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28th ANNUAL CONGRESS • 17-19 JUNE 2026
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# Person-centred palliative care: Relational, cultural and measurement factors


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# Disclosures

Nil to disclose

# Acknowledge

Patients and nurses who have been an integral part of my journey

# The Key Question

**Simple and complex: Palliative care is fundamentally relational; how can we measure it?**

**PREMs** – Evaluate healthcare from the patient perspective

**Limitations of PREMs:** Measure communication, respect and service delivery

**Relational Care:** involves nuanced experiences such as trust, emotional presence cultural sensitivity and identity recognition

Not easily reduced to survey items

# Why person-centred care matters

Person-centred palliative care is consistently described as:

- Care that is **relational**, not task-driven
- Care that attends to **identity, meaning, culture, spirituality, and family**
- Care that relies on **trust, communication, and presence**, especially near the end of life
- **Health systems value measurement**, but person-centred care is lived and relational.

International Journal of Nursing Studies 94 (2019) 51–59

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns

# The lived experience of expatriate nurses providing end of life care to Muslim patients in a Muslim country: An integrated review of the literature

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European Journal of Oncology Nursing 48 (2020) 101793

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

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# Telling their story: A qualitative descriptive study of the lived experience of expatriate palliative care nurses in the United Arab Emirates

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Palliative Medicine
Volume 38, Issue 10, December 2024, Pages 1105-1120

https://doi.org/10.1177/02692163241277380

Sage Journals

*Review Article*

# Fostering nurse-patient relationships in palliative care: An integrative review with narrative synthesis

Suzanne Bishaw [1,2], Elisabeth Coyne [1,3], Georgia KB Halkett [2], and Melissa J Bloomer [3,4,5]

# What patients and families say matters

## Value

- Being **seen as a person**
- **Authentic presence**
- Feeling **heard and understood**
- Respect for **culture, faith and family roles**
- Time to build **trusting relationships**

- **Cultural safety and relational care** is prioritised
- **Non-verbal communication and presence** transcends language barriers

Oakley et al. (2019, 2020)

- **Person-centred care** is enacted through **nurse-patient relationships**
- **Trust** is contingent on nurses' **authenticity and consistency**

Bishaw et al. (2024)

# Fundamentally

- **Creating connections**
  - Authenticity, empathy, presence, seeing the person
- **Fostering meaningful engagement**
  - Listening with intent, responding to emotional cues, and silence
- **Negotiating choices**
  - Shared decision-making within power, time, and system constraints
- **Building trust**
  - Trust is action-based, fragile, and central to person-centred care

**Key insight:**
Person-centred care is not an attitude alone; it is enacted moment-by-moment in relationships.

# Cultural context and relational care

**Culture, religion, language, and family structures** shape how care is experienced

- Expatriate nurses often negotiate:
  - Late referral to palliative care
  - Family-led decision-making
  - Different meanings of autonomy and “a good death”

**Crucial point:**
Person-centred care is culturally situated. What feels respectful and compassionate is context-dependent.

- This has direct implications for **how PREMs are designed and interpreted**.

# Enter PREMs: Why measure experience?

PREMs are intended to:

- Capture patient and family experiences of care
- Inform quality improvement
- Centre the patient and family voice

But the key question raised by Virdun et al. (2023) is not ***whether*** to use PREMs, but:

**Do current PREMs measure what actually matters in palliative care?**

# What PREMs currently measure

- 44 PREMs identified for **hospitalised palliative care patients**/families
- 66% of items focus on **person-centred care**
- Strong emphasis on communication, information sharing, respect and compassion
- Many are **long**, complex, and cognitively demanding
- Most are **family-reported**
- Readability often exceeds recommended levels

Virdun et. 2023

# What PREMs miss or under-represent

- Despite strong relational evidence, PREMs often under-capture:
  - **Trust** as a dynamic, relational process
  - **Maintaining role, meaning, and identity**
  - **Being present**, silent, and emotionally available
  - **Cultural and spiritual safety**, especially beyond token items
  - **Power imbalances and negotiation** in decision-making

< 5% of PREM items address **role, meaning, and identity**, despite patients identifying this as central.

