What you say and what I want: Priorities for public health campaigning and initiatives in relation to dementia

Irja Haapala | Ashley Carr | Simon Biggs

Objective: To examine the overlap between priorities expressed by representatives from national and local campaigning organisations and the views of key voices in relation to dementia.

Methods: Semi-structured, in-depth telephone interviews were conducted with 19 representatives from campaigning organisations, including nine countries and six local community initiatives in Australia. Responses were categorised into nine priorities. Views were compared to the voices of people with dementia (n = 19), carers (n = 28), and health-care (n = 21), social work (n = 23) and service professionals (n = 20).

Results: Local groups prioritised user-led decision-making and community normalising agendas. National groups were influenced by service frameworks and increasing public awareness. Professional and carer groups focused on increasing understanding and communication skills while people with dementia valued being a normal part of society.

Conclusion: Future campaigning should use both national and local approaches to changing social relations, through interpersonal connections, advocacy and social mobilisation, to promote a normalising approach to attitude change.

KEYWORDS
campaign, communication, dementia, public health, social attitudes, attitudes to health

1 INTRODUCTION

The place of dementia in the public domain is becoming increasingly important with (a) more people living with dementia as a consequence of rising numbers of older people; (b) a shift towards care in the community which has made dementia more visible; (c) stigmatising attitudes to ageing and to dementia affecting older people's sense of confidence, social engagement and positive or negative identity; (d) dementia becoming associated with the rising costs of health and social care provision, both nationally and internationally; and (e) people with dementia and carers finding their individual political voices to reduce the dominance of professional voices as the foremost perspective determining service systems and wider public attitudes.

A person's position or “voice” in connection to dementia can affect how people feel, think and act in the public domain and how they construct a perspective on dementia and those affected by it. This in turn will influence their priorities when it comes to social responses to the phenomenon, the perceived relevance of campaign messages and the place of people living with dementia in society. The strengthened voice of people with younger onset dementia and the adoption of the wider disability movements’ principle of “nothing about us without us” illustrate a changed climate in the way that messages are generated and received. An effective public health campaign initiative raises...
public attention by making the issue visible and serious at the personal level, but it should also present effective, accessible and available options for action that are compatible with one’s lifestyle and circumstance.6 National organisations responsible for public campaigning on dementia have been criticised for neglecting the latter part of the process. In allowing a negative frame to imprint on people’s minds, they have rarely influenced positive attitude change.7 Past campaigns, it is argued, have succeeded in framing dementia as a serious, risky condition to fear, but the appeal for taking positive action has been underplayed.7,8 While changes are taking place at national9 and local2 levels, the relationship between the priorities of the sender and recipient of messaging has not been fully researched.

As a means to wider action, the World Health Organization’s Global Action Plan on the Public Health Response to Dementia (2017-2025)10 has prompted individual nation states, including Australia, to establish a national action plan and strategy for dementia, and at least 94 countries have a central association for the condition under the name of Alzheimer’s or Dementia.11 Most of these plans contain an element of public campaigning to raise awareness, but the questions of “how” and “what then?” are yet to be answered. A central question here is whether sufficient attention will be paid to appropriate needs identification within specific target groups and whose voice will be taken into account when designing public campaigning and interventions.

In this paper, we have used dementia as an umbrella term to refer to the different types of progressive neurological conditions affecting the brain.12 While dementias consist of a number of diverse conditions, in the public mind these frequently exist as a common and simplified social category.13

We examine the overlap between campaigning priorities expressed by representatives from national and local campaigning organisations and the views of key voices in relation to dementia. These voices include people with dementia, carers, and health-care, social work and service professionals.

2 | METHODS

Findings are presented from a three-year research project, “Dementia in the Public Domain,” funded by the National Health and Medical Research Council via the Cognitive Decline Partnership Centre (CDPC) (https://cdpc.sydney.edu.au/). The project received approval from the University of Melbourne Project Ethics Committee (ID: HREC 1647136.1, 2016-2018). All participants provided signed informed consent following the guidelines in National Statement on Ethical Conduct in Human Research, 2007/2015,14 and the Alzheimer Europe 2011 Report on Ethics for Dementia Research.15

