Sharing the Caring: Time for Community-Led Solutions

Professor Samar Aoun

Perron Institute Research Chair in Palliative Care, UWA

Chair, Compassionate Communities Australia

Under the prevailing model of care

Who are the “Winners”?

Who are the “Losers”?

Palliative and End of Life Care in Western Australia

About 15,000 deaths per year in WA

↓

65% = predictable deaths and amenable to palliative/EOL care (n=10,000)

↓

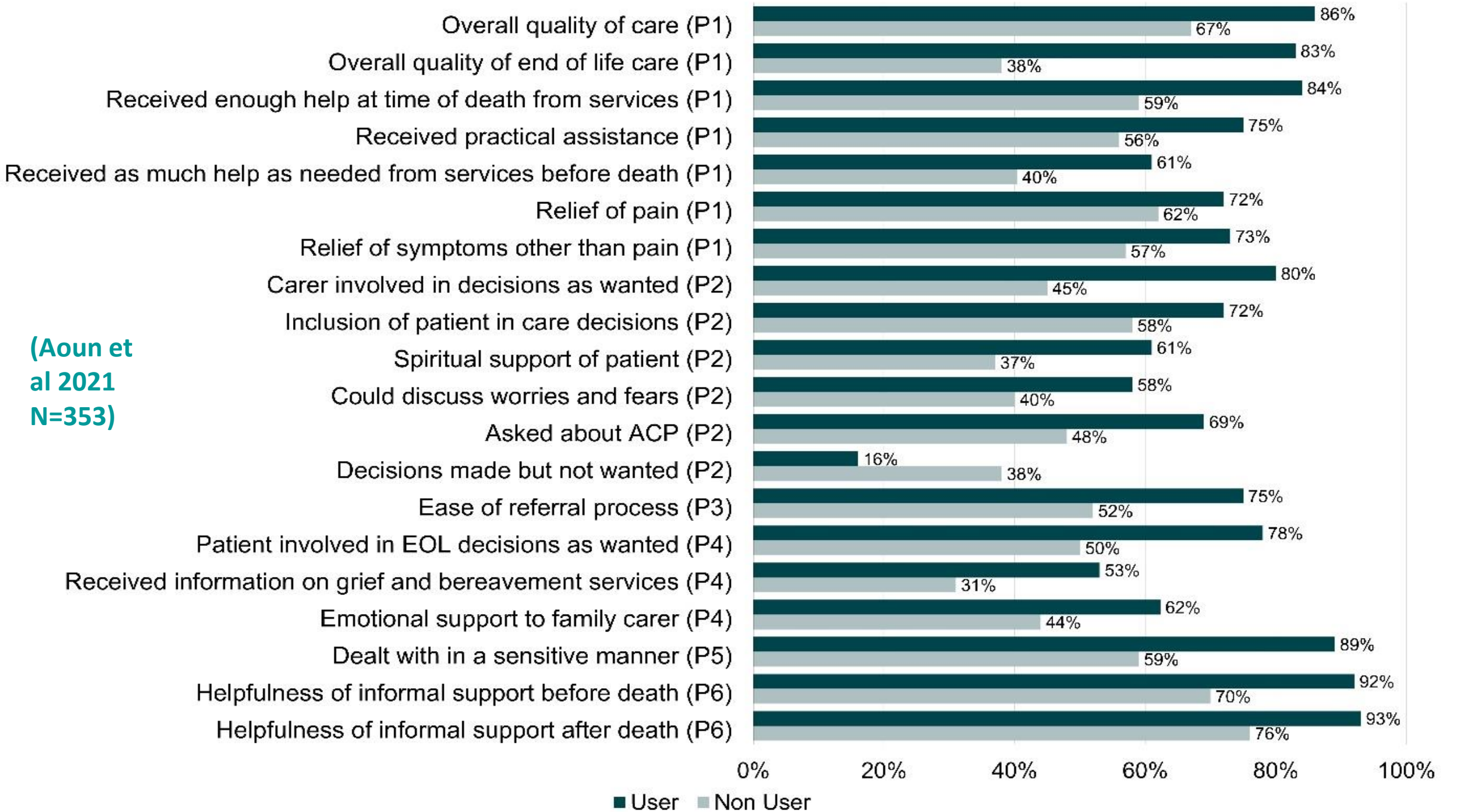
40% of the predictable deaths actually receive palliative/EOL care (n=4,000)

60% of the predictable deaths do not receive palliative/EOL care (n=6,000)

