Inequities of access to healthcare services related to geographic location in rural Australia: Palliative care case study.

Shirley Papavasiliou Professor Stephen Boyle Doctor Mohammadreza Akbari Associate Professor Carmen Reaiche

College of Business, Law and Governance





Welcome

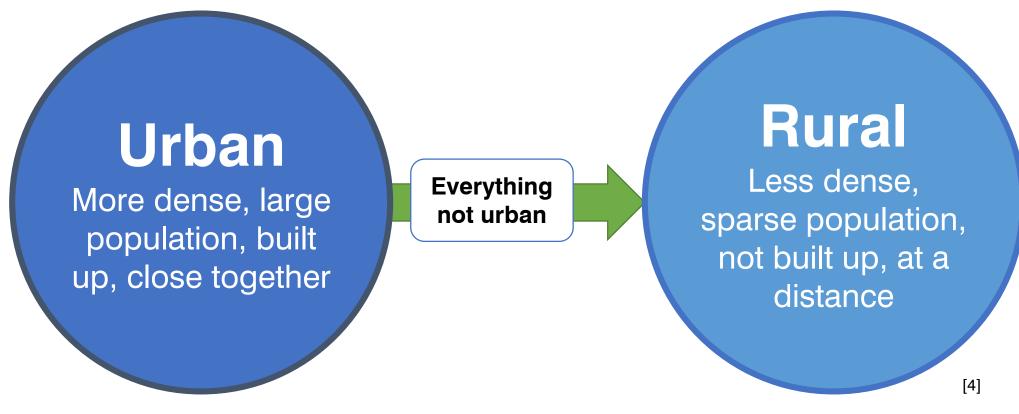
PHYSICIANS VOLUNTEERS NURSES PATIENT SOCIAL **SPIRITUAL** COORDINATORS **WORKERS FAMILY** HOSPICE BEREAVEMENT COORDINATORS **AIDES OTHER** TEAM **MEMBERS** [1]

COMMUNITY PALLIATIVE CARE

.Community or home-based care provided to individuals diagnosed with a life-limiting illness and their families [2,3]



PERI-URBAN LOCATION





BACKGROUND

Counterurbanisation

COVID-19

Peri-urban areas

Palliative care

Urban Sprawl - affordable housing within commute distance

Opportunity to downsize - lifestyle options, remote work/study

Infrastructure/services lagging residential development [5,6]

Changed where people live

Accelerated use of digital health

Delayed diagnosis and treatment [7,8]
Potential for urban-rural health and digital

Expectations of urban services [9,10]
Increasing population with aged and chronic

Increased pressure on hospitals
Psychosocial and physical risks from unmer



Imagine the scenario...

You have found your forever home

You receive an unexpected diagnosis

You wish to remain at home

Everyone is overwhelmed and home help is not available

Now what?





RATIONALE

Every person has the right to access the healthcare services they need, when and where they need them.



RESEARCH AIM

RESEARCH OBJECTIVE

To understand if choice of home location in a peri-urban area influences access to community palliative care services

To create recommendations to fill any identified discrepancies in policies and practices to ensure best practice in community palliative care services is maintained



RESEARCH QUESTION

How does counter-urbanisation influence community palliative care provision in peri-urban Australia?

Required knowledge:

- Clear definition of peri-urban location
- Classification of peri-urban location used in community health service planning
- Effective modes of service delivery in peri-urban locations
- Key influences of access
- Community expectations to aid planning and allocation of resources



PILOT STUDY

To confirm the feasibility of the research method prior to developing the larger study

- Ethnographic approach
- Health care workers from 3 teams, 2 providers (public and private)
- Data collected from observation, informal discussions
- Face-to-face and via Zoom, Teams [13,14]
- Conducted between January 2021 and March 2023



THEMATIC ANALYSIS: KEY FINDINGS

- Demonstrated the existence of a problem space, closely aligned with the literature review
- A one-size-fits-all approach in service delivery was problematic
- Emotional toll and risk to care providers
- Guided the data collection method, participant recruitment and survey questions in the larger study



Identification and conceptualisation of problem space

Qualitative

Researcher lived experience

Pilot -study

Secondary sources - Literature Review Exploration of problem and identification of gaps

Research Design

Exploratory

Mixed Methods

Methodology design Qualitative Interpretive Framework

Survey design
Pretesting Survey questions, feedback from expert sources

Data collection
Online survey distributed via URL link to e-newsletter

Data Analysis

Qualitative - Thematic Analysis

Quantitative - Descriptive Statistics

Analysis and Reporting

RESEARC **H DESIGN**



RESEARCH INSTRUMENT:

Data collection instrument	Method design	Participants	Responses	Data Analysis	Statistical tests
Online questionnaire x 1	Quantitative and Qualitative	People experienced with accessing community	171	Thematic analysis	N/A
Participants in 3 sections: Health professionals Family caregivers Patients	(Mixed methods)	palliative care in Australia		Quantitative analysis	Descriptive analysis: Mean, Std Deviation.