Nineteen semi-structured, in-depth telephone interviews were conducted between November 2017 and April 2018, with representatives of national- and local-level campaigning organisations. Campaigners, who were purposively selected, were invited by email and a follow-up telephone call to discuss their campaign priorities and what, in their mind, would facilitate an effective campaign in relation to dementia. Ten of the 13 invited national-level campaigners from English-speaking and Nordic countries accepted the invitation. All nine of the invited local-level campaigners in Australia accepted (from Victoria, New South Wales, Queensland and Western Australia). In a previous paper, we have presented findings from interviews with people from five different voice perspectives on dementia.16 Here, we present two new perspectives, those of national and local campaigners, and undertake a new analysis comparing the five perspectives with campaigners’ views. The five voice perspectives arose from 111 in-depth, semi-structured interviews with self-selected people living with dementia, carers, and health-care, social work and service professionals in five Australian states conducted between March and September 2017 (Table 1).

During the interviews, we asked people from different voice and campaign perspectives about their priorities for campaigning, using the question: “What would an effective campaign on dementia look like?” Audio-recorded telephone interviews lasting about an hour were carried out by the first and second author, independently, with frequent debriefing of progress with each other and the project lead (third author). Both interviewers (one female and one male) had previous

Policy Impact

Policy on the targeting of messages should address the specific priorities of different voice perspectives. When compared to public health research, these results indicate that future research should place greater emphasis on who is receiving the message rather than whether the recipients have accepted the predefined messages.

Practice Impact

National and local campaigning have complementary functions as change agents in their practices towards social aspects of dementia. Results contribute to public health on attitude and behaviour change which recommends distinct communication channels and patterns that can support the adoption of new ideas, attitudes and skills. While both forms of campaigning have taken on board the position of people with dementia, they pay less attention to carers’ and professional perspectives.
experience and training in interviewing in clinical and field research settings, including with people with dementia. The advisory group, consisting of three representatives from care provider organisations and four from the consumer dementia research network, was also briefed and consulted at regular intervals. An interview protocol, including a set of questions, was developed and pilot-tested with two participants, resulting in minor changes to wording to make the questions easily understandable.

Data from the transcripts were imported into NVivo 11, and coded by emerging themes (by the first and second author), after discussing any discrepancies and resolving these within the team. Consultation with the advisory group about thematic validity also took place. For campaigners, this resulted in 511 coded items under nine main campaign priority areas, six of which overlapped with those arising from the five voice perspectives (with 330 coded items under 34 first-level themes categorised under six main campaign priority areas), and 144 coded items under nine main categories of facilitating factors for effective campaigning (see coding frame in Table 2). Categorised data were extracted and imported into Excel to produce the descriptive tables and figures. Data are presented as the proportion of mentions within each group, calculated as the number of mentions (for suggestions for effective campaign) divided by the total number of mentions within group.

3 | RESULTS

3.1 | Campaigners’ perspectives

National campaigning priorities, as described by the ten participants, reflected areas of domestic priority, often connected to National Strategic Planning or grasping public attention in their specific contexts. These priorities echoed historical foci on specific service areas, cultural understandings of dementia and carer roles, a relative emphasis on market positioning, branding and fund-raising, depending on type of welfare economy, and alliances with other campaigning groups (Table 3).

Local-level campaigners showed a relatively high level of consensus on key foci. Their focus was skewed towards normalising dementia, in wanting people living with the condition to be accepted as a normal part of daily and neighbourhood life. Increased understanding and know-how when it comes to the interaction between people with dementia and others, plus dignity, respect and rights, were also priority issues (Table 3).

3.2 | Comparing national and local campaigning priorities

When national and local campaigner priorities were compared, national campaigns were more likely to give a balanced
weighting to multiple priorities. National organisations’ priorities emphasised dignity, respect and rights (19.1%), normalising dementia (18.0%) and increasing understanding and interaction skills (18.0%) plus health-care systems and services (12.4%) (Figure 1).

Local campaigner organisations were closer to each other in their understanding of priority issues, but more skewed in the priority emphasis given to specific concerns. Local campaigns were particularly concerned to normalise dementia within communities (34.8%) with an emphasis on dignity, respect and rights (27.9%) plus increasing understanding and interaction skills (17.2%). Their response, in other words, was more uniform as a group than national campaigners’, possibly reflecting a common experience of local priorities embedded in everyday community activities (Figure 1).

