering them to make decisions regarding their own care ahead of crisis times		**psycho-socio-economic environment** in which the patient was sit- uated. Specifically, the family's emotional competency to care for a dying member, community services that supported the fulfil- ment of wishes expressed by the patient, and the financial cost of specialized healthcare determined		
20. Communication with terminal cancer patients in palliative care: are there differences between nurses and physicians?	The basic principles of palliative care include excellence in assessment and **management of physical and psychosocial symptoms** and **communication** with patients and families	Questionnair the 135 nurses are compared with only 110 of the physicians	Both groups believed that knowledge of the diagnosis and stage of disease was associated with a better quality of life;	owing to the strong influence of **culture.**	Zwitserland / België / Frankrijk
	confirming the influence of the **cultural context on communication and ethical issues**		Both professional groups also largely agreed that a DNR order should be discussed with the patient or proxy;	whether nurses and physicians have the same perception concerning specific elements of **information giving, decision-making processes, and ethical principles** in palliative care.	
	interdisciplinary team work is one of the basic principles of palliative care		Two-thirds of the respondents in both groups agreed that **shared decision-making** would be most appropriate.	the cornerstones of palliative care - **interdisciplinarity**	
			Nurses clearly favored **"autonomy" over "beneficence"**	experiences from **communication skill training** sessions designed to improve the competence and the confidence of health care professionals in breaking bad news	
				who more often favor **"autonomy"** and **"justice"** over **"beneficence**	
				where physicians most often make decisions, and the ideal situation, a **shared decision-making process** being considered preferable.	
21. Using Nurse Ratings of Physician Communication in the ICU To Identify Potential Targets for Interventions To Improve End-of-Life Care	ICU nurses frequently identify **communication** as an **important source of conflict** among ICU team members and between the ICU team and family members, and this conflict might have consequences for important patient-related outcomes, including **decreased quality of patient care.**9–11	cluster-randomized trial of an interdisciplinary, multifaceted intervention to improve end-of- life care for critically ill adult patients and their families	communication was associated with higher nurse-QODD-1 ratings. specific family questions, family dynamics, **spiritual considerations, and cultural considerations**.	physician-nurse communication around the topics of family questions, family dynamics, **spiritual** considerations, and **cultural** considerations were significantly associated with higher nurse ratings of the **quality of dying.**	USA
	improved physician- nurse **communication** has been associated with **enhanced provider satisfaction** and **improved patient outcomes**, such as **reduced ICU lengths of stay and costs of care**	The nurse-QODD-1 is a single-item question assessing the patient's experience from the nurse's perspective: "Overall, how would you rate the quality of the patient's dying?	Higher ratings for each of the measured topics of physician-family communication, including four specific topics and one overall communication rating, were associated with higher ratings on the nurse- QODD-1	Focusing end-of-life conver- sations on spiritual concerns could **improve quality of dying.**	

	physician-family communication has been shown to have an important effect on **family psychological outcomes, such as depression, anxiety, and posttraumatic distress**			improved overall physician-nurse communication and **collaboration** in the ICU is associated with better quality care,	
	use ICU nurse assessments of quality of communication and quality of dying to identify specific targets for communication interventions to improve patients' dying experiences.			improved physician-family communication is associated with **reduced prolongation of patient dying** in the ICU and **improved family outcomes**.	
	Introductie	Methodologie	Resultaten	Discussie	
22. A novel questionnaire to measure staff perception of end-of-life decision making in the intensive care unit--development and psychometric testing		**Interdisciplinary** collaboration and participation of the whole team are considered desirable and important			USA
		Moreover, **participation in decision making** may be a relevant resource to **prevent the development of burnout**			
		Three typical regulation problems were chosen and adapted to the context of EOL decision making and communication: role ambiguity (also known from role theory), informational difficulties, that is, lack of relevant information to fulfill a task, and interruptions of work processes.			
