

Working with communities: Helping you to live well as long as you can (promoting death literacy in ethnic minority communities)

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BACKGROUND

- Under-served and under-studied population groups are disproportionately affected by social inequalities, and do not habitually access palliative care services.
- Individuals in these groups do not have access to palliative information and services that meet their needs, contributing to and reflecting low levels of health and death literacy (i.e., the language, knowledge, and practical skills needed to make active end-of-life choices).

OBJECTIVES

To evaluate

- if working with community leaders with four targeted ethnic minority communities to design and deliver materials via culturally appropriate, accessible language and modes of delivery is associated with an increase in death literacy within their communities; and
- the experiences and observations of community leaders regarding their involvement and perceived outcomes.

DESIGN Mixed methods, including quantitative pre-post evaluation using the Death Literacy Index (DLI) and qualitative focus groups with ethnic minority community leaders.

RESULTS

Quantitative DLI survey (see Table)

DLI data from each community group at pre (T1) and 6-months post intervention study (T2) assess the effectiveness of community-led activities in promoting discussion and knowledge regarding death, dying, and palliative care, accounting for local conditions and cultural factors.

Matched-pairs DLI scores are presented across four knowledge domains (Community, Practical, Factual, and Experiential) for four cultural groups at two time points (T1 and T2). Sample sizes varied across the domains and cultural groups (Filipino: 21–22, German: 24–29, Italian: 16–19, Vietnamese: 27–30), providing an adequate representation for cross-cultural comparisons.

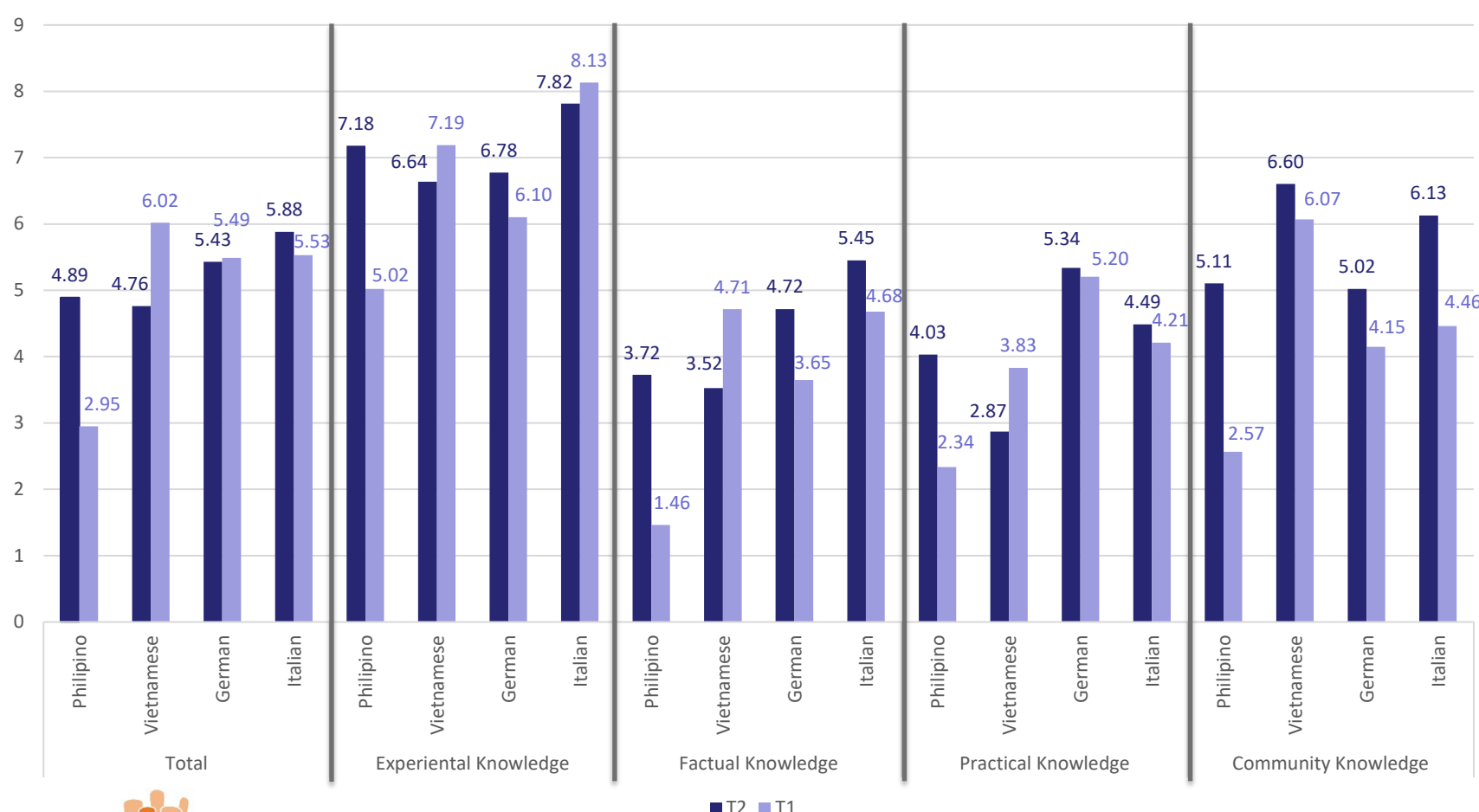
Qualitative focus groups

- Findings highlighted complexities of researching sensitive and taboo topics with ethnic minority groups.
- Community leaders from each cultural group were highly motivated to increase awareness of and access to palliative care resources in their communities. They facilitated multiple death literacy intervention activities, including seminars, workshops, radio segments, podcasts, movies, and social media and web content.
- Leaders shared insights regarding cultural and linguistic barriers to participation in this research, including translating the DLI tool into various community languages.



Pictured: Staff and community leaders at Multicultural Communities Council of South Australia, and researchers from the University of Adelaide.

T1 and T2 DLI Scores by Cultural Group



CONCLUSION

- Overall, the data underscores the need for culturally tailored education to address knowledge gaps and ensure a well-rounded understanding of death literacy across all groups.
- Future collaborative research with other under-served populations regarding discussions about, promotion of, and conduct of research about death literacy is required.



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