SURVEY PARTICIPANTS BY GROUP AND LOCATION

Classificatio n	Peri- urban <i>n</i>	Rural n	Regional <i>n</i>	Metropolitan <i>n</i>	Total n
Health Professionals	35	5	3	7	50
Family caregivers	57	12	7	15	91
Patient	14	9	4	3	30
Total	106	26	14	25	171



THEMATIC ANALYSIS SURVEY RESULTS

First order codes

- I dislike phone conversations
- Preference for face-to-face consultations
- Not enough time for home visits
- Specialists available by telehealth
- Grief/bereavement support totally lacking
- Total lack of resources including staff, equipment, medication
- Nobody helped me
- We couldn't manage. It was awful needed more hours per day than we could get

Second order Thematic codes

Aggregate dimension 1

Mode of Service

Delivery

Resources

Organisational
characteristics &
system led policy,
culture,
procedures,
priorities, funding



THEMATIC ANALYSIS SURVEY RESULTS

First order codes

- Time and distances to drive and the difficulties
- No staff would visit too far to drive.
- Travel expensive 420kms per week
- Clients living close by receive most attention purely to time spent travelling
- spent travelling
 I have had trouble arranging
 the equipment they need
- Local GP will not visit the house and does not supply the scripts needed
- What we call hospice is a single room in the local hospital

Second order Thematic codes

Aggregate dimension 2

Distance/time in travel

Community

infrastructure

Peri-urban

home location



THEMATIC ANALYSIS SURVEY RESULTS

First order codes

- Moved closer for more services
- Moved to hospital when too hard at home
- We sent her to hospital when her pain got really bad and she died there
- Not able to access service as often or when I want
- Should not be expectation for family to give up everything and take over care
- I had to call ambulance in middle of night to take her to hospital

Second order Thematic codes

Aggregate dimension 3

Influence to person-centred care

Individual perceptions of care

Needs and expectations



AGGREGATED THEME RELATIONSHIPS

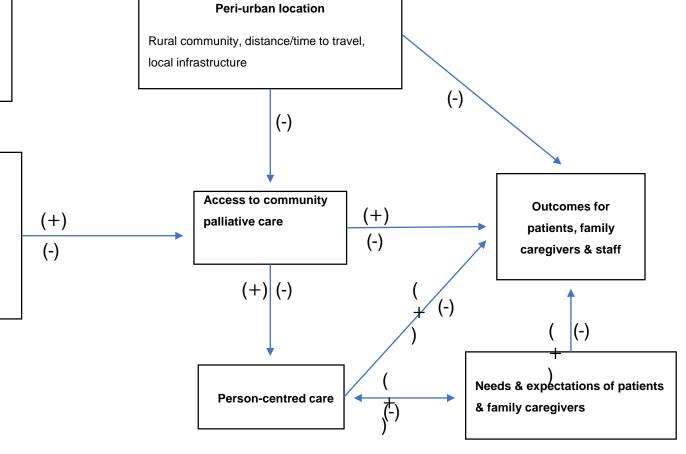
Healthcare system & Organisation

Policies, procedures, culture, funding, support, model of care



Resources

Allocation & availability of staff including specialists, equipment, training, medication, method of service delivery





HEALTH PROFESSIONALS' PERSPECTIVE: BARRIERS TO ACCESS

Key findings

- Home location distance a barrier to resource provision
- Lack of recognition and support from employer

Resulting in:

- Changes in service delivery methods
- Potential for caregiver burnout, stress and relocation of patients
- Lack of satisfaction and increased frustration for clinicians
- Poor outcomes



FAMILY CAREGIVERS' PERSPECTIVE: BARRIERS TO ACCESS

Key findings

- Home location travel influencing decision-making
- Unmet needs and expectations

Resulting in:

- Distress and an emotional toll on the family unit
- Disappointment in the carer experience



PATIENTS' PERSPECTIVE: BARRIERS TO ACCESS

Key findings

- Home location travel influenced decision-making
- Unmet needs and expectations

Resulting in:

Disappointment, relocation and loss of choice



CONTRIBUTION TO PRACTICE

Key research findings have been summarised in a report directed to Dr Robyn Lawrence, the Chief Executive of the Department for Health and Wellbeing, South Australian Health Department:

Recommendations:

- 1 Build flexibility into allocation of resources and methods of service delivery.
- 2 Provide access to equipment.
- 3 Provide 24/7 after-hours telephone support for ongoing education and information.
- 4 Support access to essential medication for end-of-life care.

- 5 Increase funding to support choice of location for end-of-life care
- 6 Target strategies to improve physical access to specialist services in peri-urban areas.
- 7 Increase workforce capacity.
- 8 Support access to bereavement support.
- 9 Promote a supportive working environment.



CONTRIBUTION TO KNOWLEDGE

- Peri-urban locations retain the characteristics of barriers to access known to exist in rural and remote Australia.
- No clear definition or classification of peri-urban location currently exists which adds to the lack of clarity in allocation of appropriate resources and methods of service delivery.
- The social impacts on health and dying from barriers to access are substantial and significant for the increasing numbers of people relocating to peri-urban locations.
- Lack of person-centred care impedes quality of life and increases physical and emotional risks to care providers and recipients.
- The literature and this study both indicate a need for further research into peri-urban locations.



Thankyou for listening

Questions?



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