Expanding the Scope: From Standards to Global Practice

How the definition and scope of children's palliative care have evolved, and what it means for the future of the field

Dr. Megan Doherty

Globally,

> 10 million children need palliative care...

...very few are receiving it



Inequitable access to palliative care

Country	# Services	Total need for PC	% Need met
Income group			
Low-income	405	7 488 000	0.72%
Lower-middle-income	1504	25 240 000	1.11%
Upper-middle-income	7539	26 002 000	8.61%
High-income	24 272	14 722 000	53.42%

Early Work on Defining the Scope

Types of conditions

1997

1998

WHO Definition

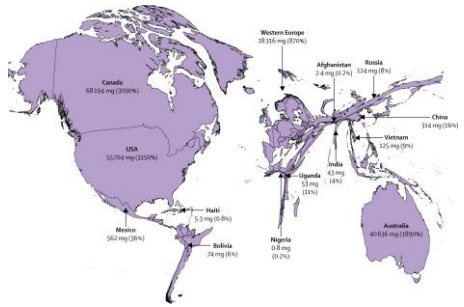


Standards in Europe

2007

2017

Serious Health Related Suffering



Global and Regional Atlases

2025



The Solution

“Ideal Future”



An Ideal Future, where Palliative Care...

...is fully **integrated into health systems**

... has a**dequate funding, supportive policies and a well-trained workforce**



...is **informed and shaped by communities whose lived experience**, cultures, and wisdom

We can eliminate serious health related suffering for children

Early Global Elimination Initiatives

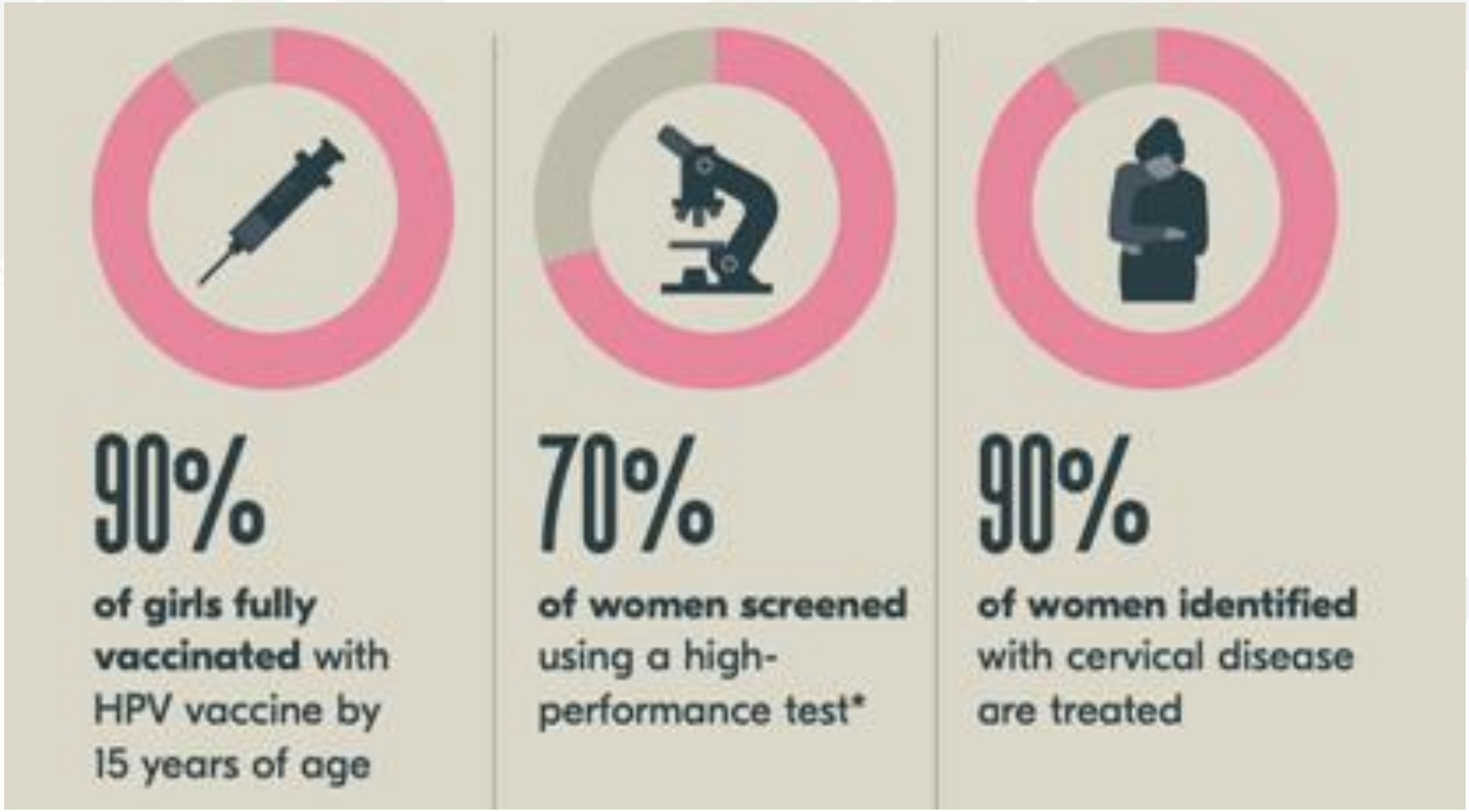
Malaria (1955): early success, but unsustainable due to cost, drug resistance, and logistics.

