End-of-Life Care & EOLC research: where does it come from and where should it go to?

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END-OF-LIFE CARE RESEARCH GROUP

UNIVERSITEIT GENT

VUB

COI statement

- **no COI**
- Sociologist
- >30 years research experience in PC & EOLC
- Former co-chair EAPC RG Public Health Palliative Care
- President Public Health Palliative Care International

Alliance Interdisciplinary Research Group of VUB University in Brussels & Ghent University

Collaboration is key to success in both research and practice

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what were the palliative care responses to the challenges surrounding death, dying & loss ever since 1970s ?

palliative care responses to challenges surrounding dying & loss since 1970s: stage 1 (1960-1975)

Awareness raising

Resource mobilising

palliative care responses to challenges surrounding dying & loss since 1970s: stage 2 (since 1975/80 & still ongoing)

Awareness raising

Health services responses

Resource mobilising

Shaping a new field of medicine
Integrated Care models

STAGE 2 (1975/80 – today):

PC development with main focus on specialised PC service development, professionalisation, medicalisation, without noticing the wider societal picture

palliative care responses to challenges surrounding dying & loss since 1970s: stage 3 (since 2000; Temel study 2010)

Awareness raising

Resource mobilising

Health service responses

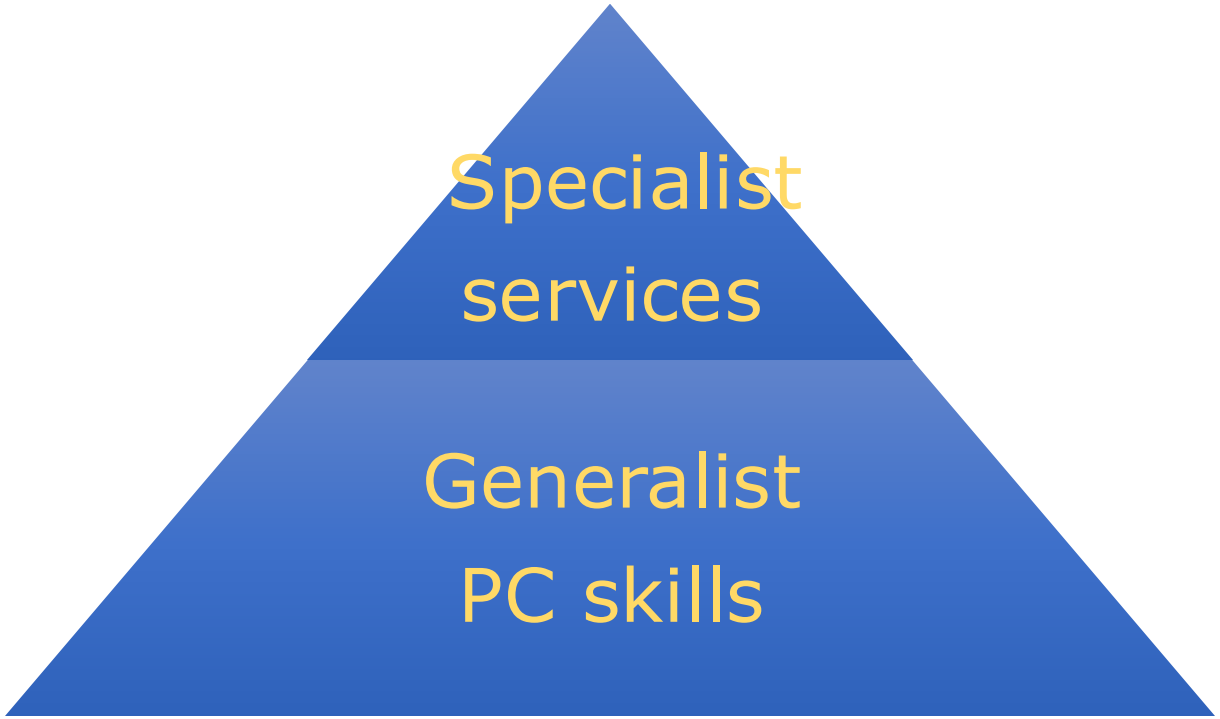
Shaping a new field of medicine
Developing of Models of Care
Interdisciplinary

