Steps towards equitable care: creating web pages to highlight diversity for Australia's aged care and end of life care workforce

Georgia Rowley[A,*], Jennifer Tieman[B] and Kelly Jones[B]

For full list of author affiliations and
declarations see end of paper

*Correspondence to:
Georgia Rowley
College of Medicine and Public Health,
Flinders University, Adelaide, SA 5042,
Australia
Email: georgia.rowley@flinders.edu.au

ABSTRACT

Background. The impact of Australia's diverse population on the aged care sector has been acknowledged, with the Royal Commission into Aged Care Quality and Safety findings providing evidence of the importance of population diversity for consumer-directed and person-centred care. Similarly, the Aged Care Quality Standards and Aged Care Diversity Framework acknowledge the diversity of Australia's ageing population and potential implications for equitable access to care and the ensuing importance of culturally appropriate and culturally safe care. This paper reports on the development of informational web pages and utilisation findings for use by the aged care workforce supporting diverse populations. **Methods.** Content was created for the End of Life Directions for Aged Care website, based on rapid review findings relating to barriers and limitations for people accessing equitable care in the aged care and palliative care sectors. **Results.** Website pages containing embedded links to useful content and resources for health professionals and care workers who work with older diverse adults are shown to be well received among users. **Conclusions.** As Australia's future population will age with increasing diversity markers, with implications for aged care and palliative care service provision, workforce access to up-to-date, relevant and evidence-informed information on best practice non-clinical support for individuals from diverse backgrounds towards the end of life promotes a person-centred care approach. Access data shows that the website content is being utilised increasingly over time and suggests that it is filling a gap in comprehensive and accessible end of life resources that have been missing from the Australian aged care and palliative care workforce.

Keywords: aged care, consumer-directed care, diversity, healthcare disparities, health services, palliative care, person-centred care.

Introduction

Internationally, the ageing population challenges governments and communities to consider the structures and systems that support older people as they age. Australia's ageing population comprises 3.8 million people aged 65 years and above, representing 15% of the total population (Australian Institute of Health and Welfare AIHW 2017). Older people are diverse in their culture and language, gender and sexuality, socio-economic background, religion and spirituality, geographic location, and life experiences. Australia's policy, system, and societal responses to ageing acknowledges a human right to person-centred care reflecting the person's identity. Australia's legislative settings acknowledge human diversity. This is reflected in expectations for the provision of aged and end of life care that address the unique requirements of the individual. The Aged Care Act 1997 defines ten diverse groups where diversity consideration may be required: Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse (CALD) backgrounds, people who live in rural or remote areas, people who are financially or socially disadvantaged, veterans, people who are homeless or at risk of becoming homeless, care leavers, and the lesbian, gay, bisexual, transgender, and intersex (LGBTI) community (Australian Government 1997). Carers and those with spiritual or faith beliefs also have unique

considerations concerning aged care and palliative care, with potential implications for wellbeing.

While providing equitable access and support to all older Australians is a policy goal, there are currently gaps in access and provision of appropriate aged care and end of life care services when it comes to providing culturally appropriate and safe care (Commonwealth of Australia 2020). Older people with diverse needs often have challenging experiences accessing and receiving optimum end of life care or experience disparities in the quality and safety of health care due to socio-cultural factors (Chauhan *et al*. 2020). Differing levels of disadvantage may apply across different groups and to different levels across individuals, following an intersectional approach. For example, people who experience social disadvantage or are at risk of homelessness face barriers that can limit their ability to access and maintain access to various services (Shulman *et al*. 2018), including aged and end of life care. There is little understanding in Australia of the unique issues faced by LGBTI people in end of life care and advance care planning, coupled with a lack of recognition of sexual or gender identity and lack of knowledge around legal rights (Griebling 2016; Valenti *et al*. 2020).

Similarly, rural and remote Australians face access issues and barriers to aged care and palliative care, primarily due to geographic isolation (Aged & Community Services Australia (ACSA) 2013). Spirituality or faith beliefs often influence decision making preferences and impact end of life care (O'Brien *et al*. 2013). Earlier life experiences among veterans, care leavers, and carers can impact interactions with aged and end of life care and inform preferences in older age.