Smallpox eradication (1980): first and only human disease eradicated

Global Initiatives…Some Key Lessons

1. Simplicity and feasibility matter (clear diagnosis, effective treatment).
2. Local staff, well-trained and supervised, can achieve high impact.
3. Balance eradication goals with strengthening health systems.

WHO Cervical Cancer Elimination Strategy (2020)



90-70-90 Targets

- Clear and measurable goals
- Move from aspiration to **targets and plans**
- Clear accountability and tracking of progress

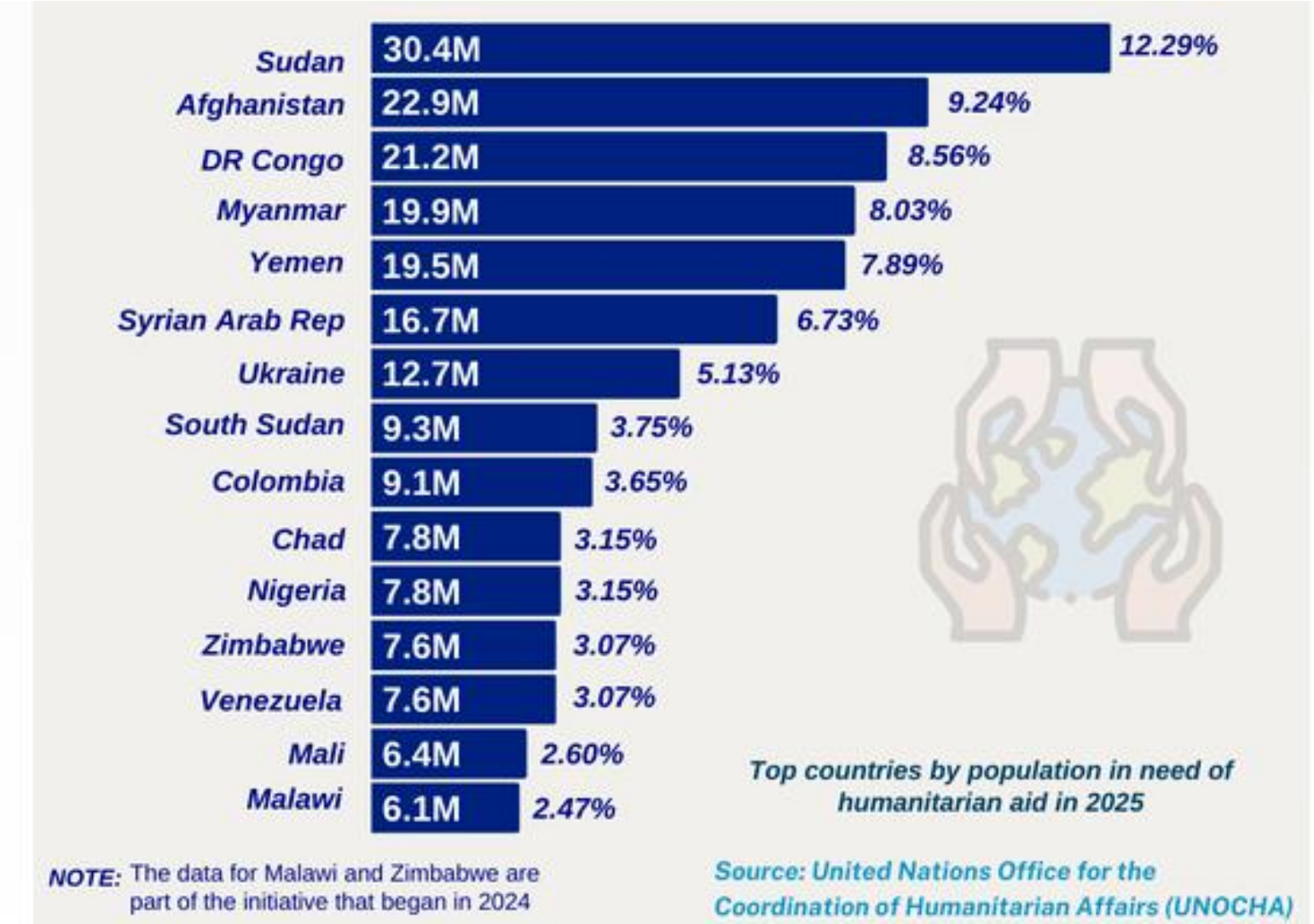
Expanding the Scope



Our Blind Spots

- Services are concentrated in high-income settings
  - Humanitarian emergencies
  - Rural, remote and under-served areas
- Health systems determine if care reaches patients

Scale of the need in humanitarian settings



- >300 million people will require humanitarian assistance during emergencies this year
  - More than 50% are children

Palliative care is needed in humanitarian emergencies

Serious or life-limiting conditions (pre-existing)	Conditions without access to treatment in the emergency	Conditions generated by the emergency
• E.g. Cancer, cerebral palsy	• E.g. Extreme prematurity, congenital heart disease	• E.g. Severe malnutrition, severe injuries or burns

The Sphere Project | *Humanitarian Charter and Minimum Standards in Humanitarian Response*

Palliative care standards

1

Provide care:

- Symptom Relief
- Communication

2

Community-based care

3

Train healthcare workers

4

Provide **essential medical supplies and equipment**.

Health Systems: WHO “House” Model of Palliative Care



- Empower people and communities
- Health policies
- Research
- Education and Training
- Use of Essential Medicines
- Provision of Palliative Care



Community Based Palliative Care: Rohingya refugee crisis, Bangladesh

CASE STUDY

Community palliative care in the Rohingya refugee response



- Community health worker-led program
  - From the Rohingya community
  - 10 days training
  - Supervised by a doctor and nurse

Expanding the Scope

- Defined basic palliative care for community health workers:
  - Bathing, feeding
  - Taking medications
  - Caregiver support and training
  - Access to health services
    - Accompany family to appointments
  - Adherence to recommendations from hospitals
    - Practicality of recommendations

