Die europäische und internationale Perspektive der Hospizarbeit und Palliativmedizin

European Association for Palliative Care

One Voice, One Vision in Palliative Care

Christoph Ostgathe, Präsident

European Association for Palliative Care (EAPC)

EAPC ‘one voice and one vision’

- … ist ein Forum für alle, die in Europa und darüber hinaus in der Palliativversorgung aktiv sind oder sich für Palliative Care interessieren
- … hat 53 Mitgliedsverbände, drei aus Australien / Neuseeland und 50 aus 33 europäischen Ländern sowie Einzelmitglieder aus 42 Ländern weltweit
- … ist Fürsprecherin für die Entwicklung der Palliativversorgung durch ihre Aktivitäten und ihre Arbeit bei der Weiterentwicklung der Praxis der Palliativversorgung in Europa und der Welt
- … ist vom Europarat anerkannt
- … fördert die Forschung u.a. durch Beteiligung an EU-Projekten
- … multiprofessionelle Mitglieder engagieren sich für Palliativ-versorgung über die gesamte Lebensspanne hinweg aus einer Reihe von Perspektiven: u.a. spezialisierte und allgemeine Palliativversorgung, Ausbildung, Politik und Forschung.

EAPC consensus papers

Definition and recommendations for advance care planning: an international consensus supported by the European Associatio

Judith A C Rietjens, Rebec
Daren K Heyland, Dirk Ho
Association for Palliative

White paper defining optimal palliative care in older people with dem rec Ass

Jenny
Maril
Anne
Raym
Euro

Palliative Medicine
2014, Vol. 28(3) 197–209
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DOI: 10.1177/0269216313493685
pmj.sagepub.com

EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services – Recommendations from the European Association for Palliative Care (EAPC) Task Force on

Claudia Bausewein[1], B
Julia Downing[4], Luc D
Pedro Lopes Ferreira[8]
and Irene J Higginson[2]

Palliative Medicine
1–17
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DOI: 10.1177/0269216315589898
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SAGE

Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care

Lukas Radbruch[1,2], Carlo Leget[3], Patrick Bahr[1], Christof Müller-Busch[4,5], John Ellershaw[6], Franco de Conno[7] and Paul Vanden Berghe[8]; on behalf of the board members of the EAPC

1–13
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DOI: 10.1177/0269216315616524
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EAPC consensus papers

EAPC update

White Paper on standards and norms for hospice and palliative care in Europe: part 1

Recommendations from the European Association for Palliative Care

In this official position paper of the European Association for Palliative Care (EAPC), Lukas Radbruch, Sheila Payne and the Board of Directors of the EAPC outline and explain the association's recommendations for a common terminology and common quality norms

1. Background

The modern hospice movement was introduced by Cicely Saunders with the opening of St Christopher's Hospice in London in 1967. However, as early as 1975, Balfour Mount found a confusion of terms when he looked for a designation for his new inpatient unit in Montreal, as in French-speaking Canada 'hospice' was already used in a different context, leading to the introduction of the term 'palliative care'.

The struggle for a common language has been going on since then in hospice and palliative care throughout the world and has hampered the development of international standards and norms. Recently, the European Association for Palliative Care (EAPC) commissioned a survey on the development of palliative care in European countries. The Task Force on the Development of Palliative Care in Europe, led by Carlos Centeno and David Clark, has just published the results in the *EAPC Atlas of Palliative Care in Europe*, providing for the first time valid data for comparison of the state of palliative care across European countries.[1,2] This evaluation showed some common structures, but also a wide variety in the structure of service development and care delivery. These differences are at least partly related to different understanding of the underlying concepts and the terms of palliative medicine. The development of a common terminology has been claimed as a prerequisite for meaningful comparisons.[3]

Following this lead, the EAPC is now putting forward suggestions for a common European terminology following a consensus process with the national associations. Norms will be defined on the basis of this consensual terminology. Guidance on norms and standards are necessary not only for healthcare professionals working in hospice and palliative care settings, but also for decision-makers in healthcare who are responsible for adequate access to palliative care for patients.

With the ongoing development of palliative care throughout Europe, decision-makers are challenged not only to decide where and when palliative care services should be developed, but also how they should be equipped and configured. Adequate structural quality is a prerequisite for high quality of care. Administrative and political decision-makers will aim for cost-effectiveness, and try to reduce costs by allocating a minimum of staff or reimbursement. Care providers will negotiate for adequate staff resources necessary for high quality of care. In this conflict, both sides will seek guidance on structural quality.

In this paper, the EAPC presents norms on structural quality for the provision of palliative care with in- and outpatient services in different settings. This *White Paper* takes into account the different concepts in the European countries and regions. This is acknowledged by the description of norms rather than the definition of standards. Whereas standards would imply an absolute limit below which quality palliative care is not possible (minimal standards), norms represent a consensus on quality goals that have to be aimed for (aspirational norms). If (or

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EUROPEAN JOURNAL OF PALLIATIVE CARE, 2009; 16(6)

- Ringen um eine gemeinsame Sprache von Anfang an (Saunders vs. Mount)
- Delphi-Studie - 35 nationale PC-Organisationen: 22 europäische Länder
- Unterschiedliche Arten von Diensten in verschiedenen Ländern
- Mangel an einheitlichen Standards und allgemein akzeptierten Definitionen für jede Art von verfügbaren Ressourcen
- Unterschiedliche Auslegungen dessen, was als "spezialisierte Palliativversorgung" angesehen wird
- Konsens darüber erforderlich, was eine qualitativ hochwertige Palliativversorgung ausmacht

Aktualisierung 2021 durchgeführt und eingereicht

Radbruch L., Payne S. (2009) White paper on standards and norms for hospice and Palliative care in Europe: Part 1 Recommendations from the European Association for Palliative Care. EJPC 16(6)278-289

EAPC ‘one voice and one vision’

EAPC Board 2019 -2023

EAPC ‘one voice and one vision’

EAPC Board 2019 -2023

WHA - Resolution Palliative Care

SIXTY-SEVENTH WORLD HEALTH ASSEMBLY **WHA67.19**

Agenda item 15.5 **24 May 2014**

Strengthening of palliative care as a component of comprehensive care throughout the life course

The Sixty-seventh World Health Assembly,

Having considered the report on strengthening of palliative care as a component of integrated treatment throughout the life course;[1]

Recalling resolution WHA58.22 on cancer prevention and control, especially as it relates to palliative care;

Taking into account the United Nations Economic and Social Council's Commission on Narcotic Drugs' resolutions 53/4 and 54/6 respectively on promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse, and promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse;

Acknowledging the special report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purposes,[2] and the WHO guidance on ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines;[3]

Also taking into account resolution 2005/25 of the United Nations Economic and Social Council on treatment of pain using opioid analgesics;

Bearing in mind that palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual;

Recognizing that palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received;

---

[1] Document 67/31.