Mainstreaming

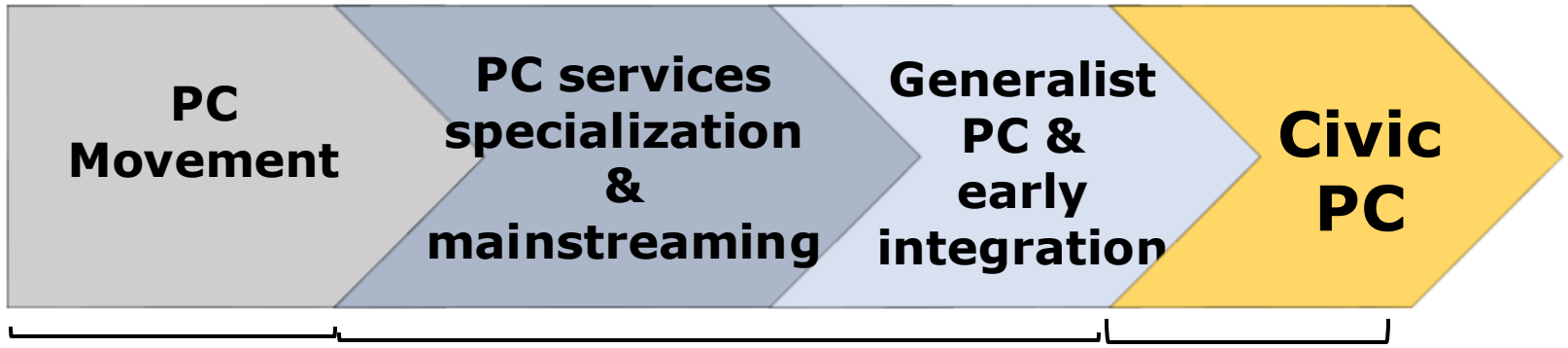
Integration into the HCS
Generalist PC
Timely/early integration

STAGE 3 (2000 – today):

PC development with attention for the integration in and collaboration with the regular care (GP, oncology, pneumology, etc),
without noticing the wider societal picture



palliative care responses to challenges surrounding dying & loss since 1970s: 4 stages (since 2010)



Awareness raising

Resource mobilising

Health services responses

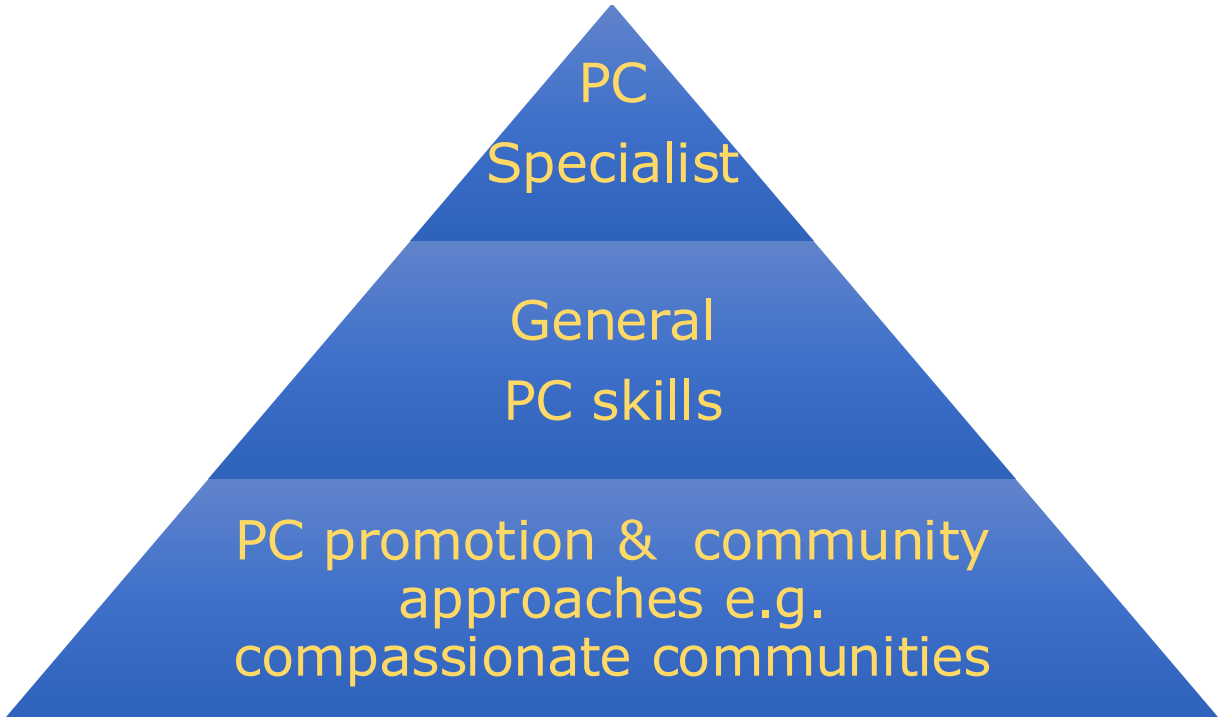
Shaping a new field of medicine
Integrated Care models