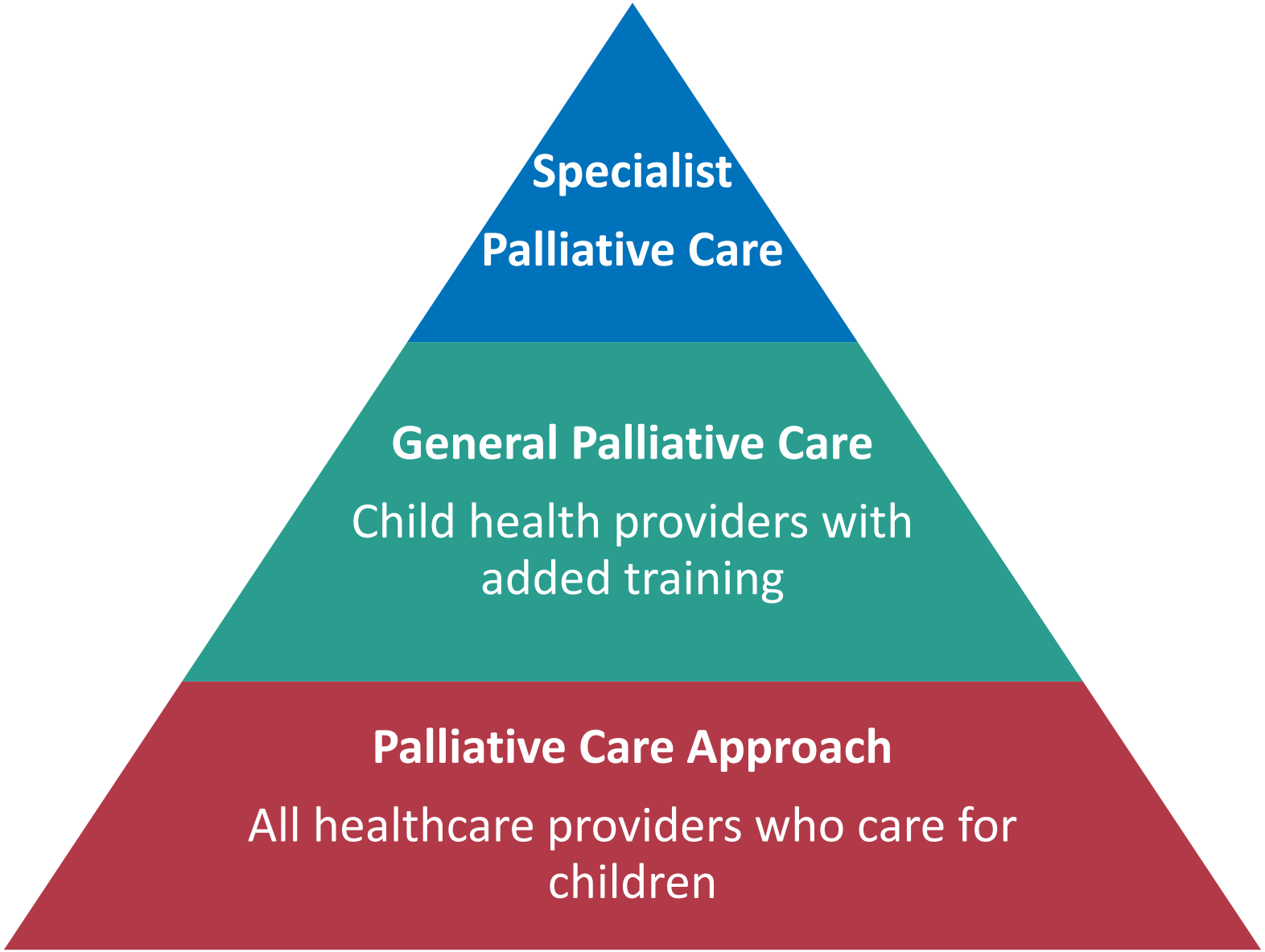
Holistic Support: Expanding Beyond Medical Needs

- Food
- Winter clothing and blankets
- Supporting sibling education





Expanding the scope of who delivers care



3 Keys to Our Shared Success



2014: World Health Assembly Resolution on Palliative Care



WHO calls to action from the resolution

01

Ensure palliative care is **integrated** into global disease control and health system plans

02

Evidence-based **guidelines and tools** on pain and symptom management

03

Develop **guidelines on integration of palliative care into national health systems**

Country calls to action from the resolution

01

Palliative care policies to support integration of palliative care services

02

Funding and allocation of human **resources** for palliative care

03

Palliative care training (basic, intermediate, advanced)

World Health Organization

NEW COURSE

Palliative Care Service Planning



Learn about palliative care and how to plan health services that deliver palliative care.

- Understand and assess palliative care services
- Design health service packages to deliver palliative care

Local

Success depends on collaboration more than your expertise



What does each person bring to the table?



Six key components of the WHO model



- Empower people and communities
- Health policies
- Research
- Education and Training
- Use of Essential Medicines
- Provision of Palliative Care

WHO Palliative Care Working Group



Personal

Success requires that you develop yourself as a leader

Voices of hope, unity and leadership

Leadership is not a position — it’s showing up and leading from where you are.