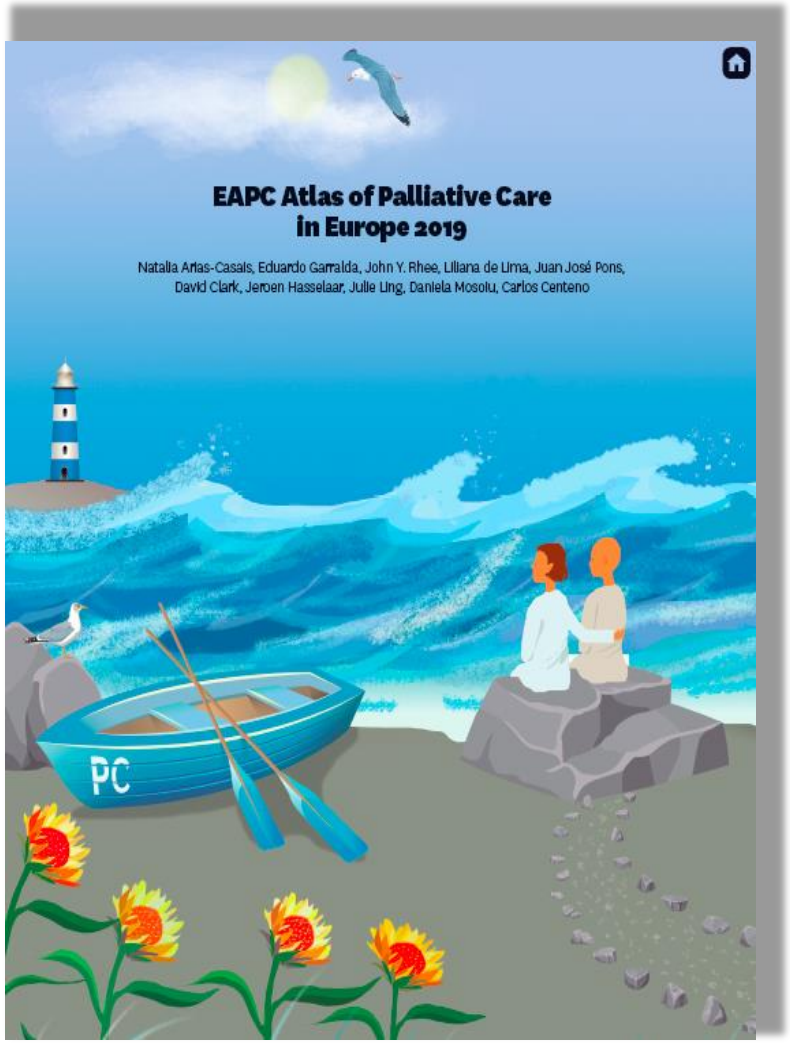
[2] Document E/INCB/2010/1/Supp.1.

[3] Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011.

WHA - Resolution Palliative Care

- WHA fordert die Mitgliedstaaten auf
  - Nationale Strategien zur Palliativversorgung zu entwickeln
  - ausreichende (finanzielle und personelle) Ressourcen für die Palliativversorgung im Gesundheitswesen bereitzustellen,
  - Ehrenamtliche und pflegende Angehörigen zu unterstützen
  - häusliche Versorgung zu sichern
  - Ausbildung auf der Ebene der allgemeinen und spezialisierten Palliativversorgung zu fördern und
  - Essentielle Medikamenten bereit zustellen, incl .der Überprüfung und falls erforderlich auch Änderung der gesetzlichen Regelungen zu Opioiden

Situation in Europa



EAPC Prize 2019

Carlos Centeno (Spain)

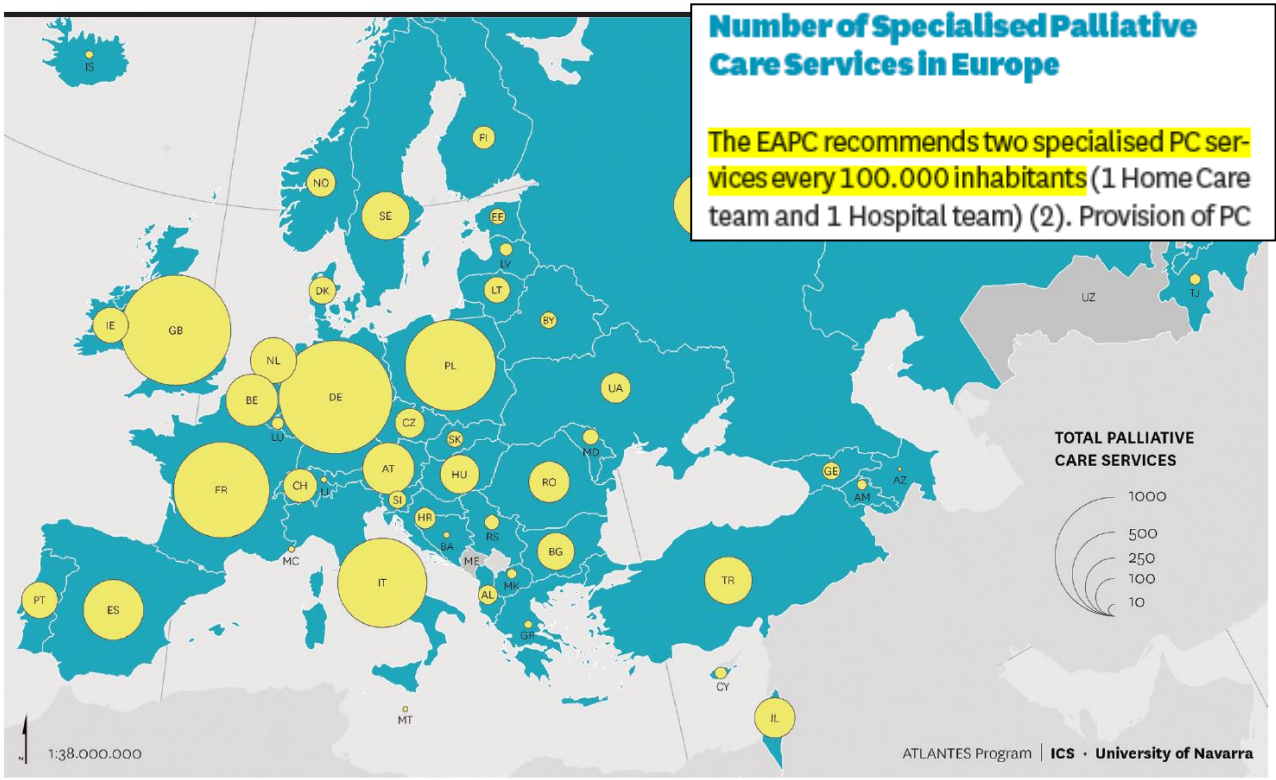
Awarded to Carlos for his outstanding contribution to the work of the EAPC over many years including the development and ongoing work on the EAPC mapping project.

