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SUBMISSION TO THE ROYAL COMMISSION

Questions about you

Submitted By: Sabine Wardle
Email: [redacted]
Phone Number: [redacted]
State: NSW

Do you live in a remote, rural or regional area? : Regional area
Previous submission:
This submission is on behalf of : Other
Name of service provider or other person : older culturally and linguistically diverse (minority and burgeoning communities) population residing inregional locations of Australia

About your submission

Which of the Royal Commission's terms of reference is your submission about?: Challenges and opportunities to deliver accessible, affordable and high quality aged care services to those who wish to remain living at home and/or those living in remote, rural and regional Australia;Challenges and how to ensure high quality and safe end of life care;Examples of good practice and innovative models in delivering aged care services
What, if any, specific concern/s does your submission relate to? Dignity;Nutrition (including malnourishment);End of life care
What type of aged care services does your submission address? Care in an aged care home (nursing home);Other
Other service addressed : End of life care in palliative care settings of resdiential aged care facilities

Your Submission

What would you like to tell the Royal Commission?

. What are the challenges and how can the provider, or Australia generally, improve the quality and safety of **end of life care** and what are your primary concerns?

Primary Concerns:

- Unequitable palliative care services for the older culturally and linguistically diverse (CALD) population residing in regional locations;
- language barriers in providing information on palliative care and related services to CALD population groups;
- Lack of access to palliative care services by older CALD population due to language communication barriers;
- Inconsistent understanding and confusion around the concept of palliative care among older CALD population and their families;
- Non-availability of culturally appropriate food crucial to end-of-life care needs of CALD population groups in aged care services;
- Insufficient data on adverse satisfaction rates in order to capture the range of cultural and religious needs experiences of CALD service users of residential aged care services;
- Poor availability of the interpreters in languages spoken by burgeoning and minority population groups;
- Lack of pastoral care which goes beyond the current model founded in the Christian faith in the majority of residential aged care facilities;

Recommendations:

- Considering the ageing population and associated increase in the number of patients requiring palliative care, it is

vital to explore the public's understanding of this concept. Modification of public perceptions and understanding of palliative care is central to improving knowledge of and access to services, empowering individuals and involving communities in palliative care and end-of-life care;

- It is recognised that public attitudes to palliative care and end-of-life care are complex and equivocal and that efforts to improve public awareness need to take account of cultural characteristics, demographic factor ; ethnicity, social structure, and religious affiliation; To achieve more consistent understanding on the concept of palliative care and share what palliative care offers and aims to deliver for people needing services at end of life and their families, there needs to be a more consistent definition of the concept at a state and national level which is compatible with the international understanding of the concept. To avoid any further confusion on the concept of palliative care, especially for CALD population, the state health system first needs to accept a simplified definition of the concept of palliative care. Such definition needs to rule out the core confusion about the use of terms, which seems to be whether it is only Specialist Palliative Care Services that provide Palliative Care, or whether all services meeting the needs of a person with a life-limiting illness can be considered as palliative care. Once this confusion is resolved by a unanimous understanding of the concept of palliative care, the information needs to be shared with the community in English as well as in languages targeted at CALD minority and burgeoning population groups which they can understand;
- A clear commitment to and articulation of the purpose of the service provided at regional Residential Aged Care Facilities as one that provides culturally appropriate and congruent support beyond the clinical assessment and treatment essential for the pain management and clinical care;
- Improvement in sharing appropriate information on palliative care and related services by making use of the interpreters with a shorter turn-around time to address the language barrier for CALD population groups residing in regional locations available in regional locations;

