

Integrating palliative care in fragile settings; a transformative paradigm

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'Palliative care in a changing climate'

PallCHASE www.pallchase.org

www.cairdeas.org.uk
[@CairdeasIPCT](https://twitter.com/CairdeasIPCT)

- Whichever way we turn, O God, there is Your face in the light of the moon and patterns of stars, in sacred mountain rifts and ancient groves, in mighty seas and creatures of the deep.
- Whichever way we turn, O God, there is Your face in the light of eyes we love, in the salt of tears we have tasted, in weathered countenances east and west, in the soft skin glow of the child everywhere.
- Whichever way we turn, O God, there is Your face, there is Your face among us.

John Philip Newell



Transformative paradigm of palliative care

- *Values based care; promoting dignity, relieving suffering, demonstrating compassion, fighting for justice*

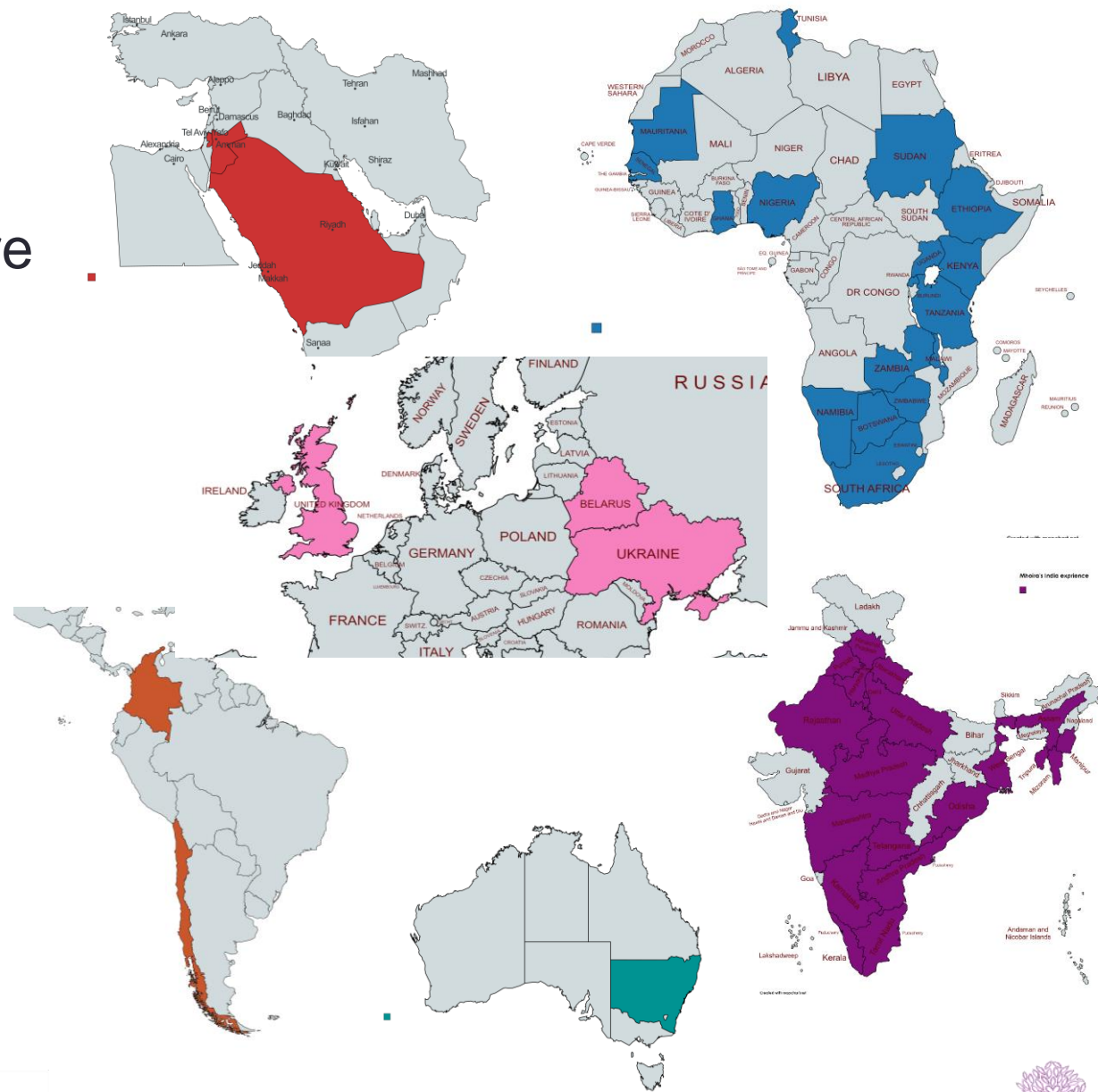
- Transforming lives
- Transforming practise
- Transforming systems
- Transforming societies



Experience

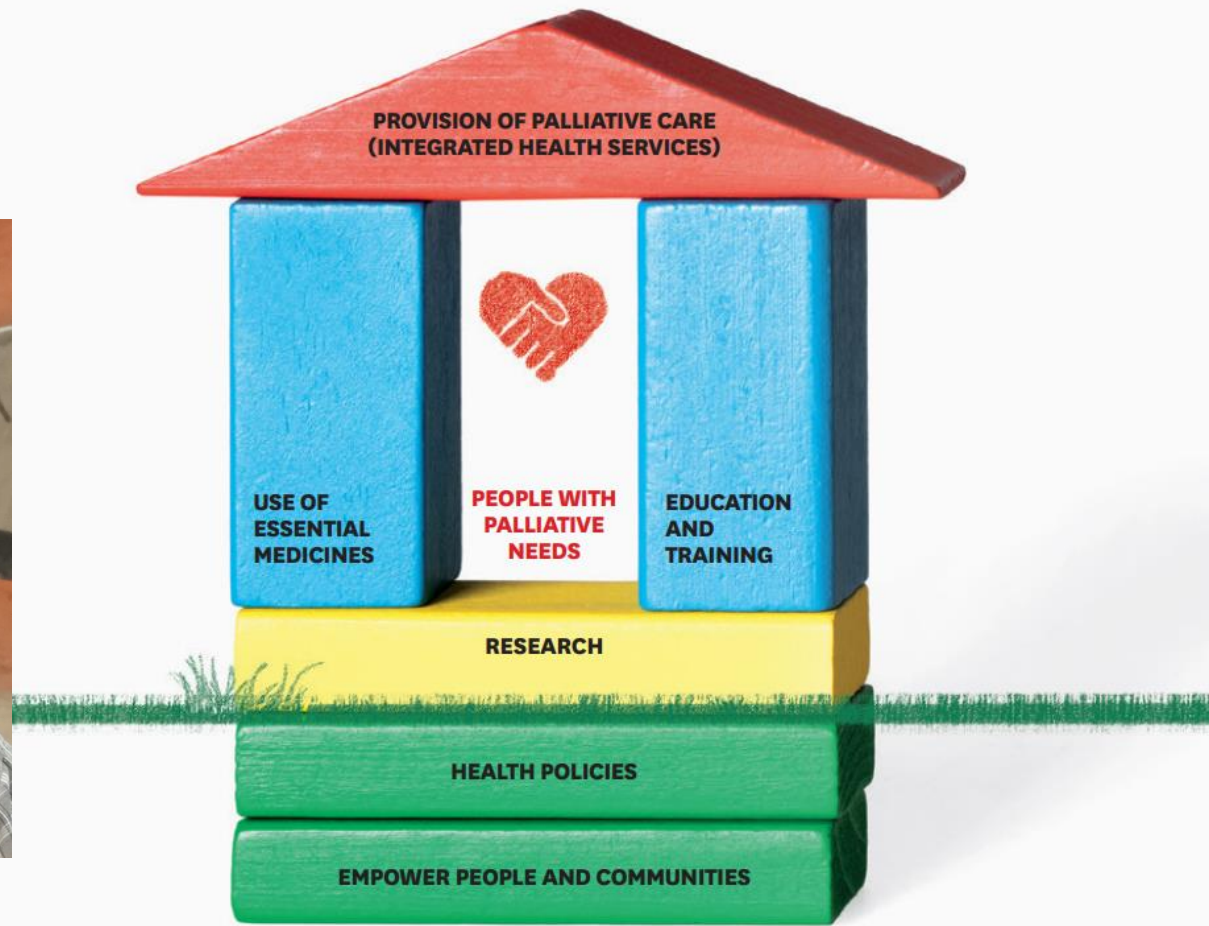
- UK; Internal medicine and palliative care speciality training
- UK; Aberdeen, Scotland 10 years NHS consultant
- 1999 to 2022 India started with visit to Calicut
- 2006 started CairdeasIPCT *'friendship'* and left NHS for India
- 2008 ongoing Makerere University Uganda
- 2014 ongoing IUG, Gaza and OTP