		Difficulties and stress perceived in the EOL context might induce ICU staff to avoid initiation of or **participation in decision making and communication with patients' families.**			
	Introductie	Methodologie	Resultaten	Discussie	
23. Perspectives on palliative care in Lebanon: knowledge, attitudes, and practices of medical and nursing specialties	In all countries, oncologists and geriatricians had the lowest score for use of "lethal drugs" and the highest score for preserving life; anesthesiologists had the lowest scores for preserving life.		Statistically significant differences were found in attitudes and practice levels among the **different specialties** in general	In this study, 24.4% of oncology nurses believe that PC destroys hope and leads to despair and depression	Lebanon
	Hanratty et al. (2006) reported that cardiologists in England believed that **dealing with the death of their patients meant dealing with their failure**		In general, more nurses than physicians in the medical and surgical specialties perceived the patient's and family' s outbursts and questions negatively.	More medical and surgical nurses than physicians **viewed the patient's and family's outbursts, questions, and concerns in a negative manner**. These results can be attributed to lack of knowledge and communication skills and to the nurses' inability to deal with emotional outbursts in difficult stressful situations.	
	A number of studies in oncology (Hilden et al., 2001; White et al., 2001; Cherny & Catane, 2003; Wang et al., 2004; Stegina et al., 2005; Morita et al., 2006) addressed the **self-assessment level of competence** in dealing with dying patients; some nurses and physicians felt competent dealing with physical symptoms and less competent with psychological symptoms.		Furthermore, physicians of these specialties were more likely than nurses to report **"DNR as a right"** (	Although similar results have not been reported elsewhere, in the study by Boyle et al. (2005), intensive care unit nurses and physicians believed **good communication** among physicians, nurses, patients, and family to be the most important factor in end-of-life care in the intensive care units but found it to be the least accomplished	
	s. Discrepancies were found between physicians and nurses regarding **informing patients and their families about diagnosis and prognosis** and involving them in the decision-making process		**Same religious belief** was reported to enhance the caring process among medical, surgical, and oncology nurses more so than their physician counterparts (	These results affirm the importance of PC **knowledge and communication techniques** in the educational preparation of nurses and physicians	
	Almost all fellows considered it the **physician's responsibility to assist patients in facing the end of life** and preparing them for death.			In general, **social attitudes and the societal prevailing norms** regarding communication and truth telling are known to be affected by cultural beliefs and norms.	
				Sharing the **same religious belief** was found to enhance the caring process among medical, surgical, and oncology specialties, but significantly more among nurses than physicians	
	Introductie	Methodologie	Resultaten	Discussie	
24. Knowledge and Experiences of Final Year Medical and Nursing Students with Regard to Palliative Care at Government University in Oman: A Questionnaire Based Study	Knowledge and Experiences of Final Year Medical and Nursing Students with Regard to Palliative Care at Government University in Oman: A Questionnaire Based Study		Also, most of the students (83.1%) thought that the ultimate aim of PC was only to **reduce the patient's suffering**, rather than to alleviate the suffering of the patient's family members as well (	Although the students were aware of the concept of PC, most of the participants in this study admitted that they only had a vague idea of what PC was and few of them could provide the correct definition of PC, including the involvement of the patient's family members in their care	Oman
			Most of the students also thought that nursing should not take precedence over the **patient's comfort**	Although the optimal implementation of well-structured, formal PC education in the teaching curriculum is still a matter of debate, several studies have described the positive effects that such courses can have	
				It has been noted that students who have more clinical exposure to terminally ill patients during their undergraduate education are more likely to feel prepared to discuss end-of-life issues with patients, treat common PC symptoms, and are competent in providing quality end-of-life care	
				For most patients, their home represents familiarity, due to the presence of loved ones, and they can enjoy a normal life	
				The students in this study stated that special psychological support should be provided for doctors and nurses who provide PC services, due to a concern over the inevitable professional burnout.	