European Association for Palliative Care

One Voice, One Vision in Palliative Care

http://dadun.unav.edu/bitstream/10171/56787/6/Atlas%20Europa%202019_DEF.pdf

Palliative Care Angebote für Erwachsene

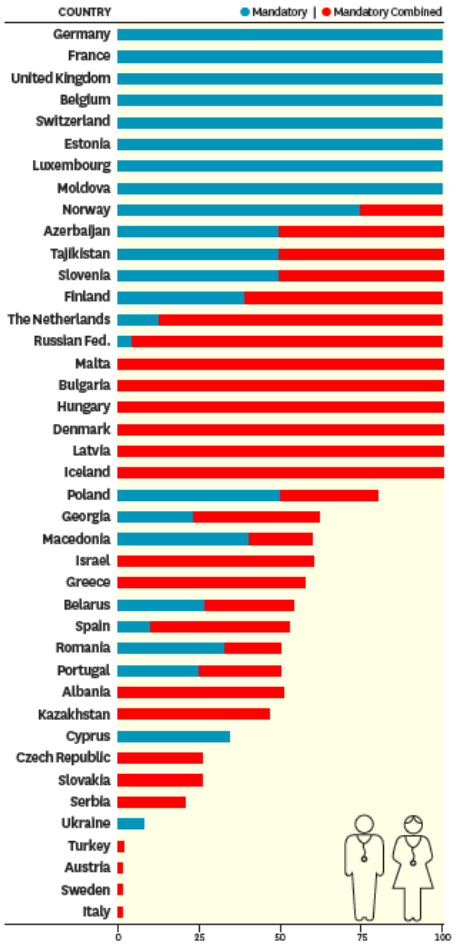


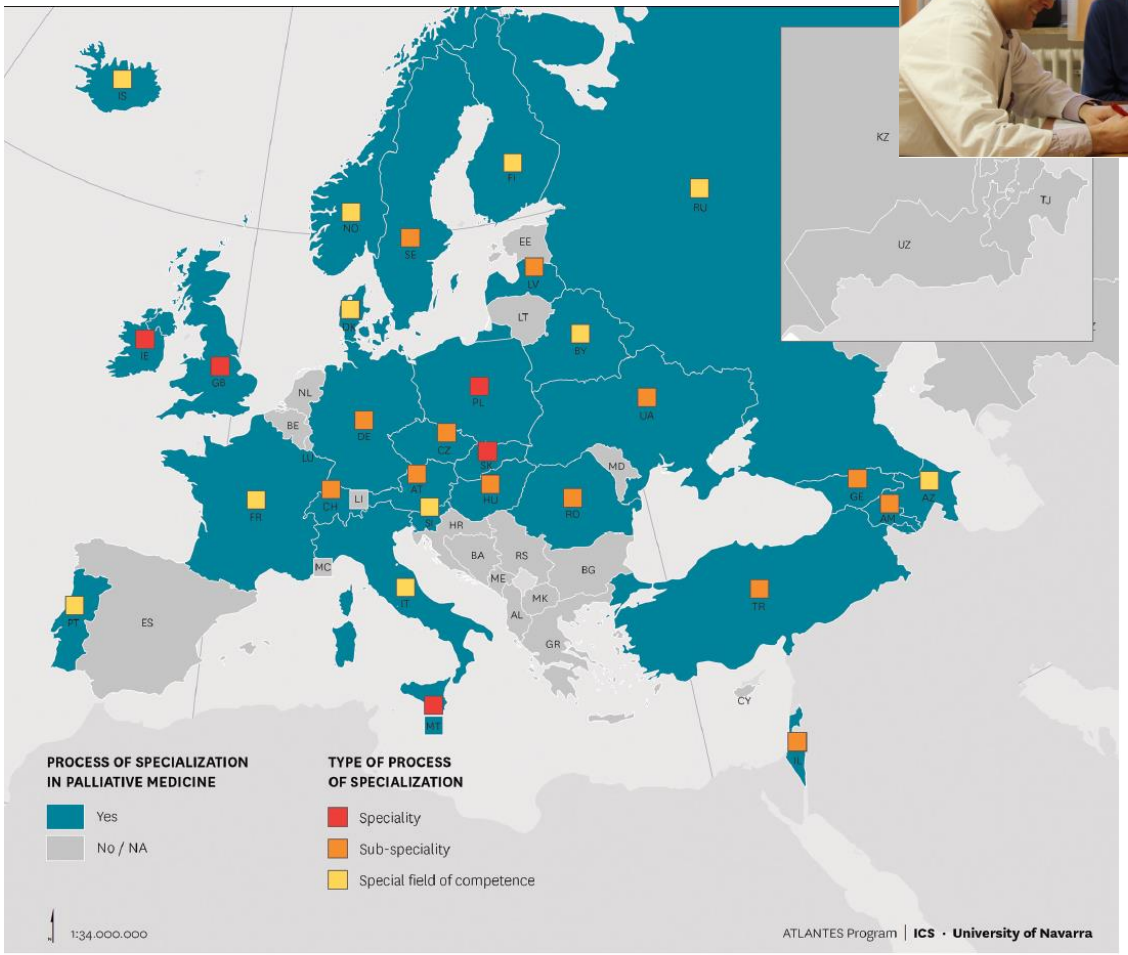
Map 1.2. Total Palliative Care Services.

QUARTILES	COUNTRY	TOTAL SERVICES	SERVICES PER 100,000 INHABITANTS
FIRST QUARTILE	Austria	193	2,2
	Ireland	92	1,9
	Luxembourg	11	1,8
	Lithuania	49	1,7
	Belgium	197	1,7
	Sweden	165	1,6
	Poland	587	1,5
	Iceland	5	1,5
	Bulgaria	100	1,4
	Estonia	18	1,4
	Israel	119	1,4
	United Kingdom	860	1,3
	Norway	61	1,2
SECOND QUARTILE	Hungary	112	1,1
	Germany	914	1,1
	Slovenia	22	1,1
	France	653	1,0
	Switzerland	82	1,0
	Italy	570	0,9
	Albania	27	0,9
	Denmark	54	0,9
	Portugal	96	0,9
	Cyprus	11	0,9
	Netherlands	150	0,9
	Croatia	32	0,8
	Finland	39	0,7
THIRD QUARTILE	Romania	122	0,6
	Latvia	12	0,6
	Czech Republic	63	0,6
	Georgia	22	0,6
	Spain	260	0,6
	Moldova	18	0,5
	Malta	2	0,4
	Slovakia	20	0,4
	Macedonia	7	0,3
	Armenia	7	0,2
	Serbia	16	0,2
	Russian Federation	321	0,2
FOURTH QUARTILE	Belarus	20	0,2
	Turkey	164	0,2
	Kyrgyzstan	12	0,2
	Ukraine	66	0,1
	Tajikistan	9	0,1
	Bosnia & Herzegovina	3	0,1
	Kazakhstan	12	0,1
	Greece	5	0,0
	Azerbaijan	1	0,0
	Montenegro	0	0,0
	Uzbekistan	0	0,0
TOTAL	49 countries	6387	0,8