32 years; 4 continents

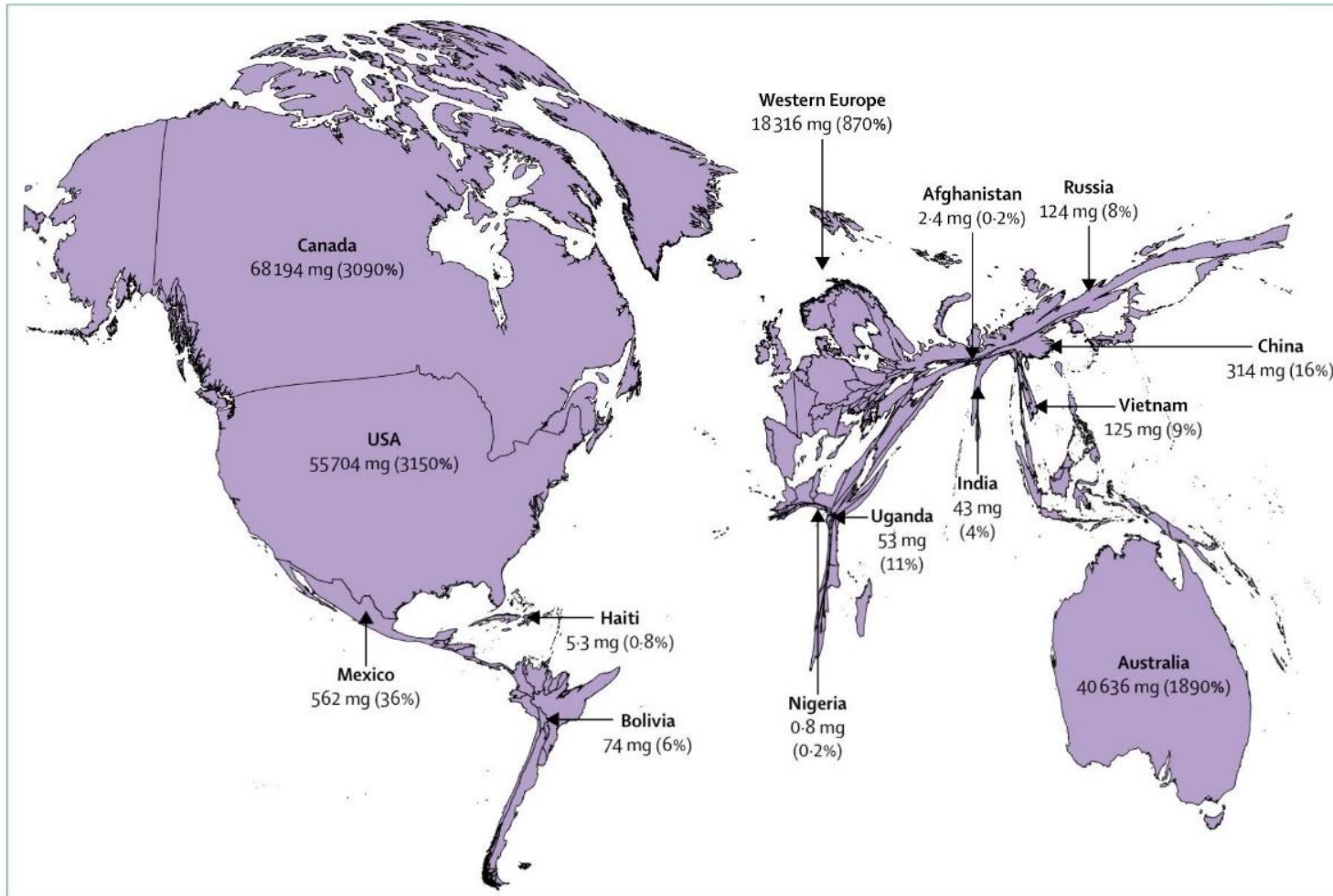


Transforming systems; integrating palliative care

- Engaged communities and people
- Policy
- Research
- Education and training
- Essential medicines
- people at the center



Transforming systems; access / opioid availability



'Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage'
Lancet Commission Oct 2017

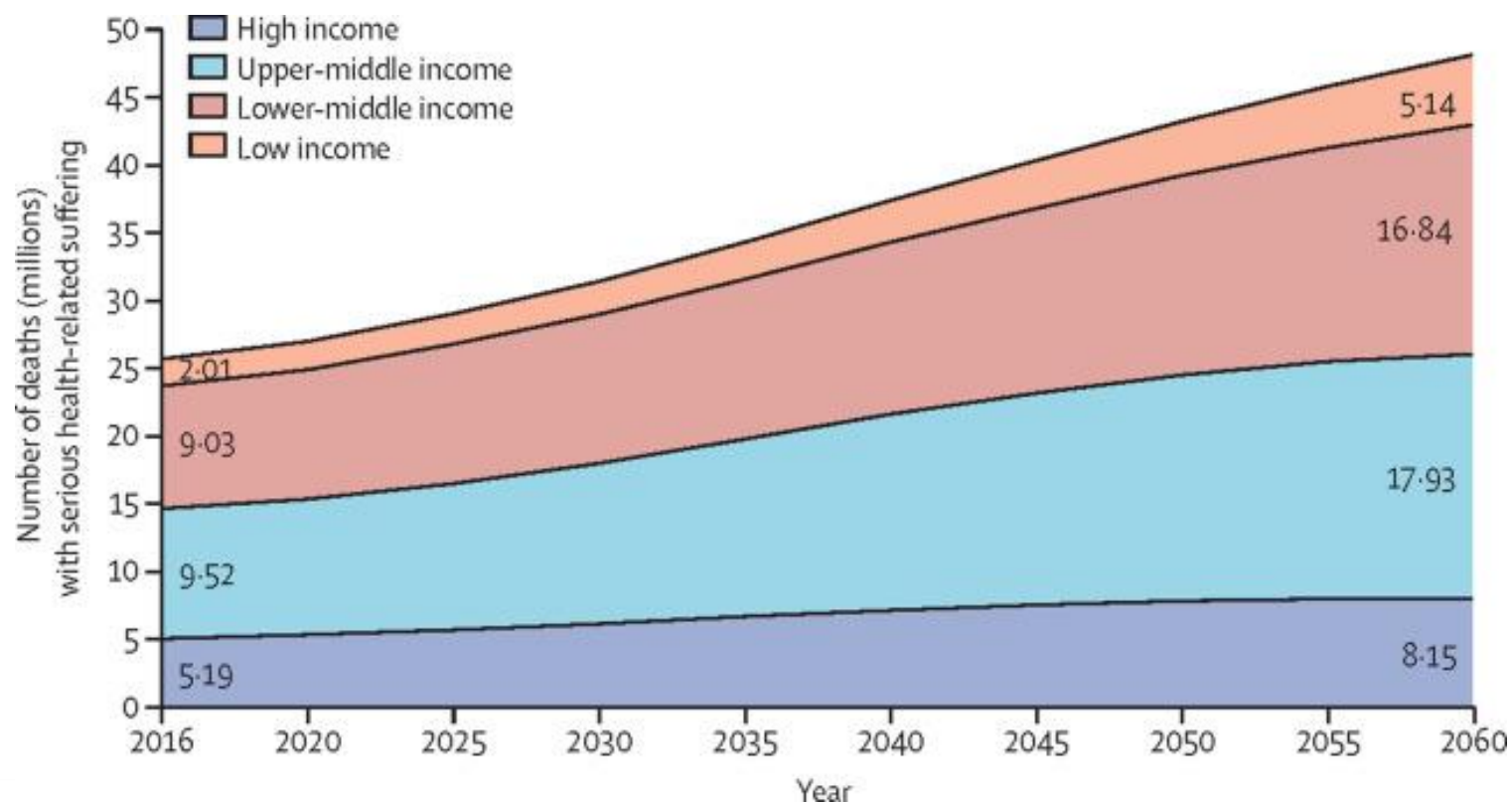
WHPCA Global Atlas of Palliative Care 2nd edition 2020