The Royal Commission into Aged Care Quality and Safety has highlighted diversity as critical to the aged care system and providers and argues that diversity should be seen as 'business as usual' for aged care (Commonwealth of Australia 2020). Quality care requires that the dignity and human rights of older Australian's are embraced. The characteristics and life experiences that influence care and well-being should be considered (Aged Care Quality and Safety Commission (ACQSC) 2019). These issues are highlighted in the Aged Care Diversity Framework (Department of Health 2017) and the Aged Care Quality Standards (Aged Care Quality and Safety Commission (ACQSC) 2019). Older Australians with different social, cultural, linguistic, religious, spiritual, psychological, medical and care needs and life experiences should be able to access respectful, appropriate, fair, inclusive and sensitive, culturally safe, and trauma-informed care. The principles of the diversity framework also need to be applied to an end of life context, where equitable care is paramount to the health and quality of life of older adults, families and carers. Person-centred care or consumer-directed care for older Australians means being supported to live in accordance with their preferences, needs, and goals (including culture, language, sexuality, faith and identity) towards the end of life (Johnston *et al*. 2015; Bulamu *et al*. 2017) and having greater choice and control of their care.

Online information is an important source of guidance for the health workforce (Lenaerts *et al*. 2020). To be efficient, online health information and resources must be accessible, trustworthy, sustainable, and relevant to users' information needs (Tieman 2016). End of Life Directions for Aged Care (ELDAC) is a project funded by the Australian Government Department of Health to support quality care for older Australians at the end of life by connecting aged care staff with palliative care, advance care planning information, resources, and services. Resources are available to build knowledge and guide care provision at the individual, team, and organisational level (www.eldac.com.au). Enabling access to trustworthy resources, developing specific resources, and hosting information relevant to the aged care workforce and services is an essential precursor to knowledge uptake and knowledge application within aged care (Ellen *et al*. 2017). This paper concerns the development of web pages to host tailored content regarding population diversity and aged care and end of life care considerations for the ELDAC website (www.eldac.com.au).

The aim of this project was to create web pages with relevant information on population diversity and implications for end of life care. By creating diversity specific web pages, organisations, providers, services and staff can build their knowledge, develop local guidance, or support broader service and organisational initiatives around diversity, equity, and access. Easy access to relevant information and tailored approaches for those with diverse requirements is fundamental to care planning and delivery for individuals at the end of life. It promotes engagement with care Standards by supporting person-centred care (Aged Care Quality and Safety Commission (ACQSC) 2019).

Methods

The specific groups of older Australians identified for the development of information on the ELDAC website were based on the Aged Care Act 1997 recommendations: people from Aboriginal and Torres Strait Islander communities, people from CALD backgrounds, people living in rural or remote areas, financially or socially disadvantaged individuals, veterans, people who are homeless, care leavers, and the LGBTI community. ELDAC recognised carers and those with diverse spirituality and faith beliefs as additional groups for tailored information.

The web page content was informed by individualised rapid reviews of existing literature and resources, with searches focusing on the intersection between 'diversity', 'aged care', 'palliative care' and 'advance care planning'. Peer-reviewed journal articles, grey literature, key government and organisational websites, publications and reports, and other relevant sources, including the Aged Care Diversity Framework and the Aged Care Quality Standards, were accessed to reflect the focus of the national project.

Emphasis was on information and resources specific to the Australian aged care and end of life setting. Existing literature was collated and synthesised into short summaries, highlighting information and resources relevant to aged care and end of life care. Based on these rapid reviews, synthesised web page content was written and structured under thematic headings relating to aged care, end of life, palliative care and advance care planning. Priority was placed on including useful links to relevant external content concerning aged care, palliative care, and advance care planning.

The language, structure and presentation of web pages were tailored to suit the existing tone of the website and anticipated literacy of website users. The web page content was written (GR) and edited (KJ) by the authors and sent to external reviewers with specific subject matter expertise, strengthening the pages through a peer-review process. The web pages were created and published on the ELDAC website in a staggered manner between July 2019 and February 2020, subject to their completion and review. A landing page provided introductory content, introduced the concept of diversity among Australia's ageing population and contextualised the content within aged care and end of life settings. Links to the diversity pages were also included within other sections of the ELDAC website to ensure an integrated approach to knowledge provision.

A multi-channel, targeted promotional campaign of the diversity web pages was conducted between 20 January and 28 February 2020. Various content relating to the web pages featured in monthly ELDAC newsletters and social media channels (including Facebook, Twitter, and LinkedIn)

during 2019 and 2020. The content was promoted in external newsletters, various primary health networks, and other Australian aged and palliative care sector newsletters. Several Facebook advertising campaigns relating to the web pages ran between January and April 2020. Data capture of web metrics through Google Analytics was set up to monitor patterns of use as an indicator of user and sector engagement with the web content (Crutzen *et al.* 2013).

Ethics approval

Ethics approval was not required for this study.