				Some students in this study felt that family members of terminally ill patients have the right to remain at the patient's bedside until death occurs; a greater percentage thought that family members require similar levels of spiritual and psychological support to those received by the patient	
	Introductie	Methodologie	Resultaten	Discussie	
25. A profile of the belief system and attitudes to end-of-life decisions of senior clinicians working in a National Health Service Hospital in the United Kingdom	A profile of the belief system and attitudes to end-of-life decisions of senior clinicians working in a National Health Service Hospital in the United Kingdom			When faced with the clinical scenario of a dying patient, the attitudes of clinical staff varied both within and between professional clinical groupings	UK
	There is much evidence which shows that a patient's **personal religious and spiritual beliefs** influence their **experience of and response to illness including dying**			Different opinions and attitudes to decisions at the end of life between consultants and nurses may lead to potential tension and conflict in agreeing an action plan for the patient unless sensitively handled.	
	There is some evidence from outside the United Kingdom to show that physicians' religious beliefs and attitudes to life and death influence decision making at the end of life			This study illustrates that although clinicians may believe they act in the best interest of the patient, the interpretation of best interest may differ within and between clinical groupings	
				It highlights the need for appropriate communication with the patient during their illness to determine their wishes	
				Spirituality remains a sensitive area for clinicians. However, spiritual values and the need to address the spirituality of patients are increasingly being recognised as an integral part of care	
				It would appear that stating the importance of a belief or religion may not relate to being active in that belief	
	Introductie	Methodologie	Resultaten	Discussie	
26. Palliative care for patients with heart failure: facilitators and barriers - a cross sectional survey of German health care professionals	Palliative care for patients with heart failure: facilitators and barriers - a cross sectional survey of German health care professionals	Analysis of the interviews showed, that a lack of knowledge of palliative care, shortcomings in communication and cooperation between health care professionals, the inability of cardiologist to accept medical limits and death as an entity of CHF, and the difficulty to determine the right time to initiate PC in CHF patients were identified as barriers to PC.	Participants' evaluations regarding aims of PC are displayed in Table 3. They agreed that the aim of PC is to maintain the best possible quality of life and to provide a dignified death.	However, main barriers seem to be a lack of clear responsibilities, undefined communication structures, and HCP-patient-relative knowledge deficit regarding the content and the meaning of PC. In addition, HCPs shared the view that it is difficult to determine the right point of time to start PC treatment.	Duitsland
		Participants of this study part expressed their hope that better communication and cooperation between the medical disciplines as well as education about PC and CHF for physicians, nurses, patients and for the public would foster PC for patients with CHF.	Supporting the patient, relieving physical symptoms, and discomfort were seen as measures of PC.	The question of "who" is responsible for patient education should be considered in light of the current structure and resources	
			Additional comments by the participants suggest that the aim of PC should be to care for the patient at home	Health care providers, especially physicians express also their feelings about PC in terms of losing the patients or experiencing a defeat when the patients die. I	
			Participants' statements reflect also the opinion that PC should always include all people affected by the disease of the patient, i.e. relatives and HCPs, which was reflected by one participant's statement: "[Within palliative care] **all significant persons involved with the patient should be included** [...]" .	It seems that HCP's attitude towards PC are based on "an inappropriate notion of ideal medicine", in which death is something, which should not take place	
			Participants believed that cooperation of all HCP and medical disciplines are essential for PC of patients with CHF, as well as interdisciplinary collaboration to create and maintain clarity	Even though in Germany PC services are at an advanced level, a clear agreement or idea of who is responsible for CHF patients does not seem to exist	
			As displayed in Table 5, HCP perceived that the lack of information provided to patients and relatives regarding the progression and severity of the patient's disease (CHF) as being one of the main barriers		
			The respondents also believed that death is still a taboo subject within the society and that patients do not like to accept that life is limited because of the disease. In addition, it was assumed that PC is put on the same level as euthanasia by the patients. I		
			Most participants also agreed to the statement that it is easier to continue the started therapy than to change it.		