Figure 1: Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010-13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering

Source: International Narcotics Control Board and WHO Global Health Estimates, 2015. See additional online material for methods.

Transforming systems; unmet need

- Projection for burden of **Serious Health related Suffering**



Each year an estimated 56.8 million people are in need of palliative care, most of whom live in low- and middle-income countries. WHO fact sheet 2020

Transforming systems; quality of death

- Poverty; economic impact on quality of death

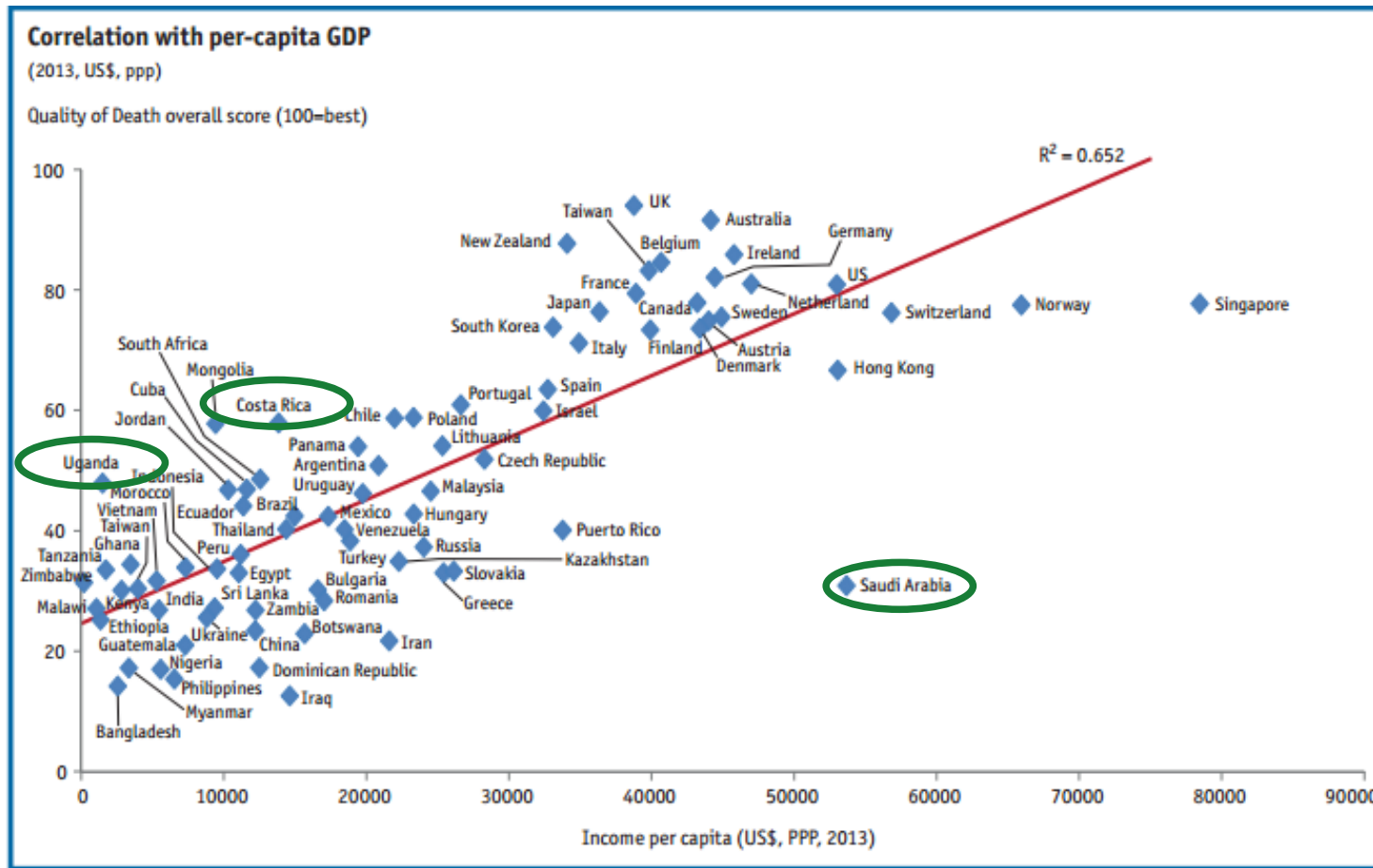
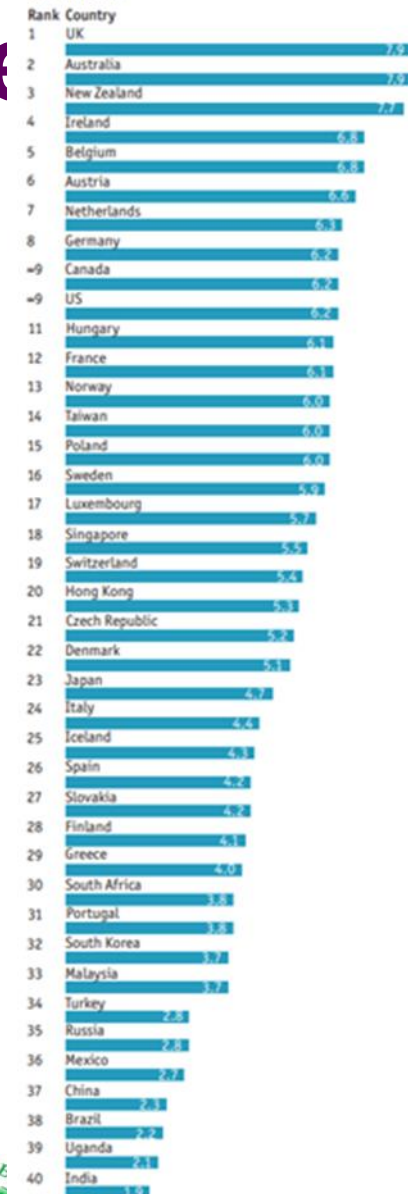