Western Australia (WA) End of Life Strategy

Six priorities to developing and improving palliative care services across WA

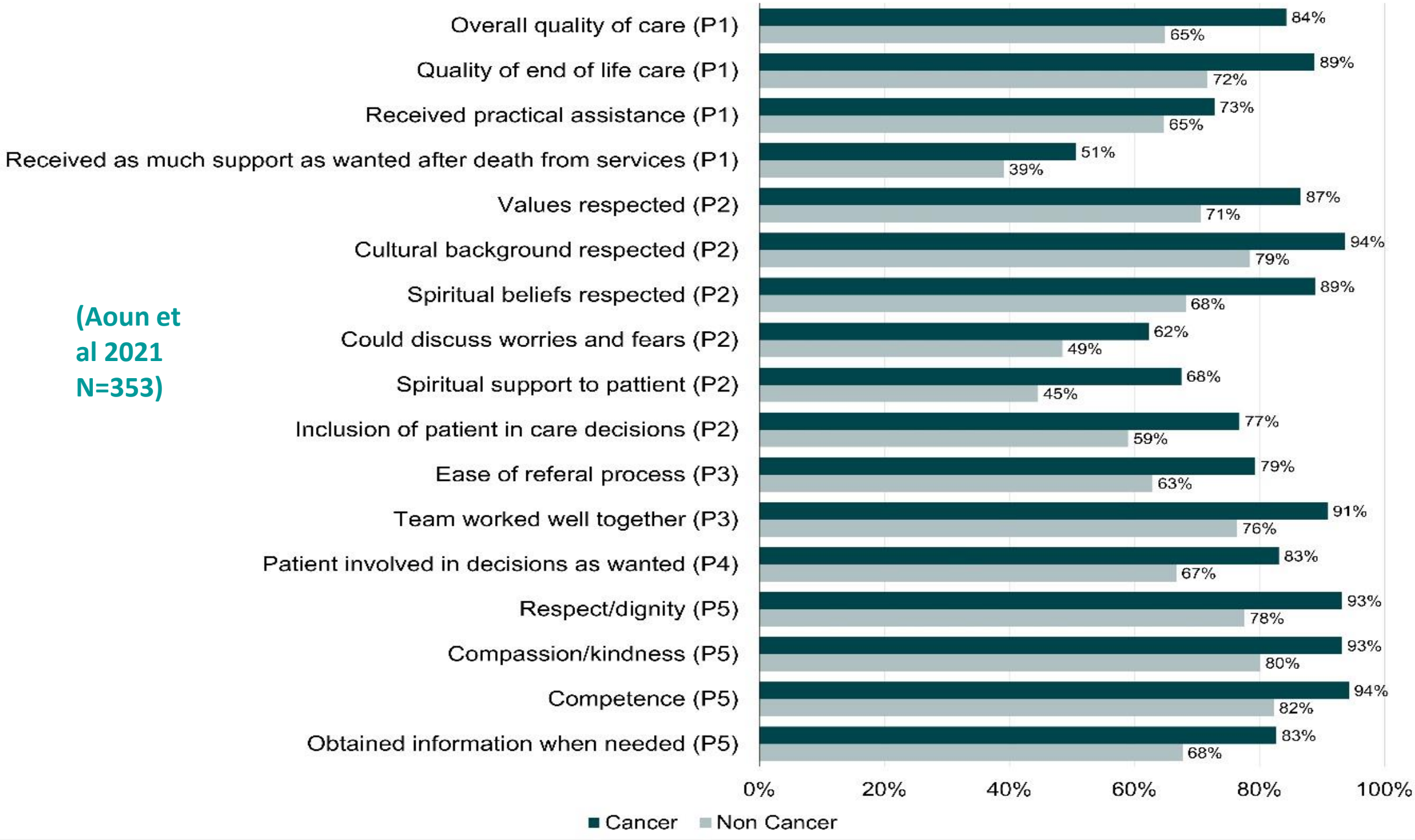
1. Care is accessible to everyone, everywhere
2. Care is person centred
3. Care is coordinated
4. Families and carers are supported
5. All staff are prepared to care
6. The community is aware and able to care



(Aoun et al 2021 N=353)

Blind Spot!
Where is the equity? Hard to Reach?

- *"Without an approximate life expectancy given unknown nature of progression of her MS it was difficult to know when to start palliative care and as such as found no one really knew the appropriate way to access this. I feel palliative care services maybe easier to understand and get access to if a patient has a clear life expectancy."*
- *"For a family trying to cope with full time care and make the millions of calls to chase up the process and get some action and funding, it is a nightmare. No idea how old people on their own would get through this."*



(Aoun et al 2021 N=353)

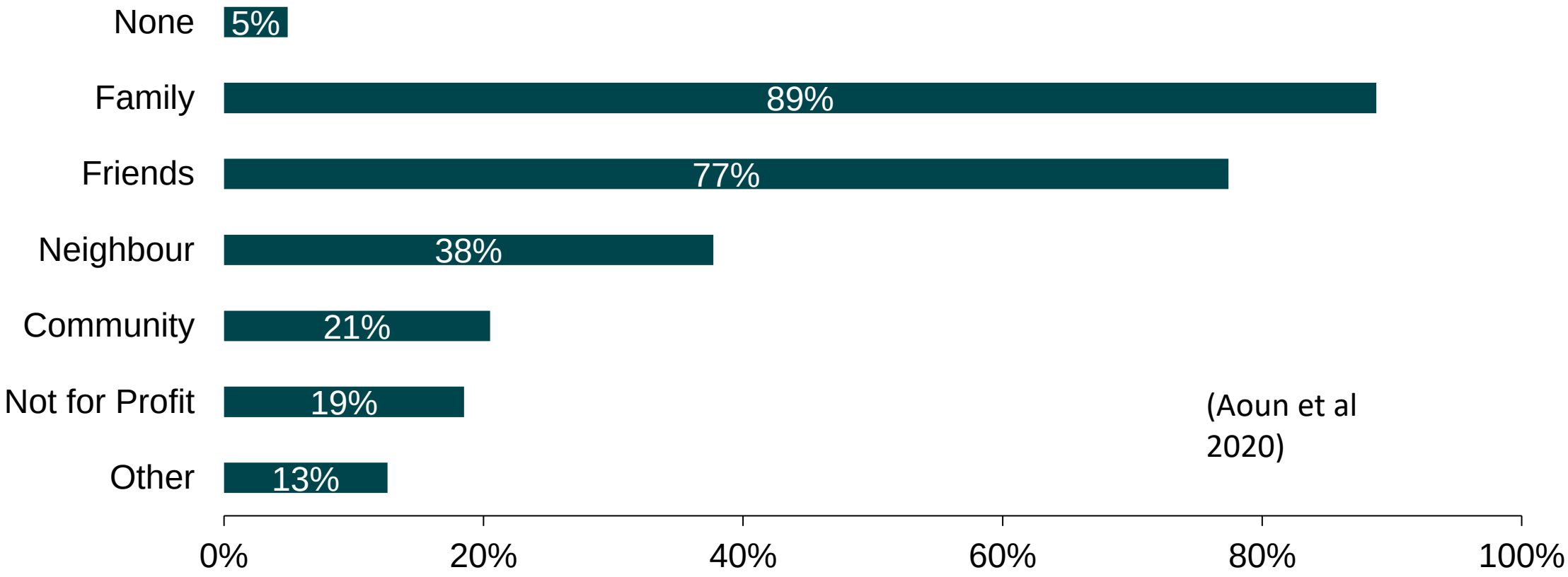
Blind Spot!
Example of what is happening to some of the 75% of deaths that are non-cancer