Societal responses

PH approaches
Community Care

STAGE 4 (2010 to today):

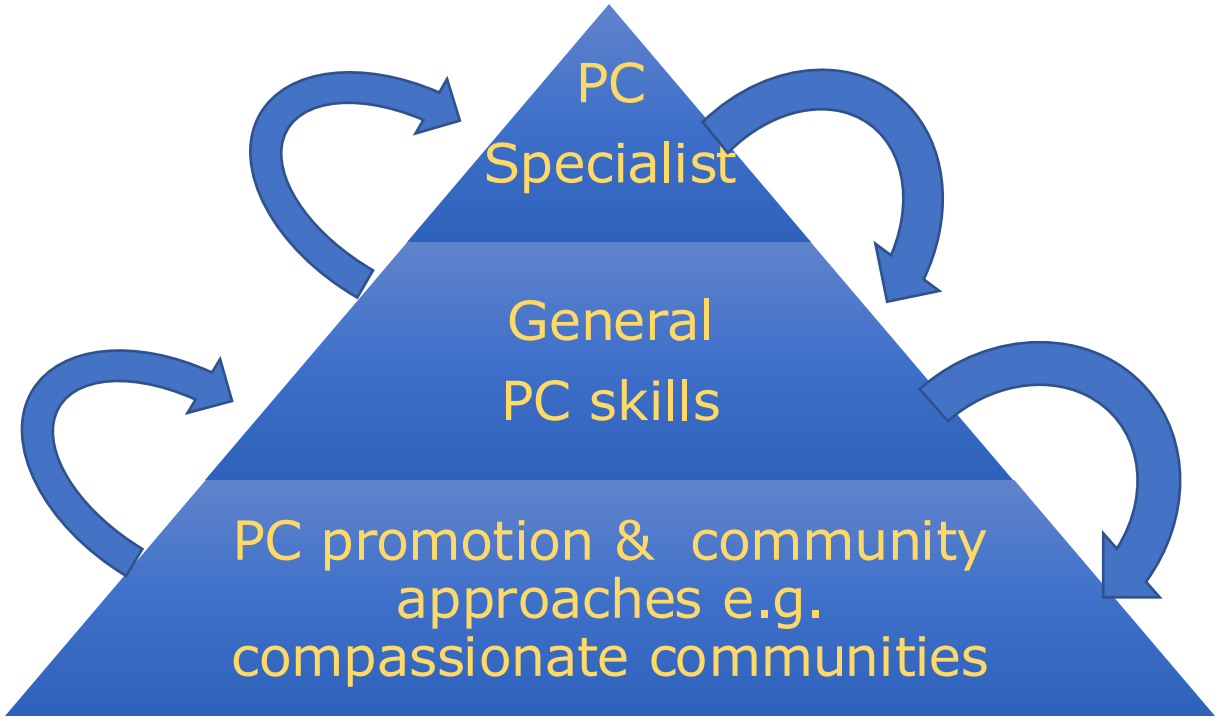
Developing of public health approach in PC



The largest potential to create capacity in PC is at the societal level of the policy pyramid

STAGE 4 (2010 to today):