Results

Website metrics are presented in Table 1 and relate to a one year period (August 2019 to August 2020). Google Analytics show that the diversity web pages resulted in 5283 new website users during the period compared with 7165 overall ELDAC users. Google defines a user as a visitor who has initiated a web session. In some cases, users were greater than sessions due to a custom report filter being applied to only include this particular group of pages. Data suggests that this new content has attracted a broader audience to the ELDAC website than previously expected. Users engaged in 7009 separate sessions across all pages between 2019 and 2020 and visited an average of 3.26 pages per session. This suggests that users are simultaneously interested in multiple population group web pages. The web pages have attracted

Table 1. Website user data/metrics for ELDAC population diversity webpages: August 2019–August 2020.

Page title	Users	New users	Sessions	Page views	Pages/ Session	Number of sessions per user	Date of release
Total	7165	5283	7009	22 815			
Population Diversity – landing page	1873	1290	1954	7019	3.56	1.05	02/07/19
Culturally and Linguistically Diverse	1426	1138	1470	3849	2.62	1.03	08/07/19
Aboriginal and Torres Strait Islander Peoples	1199	910	1163	3389	2.9	0.97	08/07/19
Lesbian, Gay, Bisexual, Transgender and Intersex	789	605	766	2212	2.89	0.97	08/07/19
Care Leavers	231	132	192	987	5.14	0.83	18/10/19
Carers	96	29	43	496	11.53	0.45	24/10/19
Spirituality and Faith	285	180	217	912	4.2	0.76	27/11/19
Veterans	196	112	164	818	4.99	0.84	02/12/19
Financially or Socially Disadvantaged	929	867	1000	2474	2.47	1.08	12/12/19
Rural and Remote	88	17	29	379	13.07	0.33	24/02/20
Homelessness	53	3	11	280	25.45	0.21	24/02/20

a total of 22 815 page views over the reporting period, with the most page views naturally landing on the introductory page. The CALD web page has attracted the second highest views over the reporting period (3849), followed by the Aboriginal and Torres Strait Islander page with 3389 views. It should be noted that these two population pages were the first that were uploaded into the website in 2019 and therefore had a longer period in which they could be accessed. The page with the third largest views was the financially or socially disadvantaged web page (2474), followed by the LGBTI web page (2212 views). Web pages with content regarding spirituality and faith, care leavers, veterans, carers, rural and remote, and homelessness had comparatively fewer page views. These analytics suggest that the aged care workforce is seeking specific information on supporting the people they care for to enable person-centred and quality care. Content related to people from CALD backgrounds and Aboriginal and Torres Strait Islander peoples may be more popular as they attract more mainstream media attention than other groups. Pages with fewer views were among the later web pages to be uploaded to the website, which has likely impacted on respective user metrics for these particular pages within this time frame.

Various content relating to the diversity web pages featured in numerous monthly ELDAC newsletters in 2019 and 2020. They attracted relatively high open rates (30–32.7% of 3500 recipients), with click rates between 8.5 and 12%. Blogs and articles based on diversity content in January and February 2020 generated over one thousand reads per post. These measures generated additional support and uptake of the online information and resulted in new users to the website, justifying the need for this content on the ELDAC website. Web metrics are primarily an indication of reach and uptake but can provide useful information on the effectiveness of promotion and topics of most interest. However, web metrics cannot provide detailed information on subsequent knowledge or practice change.

Discussion

Specific population characteristics can increase the risk of discrimination and vulnerability. Individuals who identify with multiple forms of minority group status are among the most vulnerable and often experience cumulative disadvantage over the life-course and/or end of life. An appreciation that all older Australians age and die within a unique cultural, linguistic, historical, social, religious, gendered and sexual context is fundamental to a person-centred approach to care. Being marginalised or identifying with diverse identities often represents a further barrier to receiving appropriate care and support towards the end of life (Gardner *et al.* 2018). Indeed, the intersection of information regarding aged care and palliative care is important, given the Australian Royal Commission into Aged Care has called for

increased access to and provision of palliative care within aged care settings, including residential and home care. End of life care is a public health care responsibility, extending beyond specialist palliative care to provide equitable palliative care across the whole system and public health workforce. Comprehensive provision of palliative care within aged care settings should be facilitated for all older people as it normalises the provision of culturally appropriate and trauma-informed care within these settings. A person's unique social and cultural background and identity can influence their thoughts, preferences and responses to ageing, care and support, advance care planning, death and dying, and bereavement.