"Our care was chaotic. No one knew who was doing what, no co-ordination.

Much of my time was spent trying to wrangle specialists and appointments whilst trying to deal with caring for my husband in the face of his terminal illness diagnosis. We both were in shock and had not really faced any reality of his diagnosis when he suffered respiratory failure in our home in the middle of the night, just days after an appointment with a respiratory specialist and only 3 months after his eventual diagnosis with MND.

3 months of stress and trauma trying to get the right care and support services in place instead of any worthwhile time together. The process not his illness exhausted us both and I believe took him before time."

Sources of informal support (users and non-users)



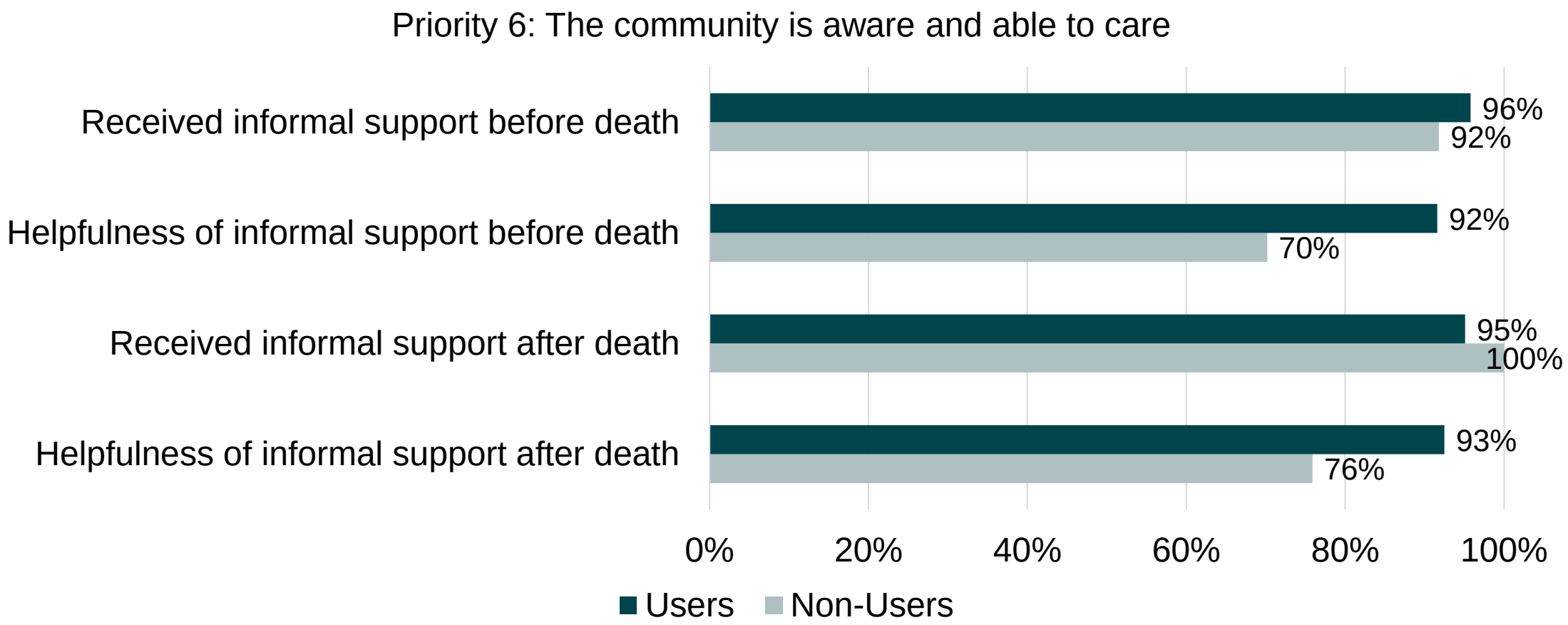
Some examples of reported community support

"Friends and neighbours who just dropped around to help normalise my life …, lend books, bring food, help with the garden. Family who would video conference from overseas in support."

"Emotional support, physical support with help around the house, paying bills, chores, gardening, watering, walking the dog."

"Local church group prayer chain and emergency contact chain (six mobile phone numbers that the patient can contact by text [she can't speak] in my absence. Can cascade to next number if first number doesn't respond). Also provide home visits and telephone checks to ensure all is as well as can be expected".