	Introductie	Methodologie	Resultaten	Discussie	
27. Palliative care practice and moral distress during COVID-19 pandemic (PEOpLE-C19 study): a national, cross-sectional study in intensive care units in the Czech Republic					
	Introductie	Methodologie	Resultaten	Discussie	
28. Creation and the Empirical Validation of the Dignity Care-Sort Tool To Assess Factors Influencing Erosion of Dignity at Life's End	In order to best facilitate a sense of dignity and dignified deaths, for all patients, first of all, perceptions of the concept of dignity and death with dignity must be first better understood. This concept is a very subjective one and much influenced by an individual's personal, cultural, social and spiritual constructs.	They endorsed the need for this line of research and stated that health professionals' perceptions and behaviors are likely to have a significant influence on patients' perception of their dignity		The health professionals felt that treating a patient with disrespect and not carrying out their wishes resulted in greater erosion of patient dignity	USA
	Both quality of care and care tenor can either augment or erode patient dignity.			In contrast patients felt that receiving poor medical care and dying in pain led to erosion of their dignity.	
				It has been acknowledged that the behavior and the care tenor of health professionals greatly influences patient dignity and it is indeed true that respect33 is a very important determinant of quality of care.	
				It is possible that health professionals (nurses and physicians alike) may have felt that the basic needs of dying patients like quality palliative care and good pain control are "a given" and thus may have focused on more abstract concepts like "respect" and " ability to choose."	
				The patients (especially the cohort of hospice patients) who were actually faced with the physical reality of the debility and vulnerability that usually accompanies a chronic terminal illness were likely in a different frame of mind compared to the health professionals who were probably responding to the question somewhat hypothetically.	
				Also the construct of dignity and its loss at the end of life is likely to be altered as patients' journey through the dying process (although one of our samples was a cohort of dying patients).	
	Introductie	Methodologie	Resultaten	Discussie	
29. Palliative care for advanced dementia in Japan: knowledge and attitudes				A more positive attitude was observed in facilities that had established a manual on end-of-life care as well as in facilities that had a physician's written opinions on end-ofife care. H	Japan

				Knowledge of palliative care for advanced dementia was greater among nursing home staff with higher education levels and those in facilities that had a manual.	
				Attitudes towards palliative care for terminally ill patients were more positive among nursing home staff who were nurses and those who had a longer tenure as a care worker.	
	Introductie	Methodologie	Resultaten	Discussie	
30. Patient participation in palliative care decisions: An ethnographic discourse analysis	Patient participation in decision-making is deemed particularly appropriate towards the end of life because these decisions are preference-sensitive, involve significant uncertainty, and often present medically equivalent treatment options, a notion known as equipoise		Patients and their family members frequently cared about outcomes that were difficult to quantify, that had not been researched, or that could only be achieved through undesirable trade-offs.		USA
	Palliative care consists of a holistic and interdisciplinary approach to care that seeks to improve the quality of life of patients and their families when confronted with a life-threatening illness		From the way palliative care providers taught students and the types of concerns that were discussed during interactions among team members, it was apparent that maintaining quality of life, as defined by the patient, constituted a paramount goal of care.		
	This literature suggests that a majority of palliative care patients prefer a shared or active role in decision-making.		Respecting patients' ideas about quality of life therefore represented a way of reorienting care when interventions became unlikely to affect the life expectancy of patients.		
31. Palliative/hospice care in Poland					Polen
32. Initiating decision-making conversations in palliative care: an ethnographic discourse analysis	Given the preference-sensitive nature of palliative care decisions, **patient involvement** in decision-making is being promoted as appropriate in this clinical context		A **long-term doctor-patient relationship** in palliative care also affected their discursive practices initiating decision-making.	The origin of the referral to the palliative care service, its timing in the patients' illness trajectory and the development of the therapeutic relationship all shaped whether patients were ready and able to discuss their impending death	
	The **tendency to delay decisions** about advance directives and to focus on curative treatments are major barriers to involving patients in making decisions about palliative care options			Second, the fact that discussing and planning end-of-life care was implicitly constructed as the patient's prerogative during clinical discourse could explain why there is a tendency to delay decision-making and to wait for patients to bring up concerns about death and dying themselves	
	Given the importance of addressing decisions early on to ensure that terminally-ill patients have an opportunity to participate in decision-making about their care, we sought to address this important knowledge gap.				