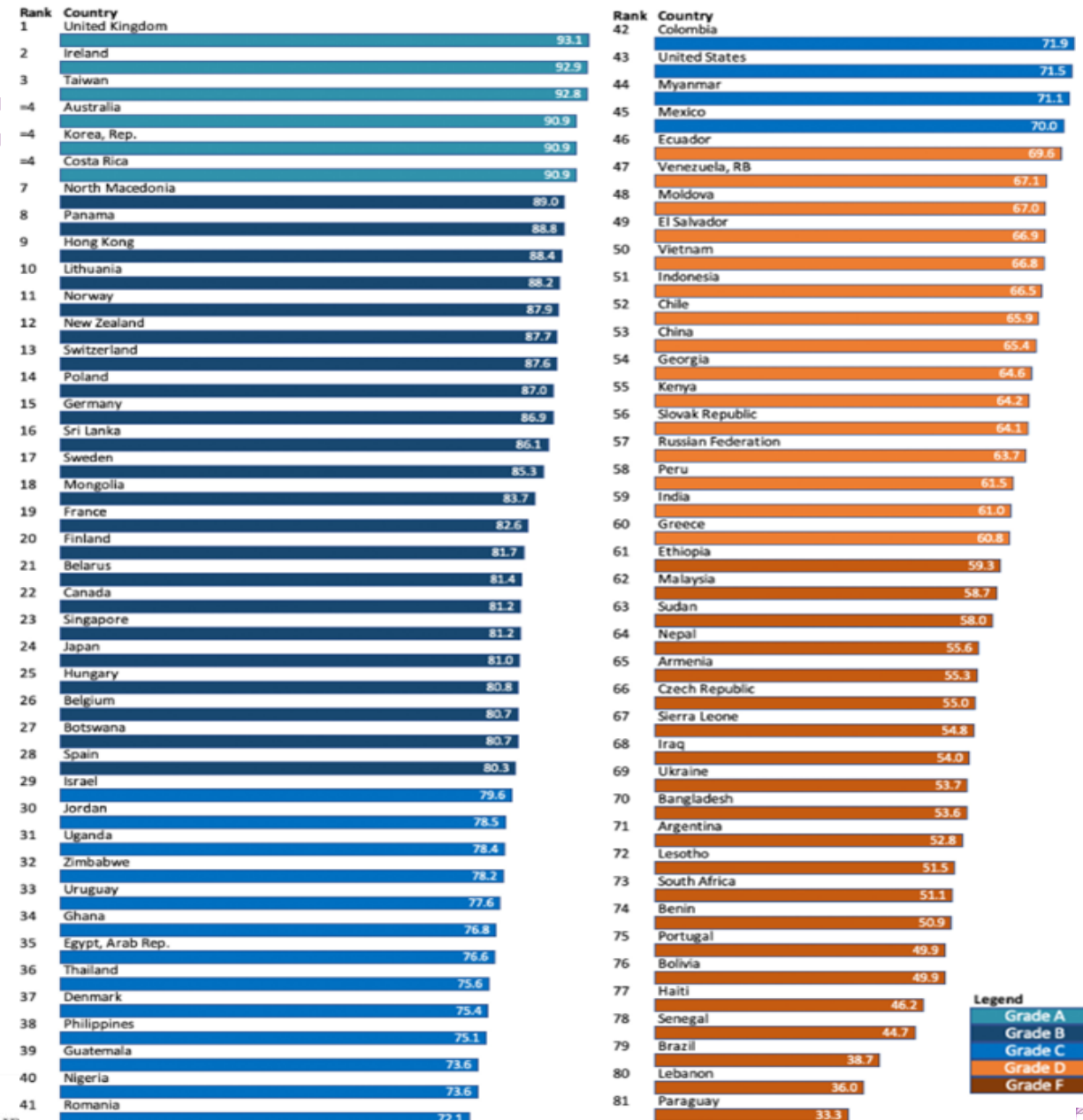
Figure 1
Overall score



Transforming systems;

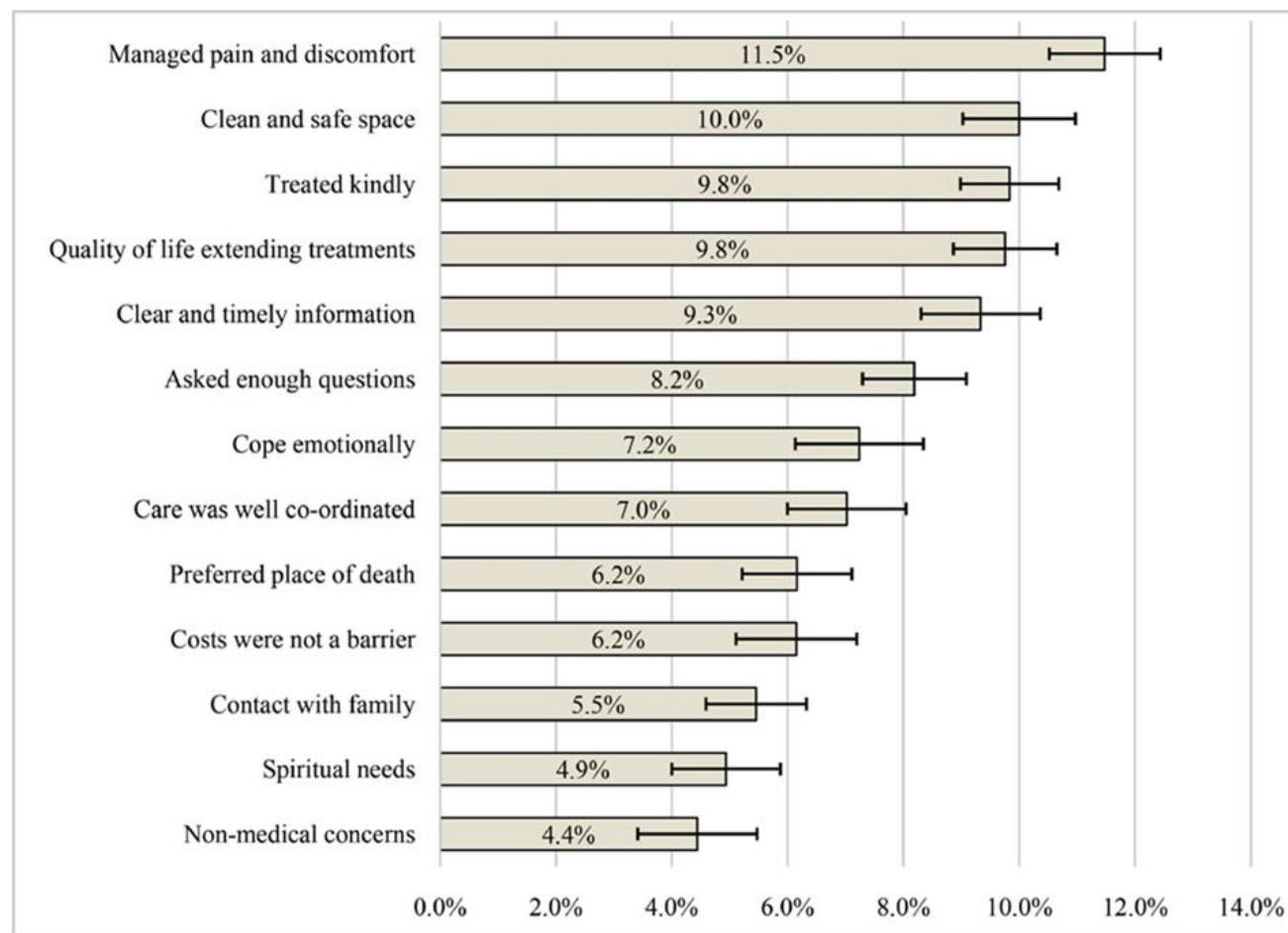
- Significant inequality
- 181 experts 81 countries.
- 6 countries with scores/ grade A
 - United Kingdom, Ireland, Taiwan, Australia, Republic of Korea, and Costa Rica (only upper middle)
- Uganda (ranked 31st) first LIC
- 21 countries 'failing grade'
 - 2 HIC; Czech Republic (66th), Portugal (75th)