Receipt and helpfulness of informal support (Aoun et al 2020)



"Palliative care is so important and when you've had good palliative care it makes a huge difference to your experience. Cancer patients that I've spoken with who have palliative care seem to have a much better experience than those who go without. But it's not just the patient .. the family too cope better when there's a pal care team involved. They have someone to call and they have a plan - there is support." (CANCER)

Those who received the best quality end of life care:

- Aware of palliative care as an EoL option.
- Qualified for admission to, and were able to access, a specialist care program.
- More likely to have a cancer diagnosis.
- Supported throughout their illness by family and a wider social network.

Those who received care at EoL that was adequate rather than best practice:

- Unaware of palliative care as an EoL option or did not qualify, or were unable to access specialist palliative care.
- For the most part had a non-cancer diagnosis.

Also family carers not being supported during caregiving and during bereavement.

"Our experience has been heartbreaking and we are still in the midst of it. My dad is being moved from hospital to hospital and finding palliative care is impossible. The system is broken and needs to be fixed. MND is a diagnosis that needs its own system to help understand the impact." (MND)

Improvements suggested by consumers

(Aoun et al, 2020)

- More equity: Non-cancer Conditions
- Death and Grief Literacy Consumers/HPs
- Family Carer Support
- Workforce Education and Training
- Grief and Bereavement Support
- Models of Integrated Care

The preferred model of care is one:

- Grounded in community upskilling/ knowledge.
- Supported consistently by generalist palliative care.
- With specialist palliative care providing ‘episodic’ care as particular needs arise during the illness journey.

Public Health Approach to Palliative and End of Life Care

ENABLERS

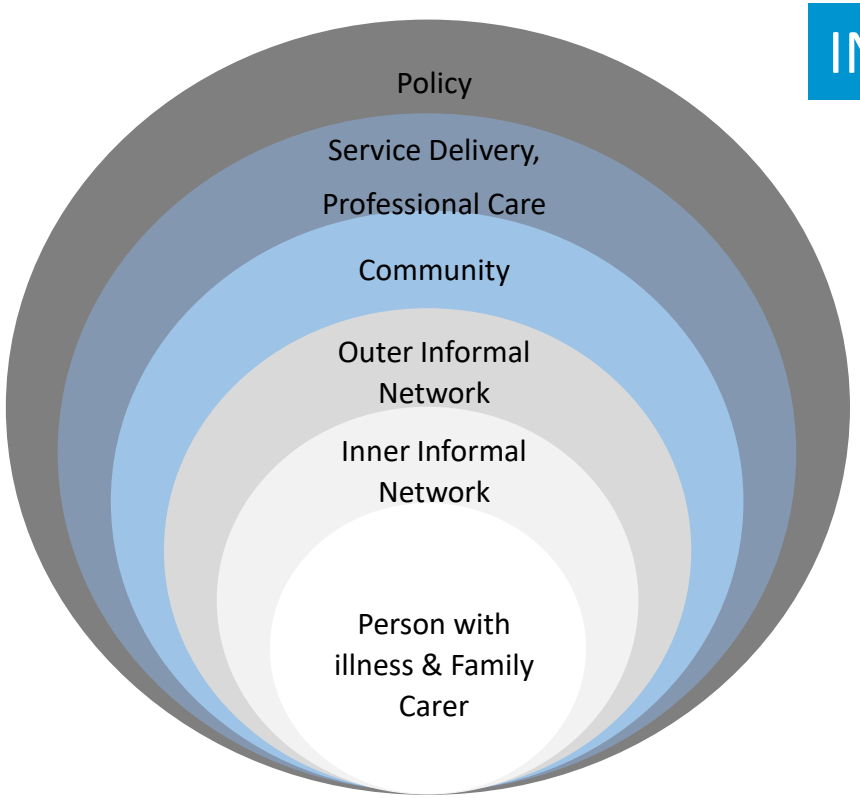
Digital and Assistive technologies:
Telehealth, Equipment

Advance Care Planning

Education & Training Programs

Compassionate Communities
Social Network Enhancement

Not For Profit organisations &
Other NGOs



CIRCLES OF CARE

INTEGRATION OF SERVICES

Disability Sector, NDIS

Aged Care Sector

Specialist Palliative Care

Generalist Palliative Care

Disease specific clinics

Primary Care &
Allied Health Care

healthcare

MDPI

Article

Winners and Losers in Palliative Care Service Delivery: Time for a Public Health Approach to Palliative and End of Life Care

Samar M. Aoun [1,2,*], Robyn Richmond [1], Leanne Jiang [1,2] and Bruce Rumbold [2]

[1] Perron Institute for Neurological and Translational Science, Nedlands, WA 6009, Australia; robyn.richmond@perron.uwa.edu.au (R.R.); leanne.jiang@latrobe.edu.au (L.J.)

[2] Public Health Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, VIC 3086, Australia; b.rumbold@latrobe.edu.au

* Correspondence: samar.aoun@perron.uwa.edu.au

Abstract: Background: Consumer experience of palliative care has been inconsistently and selectively investigated. Methods: People in Western Australia who had experienced a life limiting illness in the past five years were recruited via social media and care organisations (2020) and invited to complete a cross sectional consumer survey on their experiences of the care they received. Results: 353 bereaved carers, current carers and patients responded. The winners, those who received the best quality