Providing quality appraised and trustworthy information and resources via online platforms is an essential component of knowledge translation. Targeted online information and resources like the ELDAC web pages are necessary for program-based change to support aged care staff to care for all Australians, regardless of their background and life experiences.

The provision of educational materials via online platforms represents one potential strategy to upskill the aged care workforce. Such approaches can contribute to continuing professional development among staff, which may impact practice. The ELDAC webpages represent an introduction to considerations for diversity in aged care and palliative care settings, which has been missing from Australian specific aged care and palliative care resources for workers in aged care. The web pages connect the aged care workforce with different forms of information, tools and resources to enact change at the individual and organisational level.

The Australian aged care sector has moved to a person-centred and consumer-directed care approach (Bulamu *et al.* 2017). Consumer-directed care can be a negative experience for people from diverse backgrounds and identities due to lack of awareness and confidence with decision making, lack of knowledge of systems and processes (Commonwealth of Australia 2020), lack of information around the principles of consumer-directed care, and overall complexities associated with navigating the aged, health care, and disability systems. Failing to meet the needs of diverse clients represents a serious shortfall in care provision.

Culturally safe and trauma-informed models of care are essential in building trust, facilitating communication and social connection, and appreciating culture and other forms of connection with people of shared experience and background (Cations *et al.* 2019; Department of Health 2019). Some aged care organisations have diversity frameworks to encompass key policies within a human-rights perspective. Providers adhering to the rhetoric of 'treating everyone the same' often do not recognise the diversity of their service populations. They may fail to deliver tailored person-centred care to meet peoples' specific needs. A systemic response is required to provide appropriate care for those with diverse needs and to appreciate the intersectional experiences of exclusion, discrimination, and stigma

experienced by many older Australians over the life-course. As website analytics suggest, the web pages contain information that staff are searching for. Additional training may be one approach to addressing knowledge gaps and informing better service and care delivery.

The development of these web pages also highlighted the uneven availability of literature and resources relating to aged care and palliative care for the nominated population groups. There were also some knowledge gaps in the types of research being undertaken. Future studies could explore the lived experience of aged care and end of life care for those who identify with different marginalised groups and identities to ensure inclusion and representation in research.

Access to information and resources is a critical first step to providing culturally sensitive and trauma-informed care in aged care settings. Many workers feel ill-prepared, especially when working with older diverse adults at the end of life. Ultimately, improving care to all Australians is key. Within the ELDAC project, there remains scope to further track the use of online materials in the aged care sector, to increase engagement with web users, and determine the value of such educational web pages on workforce practice. The webpages also connect to a larger body of materials, including educational toolkits, and speak to the value of the project in enabling access to relevant information for staff.

Limitations

Google Analytics is limited in its capacity to allow interpretation beyond page hits and associated analytics, particularly regarding engagement with the material accessed and the subsequent impact on practice change. Measuring engagement with online professional development resources requires further consideration.

Further limitations to the rapid review and web page content included general project time constraints and a lack of targeted and relevant information available and accessible online for some diverse groups. For some groups, existing knowledge relating to considerations for aged care, palliative care and advance care planning content was abundant and accessible, while for other groups, extant research, information and tailored resources were far more limited and difficult to source, particularly within an Australian context. Much literature has limited inclusion of the lived experience of older people from diverse backgrounds.

Conclusion

It is a societal expectation that health professionals and aged care staff will provide equitable care to all older Australians. Being marginalised or identifying with diverse identities is often a barrier to receiving appropriate care and support as an older adult and towards the end of life. Caring for all older adults towards the end of life requires staff to be aware, sensitive, and empathetic to different life experiences and backgrounds. These web pages and their use since publication highlight the recognition of the aged care workforce on respecting the diversity of individuals and address some of the key considerations towards end of life for various groups.

References

Aged & Community Services Australia (ACSA) (2013) Issues facing aged care services in rural and remote Australia. Canberra, Australia.

Aged Care Quality and Safety Commission (ACQSC) (2019) Quality standards. (ACQSC: Canberra, ACT, Australia) Available at https://www.agedcarequality.gov.au/providers/standards [Verified 30 October 2020]

Australian Government (1997) Aged Care Act 1997. Available at https://www.legislation.gov.au/Details/C2013C00389 [Verified 30 October 2020]

Australian Institute of Health and Welfare (AIHW) (2017) 'Australia's changing age & gender profile. Older Australia at a glance.' (AIHW: Canberra, ACT, Australia) Available at https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/demographics-of-older-australians/australia-s-changing-age-and-gender-profile [Verified 15 September 2020]