Arias et al. "EAPC Atlas of Palliative Care in Europe 2019". Vilvoorde: EAPC Press, 2019

Aus-/Weiterbildung Ärzt:innen

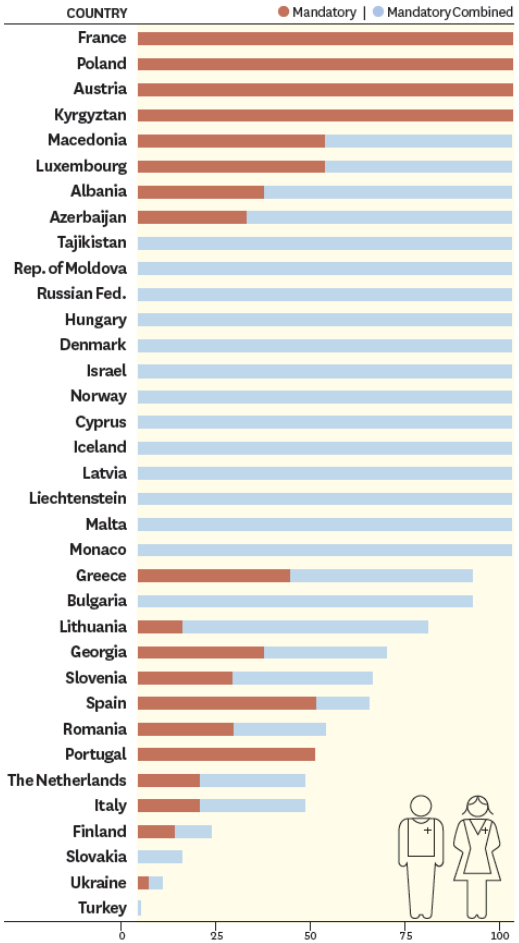




Map 4.1. Palliative Care Education.

Arias et al. "EAPC Atlas of Palliative Care in Europe 2019". Vilvoorde: EAPC Press, 2019

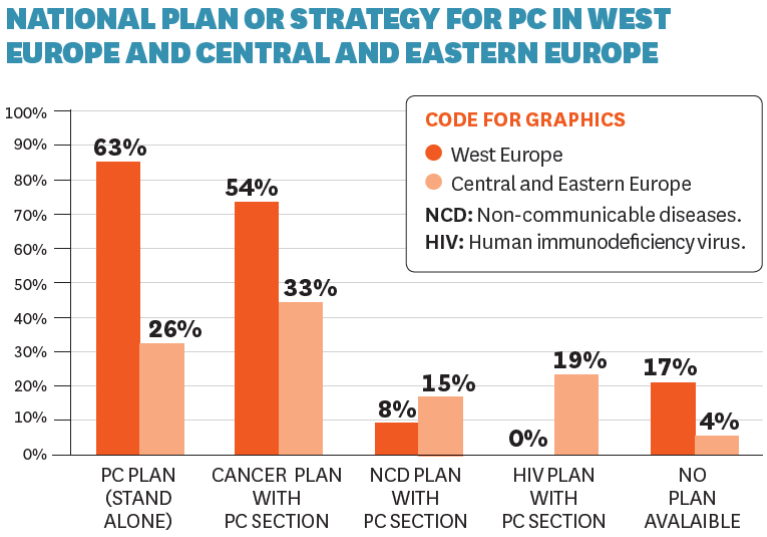
PC Ausbildung – Pflege



Arias et al. "EAPC Atlas of Palliative Care in Europe 2019". Vilvoorde: EAPC Press, 2019

Situation in Europa

- Dynamische Entwicklung in vielen Ländern in den letzten 50 Jahren
- 76 % der europäischen Länder haben Palliative Care in die nationale Gesetzgebung integriert
- Angebote sehr heterogen
- Palliative Care korreliert mit Wohlstand
- Einige Länder verfügen nur über minimale Angebote



Globale Situation

- Ca. 40 Millionen Menschen weltweit benötigen jährlich Palliative Care
- 78% von ihnen leben in Ländern mit niedrigem und mittlerem Einkommen (LMIC)
- Weltweit erhalten derzeit nur etwa 14% der Menschen Palliative Care, die es benötigen

Fact Sheet WHO; Fotos WHO

WHA - CoViD-19 response

SEVENTY-THIRD WORLD HEALTH ASSEMBLY **WHA73.1**

Agenda item 3 **19 May 2020**

COVID-19 response

The Seventy-third World Health Assembly,

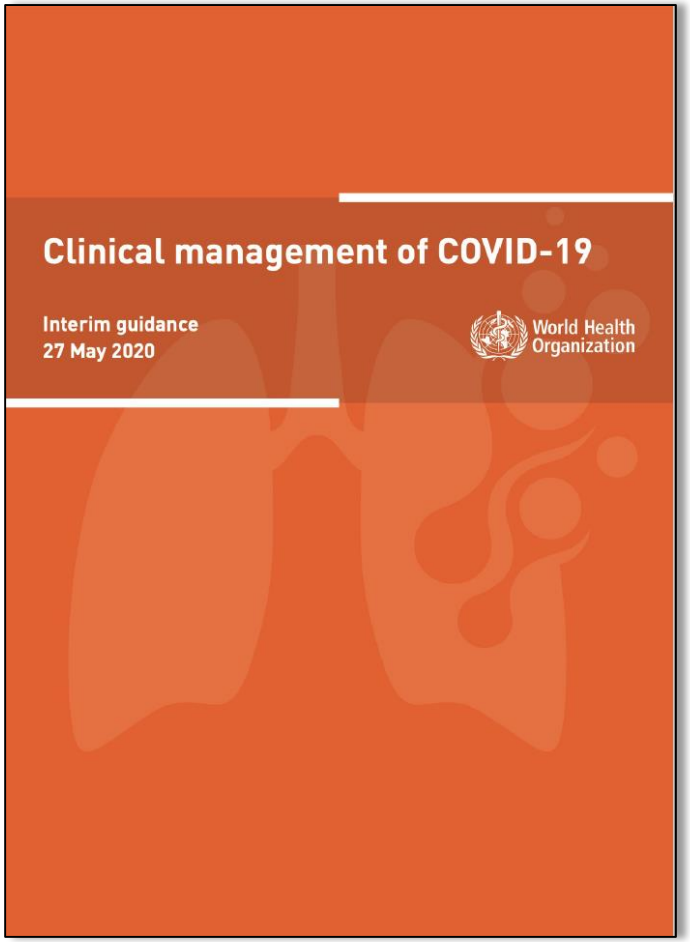
⋮

7. CALLS ON Member States,[1] in the context of the COVID-19 pandemic:

⋮

(7) to provide access to safe testing, treatment, and palliative care for COVID-19, paying particular attention to the protection of those with pre-existing health conditions, older people, and other people at risk, in particular health professionals, health workers and other relevant frontline workers;

WHO - CoViD-19 Clinical Management



21. Palliative care and COVID-19

Palliative care is a multifaceted, integrated approach to improving the quality of life of adults and paediatric patients and their families facing the problems associated with life-threatening illness such as COVID-19. Palliative care focuses on prevention and relief of suffering by means of early identification, assessment and treatment of physical, psychosocial and spiritual stressors. Palliative care includes but is not limited to end-of-life care *(200)*. Palliative interventions should be integrated with curative treatment *(200)*. Basic palliative care, including relief of dyspnoea or other symptoms and social support, should be practised by all doctors, nurses, social workers and others caring for persons affected by COVID-19 *(200, 201)*. Refer to the WHO guide *Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises (200)*.