perron institute EST. 1982 for neurological and translational science

Compassionate Communities Australia

THE UNIVERSITY OF WESTERN AUSTRALIA

Why we should use a compassionate communities approach in clinical practice

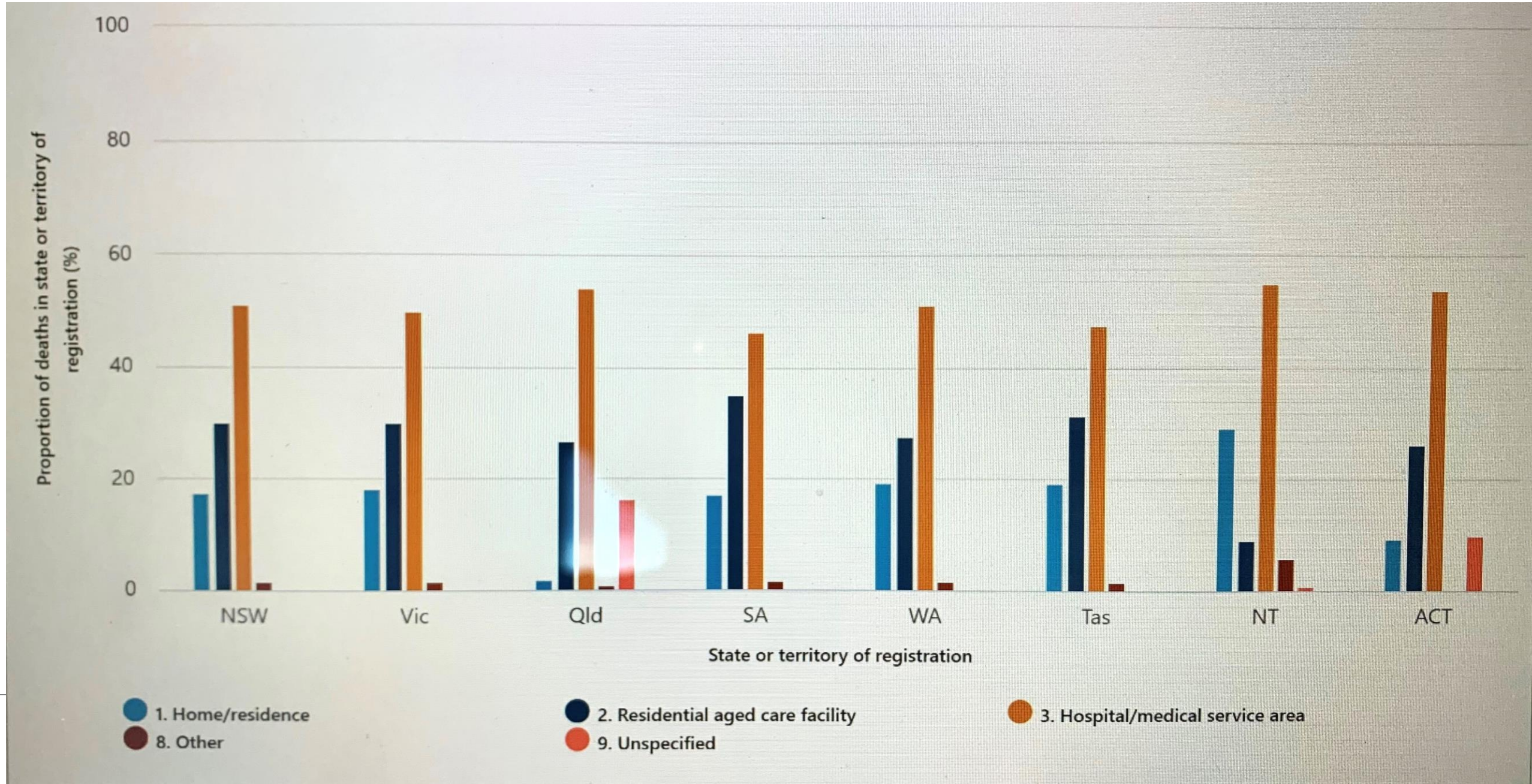
(J. Abel)

Increases enormously the range of interventions we can talk about and use

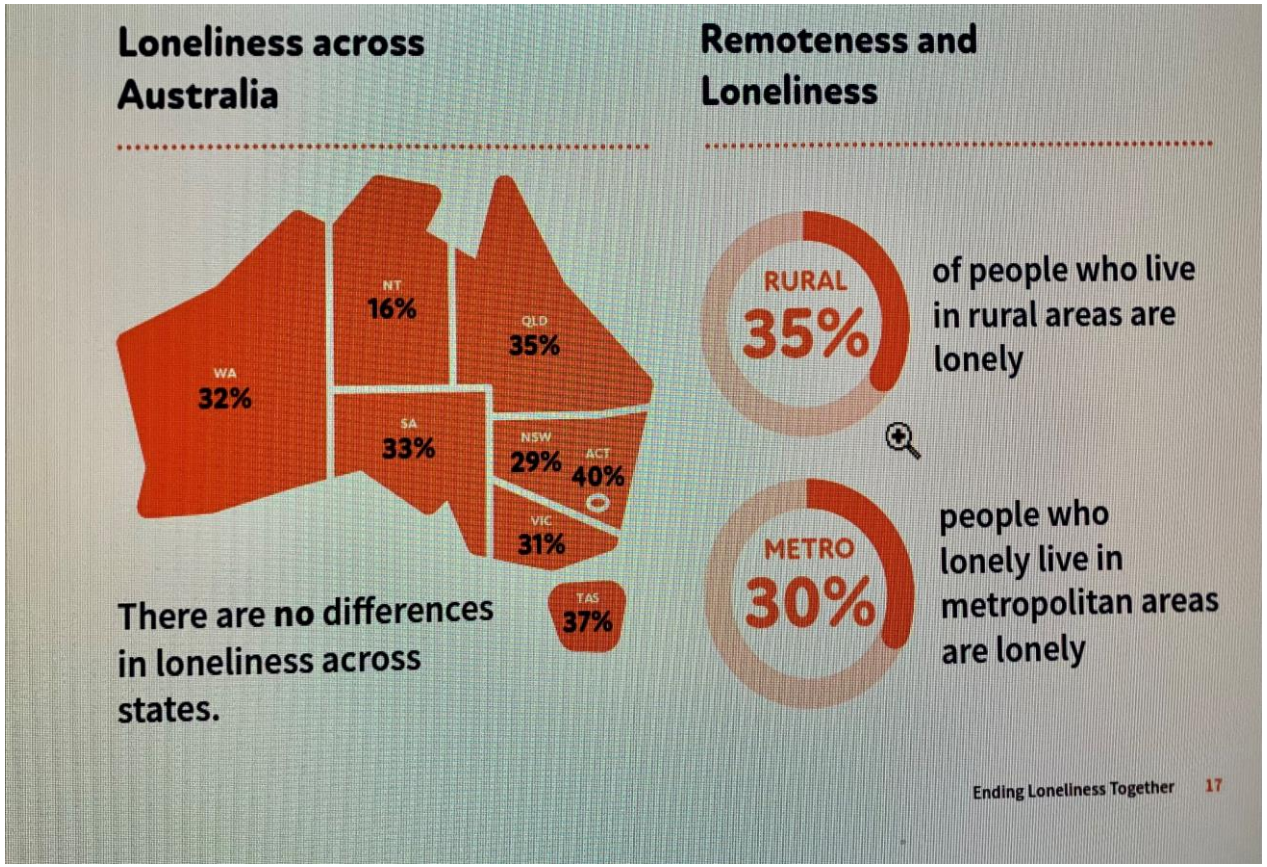
Changes the nature of the clinical consultation to focus on what is most meaningful