Developing of public health approach in PC



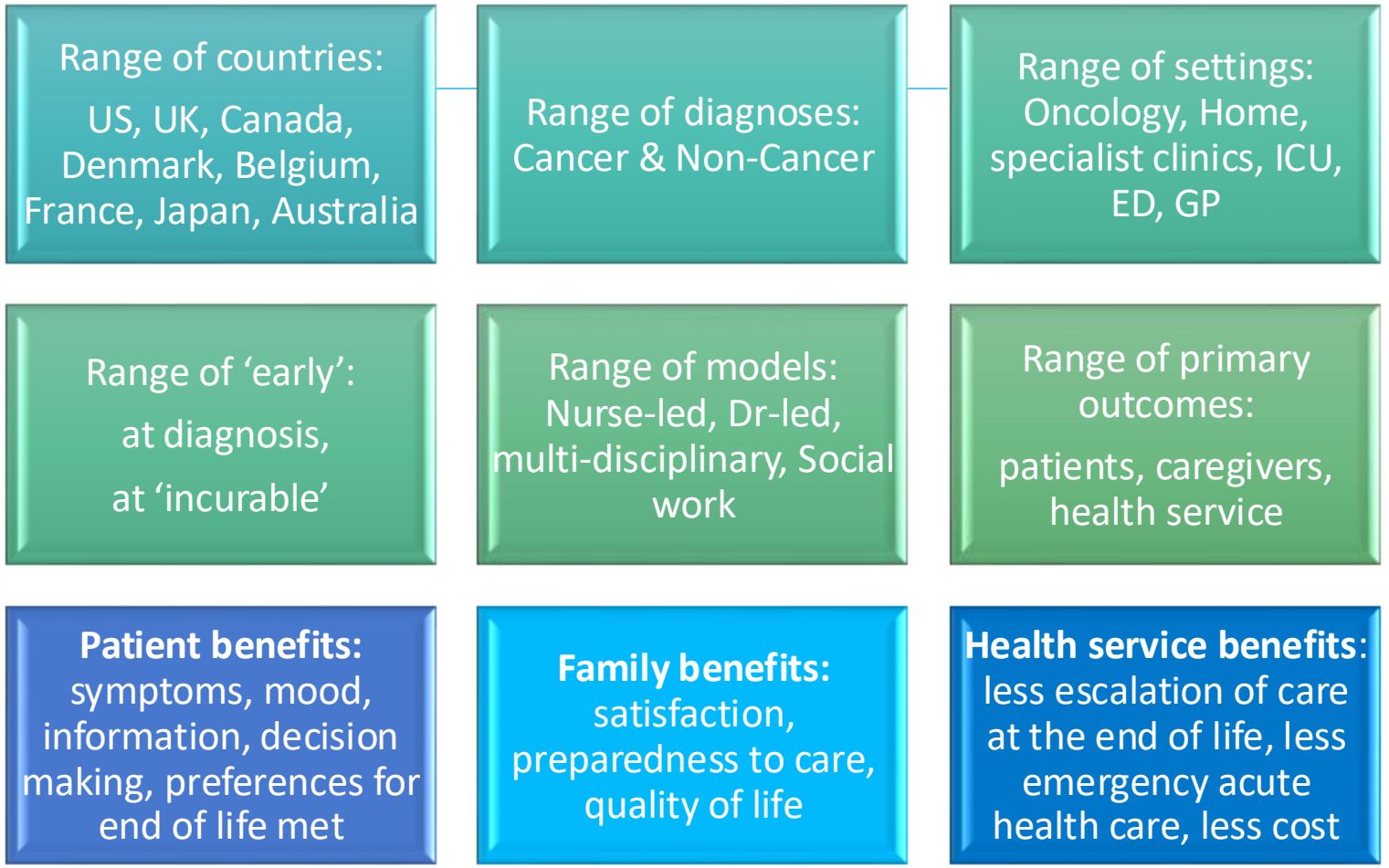
How much evidence do we have for PC?

1980 - today

exponential growth of the EBP PC

- substantial evidence has been published in scientific journals
- substantial growth in number of PC journals
- syntheses of the EBP of PC has been distributed via textbooks, conferences, education, trainings, etc
- PC fully recognised as separate field in medicine

> 30 RCT studies shown the benefit of early PC integration



Temel 2010
Higginson 2014
Zimmerman 2014
Dalgaard 2014
Bakitas 2015
Davis 2015
Huan 2017
Groenvold 2017
Temel 2017
Hancock 2018
Koffman 2019
Fulton 2019
Vanbutsele 2020

Is there a discrepancy between evidence and practice?

Timing of PC uptake: Systematic review

- 169 studies from 23 countries were included, involving 11,996,479 patients.

- Prior to death, the median duration from initiation of palliative care to death was **18.9 days**

- Significant differences between duration were found by
  - **disease type** (15 days for cancer vs 6 days for non-cancer conditions),
  - **service type** (19 days for specialist palliative care unit, 20 days for community/home care and 6 days for general hospital ward)

Duration of palliative care before death in international routine practice: a systematic review and meta-analysis. Jordan RI, Allsop MJ, ElMokhallalati Y, Jackson CE, Edwards HL, Chapman EJ, Deliens L, Bennett MI. BMC Med. 2020 Nov 26;18(1):368.