- Wir empfehlen, bei allen Patienten zu ermitteln, ob sie eine Vorausverfügung (PV , ACP /BVP) für COVID-19 haben (z. B. Wünsche nach intensivmedizinischer Unterstützung) und ihre Wünsche zu respektieren, um die Versorgung maßzuschneidern und unabhängig von der Wahl der Behandlung die beste Versorgung zu bieten.
- Palliativangebote sollten in jeder Einrichtung, die Personen mit COVID-19 betreut, zugänglich gemacht werden.

- The GREEN symbol denotes a strong recommendation or a best practice statement in favour of an intervention.
- The RED symbol denotes a recommendation or a best practice statement against an intervention.
- The YELLOW symbol denotes a conditional recommendation in favour of an intervention, or a recommendation where special care is required in implementation.

WHO - CoViD-19 Clinical Management

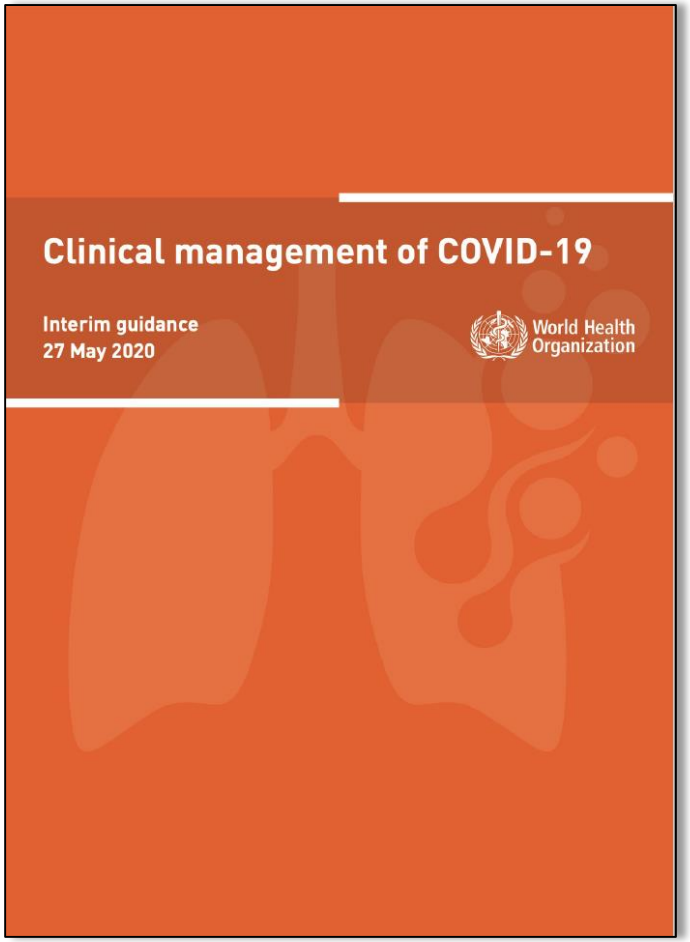
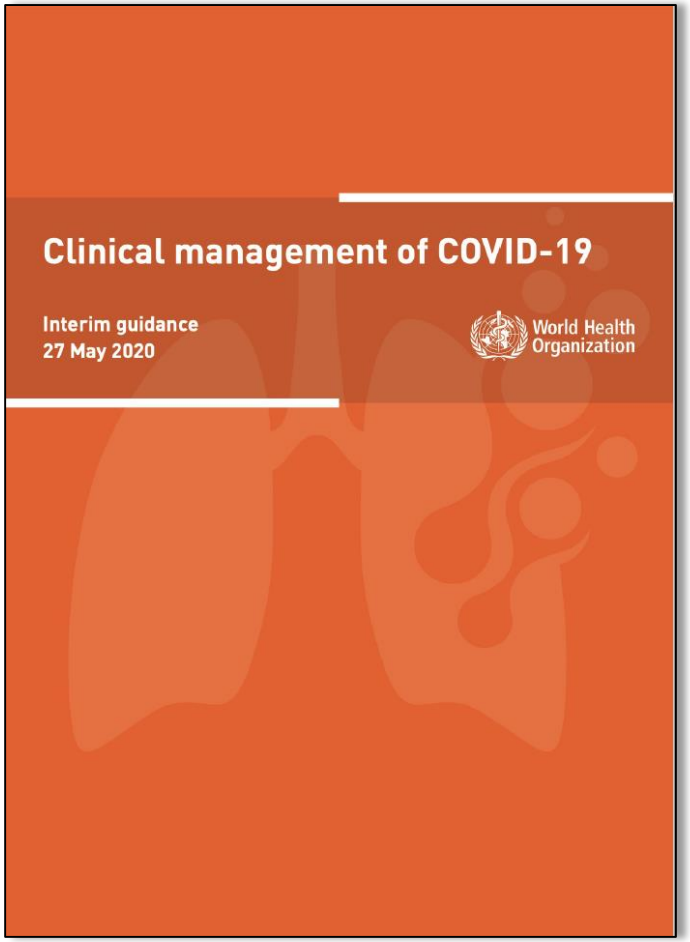


Table A3.1 Essential package of palliative care: interventions, medicines, equipment, human resources and social supports

	Inputs			
Interventions	**Medicines[a]**	**Equipment**	**Human resources[b]**	**Social supports**
Prevention and relief of pain or other physical suffering,[c] acute or chronic, related to COVID-19	– Amitriptyline, oral – Bisacodyl (senna), oral – Dexamethasone, oral and injectable – Diazepam, oral and injectable – Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate), oral and injectable – Fluconazole, oral – Fluoxetine, oral – Furosemide, oral and injectable – Haloperidol, oral and injectable – Hyoscine butylbromide, oral and injectable – Ibuprofen (naproxen, diclofenac, or meloxicam), oral – Lactulose (sorbitol or polyethylene glycol), oral – Loperamide, oral – Metaclopramide, oral and injectable – Metronidazole, oral, to be crushed for topical use – Morphine, oral immediate release and injectable – Naloxone, injectable – Omeprazole, oral – Ondansetron, oral and injectable[d] – Oxygen – Paracetamol, oral – Petroleum jelly	– Pressure-reducing mattresses – Nasogastric drainage and feeding tubes – Urinary catheters – Opioid lock boxes – Flashlights with rechargeable batteries (if no access to electricity) – Adult diapers or cotton and plastic	– Doctors (with basic palliative care training) – Nurses (with basic palliative care training) – Community health workers (if available)	

All interventions described in Appendix 3 should be accessible at each institution that provides care for persons with COVID-19. Efforts should be made to assure accessibility of interventions at home *(200)*.