33. Addressing religion and spirituality in the intensive care unit: A survey of clinicians	Although patients look to clinical care teams for physical healing, they **also desire emotional and spiritual healing** as well		A majority of ICU clinicians generally agreed that it was their **responsibility** to inquire about the religious and spiritual needs of patients.	Given that ICU clinicians see it as both their **responsibility** to inquire about religion and spirituality and **feel comfortable** broaching those subjects, one would believe that this would be a regular part of clinical practice	UK
	A study in cancer outpatients showed that patients with positive religious coping tend to have higher rates of ICU death and more aggressive care at the end of life, signifying that a patient's **religion may play an important role** in healthcare decision-making particularly at the end of life		We found that both level of **religiosity and spirituality** correlated with how clinicians view their responsibility in addressing religious and spiritual concerns of patients. And these factors also affect how comfortable clinicians feel addressing these issues.	We found that nurses reported more comfort and engagement addressing spiritual needs than physicians. However, only a minority of nurses said they frequently make it a regular part of clinical practice even though a templated question on preference for a chaplain visit is included in our medical center's new patient intake	
	However, **when spiritual needs are met** by a member of the healthcare team, patients have higher levels of hospice utilization, lower rates of ICU death, and lower healthcare costs at the end of life			This finding is similar to past work that showed that **more junior medical trainees find discussing religious and spiritual topics more complex** than simply discussing do not resuscitate topics	
	In addition to these objective measures, addressing the spiritual needs of patients has implications for **patient satisfaction**			In summary, addressing religious and spiritual needs is important to both patients and families, particularly at the end of life, although we found evidence that suggests there is discordance between clinicians' beliefs and their actual practice.	
	Physicians have reported that they often, in particular, **feel unprepared** to not only to elicit spiritual beliefs, but also to address spiritual needs that may be identified				
34. Health care providers' knowledge, confidence, difficulties, and practices after completing a communication skills training program for advance care planning discussion in Japan					Japan
35. Health-Care Provider Personal Religious Preferences and Their Perspectives on Advance Care Planning With Patients	**Religion** has been documented as a stated significant personal factor influencing patients' ACP wishes,which is also likely true for clinicians as patients		As noted in Table 2, HCPs **stating a religious preference were more likely to have personal ACP**, including their own living will and a written designation of a health-care power of attorney (HCPOA)	This lack of differences suggests that health-care **professionals can separate their own ACP beliefs and experiences from the desires of their patients and significant others**, similar to that found in the Ethicalt study from the Netherlands.	USA
	Braun et al reported that physicians in **focus groups generally did not think their own faith or religious beliefs influenced their ACP**, although there were some differences by **ethnicity**			Those who **were older** were more likely to have a written living will and a designated HCPOA, as well as a stated religious preference	
	In another study, most physicians believed it appropriate to discuss religious/spiritual issues during EOL care when a patient brings them up and would **encourage patients in their own beliefs** and practices,8 implying that their own personal religious views would not be determinant			While the stated religious affiliation of the HCPs was associated with the presence of their own personal living wills and/ or a designated HCPOA, this was **partially a function of age**	
	Introductie	Methodologie	Resultaten	Discussie	
36. Advance care planning in COPD: guidance development for healthcare professionals	growing evidence that ACP is associated with positive outcomes, including **improvements in the quality of end-of-life care**, but most studies to date have been observational and performed with elderly patients, nursing home residents and hospital inpatients.		The majority of participants agreed with the statements related to **patient autonomy,** including 'Patients with decision making capacity who are not terminally ill should have a right to refuse treatment even if that decision may lead to death' and 'Healthcare professionals should comply with a patient's wishes even if they conflict with the family's wishes'.	Among the most important findings of this study were that (1) although Irish healthcare professionals have positive attitudes towards ACP, **self-reported confidence levels** in initiating discussions are low, and relatively few are actually initiating ACP discussions with patients with COPD;	Ierland
	ACP interventions may lead to **improvements in patient–physician communication** and COPD symptoms.		Levels of self-reported confidence to undertake ACP discussions were relatively low, with a mean confidence score of 2.23 (out of 4.0).	while most healthcare professionals agree that ACP should be part of the management of patients with severe COPD, there is some uncertainty around whether it should be introduced for patients with **less severe disease**;	
	Qualitative studies with patients with COPD have found that the **absence of ACP leads to distressing discussions about resuscitation** during acute exacerbations, and in general, patients want to make informed decisions about their treatment			levels of confidence related to interpreting the **relevant ACP legislation** and the roles of decision-making support persons are particularly low.	