Finkelstein EA et al. Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021. J Pain Symptom Manage. 2022 Apr;63(4)



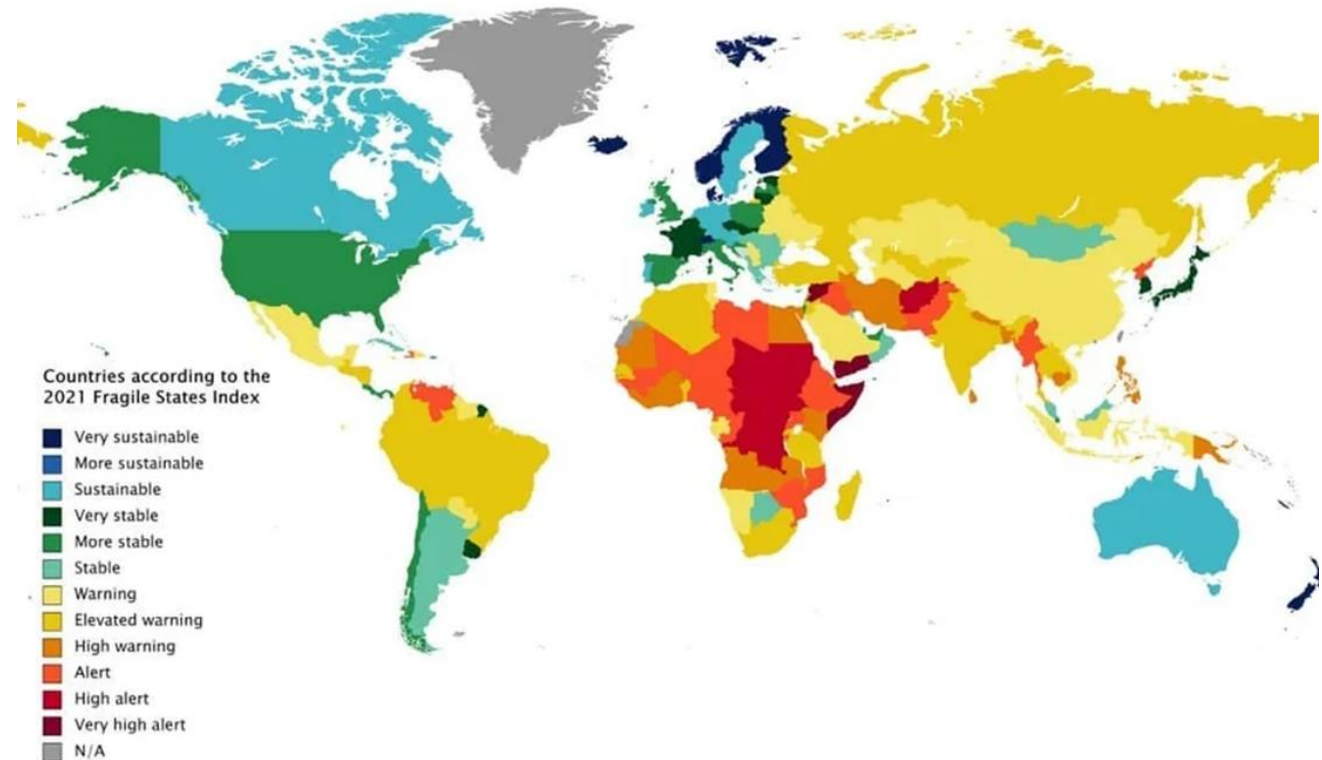
Transforming systems; patients and families

- Discrete choice experiment (DCE) survey; preference weights associated with each of the key indicators of EOL care
- What did patients and caregivers say?



Fragile, conflict-affected and vulnerable settings

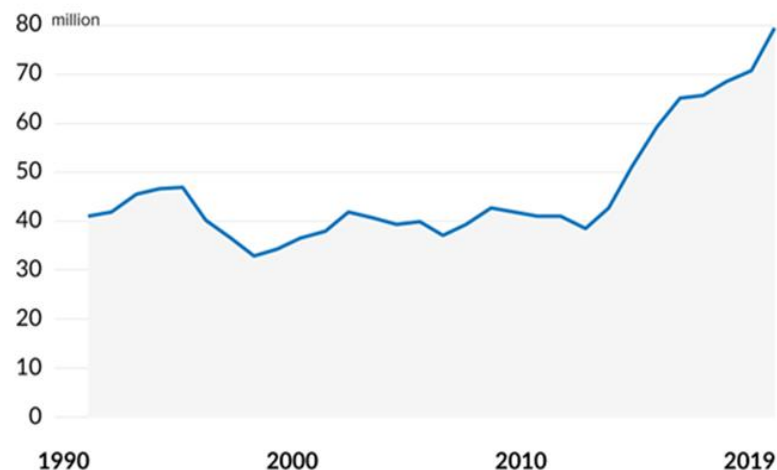
- broad term describing a range of situations including humanitarian crises, protracted emergencies and armed conflicts.
- almost ¼ global population affected by conflict, displacement and natural disasters.
- often weak national health systems,
- high burden of disease and death



Transforming systems; 'people on the move'

Source: UNHCR / 18 June 2020

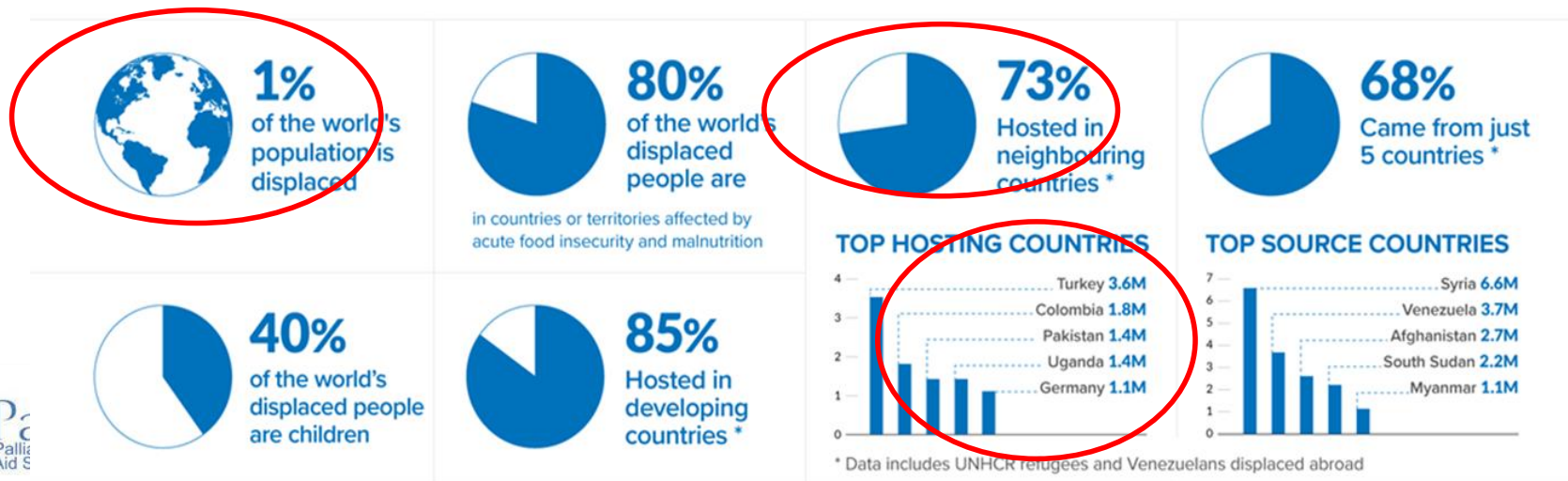
79.5 MILLION forcibly displaced people worldwide at the end of 2019



4.2M Asylum-seekers

3.6M Venezuelans displaced abroad

2021 89.3M
almost 1/2 under 18
1 in 88 global population
many millions are stateless





Missing pieces, Bruno Catalano
emigrants being 'uprooted' 'suffering' 'something left behind' 'walking towards the hope of a better future'

Transforming systems; planetary health

- *'Palliative care in a changing climate'*
- Disproportionately affects fragile settings; famine, drought, floods, conflict eg water and resources, displaced people
- Scale up adaptation finance to prevent, prepare for, and respond to growing humanitarian crises, and to make communities more resilient.