WHO - CoViD-19 Clinical Management



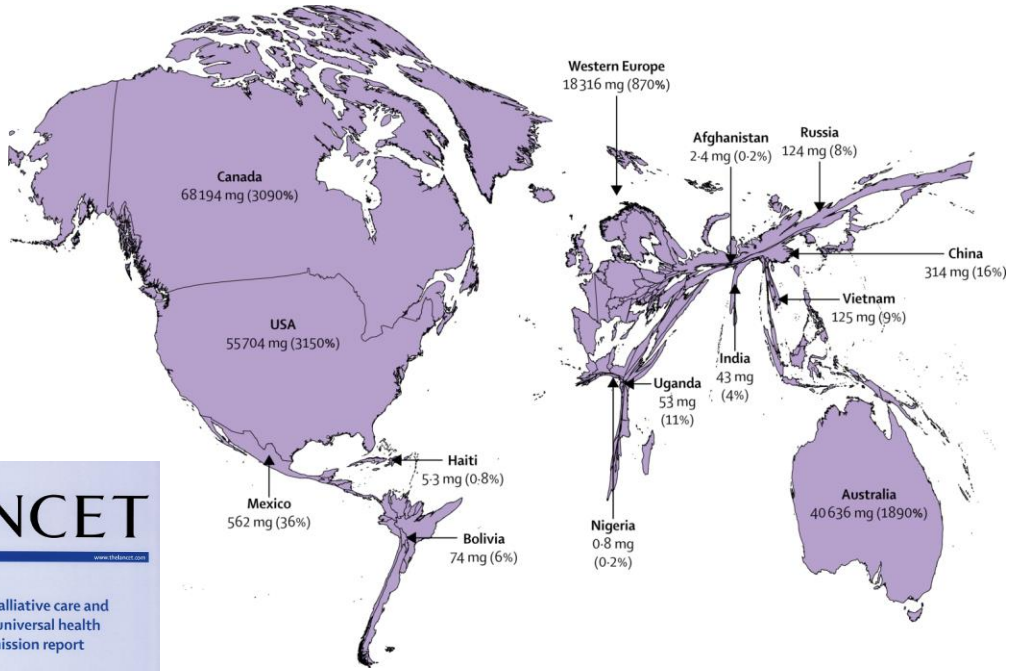
1. Alle in Anhang 3 beschriebenen Angebote sollten in jeder Einrichtung, die Personen mit COVID-19 versorgt, zugänglich sein. Es sollten Anstrengungen unternommen werden, um die Zugänglichkeit von Interventionen zu Hause sicherzustellen

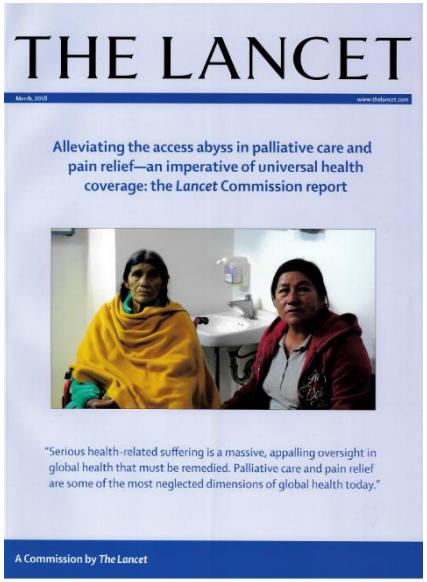
2. Palliativpflege ist nicht beschränkt auf das Lebensende. Palliativversorgung sollte in die kurative Behandlung integriert werden. Allgemeine Palliativversorgung, wie Linderung von Dyspnoe oder anderen Symptomen und soziale Unterstützung sollte von allen Ärzten, Krankenschwestern, Sozialarbeitern und anderen Personen geleistet werden, die sich um die von COVID-19 betroffenen Personen kümmern.

3. In Krankenhäusern ist für die Palliativversorgung keine separate Station oder Abteilung erforderlich. Palliativversorgung kann in jeder Umgebung angeboten werden.

4. Ziehen Sie Opioide und andere pharmakologische und nicht-pharmakologische Interventionen in Betracht zur Linderung von Dyspnoe, die therapierefraktär zur Behandlung der zugrundeliegenden Ursache ist und/oder als Teil der Betreuung am Lebensende. Die schmale therapeutische Breite von Opioiden bei der Behandlung von Dyspnoe macht es erforderlich, dass Opioide in Übereinstimmung mit evidenzbasierten Behandlungsprotokollen verschrieben werden und dass die Patienten genau überwacht werden, um negative unbeabsichtigte Wirkungen aufgrund einer unangemessenen Anwendung von Opioiden zu verhindern. Die Leistungserbringer sollten ihre institutionellen Standards in Bezug auf den potenziellen Einsatz von Opioiden bei Dyspnoe bei Patienten mit COVID-19 beachten.

Opioide weltweit





- Von 300 Tonnen Morphin-Äquivalent gehen weltweit 0,1 Tonne in Länder mit niedrigem Einkommen
- 50 % der Weltbevölkerung (3,6 Milliarden Menschen leben in den ärmsten Ländern) erhalten nur 1 % des weltweit distributierten Morphins

Beispiel Indien

Vor der Pandemie

- 10 Millionen Menschen mit Schmerzen und anderen schwerwiegenden gesundheitlichen Problemen („serious health related suffering“)
- kaum Zugang zu primärer Gesundheitsversorgung / Palliativteams machen dort so sie existieren häufig Primärversorgung
- ~363 Millionen (~30%) Inder leben unterhalb der Armutsgrenze – keine Ersparnisse, abhängig vom Tageslohn
- Jährlich rutschen 55 Millionen Menschen unter die Armutsgrenze durch individuell sehr hohe Gesundheitsausgaben

Beispiel Indien

Vor der Pandemie

- Bei 20 % der Suizide liegen gesundheitliche Gründe vor
- 90% der Menschen arbeiten ohne Vertrag / ohne Absicherung
- 139 Millionen Arbeitsmigranten aus dem eigenen Land

Beispiel Indien

Seit Beginn der Pandemie

- 120 Mio. Menschen haben im ersten Lockdown 2020 ihre Arbeit verloren (Arbeitslosigkeit zwischenzeitlich 23%)
- Social Distancing kaum möglich (z.B. Mumbai Slums mit 700.000 auf 2 (!) km²)
- Produktion von Medikamenten / Lieferketten sind oft unterbrochen
- Nationale Medikamentenreserven sind oft aufgebraucht
- Mangel an / Nichtvorhandensein persönlicher Schutzausrüstung

Beispiel Indien

- mangelnden Zugang zu sauberem Wasser und Desinfektionsmitteln

- Viele Patienten mit schwerem COVID-19 werden zu Hause leiden und sterben und von Familienmitgliedern
  - ohne Schutzkleidung,
  - ohne Zugang zu relevanten Informationen,
  - Schulungen oder
  - Palliativmedizin versorgt.