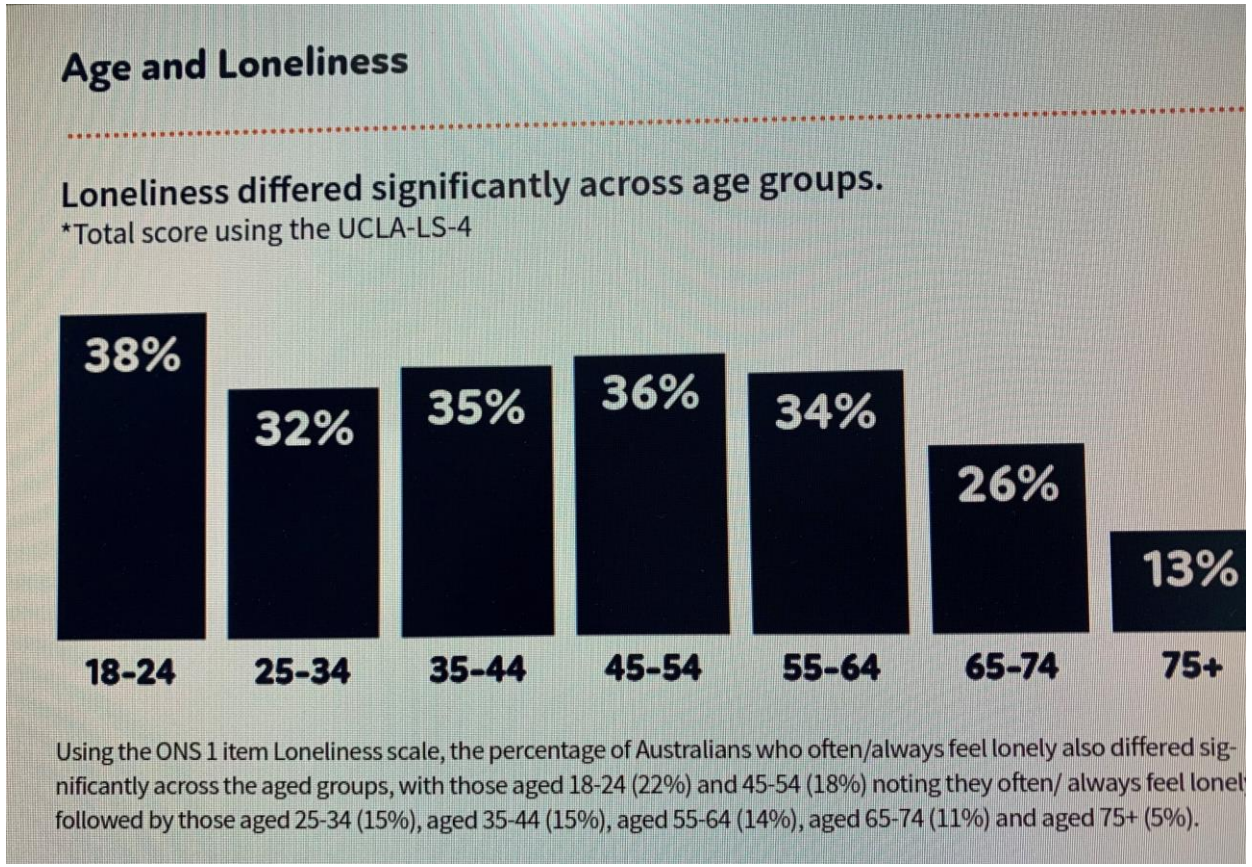
Works directly with patients and caring networks

Hospital deaths-Majority in Australia-Until when?