Spiritual distress

- When our world has been shaken



Transforming systems; humanitarian settings

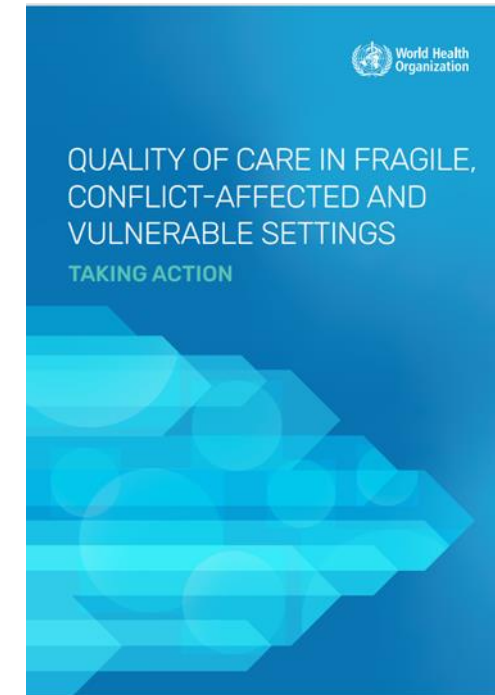
73rd World Health Assembly

“COVID-19 Response,” committing governments to deliver palliative care services alongside safe testing and treatment for COVID-19” *May 2020*

Lancet May 2020

*" The call to **fully incorporate palliative care into global health** could finally be **realised in the urgency of the pandemic**. If so, the COVID-19 pandemic will have **catalysed medicine to better alleviate suffering in life and death**"*

Richard Horten

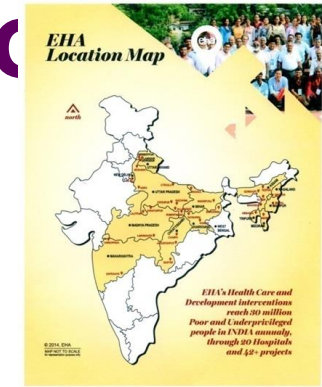


Briefing note; Palliative care in Refugee Camps and Humanitarian settings
<http://globalpalliativecare.org/covid-19/>

Transforming systems; poverty reduction

- Evidence based; poverty reduction
- Holistic palliative care can reduce the desperate poverty driven by life-limiting illness
 - systematically, on a large-scale, in-depth
 - especially if started early in the illness
 - home-based care also frees up hospitals to serve more patients with treatable conditions.

Ratcliff C, Thyle A, Duomai S, Manak M. Poverty reduction in India through palliative care: A pilot project. *Indian J Palliat Care* 2017;23:41-5



J Bates et al. Palliative care and catastrophic costs in Malawi after a diagnosis of advanced cancer: a prospective cohort study *The Lancet Global Health*, Volume 9, Issue 12, e1750- e1757

Transforming practise; learning

- **Competency based : values orientated**
- *“an orientation which holds that the way learners interpret and reinterpret their sense experience is central to making meaning and hence learning.”* Mezirow
- (a) having experiences; (b) making assumptions; (c) challenging perspectives; (d) experiencing transformative learning. Norma Nerstrom 2014
 - critical participants in the learning process and well-practiced at **critical thinking, goal setting** and **reflection**
 - inquiry-based learning, clinical learning, and project-based learning, disorientating dilemma
 - **embrace failure** as an essential step toward overall success
 - **engage in complexity** and **struggle**
 - **acknowledge excellence** while also **addressing helplessness**

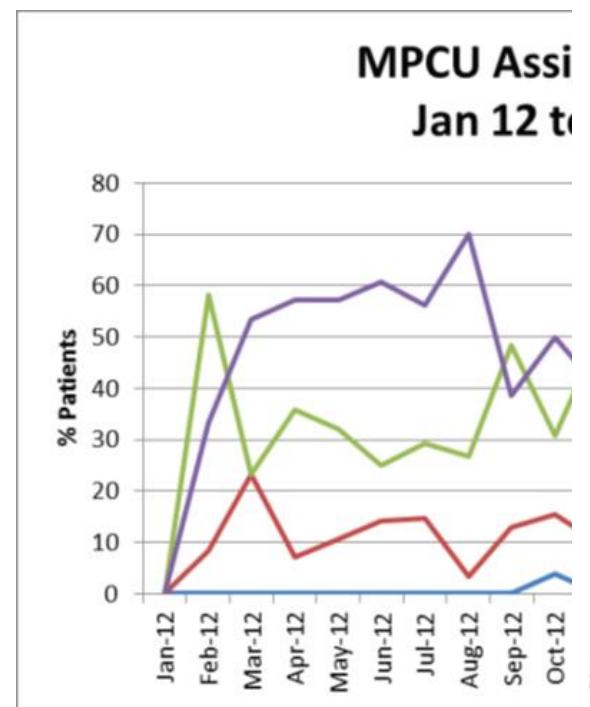
Transforming practice; models of care

Clinical care

- levels of care and empowerment



Grant L et al Integrating palliative care into national health systems in Africa: a multi-country intervention study June 2017 Journal of Global Health



PALLIATIVE CARE GUIDELINES: PAIN MANAGEMENT FOR ADULTS

- Principles:**
- Pain is what the patient says it is and can have physical, psychological, social and spiritual components.
 - Aim to control pain quickly and safely. Regularly re-evaluate pain and monitor its response to treatment.
 - Benefits and burdens alongside affordability and accessibility are important factors in the choice of analgesic.
- Assessment:**
- Evaluate the cause of the pain using a holistic history, thorough examination and appropriate investigations. Pain severity should be assessed using an appropriate pain evaluation tool such as the hand scale below.
-
- Management:**
- Good holistic care requires a combination of general non-clinical measures and advice, investigation and treatment of any underlying cause(s) and appropriate symptomatic treatment(s). All three aspects of care are important and ideally should occur concurrently, however for certain patients the underlying cause of the pain may be unclear. Management for these patients should focus on improving symptoms and quality of life whilst regularly reassessing.