- Familienmitglieder haben sich selber infiziert und die Krankheit verbreitet

- Schwerkranke Patienten ohne CoViD wurden im Rahmen der Ressourcen-Reallokation aus dem System gedrängt

- Humanitäre Krise!

Radbruch L; Lancet 2020

Beispiel Indien

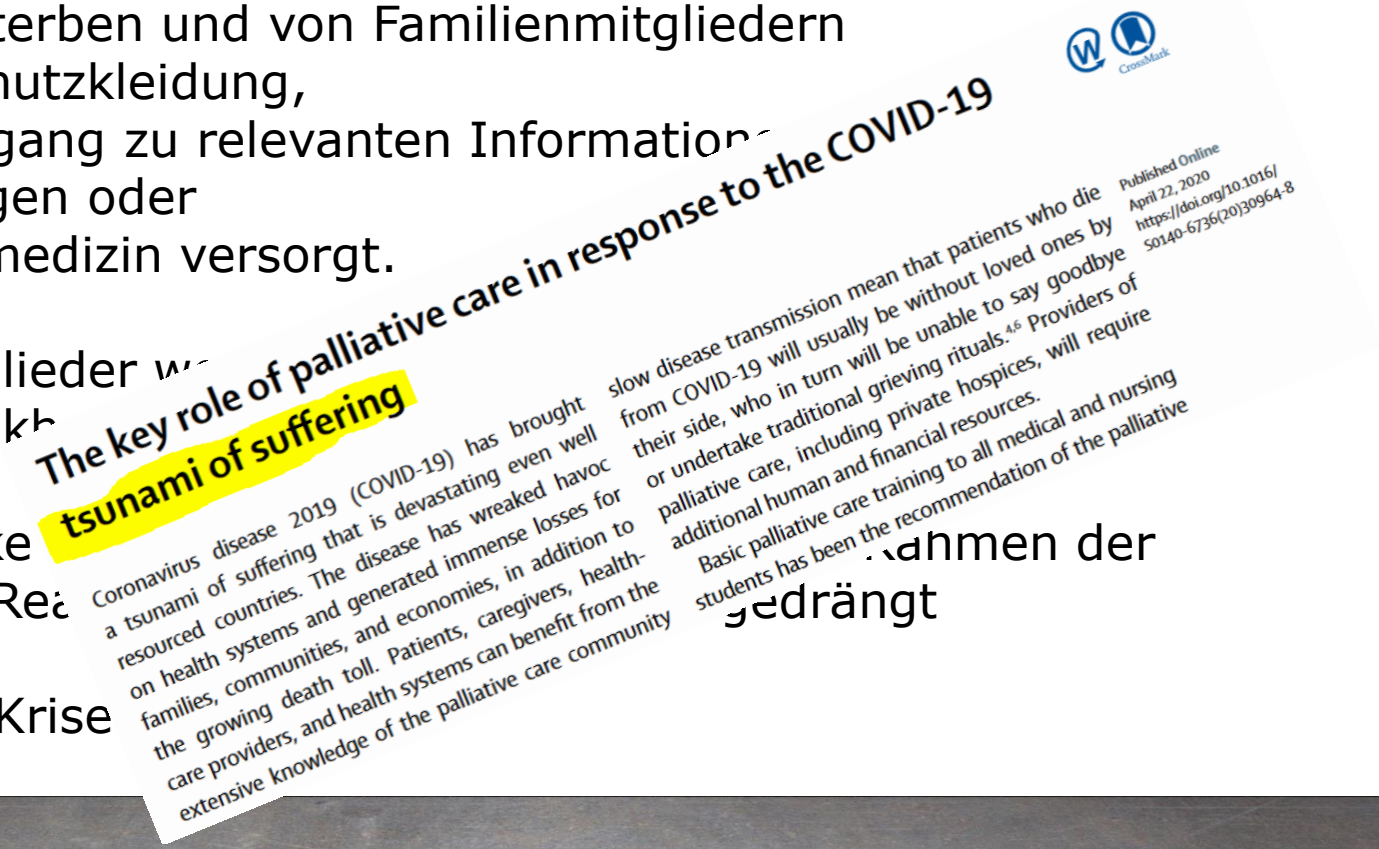
- mangelnden Zugang zu sauberem Wasser und Desinfektionsmitteln

- Viele Patienten mit schwerem COVID-19 werden zu Hause leiden und sterben und von Familienmitgliedern
  - ohne Schutzkleidung,
  - ohne Zugang zu relevanten Informatio
  - Schulungen oder
  - Palliativmedizin versorgt.