- Transformation of the system of care to one that is culturally appropriate and integrated with the existing bio-medical treatment approach by prioritising and supporting consumer self-determination and inclusion in care process through, for example the creation for deep listening and the facilitation of religious support which goes beyond the existing model of pastoral care founded on Christian values and faith;
- Provision of a prayer room within every residential aged care facility to facilitate multifaith areas of worship where one can pray to practice their faith while a family member is on the deathbed.
- CALD population groups to be treated on an equitable platform by being inclusive in palliative care service provision. This can be done by providing information on palliative care services in various languages targeting the CALD burgeoning and minority population groups in each regional location;
- Residential aged care services, particularly in regional locations need to recognise the central role that pure vegetarian food plays at end of life for some community members, their culture and ensure proper consultation with CALD community groups to include meal staples which are culturally acceptable.
- The professional care staff providing direct or indirect care at residential aged care facilities (RACFs) to commence their professional care experience with knowledge and skills grounded in culturally appropriate care. Educational institutions responsible for the training of professional care staff (nurses and personal care assistants) need to include as part of the palliative care component, significant attention to :
    - The principles of culturally appropriate care including the importance of human connection and the centrality of relationships in spite of the language barriers, through attention to the skills of deep listening and demonstrating empathy;
    - Considering a cultural perspective on the person-centered care by including person as whole that is inclusive of the family unit as a person's cultural identity and not considering a person as a standalone individual;
    - The current state, national and international policies and guidelines mandating culturally appropriate principles as the driving force of palliative care reform.
    - The current state and national policies to raise the requirements of minimum qualifications required to start working as personal care assistant at residential aged care facilities. To be eligible to work as a personal care assistant in residential aged care facilities, the minimum qualifications required need to be higher than Certificate III or Certificate IV level training.
    - A periodic review of the cultural competency training curricula for the professional care staff working at RACFs, to ensure the inclusion of the learning content on state/nationwide burgeoning and minority population groups and their cultural and religious needs at end of life.
- Commitment to the continuing development of culturally competent skills and knowledge for all professional care staff providing direct and indirect palliative care in a RACF setting, through support for attendance at cultural competency education and related professional development opportunities.

· Strengthening opportunities for further practitioner research on palliative care for CALD population groups, with a focus on burgeoning and minority population groups in regional locations;

· The integration of Palliative care programs into public health care policies, with ongoing evaluation of coverage, equity, and accessibility while developing comprehensive programs;

- Organisationally, the appointment of an expert in palliative care as a regional coordinator to bring cohesion to palliative care services in regional locations.

- At a community level, the appointment of bilingual community-based navigators to raise awareness of palliative care services and address concerns of CALD community members about the Australian health system and to improve accessibility and palliative care service usage at a community grassroots level.
- An audit of palliative care services at RACFs to determine the extent to which residential aged care services provide culturally appropriate food that is needed by CALD population groups in the local area.

The significant role of social workers in palliative care settings at residential aged care facilities

Taking the lead of the consumers, the palliative care setting needs to have a two-pronged purpose. It is a purpose that addresses immediate physical symptoms for example pain reduction as well as embeds a culturally appropriate approach in which consumers actively participate in their care through careful listening and acknowledgment of their cultural, religious and spiritual needs at end of life. In this way, the palliative care experience provides not only relief from distressing physical symptoms but also a foundation of security and healing from which to embark on life after death journey. It is a system of care that encompasses an understanding of both clinical, cultural and spiritual experience. In keeping with the culture care framework, I recommend that consumers experience should be the prominent voice in determining the purpose of palliative care. Thus, the following recommendations have been crafted.

The significant alignment between psychosocial support for those CALD residents and their families in palliative care setting place the need to follow the psycho-social model in a prominent position to actualise the RACFs potential to support culturally appropriate palliative care as an outcome for consumers from various CALD backgrounds requiring a level of care which align with their cultural and religious values. There is specific and practical importance of the cultural, religious and spiritual support to enhance well-being of CALD population groups residing in regional locations. There is a need for a dedicated position for a professional who is skilled in advocating for cultural, religious and spiritual support to these CALD population groups' needs. I suggest that social worker is one profession that can take a leadership role in reform that is already mandated by the existing policy at the state, national and international levels of providing psychosocial wellbeing as a part of palliative care provision. This is through their capacity as practitioner role models, advocates, educators, and researchers.

Supporting material provided:
Royal commission_ Recommendations Pdf.pdf

Can this submission be made public I agree to my submission being made public under my name