	For patients with COPD, one of the main barriers to implementing ACP into routine management is the **uncertainty around prognosis** and the **unpredictable disease trajectory.**				
	Other barriers for this patient group include **variability over time in patients' wishes** regarding care, **concerns about dashing patients' hopes**, and a lack of **patient and family readiness** for discussing the topic.				
	Introductie	Methodologie	Resultaten	Discussie	
37. The involvement of cancer patients in the four stages of decision-making preceding continuous sedation until death: A qualitative study	**Patient participation** in decision-making is considered to be particularly appropriate towards the end of life because end-of-life decisions are often preference-sensitive.		The initiation phase appeared to be an interplay between the medical team and the patient and could best be understood as a **continuum** with, at the extremities, the initiative driven predominantly either by the patient or by the physician.	Decision-making in all phases could be described as being paternalistic, shared or informed, but it sometimes changed between the different phases.	België, Nederland, UK
	Studies have suggested that although a majority of people with limited life expectancy **prefer a shared or active role in decision-making**, their physicians and those close them are frequently unaware of their preferences		In the first, mainly in the Netherlands and Belgium, the physician had a predominantly informative role, informing the patient about their disease progression and the possibility of using sedation and the circumstances under which it could be used.	In both types, respondents placed high value on the patient's perspective, respecting their wishes, giving them explicit information about the implications and obtaining their consent.2	
			They then either hoped to come to a **shared decision** by further exploring the preferences of the patient or they left it to the patient to make an informed decision themselves.		
			they mainly stressed the importance of responding to **patient's specific requests** and wishes or the fact that the final choice should lie with the patient, provided that the clinical conditions were fulfilled		
			The involvement of patients in this phase was dependent whether the person who was dying was considered to have **the capacity to take part** in the final stages of the decisionmaking process or not		
	Introductie	Methodologie	Resultaten	Discussie	
38. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers	Most patients from Western countries prefer **some information regarding prognosis** when first diagnosed with a life-limiting illness.2		Trust can be built by using an **empathic, patient-centred style.**4		
	However, this information can be difficult to comprehend at this time,32 and one study indicated that patients found the information distressing **if they had not asked** for it		An empathic, patient-centred style also involves using open-ended questions with an emotional content		
	If the consultation is planned, it is important to provide consistent, accurate information by reading clinical records, speaking with health care professionals, and researching the literature to **obtain up-to-date knowledge**		This approach has been shown to elicit greater expression of feelings compared with the use of closed questions		
	It is helpful for health care professionals to be aware of their own feelings of grief, anxiety or guilt (including fears about holding the discussion), particularly if they have known the patient for some time		Many patients and caregivers want information		
	Good interaction between the patient and health care professional is fundamental to effective communication,43 and patients facing a progressive life-limiting illness **place great emphasis on the relationship with their health care professional**		Patients from some cultural backgrounds may prefer non-disclosure, or disclosure negotiated through the family, when life expectancy is short		
	Most patients prefer the information to come from a **confidant expert**		Many health care professionals have difficulty in disclosing a limited life expectancy while maintaining the **patient's hope**, yet patients, caregivers and health care professionals have identified hope as an integral component of prognostic and end-of-life discussions.		
	health care professional needs to negotiate who delivers the information.				