Ending Loneliness Together (Aug 2023)





Example of a community-led solution: Compassionate Connectors program

- Improved social connectedness (practical and social/emotional)
- Increased support networks
- Reduced social isolation
- Increased community links
- Improved coping with daily activities
- Significant savings from reduced hospital usage:

  - 63% less likely to be admitted to hospital
  - spent 77% less days in hospital
  - 44% less likely to use an emergency department
  - twice as likely to use outpatient services.

SOUTH WEST Compassionate Communities NETWORK

caring, dying and grieving is everyone's business

Solution to the aged care crisis?

- **Encouraging providers to develop innovative care models and research best practices** (23 recommendations in federal Aged Care Taskforce final report).
- A new analysis reveals the extent to which the sector has failed to **investigate more efficient models of care as Australia's population ages** (from Sydney Policy Lab and Impact Economics and Policy).
  - Aged care spent just $464,953 of its $2.9 billion expenditure in 2020-21 on research and development (0.016%).

➢increased integration between aged care facilities and the community.

A freight train heading downhill towards us

(Demographer Bernard Salt- 2024)

- In just six years, the first of Australia's baby boomers will turn 85.
- The number of Australians aged 85 and over will be growing at 60,000 per year by the end of the decade, up from about 20,000 in 2024.
- A 2020 KPMG report found that by 2050, national demand for palliative care services will increase by 200%.

➢Hopeful a "calamity" can be avoided by a change in approach.

WA Health Strategic Commissioning Framework Commissioning REFORM

- Establishing a consistent commissioning framework will enable WA Health to:

Transition from purchasing hospital services to purchasing prevention and community-based health services, by optimising analysis and pricing mechanisms to incentivise HSP's to embed outcome-based commissioning.

Doing BY the Community

Doing **To**, **For**, **With** or **By** Community

TOWN TEAM MOVEMENT

It's the government's responsibility
Encourages passive consumers

Shared responsibilities
Encourages active citizens

Doing TO the community

Actions done by a government to a community based on what it thinks the community needs.

Whilst this approach can be quicker and more easily controlled, it may deliver things that the community may not want or need. It can also generate suspicion and mistrust in the community.

Doing FOR the community

Actions done by a government for a community, informed by feedback or consultation processes.

The actions are more likely to be valued by the community, but this approach can be expensive, lead to consultation fatigue and build dependency in the community.

Doing WITH the community

Collaborative actions done with the active involvement of both government and community members.

It requires a different approach and more time upfront to build trust and relationships, but can create ongoing benefits by developing the capacity of community members to be positive contributors.

Doing BY the community

Actions done by the community that are allowed, encouraged or enabled by government.

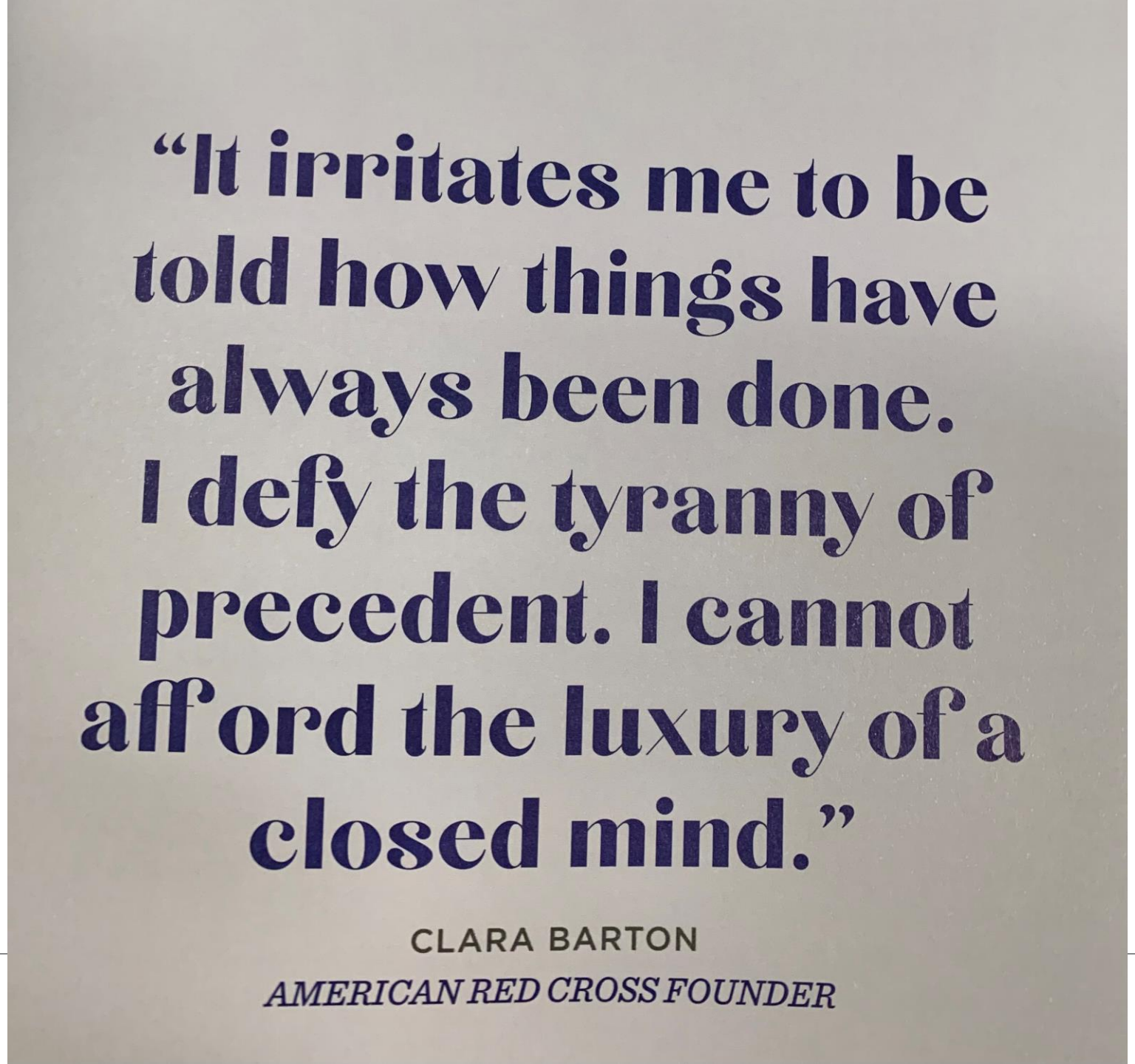
It can create win-win outcomes as governments can focus on other important things and the community can be better connected, organised and empowered. If you want to see it happen, make it easier to do!