Current versus historical palliative care access for people with cancer

Care Outcome	All Cancer deaths in 2018 (n=10,245) n(%)	Lung, prostate & breast cancer deaths 2018 (n=3,689) n(%)	Lung, prostate & breast cancer deaths 2005-2009 (n=21,339) n(%)	Comparison 2018 & 2005-2009
Any access to inpatient PC	6728 (66%)	2444 (66%)	11,611 (54%)	P<0.001
Time from first PC to death, median days (IQR)	20 (7-55)	22 (7-63)	25 (9-62)	P<0.001
Receipt of PC >3 months before death	1036 (10%)	439 (18%)	2061 (10%)	P<0.001

Philip J, Collins A et al. **Is the use of palliative care services increasing?** Palliat Med. 2022 Aug 24

how well do we perform in PC ?

⇒ **Reality check ?** **“*Too little too late*”**

- Still dominated by “**terminal care**”
- **prognosis-driven** rather than needs-driven
- **early integration failed** in most countries and most hospitals

(>15 years after the evidence of the Temel study)

how come that palliative care and patient-centred care is poorly integrated in our health care systems?

Why is PC poorly integrated in our HCS?

1) **Historical HCS focus on curative and acute care**

- focus = **disease-focused** curative medicine and institutes
- emphasizing **prolonging** life rather than comfort, dignity, and quality of life

2) **Cultural and societal attitudes**

- death and dying remain **taboo** topics in our societies
- families and professionals often view PC as "**giving up**"

Why is PC poorly integrated in our HCS?

3) Fragmented Healthcare systems

- **siloed** services (isolated units, coordination challenging)
- lack of continuity of care (no reliable navigation systems for patients)

4) Lack of training and awareness

- many clinicians limited training in PC (e.g. oncologists)
- person-centered care require empathy, skills in shared decision-making, often poorly taught or rewarded at medical schools

Why is PC poorly integrated in our HCS?

5) **Policy and funding barriers**

- **reimbursement** models favor expensive interventions, rather than communication (ACP, SDM, etc)
- PC often seen as cost rather than a value-added service

6) **Leadership and institutional inertia**

- implementing PC requires ***systemic cultural changes***
- implementing PC requires **leadership commitment**, often not present

But also limitation in our PC research !

REVIEW on PC research priorities:

The voice of the professional care provider dominates

Too few research is captering patients and families perspectives

More research needed to understand the working of the HCS: **structural** as well as **cultural** aspects

Felicity Hasson et al. **International palliative care research priorities: A systematic review**. *BMC Palliative Care* 2020 19:16

Burning challenges for PC services

- the present models of specialized palliative care in many countries is no longer sustainable
  - accessibility is already limited (<20% in many countries)
  - complementary approaches have to be developed
  - how can we reach out to all people in need in our societies?

- Many of the models of palliative care have been based on clinical or health services models, not on public health models

What are possible pathways to improve implementation of palliative care?