Bulamu N, Billingsley K, Gill L, Cameron I, McKechnie S, Fiebig J, Grady R, Ratcliffe J (2017) Impact of consumer-directed care on quality of life in the community aged care sector. *Geriatrics & Gerontology International* **17**(10), 1399–1405. doi:10.1111/ggi.12872

Cations M, Laver KE, Walker R, Smyth A, Fernandez E, Corlis M (2019) The case for trauma-informed aged care. *International Journal of Geriatric Psychiatry* **35**(5), 425–429. doi:10.1002/gps.5247

Chauhan A, Walton M, Manias E, Walpola RL, Seale H, Latanik M, Leone D, Mears S, Harrison R (2020) The safety of health care for ethnic minority patients: a systematic review. *International Journal for Equity in Health* **19**, 118. doi:10.1186/s12939-020-01223-2

Commonwealth of Australia (2020) Royal Commission into Aged Care Quality and Safety: Hearings. Available at https://agedcare.royalcommission.gov.au/ [Verified 20 August 2020]

Crutzen R, Roosjen JL, Poelman J (2013) Using Google Analytics as a process evaluation method for Internet-delivered interventions: an example on sexual health. *Health Promotion International* **28**(1), 36–42. doi:10.1093/heapro/das008

Department of Health (2017) Aged Care Diversity Framework. Available at https://www.health.gov.au/resources/publications/aged-care-diversity-framework [Verified 30 October 2020]

Department of Health (2019) Exploratory analysis of barriers to palliative care. Issues report on people from culturally and linguistically diverse backgrounds. (Department of Health: Canberra, ACT, Australia) Available at https://www.health.gov.au/sites/default/files/documents/2020/01/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-from-culturally-and-linguistically-diverse-backgrounds-issues-report-on-people-from-culturally-and-linguistically-diverse-backgrounds.pdf

Ellen ME, Panisset U, Araujo de Carvalho I, Goodwin J, Beard J (2017) A knowledge translation framework on ageing and health. *Health Policy* **121**(3), 282–291. doi:10.1016/j.healthpol.2016.12.009

Gardner DS, Doherty M, Bates G, Koplow A, Johnson S (2018) Racial and ethnic disparities in palliative care: a systematic scoping review. *Families in Society: The Journal of Contemporary Social Services* **99**(4), 301–316. doi:10.1177/1044389418809083

Griebling TL (2016) Sexuality and aging: a focus on lesbian, gay, bisexual, and transgender (LGBT) needs in palliative and end of life care. *Current Opinion Supportive Palliative Care* **10**, 95–101. doi:10.1097/SPC.0000000000000196

Johnston B, Pringle J, Gaffney M, Narayanasamy M, McGuire M, Buchanan D (2015) The dignified approach to care: a pilot study using the patient dignity question as an intervention to enhance dignity and person-centred care for people with palliative care

needs in the acute hospital setting. *BMC Palliative Care* **14**(1), 9. doi:10.1186/s12904-015-0013-3

Lenaerts G, Bekkering GE, Goossens M, De Coninck L, Delvaux N, Cordyn S, Adriaenssens J, Vankrunkelsven P (2020) Tools to assess the trustworthiness of evidence-based point-of-care information for health care professionals: systematic review. *Journal of Medical Internet Research* **22**(1), e15415. doi:10.2196/15415

O'Brien AP, Bloomer MJ, McGrath P, Clarke K, Martin T, Lock M, Pidcock T, van der Riet P, O'Connor M (2013) Considering Aboriginal palliative care models: the challenges for mainstream services. *Rural and Remote Health* **13**, 1–10.

Shulman C, Hudson BF, Low J, Hewett N, Daley J, Kennedy P, Davis S, Brophy N, Howard D, Vivat B, Stone P (2018) End-of-life care for homeless people: a qualitative analysis exploring the challenges to access and provision of palliative care. *Palliative Medicine* **32**(1), 36–45. doi:10.1177/0269216317717101

Tieman J (2016) Ensuring quality in online palliative care resources. *Cancers* **8**, 1–7. doi:10.3390/cancers8120113

Valenti KG, Jen S, Parajuli J, Arbogast A, Jacobsen AL, Kunkel S (2020) Experiences of palliative and end-of-life care among older LGBTQ women: a review of current literature. *Journal of Palliative Medicine* **23**(11), 1532–1539. doi:10.1089/jpm.2019.0639

Author affiliations

[A]College of Medicine and Public Health, Flinders University, Adelaide, SA 5042, Australia.

[B]College of Nursing and Health Sciences, Flinders University, Adelaide, SA 5042, Australia.