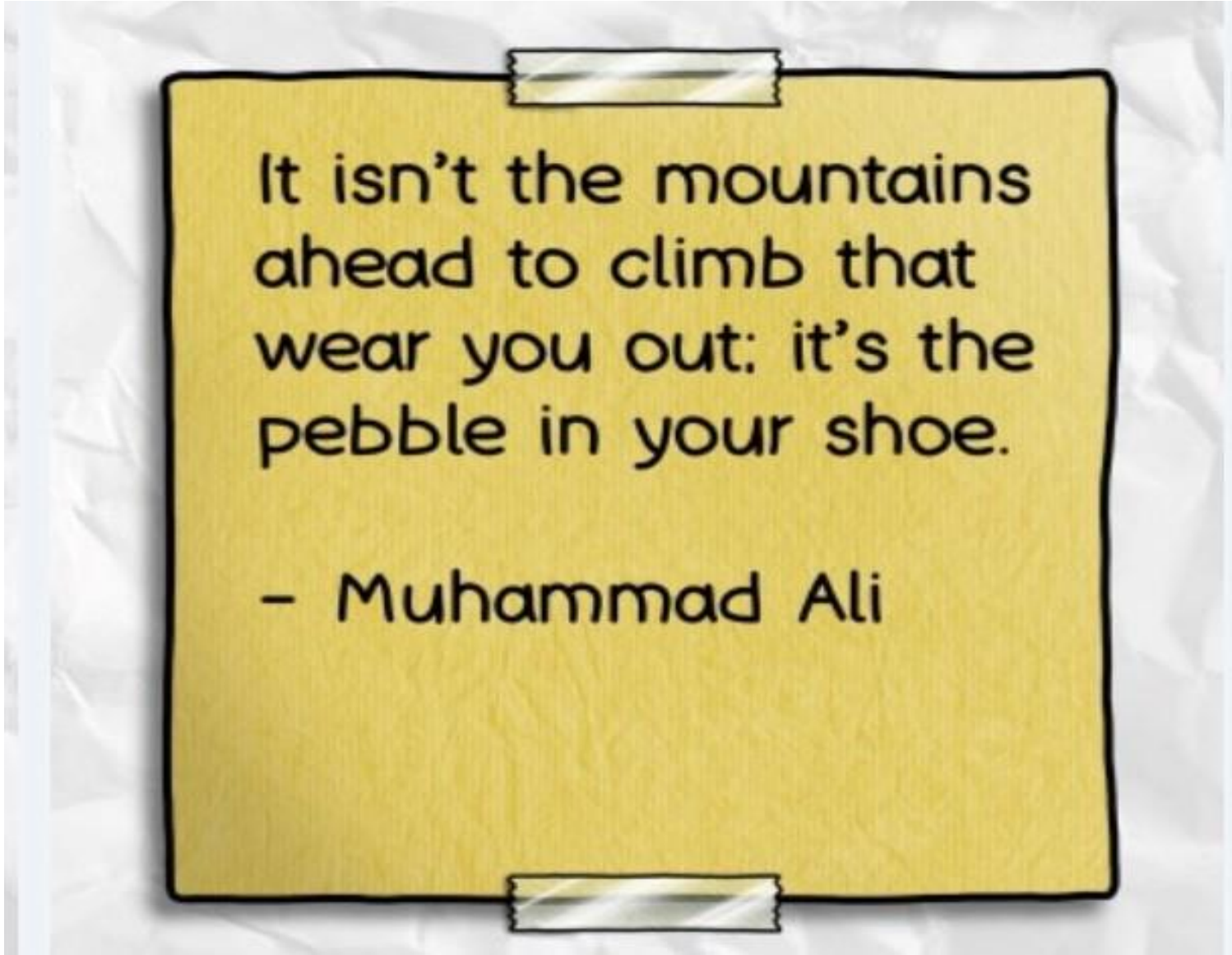
Compassionate Communities Australia

Compassionate Communities Australia

Compassionate Communities Australia is about

- Supporting communities to reclaim and own their central role in caring, dying and grieving.
- Actively promoting the role of community-based caregiving networks and our collective ability to engage with serious illness and death.
- Building the capacity of Compassionate Communities across Australia in their endeavours to enable people to care, die and grieve supported by their community.
- Becoming a hub of knowledge and skills for **community-led solutions** that would lead to social and systems change.


"It irritates me to be told how things have always been done. I defy the tyranny of precedent. I cannot afford the luxury of a closed mind."
CLARA BARTON
AMERICAN RED CROSS FOUNDER


It isn't the mountains ahead to climb that wear you out: it's the pebble in your shoe.
- Muhammad Ali