1) implementation research on how PC can work in real life conditions

2) public health approaches in PC

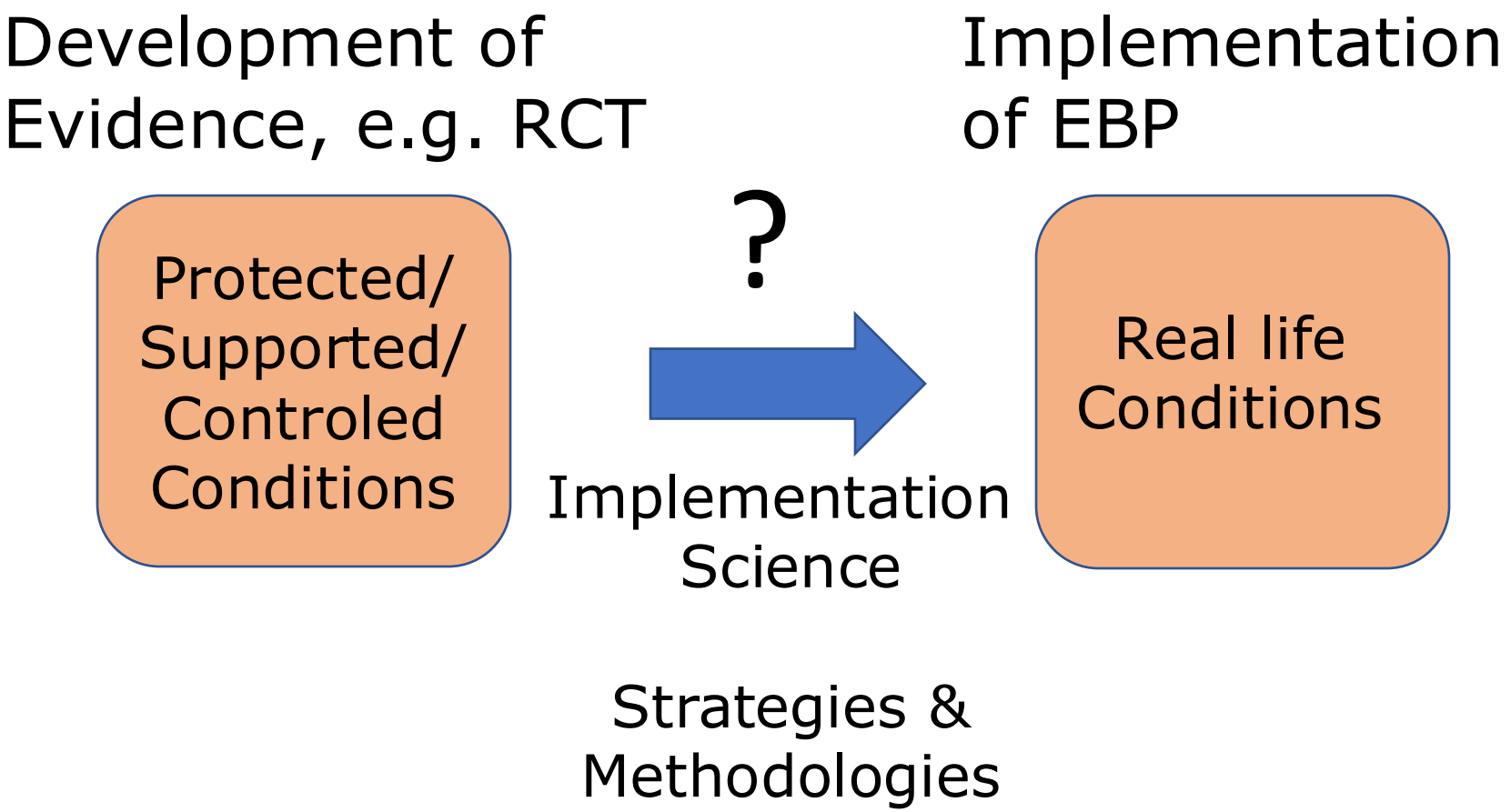
potential of implementation science research in PC ?

Implementation Research: definition

"the scientific study of methods/strategies to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services"

An introduction to implementation science for the non-specialist. Mark S. Bauer, Laura Damschroder, Hildi Hagedorn, Jeffrey Smith and Amy M. Kilbourne, *BMC Psychology* 2015; 3:32

Implementation Science



Implementation Research: WHY?

- clinical as well as health services research have little guarantee for a "public health impact"
- effectiveness trials typically depend on research resources which are seperated from the regular clinical infrastructure:
  - externally funded
  - time-limited
  - remain seldom at the local site
- consequences for regular care:
  - short "institutional memory" on the intervention
  - old routine is quickly re-adopted
  - often no technology transfer
  - *un*assisted translation of EBP practice unlikely

An introduction to implementation science for the non-specialist. Mark S. Bauer, Laura Damschroder, Hildi Hagedorn, Jeffrey Smith and Amy M. Kilbourne, *BMC Psychology* 2015; 3:32

Implementation Research: **WHY?**

- The field of implementation science has developed to facilitate the spread of EBPs
- As healthcare systems work under increasingly dynamic and resource-constrained conditions, evidence-based strategies are essential in order to ensure that research investments improve *public health impact*
- Implementation science plays a critical role in supporting these efforts

An introduction to implementation science for the non-specialist. Mark S. Bauer, Laura Damschroder, Hildi Hagedorn, Jeffrey Smith and Amy M. Kilbourne, *BMC Psychology* 2015; 3:32

Implementation Research: Why in PC?

- >85% of all health care research is being avoidably "wasted"
- palliative care is a field of healthcare in receipt of a very small proportion of research funding
- hence, it is essential to ensure that research value is maximised and EBP is being implemented
- We should realise that transfer of evidence-based practices into routine palliative care will not happen spontaneous, it requires **focused efforts**.

Felicity Hasson et al. **International palliative care research priorities: A systematic review**. *BMC Palliative Care* 2020 19:16

several barriers can impede the uptake of EBP in PC

- competing demands on the frontline providers
- Lack of knowledge and skills
- Lack of resources
- Misalignment of the research evidence with the standard procedures and routine practice in the health care setting

⇒ **There is a clear need to develop specific strategies to promote the uptake of EBP into routine palliative care!**

Success of the implementation ?

$$I = E \times C \times F$$

E = strenght of your **evidence**

C = how ready is your local **context**?
(structure & culture) e.g. *Learning HCS*

F = availability & quality of **facilitators**

US Institute of Medicine

- Any health care system should develop into a **Learning Health Care System**
- Learning HCS is required to absorbe the rapidly evolving EBP
- **Implementation science** is becoming a critical tool for the development of a Learning HCS

US Institute of Medicine Committee on the Learning Health Care System in America. Best care at lower cost. Washington: National Academy Press, 2013

Implementation Research: implications?