Lacey Ahern

Global Partners in Care

Lead and Champion Advocacy

Raise awareness at global and country level of the needs of children and families

Global Advocacy Campaign: One clear message across partners, with concrete asks for ministries of health, funders

CLOSE THE GAP
PALLIATIVE CARE FOR CHILDREN,
EVERYWHERE

CLOSE THE GAP – PALLIATIVE CARE FOR CHILDREN, EVERYWHERE

Campaign Toolkit

How You Can Get Involved



CLOSE THE GAP
PALLIATIVE CARE FOR CHILDREN, EVERYWHERE

POLICY BRIEF

May 2026

Children's Palliative Care: An Urgent Global Health Priority

CLOSE THE GAP
PALLIATIVE CARE FOR CHILDREN, EVERYWHERE

Key Messages

- Millions of children worldwide experience avoidable suffering due to lack of access to palliative care and essential health care services.
- Children's palliative care (CPC) is a core component of universal health coverage and primary health care.
- It is feasible to integrate CPC in all contexts, settings and income levels etc.
- Governments and global partners have an ethical, legal, and moral responsibility to act to ensure CPC is an essential part of health service provision.



"From a policy perspective, more resources are needed so that many other families going through difficult situations like ours have access to palliative care. Because it is essential. It truly opens doors. The palliative care team showed us possibilities we never even knew existed. Thanks to them, we discovered options, paths, and support."

Parent from Uruguay

The Issue

Over 21 million babies, children and young people live with life-limiting and life-threatening conditions globally and require palliative care, yet less than 10% currently receive it. Every child deserves comfort and connection with their loved ones. By relieving pain and other symptoms, children's palliative care ensures that children and their families can make the most of every moment together. 96% of children globally needing palliative care live in low- and middle-income countries with fragile health-care systems. As a result, many children experience preventable pain, distress and poor quality of life.

Children's palliative care focuses on improving quality of life. It manages pain and other symptoms, supports emotional and spiritual wellbeing, and provides care and guidance for families. Importantly, palliative care can begin at diagnosis and continue alongside curative treatments, through end of life and bereavement. It is not only for the final days of life, nor does it mean giving up. Care can be provided at home, in the community, at school, or in hospitals—even in places with limited resources.

Despite international commitments, access remains profoundly inequitable due to limited policy prioritisation, limited resources (e.g. funding), inadequate workforce capacity, restricted availability of essential medicines, limited data and monitoring systems and persistent misconceptions that palliative care is only for end-of-life or adult cancer care. These barriers result in delayed referrals, fragmented care, and unnecessary suffering.

Why Children's Palliative Care Matters

Access to health care, including palliative care, is a fundamental human right. All children with life-limiting or life-threatening conditions have the right to live and die with dignity, free from avoidable pain and distress.

Children's palliative care is the total care of a child's body, mind and spirit. It begins at diagnosis, continues throughout the illness trajectory and also provides support for the family. It should be provided for neonates, babies, children and young people and can be delivered across the continuum of care and in diverse settings including at home, in the community or in health facilities, even in resource constrained settings. It enables children with life-limiting and life-threatening conditions to live as well as possible until they die, and can provide them with choice of both place of care and death.

Putting it all together…

> What brought us here will not take us there. We must continue with passion and determination — but we also need a shared vision and the courage to think innovatively to create the change palliative care needs.



Ximena Garcia-Quintero

St Jude Global Palliative Care

Hope is not the thing with feathers
That comes home to roost
When you need it most.

Hope is an ugly thing
With teeth and claws and
Patchy fur that's seen some shit.

It's what thrives in the discards
And survives in the ugliest parts of our world,
Able to find a way to go on
When nothing else can even find a way in.

It's the gritty, nasty little carrier of such
diseases as optimism, persistence,
Perseverance and joy,
Transmissible as it drags its tail across
your path

-Caitlin Seida

"Hope" is the thing with feathers
That perches in the soul,
And sings the tune without the words,
And never stops at all.

And sweetest in the gale is heard;
And sore must be the storm
That could abash the little bird
That kept so many warm.

I've heard it in the chilliest land
And on the strangest sea;
Yet, never, in extremity,
It asked a crumb of me.

–Emily Dickinson