	Do not assume that the patient does not want to discuss the topic simply because he or she does not raise the issue, or because of cultural background				

	Introductie	Methodologie	Resultaten	Discussie	
39. Care of the dying in long-term care settings	CNAs have a critical role in **assessing the needs of a dying LTC** facility resident, because they are often the first to observe symptoms of critical or terminal illness.				USA
	Their **observation of subtle changes** in behavior, mood, or intake that characterize terminal decline for frail residents are critical to good patient care.				
	Residents may **confide** their fears, pain, or spiritual concerns during the dying process to a trusted and familiar CNA				
	People who are dying in LTC settings have **complex nursing needs**, including skilled assessment and management of symptoms, emotional and spiritual care, and support for grieving family members				
	Physicians are rarely on site, so the nurse becomes the **primary communication link** between physicians, residents, and family members.				
	Nurses may anticipate the **need for ethical decision** making near the end of life and must find effective ways to communicate their concerns to physicians and family members.				
	Medical authority also reassures family and residents who face difficult ethical decisions near the end of life				
	Physicians have a unique role in determining prognosis.				
	Introductie	Methodologie	Resultaten	Discussie	
40. What keeps oncologists from addressing palliative care early on with incurable cancer patients? An active stance seems key	It alsomeans **dealing with patients' feelings** of hopelessness and disappointment		Physicians **responded to patient preferences for active treatment** although it had no or only marginal benefit, but sometimes severe side effects. This was the most frequent challenge reported by clinicians experiencing this dilemma.	This finding is supported by the results of a antecedent cohort study on EOL decisions that showed that **patients in denial were involved significantly less often** than patients with an appropriate perception of their situation in decisions against life-prolonging treatment	Duitsland
	Communication with patients with incurable cancer about the transition from specific anticancer treatment to best supportive care		Physicians explained patients' unrealistic expectations as being beyond their control, as a "center effect" in which specialized cancer institutions attract patients who actively search for additional treatment.	Several studies report the physicians' discomfort discussing prognosis [13, 16] for the same reasons that were given by our interviewees: **feeling ill prepared for EOL communication**, uncertainty about the definite prognosis, and fear of destroying patients' hopes	
	Although most physicians think that patients ideally should have a realistic understanding of their prognosis [2], **the majority avoids prognosticating** in the last phase of life.		Oncologists admitted that they go along with or nourish patients' overly optimistic views of the therapeutic options because they are **afraid to destroy their patients' hope.**	However, our results support the view that it is ethically critical toelicit patient preferences and, at the same time, tell the truth about the patient's prognosis.	
	Studies showed that a "**conspiracy of silence" leads to psychological distress** [3], early palliative discussions are associated with less aggressive medical care near death, less anxiety and depression, earlier hospice referrals, and even a gain in lifetime [4–7]		Interviewees who described their **roles in active terms** aimed to facilitate the discussion with the patient about the right treatment choices at the EOL		
	In the end, palliative care can **lower total health care cost**		This was stated to be a prerequisite for **honest disclosure, minimizing unrealistic expectations and empowering patients for advance care planning**		
			They **did not consider themselves to be obliged** to prepare the patient for the last phase of life.T		
			As long as the patient feels quite well, despite poor prognosis, advanced care planning at that point is considered a "rather abstract problem.		
			Nurses described emotions as an important resource in caring for advanced cancer patients.		
			On the one hand, they said, **medical evidence shaped the framework of their decision making**; a positive benefit-harm ratio in themedical evaluation was oftenmentioned to be the key factor in theentire decisionmaking process.		