- scope broader than traditional clinical research
- focusing not only at the patient level but also at the provider, organization, and policy levels of healthcare
- "co-creation" with providers, patients, families, etc
- accordingly, implementation research requires **multi-disciplinary research teams** that include members who are not routinely part of most clinical research teams:
    - health services researchers
    - economists
    - sociologists, psychologists, anthropologists, etc
    - organizational scientists/social change managers

potential of public health palliative care interventions & research?

Public health & palliative care

- a PH approach covering death, dying and loss is lacking in PC in many countries

- PH intervention approaches (health promotion, death literacy, compassionate communities, etc) have only very recently been applied on the end of life and palliative care

Key message

if we want more policy-makers, practitioners and communities to embrace the aims and ideals of palliative care

a public health approach is an essential condition, complementary to the clinical or health services approach !

Public Health & Health Promotion

- enjoyed strong support from governments ever since the 70ies
- WHO “Health for all strategies by 2000” had an immense impact on our health care systems
- introduced the concept of the power and responsibilities of people, communities and governments for the promotion of health and prevention of sickness

Public Health & Health Promotion

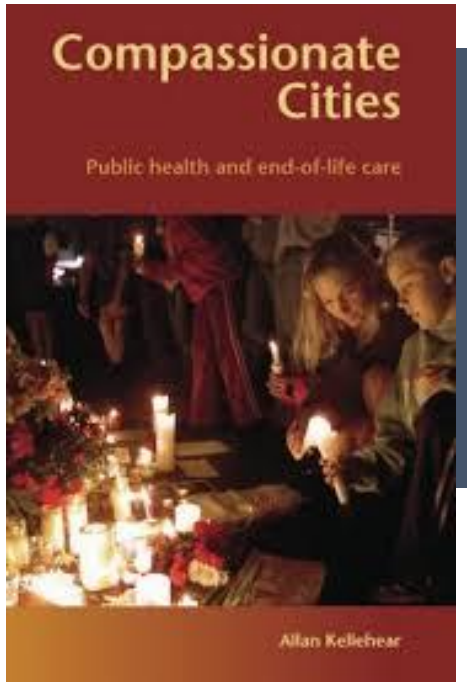
- its emphasis is on prevention and health promotion
- is integrated into national and international health policies
- a comprehensive public health approach is also less expensive than acute and chronic forms of care

public health perspectives on palliative care

- the collective pendent to individual patient care at the end of life
- it is broader than healthcare in the strict sense and includes all sectors in a society (schools, workplaces, hobby clubs, churches, cultural events, etc)
- involves non-medical disciplines e.g. social work, psychology, educational sciences, social change management, etc
- as well as policy, legislation, regulation and co-creation with citizens

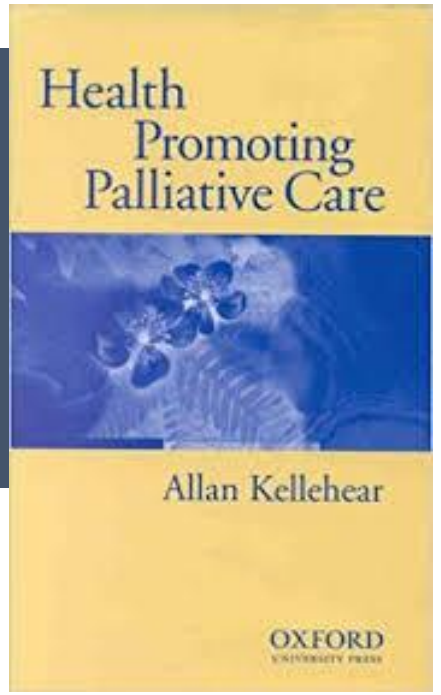
=> Capacity for PC can grow substantially via social networks

New Public Health Approaches



*Death is a **social event** with a medical component, not a medical event with a social component*

Allan Kellehear



Commonly overlooked facts about palliative care ?

- The longer part of dying occurs outside of institutional and professional care

- Palliative care is not just about symptom control
  - it is also about grief, loss & caregiving
  - is also about the family, not just the patient

- “What matters most to you?”

Why do we need *compassionate communities*?