## Bureau of Health Information NSW

**Question set for a patient in hospital**

**Preamble: Thinking about experiences of current care in hospital…**

1. Is the room or ward where you spend most of your time as comfortable as you would like?
2. Is the room or ward suitable for a family member or carer to stay?
3. How would you rate the food and drink you are offered in hospital?
4. Do you have enough time to discuss your health or medical problems with the health professionals?
5. Do the health professionals explain things in a way you can understand?
6. If your family or someone close to you needs to talk to a health professional, do they get the opportunity to do so?
7. Are you treated with respect and dignity?
8. Are your cultural, religious and/or spiritual beliefs respected by staff?
9. Are you given enough privacy during your care and treatment?
10. Do you have confidence and trust in the health professionals treating you?
11. If you need help with personal care (e.g. eating and drinking, moving around, going to the bathroom), do staff help you within a reasonable time frame?
12. Do you think the health professionals do everything they can to help manage your pain?
13. Do you think the health professionals do everything they can to help manage other symptoms?
14. Do the health professionals respond to your needs in the evenings and on weekends?

**Thinking about experiences of care over recent weeks…**

15. Do you feel your care has been well coordinated?
16. Have you been involved, as much as you wanted to be, in decisions about your care and treatment?
17. Have the health professionals given you the support you need to help with any worries or fears related to your care and treatment?
18. Have health professionals given you the support you needed to be in the place of your preference?
19. What most needs improving about the care you have received?

## Queensland Health

- Emergency department survey
- Inpatient and at home care survey
- Outpatient department survey
- Paediatric emergency department survey
- Paediatric inpatient and at home care survey
- Paediatric outpatient department survey

## Victoria

### Adult experiences of care in public hospitals - 2016

Adult experiences of care in public hospitals – 2016 is compiled from over 30,000 Victorian Healthcare Experience Survey questionnaires completed by p →

## Nationally

- PCOC
- ASQHC

PCOC
palliative care outcomes collaboration

# The patient's voice

**The practice of person-centred palliative care is often researched from the perspective of the nurse, doctor, other health care provider or family**

**Oakley, 2020; Bishaw, 2024**

**Why? Controversial and challenging**
**But…patients value the opportunity to participate in reseach**

**Bloomer et al. (2018)**

**Maybe this should have direct implications for how PREMs are designed and interpreted.**

ConsideRATE's[17,18] eight questions.

| | |
|---|---|
| Q1 | How would you rate our attention to your physical problems?<br>*things like pain, dry mouth or trouble breathing* |
| Q2 | How would you rate our attention to your feelings?<br>*things like feeling sad, worried or like a burden* |
| Q3 | How would you rate our attention to your surroundings?<br>*things like noise, light or warmth* |
| Q4 | How would you rate our respect for what matters to you?<br>*things like values, preferences about care or important activities* |
| Q5 | How would you rate our communication about your plans?<br>*things like medicines, procedures or place of care* |
| Q6 | How would you rate our attention to your affairs?<br>*things like financial planning and preparing enduring documents* |
| Q7 | How would you rate our attention to what you can expect?<br>*things like illness getting worse or time left to live* |
| Q8 | Are there any other things you want to share? |

**Feasibility and acceptability of the brief patient-reported experience measure consideRATE within the hospital setting for patients with palliative care needs, their families/carers and clinicians**

Claudia Virdun [1 2 3], Elise Button [4 5], Jane L Phillips [3 6], Catherine H Saunders [7 8], Patsy Yates [2], Tim Luckett [3]

Virdun, C., et al. (2025). Feasibility and acceptability of the brief patient-reported experience measure consideRATE within the hospital setting for patients with palliative care needs, their families/carers and clinicians. *Palliative medicine*, *39*(1), 151–162. https://doi.org/10.1177/02692163241291343

# Key contemporary themes across the literature

- **PREMs are feasible but underused** in palliative care.
- **Family-reported experience dominates**, often out of necessity.
- **Psychometric robustness and standardisation remain weak**.
- PREMs must be **brief, flexible, and culturally safe**.

There is a shift from measurement ***for reporting*** to measurement ***for improvement***.

# Implications for practice, education and policy

- **For practice:**
  - Use PREMs as **conversation starters**, not definitive judgments
  - Combine PREMs with qualitative feedback and reflective practice
- **For education:**
  - Teach students how person-centred care is enacted relationally
  - Critically appraise PREMs rather than treating them as neutral tools
- **For policy and quality improvement:**
  - Select PREMs aligned with purpose and population
  - Avoid assuming PREMs fully capture cultural safety or relational care

# Take home message

**If person-centred palliative care is relational, how do we ensure our measurement tools do not silence the very experiences they aim to capture?**

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