- Pain management is based on the WHO analgesic ladder.
 - Medications should be given regularly throughout the day and orally unless contraindicated.
 - Patients started on a regular opioid should have a laxative co-prescribed unless contraindicated.
-

Step	Analgesics	Comments	Adjuvants
Step 1 (non-opioid)	Paracetamol 1g 6 hourly or Diclofenac 50mg 8 hourly	• Continue with step 1 analgesic when moving on to step 2 and 3	• Amitriptyline 12.5-25mg nocte for neuropathic pain (can be increased to 50-75mg if tolerated)
Step 2 (weak opioid)	Morphine 2.5-5mg 4 hourly during the day with a double dose at night or Codeine Phosphate 30-60mg 6 hourly or Tramadol 50-100mg 6 hourly	• Low dose morphine is considered a step 2 analgesic and is recommended first line if available as it is cheaper than codeine or tramadol • Discontinue step 2 analgesics when starting step 3	• Clonazepam 0.5-1mg nocte for neuropathic pain second line • Dexamethasone 4-8mg od for swelling/ oedema eg. liver capsular stretch • Hyoscine Butylbromide (Buscopan) 20mg qds for smooth muscle spasm • Dexamepan 5-20mg nocte for painful skeletal muscle spasm
Step 3 (strong opioid)	Morphine 7.5-10mg 4 hourly during the day with a double dose at night to control the patient's pain	• The elderly and/or those with renal impairment may require a dose adjustment. • (For children see separate guideline)	

These guidelines are applicable to patients with chronic life limiting illnesses. Patients whose symptoms fail to respond to initial measures should be referred to the MPCU (Mulago Palliative Care Unit). Referrals can be made via consultation request form H304 delivered to the palliative care ward office on ward 4A or via phone (MPCU Mobile: 0779490784). These guidelines are based upon and designed to be used alongside other resources such as the Palliative Care Toolkit, APCA pocket book and HAU blue book (available via MPCU).

Training; in-service

- **link nurses**; increase in patient numbers being supported by 80%, empowered staff, replicated nationally in 12 hospitals, 15 internationally in 4 countries
- *“Before I had the training patients who were dying could be neglected as the staff thought they could do nothing for them. But since the teaching I realised **there is much I can do for these patients...It has changed me. It has changed my attitude.**”*
- *“What made the difference? **We do it because we want to do it – we have been inspired!!**”*



Downing et al. A palliative care link nurse programme in Mulago Hospital, Uganda: an evaluation using mixed methods BMC Palliative Care (2016)

Training: CHW/VHTs & HCW

- *‘This is one of the most important and long awaited trainings...I did not know this palliative care but **now I have been transformed I will now transform the community.**’*
- *.. [the training] added more knowledge in me to help others. **It modelled my character and now my behaviour is quite different from before I had the knowledge.**’*





- *‘If I find a person suffering I am a **bridge** between the community and Peace Hospice and we work hand in hand.’*
- *‘**We need more training**, and if there is more funds, we need to train more VHTs to ensure social behaviour change of the patients and also to help them open up on their distresses.’*



- **Philip's story**
- *'Some body may be thinking that that is the end of them, they are just there and not supported, but with counselling and talking to them and spiritual support, they can feel good..and the training helped us a lot. Even now it has helped us to train other people. You keep teaching others'*
- **Philip is now year 2 in MSW**

Impacting policy makers and opinion leaders

- *'As someone who is senior I will make sure this project will be achieved in this district...those people you see here are hard working people they will not fail you and my govt will not fail you'*
- *'We thank our Almighty God to have given heart to the people of this organisation to come and us...this is Gods love to our district...without God's love they would not come this way'*



Training; curriculum integration PG

*'The palliative care training has made a huge impact; I now see the patient as a **person and not a disease**, I don't **avoid difficult conversations**, I don't order **unnecessary investigations**, I see them as **part of a family**, I do **holistic care**. It was not like that before.'*

MMed Internal Medicine doctor Makerere.



Training; curriculum integration UG

- Values identified by undergraduate medical students at IUG, Gaza;

#love #compassion # hope #mercy #honesty
#justice #humanity #joy #dignity #respect

'The course added to the clinical practice makes us feel the suffering of patients and how we can help them'.



Islamic University of Gaza; medical school 2019



Training; leadership and research

- Compassionate leaders



Transforming practice; research

- What are the multidimensional experiences of Ugandan patients with HF over the course of their illness through diagnosis, treatment and dying?



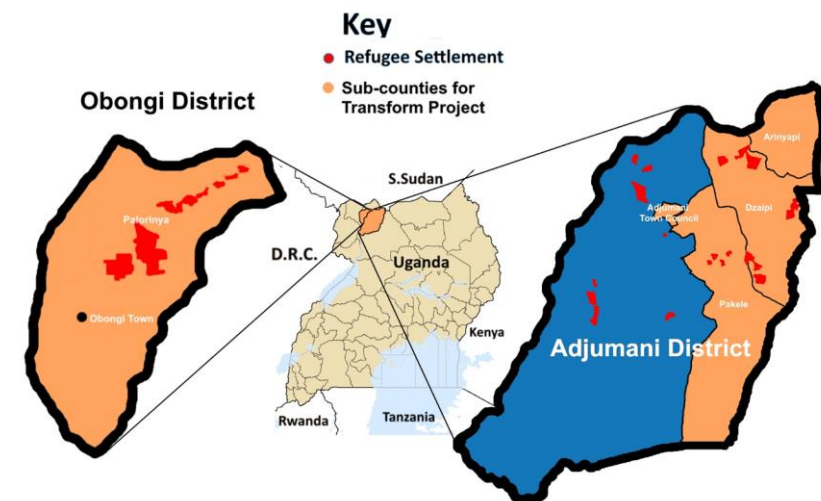
Namukwaya E et al. (2017) Improving care for people with heart failure in Uganda: serial in-depth interviews with patients' and their health care professionals. BMC Res Notes 10:184.



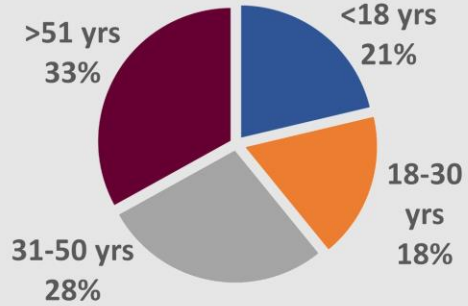
Integration; Northern Uganda

Integrate project; Adjumani District, 2018 - 2019

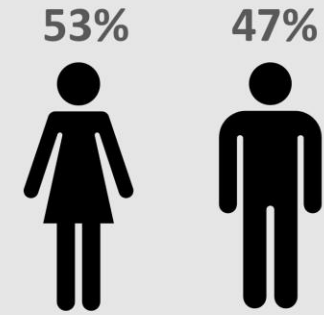
- *Mixed methods study in refugee population*
 - *Step One: Rapid Participatory Appraisal (69 interviews)*
 - *Step Two: Training and mentorship (300 HCW, VHT and FC)*
 - *Step Three: Needs assessment for chronic illness*
- **Transform project 2020 - 2022**
 - *Steps above in Obongi and Adjumani **host and refugee** populations*
 - *Addition of **mentorship** training*
 - *Novel evaluation methods including Photovoice*



PALLIATIVE CARE NEEDS IN ADJUMANI AND OBONGI DISTRICTS: SOCIAL DEMOGRAPHICS



350 individuals screened and 231 recruited.
Of the 231 participants, there were 66 South Sudanese refugees and 165 Ugandan hosts.



2 out of 5 have no education.



Only 9% advance past primary school.



56% eat once a day or less.



9 out of 10 have semi-permanent housing.



89% use a shared a water pump.



7 out of 10 have shared pit latrines.



95% live on less than \$1 a day.