PC Policy only focusing on the services =

unsustainable

80% of problems in PC are **mental and social** problems

Let us not forget

the … 95% rule

Palliative care is **everyone's** responsibility

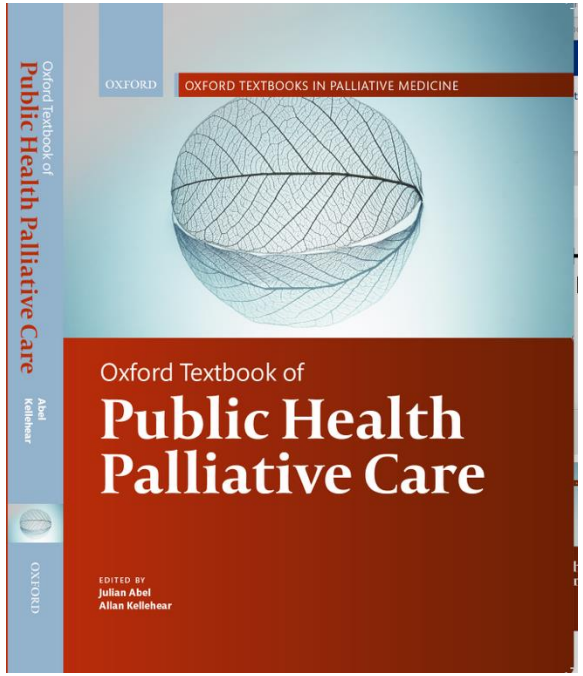
Health promotion

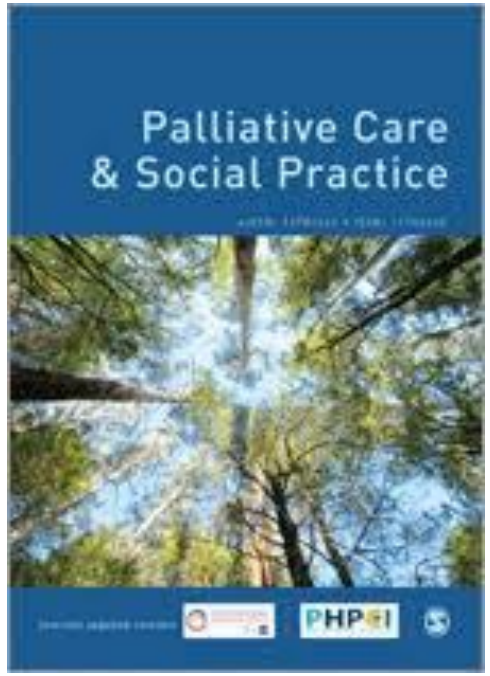
Cfr Health for All by 2000 (WHO)

Prevention, harm-reduction,

early intervention

over 15 years was needed to get Public Health approaches accepted as an academic **new paradigm for palliative care**





COMPASSIONATE COMMUNITIES ENDORSEMENT

PHPCI
ENDORSED COMPASSIONATE COMMUNITY

WHAT IS THE COMPASSIONATE COMMUNITIES ENDORSEMENT?

PHPCI has developed a Compassionate Communities Endorsement program. This program will provide Compassionate Community initiatives with a PHPCI Compassionate Communities logo, which they can use to show their participation in the movement. This opportunity is for anyone who is working to increase their community's capacity to support members who are caregiving, experiencing a serious illness, dying and/or grieving.

FOR MORE INFORMATION, CHECK OUT THE COMPASSIONATE COMMUNITIES ENDORSEMENT PAGE ON THE PHPCI WEBSITE BY SCANNING THE QR CODE

8TH PUBLIC HEALTH
PALLIATIVE CARE
ACADEMY SCHLOSS MÜNCHENWILER

PHPCI
Public Health Palliative Care International

EAPC VZW
Reference Group
Public Health & Palliative Care

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Key challenges for policy and research in palliative care:

- Recognizing the limits to service provision & health services research

- Restoring end-of-life care to the wider public health sphere of policy, practice, and language

- Understanding and facilitating the principle that end-of-life care is everyone's responsibility

  – it is also a **CIVIC responsibility**

TAKE HOME MESSAGES

- We should complement clinical research and health services research with **implementation science research**
- We should complement clinical research and health services research with **public health palliative care research**
- Integrate more **social sciences** (sociology, psychology, antropology, communication sciences, law sciences, educational science, etc) into your PC activities & research
- **compassionate communities** (neighbourhoods, workplaces, schools, universities, cities, etc) = one of the promising models
- **public health palliative care** initiatives should be integrated into global (WHO) and national health policies

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