Global palliative care experts' preferences for prioritizing care indicators for patients with life-limiting illnesses: Findings from a discrete choice experiment

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BACKGROUND

- Few studies have measured quality of end of life care globally with an emphasis on care indicators that matter most to patients and their family caregivers.
- To address this research gap, a recent study by Gonzalez et al. (2021) estimated preference weights for 13 care indicators related to patients' experience among 1250 caregiver-proxies across 5 countries.
- Whether the preference weights derived from caregiver-proxies by Gonzalez et al. are consistent with preferences of patients in the five countries considered and patients in other countries around the world remains an area for further research.

OBJECTIVE

To quantify palliative care experts' preferences to inform prioritization of core end-of-life (EOL) care domains across countries around the world, and examine how their priorities differ from that of caregiver proxies.

METHODS

Study setting and participants

- Palliative-care experts were eligible to participate in the study if they were either:
  - a health care provider (physician, nurse) involved in provision of palliative care,
  - representatives of a national in-country hospice or
  - An academic/public service employees with knowledge of palliative care.

Study setting and participants (continued):

- Respondents had to be at least 21 years of age and able to communicate in English.
- A convenience sample of at least two experts were invited from countries worldwide. 414 experts from 217 countries were initially identified by an Advisory Board/through regional contacts and sent a link to complete the survey

Survey Development:

- We used a discrete choice experiment (DCE) survey evaluating 13 care indicators during patients' last 6 weeks of life.
- In each of 6 DCE choice questions, respondents were asked to consider three hypothetical healthcare provider groups that were rated on each of four aspects of care using a 5-star rating scale. Respondents indicated which of these groups they would choose to care for a terminally-ill patient.

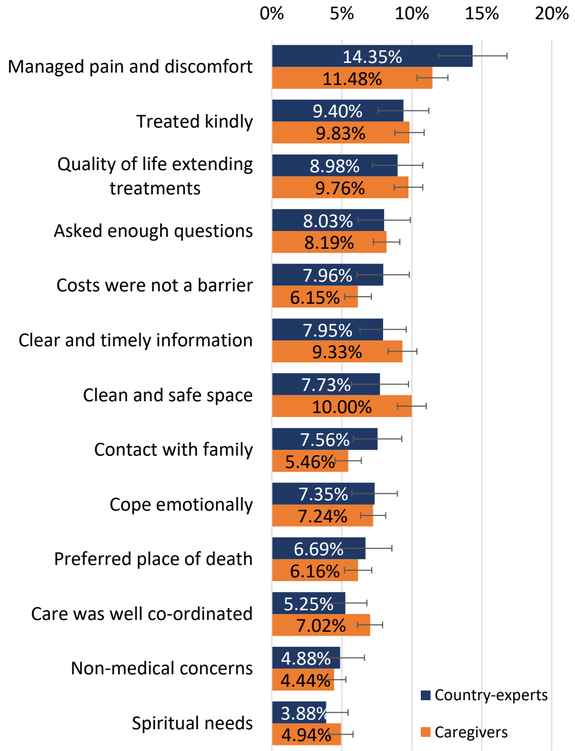
Statistical Analysis:

- Random-parameters logit was used to model choice data and estimate relative importance weights (RI) for the 13 aspects ranging from 0 (least) - 100(most important). Each care indicator was specified as an effects-coded variable.
- RI weights from country expert's responses were compared with the corresponding estimates derived from caregiver-proxies by Gonzalez et al. (2021)

RESULTS

- 193 experts in 120 countries completed the survey. All preference weights were logically ordered and exhibited diminishing value with improvements in quality ratings.
- **Relative importance of care indicators:** RI weights indicated that access to an appropriate level of pain control was the most important (RI=14.4) aspect of care for experts, followed by providing sympathetic care (RI=9.4) and access to life-extending treatments (RI=9.0). Supporting patients' spiritual/cultural needs (RI=3.9) and other nonmedical concerns (RI=4.9) were least important.

Figure 1: Relative Attribute Importance Weights (Country experts vs. Caregivers)



- **Comparison of RI weights from country-experts and caregiver-proxies:** Differences between RI weights from country-experts and caregiver-proxies were small (less than 5 percentage points) and not significantly different from one another for any of the care indicators .

CONCLUSIONS

- Diminishing marginal increases in preference weights suggest that larger improvements in the quality of EOL care can be achieved by moving from poor to moderate quality ratings, rather than moderate to excellent quality ratings.
- Consistent with preference weights derived from caregiver proxies as reported in Gonzalez et al. (2021), we find that preference weights derived from country-experts and caregiver-proxies, indicate that broad improvements across aspects of care may be more beneficial than focused investments.
- Beyond prioritizing pain management, our results indicate that providing sympathetic care and access to life-extending treatments are highly, and almost equally, important aspects of care to experts.

REFERENCES

Sepulveda, J. M. G., Baid, D., Johnson, F. R., & Finkelstein, E. A. (2022). What is a good death? A choice experiment on care indicators for patients at end of life. *Journal of pain and symptom management*, *63*(4), 457-467.

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