- Familienmitglieder w
  und die Krankh

- Schwerkranke
  Ressourcen-Rea kahmen der
  gedrängt

- Humanitäre Krise

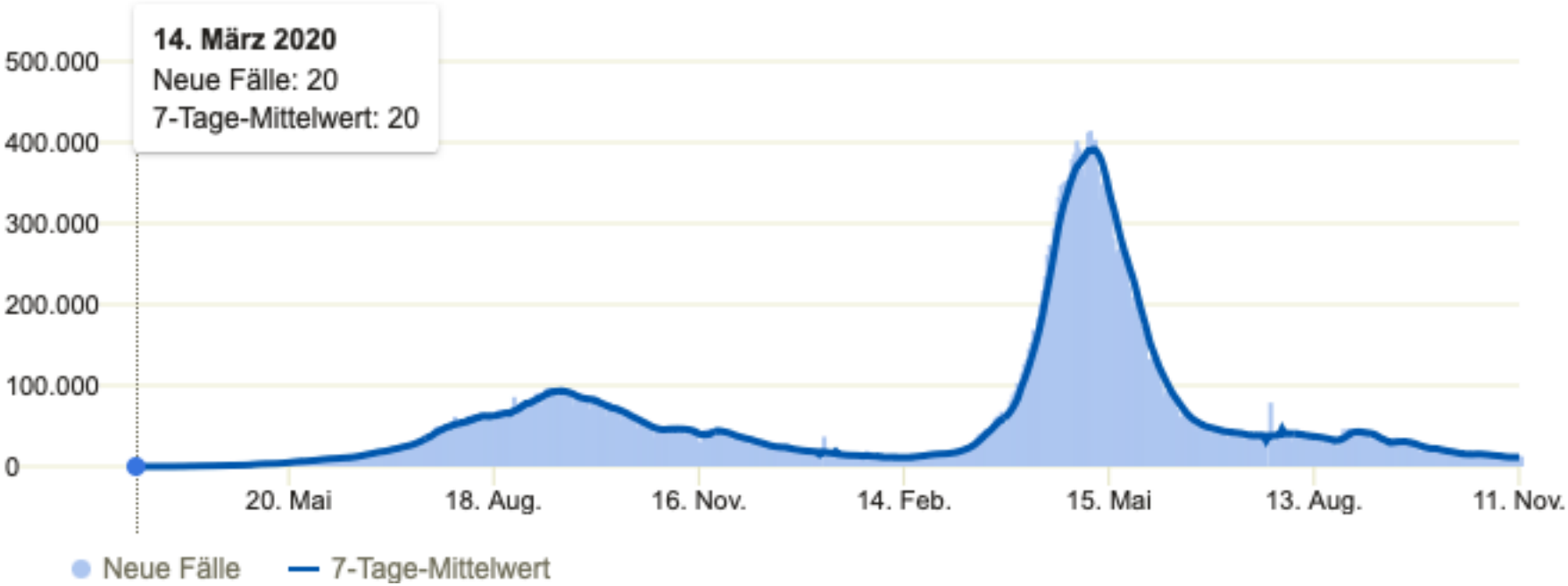


The key role of palliative care in response to the COVID-19 tsunami of suffering

Coronavirus disease 2019 (COVID-19) has brought a tsunami of suffering that is devastating even well resourced countries. The disease has wreaked havoc on health systems and generated immense losses for families, communities, and economies, in addition to the growing death toll. Patients, caregivers, health-care providers, and health systems can benefit from the extensive knowledge of the palliative care community slow disease transmission mean that patients who die from COVID-19 will usually be without loved ones by their side, who in turn will be unable to say goodbye or undertake traditional grieving rituals.[4,5] Providers of palliative care, including private hospices, will require additional human and financial resources. Basic palliative care training to all medical and nursing students has been the recommendation of the palliative

Published Online April 22, 2020 https://doi.org/10.1016/S0140-6736(20)30964-8

Radbruch L; Lancet 2020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Neue Fälle: 20
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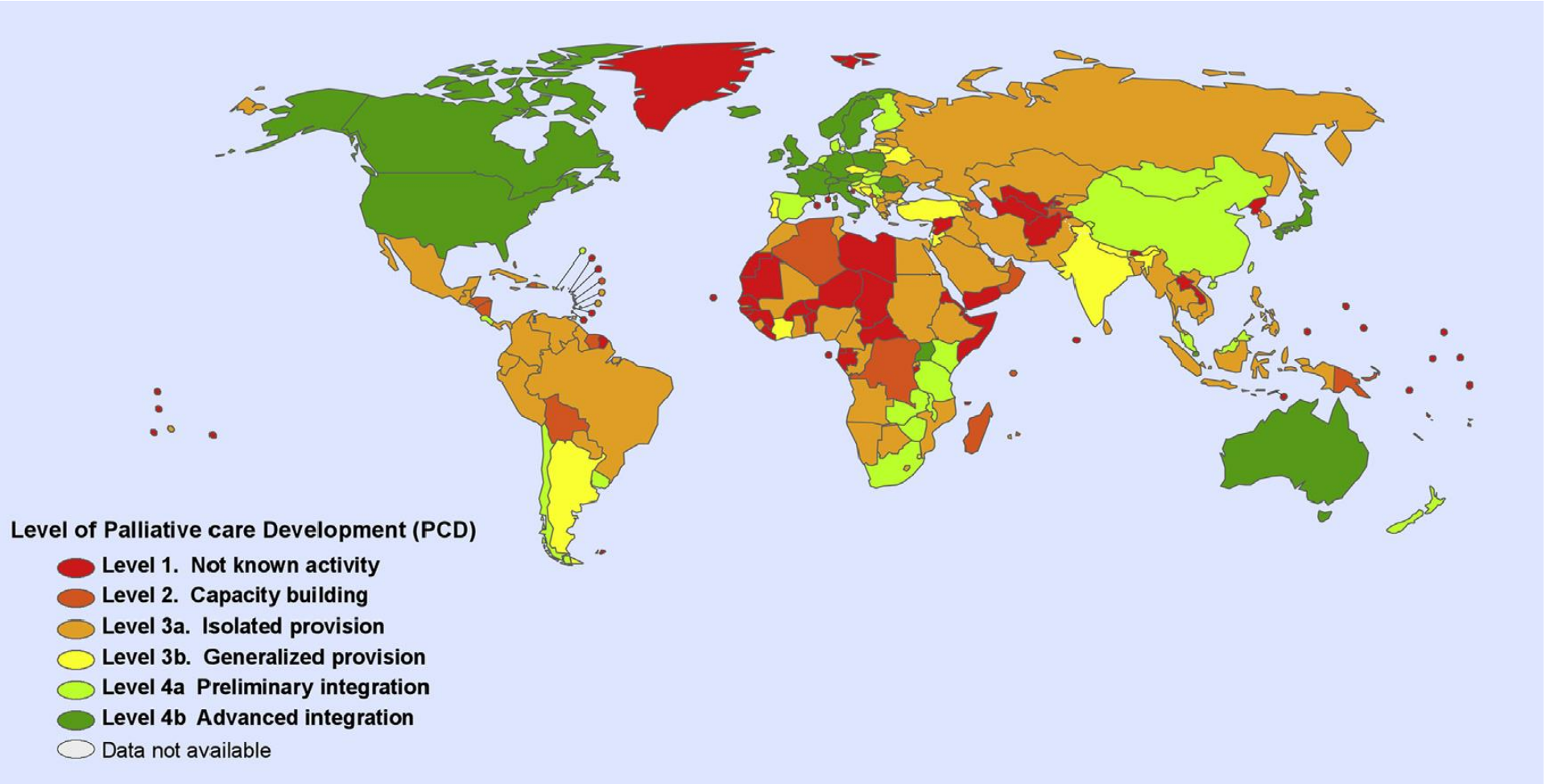
20. Mai
18. Aug.
16. Nov.
14. Feb.
15. Mai
13. Aug.
11. Nov.
Neue Fälle
7-Tage-Mittelwert

Globale Situation



WHO / WHPCA Global Atlas of Palliative Care at the End of Life 2014

“Poor people in all parts of the world live and die with little or no palliative care or pain relief. Staring into this access abyss, one sees the depth of extreme suffering in the cruel face of poverty and inequity”

„Arme Menschen in allen Teilen der Welt leben und sterben mit wenig oder gar keiner palliativen Betreuung oder Schmerzlinderung. Wenn man in diesen Abgrund blickt, sieht man die Tiefe des extremen Leidens im grausamen Gesicht von Armut und Ungerechtigkeit“

(Knaul et al., 2017)

Abschluss

- International sind wir noch weit von einer auch nur hinreichenden Hospiz- und Palliativversorgung entfernt
- Einsatz für nationale Gesetzgebungen, z.B. zum medizinischen Gebrauch von Opioiden (aktuel weiter erschwert durch die Opioidkrise in den USA)
- Intensive Kooperation mit der WHO; EAPC arbeitet ggw. an der formalen Partnerschaft

Herzliche Einladung