			Physicians described their difficulty in reconciling the need for objective or evidence-based decision-making criteria with their own emotional involvement. Consequently, decision-making within a team was viewed as fundamental for reaching emotional distance, especially when making a decision against life-prolonging treatment.		
	Introductie	Methodologie	Resultaten	Discussie	
41. Factors that influence the participation of healthcare professionals in advance care planning for patients with terminal cancer: a nationwide survey in Taiwan	Although the **intention of ADs is to respect patient autonomy**, nearly 80% of general public would like to **decide treatment preference in consultation with the doctor.** (	surveyed 600 physicians and nurses working in oncology care wards or palliative care units using a structured mailed questionnaire.	Healthcare professionals in the **participation group had better knowledge and less frequency of ethical dilemmas** for palliative care	Moreover, **end-of-life discussions** with medical professionals are associated with **less aggressive medical treatment near death and earlier hospice referrals.**	Taiwan
	Since patients who prefer to forgo CPR may **receive unwanted treatment when their wishes are misunderstood** by healthcare practitioners, the factors that affect healthcare professionals' communication of treatment preferences with the patients are important issues for study				
				Some may argue for greater attempts at **physician education** in the knowledge of and **ethical issues** involved in palliative care as a means of promoting discussions regarding end-of-life (EOL) issues	
	patients are 3 times more likely to establish ADs if they have been **asked about their wishes,**			suggested the need to shift from **promoting awareness (politiek) to teaching the skills physicians** require to.	
	Well after ADs were established as a national policy in United States, investigators reported that many healthcare professionals had insufficient **understanding of such directives** and that there was a low rate of chart documenting of living wills.				
				aggressive treatment is associated with a **lower patient quality of life** and **poorer caregiver bereavement** adjustment.	
	Moreover, ethical concerns and clinical difficulties arise when ACP is applied in **different cultures**.				
				communication about EOL care needs to be seen as a medical skill	
				the preeminent **role of family** in end-of-life decision making in Asian countries	
				difficulty in **evaluating the decision making ability of patients**	
				difficulties in **assessment of life expectancy** and in determination of the onset of dying process for patients	
				fear of abuse of ADs by medical staffs	
	Introductie	Methodologie	Resultaten	Discussie	
42. Residents from five training programs report improvements in knowledge, attitudes and skills after a rotation with a hospice program	The public's trust in their physicians' ability to **relieve suffering** and **improve quality of life** is challenged by reports that, for patients near the end of life, pain remains unrelieved, and medical care fails to reflect **informed patient preferences** or timely access to palliative and hospice care		significant improvements in their **ability to assess and treat symptoms, to tell patient/family about the dying process and to care for dying** patients at home	single hospice **rotation can effectively contribute to resident education** in multiple programs	USA 1997
	Of all of these areas for focus, **residency training** may be the most important because so many practice patterns are formed during this intense period.		Interestingly, after the rotation, more residents reported that they are "**aware of a lot of personal fears** about death"	The residency program that sent its residents for a total of 16 days showed changes in more items than those programs who sent their residents for fewer days.	
	It transmits the message that the **physician role** in end-of-life care is important			include evidence-based **symptom assessment** and **management practices, cultural and spiritual context** of medical interventions, and the **ethical principles** and **communication skills** that relate to interactions between and **among professionals, patients, and their families.**	
	A variety of efforts are underway to **improve end-of-life care (EOL) training** for physicians. Educational efforts in the undergraduate, graduate, post graduate and continuing medical education				
	educa tion combined with the clinical provision of palliative care is likely to be the most effective at ensuring the **desired knowledge, attitudes and skills.**				
	The quality of the rotation is enhanced when there is an **enthusiastic faculty who find palliative medicine professionally rewarding**				
	it exposes residents to the **"team" concept of care** as well as **normalizes the death experience** for patients, families, and the trainee.				