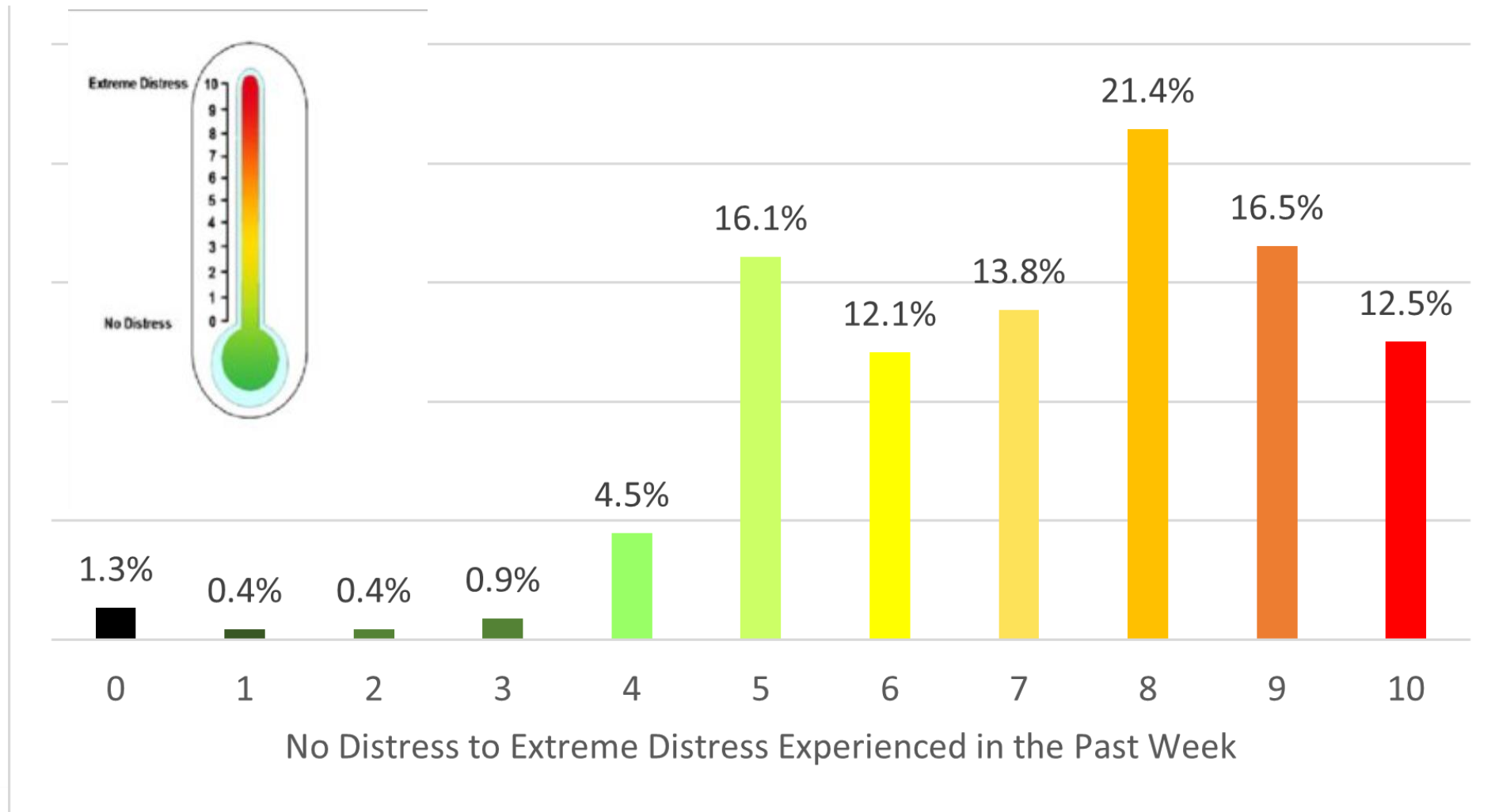


Only 4% have electricity.



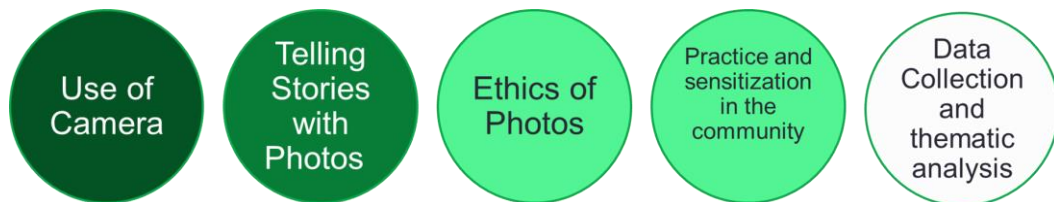
1 out of 5 have a mobile phone.

Needs assessment; Distress Thermometer



Community generated data; photovoice

- Process



- Analysis

- SHOWED questions:

- What do you See here? What is really Happening here?
- How does this relate to Our lives? Why does this situation, concern, or strength exist? What can we Do about it?



[Wang & Burris, 1997](#)

Transforming societies; community mobilisation

- Innovation
- Compassionate communities



Transforming fractured societies

- *‘Our people are in pain; we have no choice but to act.’*

*Al Shifa Hospital, Gaza
Dr Sobhi Skaik*

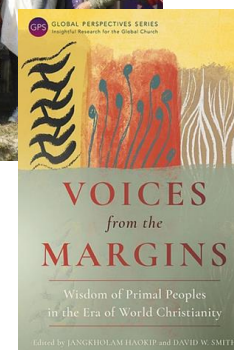


Transforming societies; indigenous communities

- Khankho: Kuki, Manipur
- *‘Life as interdependent, relational and inclusive and was shared in a community expressed through integrity, honesty, love, justice, fairness and selfless service of one another’*
- *‘Khankho is leading a life in tune with the culture grounded in love, care, fairness and justice. It expresses connectedness, interdependence and sharing in the celebration of life in community.’*

Jangholam Haokip

https://ehospice.com/india_posts/planetary-health-voices-of-indigenous-peoples-from-marginalisation-to-the-centre/



Transforming lives



‘Thank you
for my
wheelchair
and food’
Jackie, in Malawi

Transforming lives



‘Let me
be at
home’
Sasidharan,
Kerala

Transforming lives



‘Thank you for helping my son...now I can sleep through the night.’

Mother of Shibu, Kerala

Transforming lives



‘Take care of my wounds and please don’t abandon me’
Swaibu, Uganda



Transforming lives



*'Please keep
coming to see me
– that I all I ask'
Diane, Uganda*

Transforming lives

- ‘you gave me hope, you gave me pain control, you gave me love....thank you and please pray for me...make sure everyone in Uganda has this care.’



What gives hope?



Resources

- Cairdeas International Palliative Care Trust www.cairdeas.org.uk
- World Hospice and Palliative Care Alliance <http://www.thewhpc.org/>
- International Hospice and Palliative Care Association <http://hospicecare.com/>
- International Children's Palliative Care Network <http://www.icpcn.org/>
- Global Health Academy, University of Edinburgh <http://www.ed.ac.uk/global-health>
- PallCHASE <https://www.pallchase.org/>



- Lewington J, Namukwaya E, Limoges J, Leng M, Harding R. Provision of palliative care for life-limiting disease in a low income country national hospital setting: how much is needed? *BMJ Support Palliat Care*. 2012;2:140–4.
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- Namukwaya E, Murray SA, Downing J, Leng M and Grant L. (2017) 'I think my body has become addicted to those tablets'. Chronic Heart failure patients' understanding of and beliefs about their illness and its treatment: a qualitative longitudinal study from Uganda. *PLOS One*.
- Namukwaya E, Grant L, Downing J, Leng M and Murray SA. (2017) Improving care for people with heart failure in Uganda: serial in-depth interviews with patients' and their health care professionals. *BMC Res Notes* 10:184. DOI 10.1186/s13104-017-2505-0
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- Downing J, Leng M and Grant L. (2016). Implementing a Palliative Care Nurse Leadership Fellowship Program in Uganda. *Oncology Nursing Forum* 43(3) 395-398. DOI: 10.1188/16.ONF.395-398
- Downing J, Grant L, Leng M and Namukwaya E. (2015) Understanding models of palliative care delivery in sub-Saharan Africa: Learning from programmes in Kenya and Malawi. *Journal of Pain and Symptom Management*. 50(3): 362-370.
- Powell et al. Palliative care in humanitarian crises: always something to offer. *Lancet* April 2017