### 3.3 Facilitators for effective campaigns

When we looked at what campaigners mentioned as facilitators for effective campaigning, the following patterns emerged (Figure 2): national campaigners gave greater priority than local ones to organisational and inter-sectoral collaboration, interpersonal skills and funding. They also gave more emphasis to what were perceived as lesser issues among

---

**TABLE 2** Campaign priorities—nine categories explained

<table>
<thead>
<tr>
<th>Description of these campaign priorities arises from the contents of participant interviews. The first six priorities are shared between campaigners and voice perspectives:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Awareness-raising</strong></td>
</tr>
<tr>
<td>Raising awareness in the public domain about dementia as a condition, such as definitions of dementia, incidence and prevalence rates, information on dementia-related symptoms and its impact on individuals and society. Includes raising awareness about the organisations and services that can help</td>
</tr>
<tr>
<td><strong>Understanding and interaction skills</strong></td>
</tr>
<tr>
<td>Emphasis on communicating a deeper understanding of how to help and interact with people with dementia, a sense of inhibition towards people with dementia among the general public, professionals and in public places, the need for information to counter stereotypes, the use of life stories and case studies to highlight real lived experiences. Aims to change current attitudes and behaviours, specifically a better understanding of the needs of people with dementia</td>
</tr>
<tr>
<td><strong>Normalising dementia</strong></td>
</tr>
<tr>
<td>Focus to make dementia an accepted part of everyday life and conversation by increasing visibility of people with dementia, emphasising the positive aspects of dementia and care, and promoting social inclusion and dementia-friendly communities. Aims to reduce negative perceptions and language and can appeal to citizenship values, such as the responsibility of individuals to increase support for and acceptance of people with the dementia</td>
</tr>
<tr>
<td><strong>Dignity, respect and rights</strong></td>
</tr>
<tr>
<td>Focus on respecting people with dementia as still the same person and their right to live a valued and meaningful life. Includes advocacy for people with dementia and ensuring that carers are adequately supported. Can involve providing a platform for people with dementia to speak for themselves, the co-design of services and local initiatives, and ways to maintain and increase community engagement</td>
</tr>
<tr>
<td><strong>Prevention methods</strong></td>
</tr>
<tr>
<td>Promotion of proven ways to reduce the incidence and risk of dementia, such as good dietary habits and exercise. Focus also on the benefits of early intervention to help reduce the severity of dementia-related symptoms and promote help-seeking behaviour</td>
</tr>
<tr>
<td><strong>Health-care system and services</strong></td>
</tr>
<tr>
<td>Focus on improving the care and support provided to people with dementia via the health and care systems and services. Can include providing information on services available, the need for additional funding and supports, and the provision of effective approaches to ongoing care</td>
</tr>
<tr>
<td><strong>Three themes brought up by the campaigners but not the voice perspectives:</strong></td>
</tr>
<tr>
<td><strong>Organisational priorities</strong></td>
</tr>
<tr>
<td>Emphasises the needs of organisations engaged in public campaigning to sustain their activities, including care and support services. Includes demonstrating the need for services, making the services of the organisation more visible and promoting branding</td>
</tr>
<tr>
<td><strong>Fund-raising</strong></td>
</tr>
<tr>
<td>Focus on attempts to raise funding for organisations providing help and support, for research, for community groups and local services, and for increased government support for people with dementia, their carers and services</td>
</tr>
<tr>
<td><strong>Influencing policy and planning</strong></td>
</tr>
<tr>
<td>Engaging in the political and policy-making process through lobbying, appeals to political representatives, and promoting civic discussion to change and/or improve dementia-related care and other relevant policies. Also includes involving people with dementia directly in policy development and the use of research and evidence to influence the policy-making process</td>
</tr>
</tbody>
</table>
local campaigns, such as political buy-in and having an evidence base. Local campaigners placed greater emphasis on active involvement by people with dementia and good levels of community support and less emphasis on issues such as media support and health messaging. Perhaps surprisingly, neither national nor local campaigners placed particular weight on health messaging, positive media coverage, political buy-in or having an evidence base.

### 3.4 Comparing priorities between campaigners’ and voice perspectives

When national-level campaigners’ and local-level campaigners’ priorities were compared to those by voice perspective, patterns of overlap and distinctiveness emerged (Figure 3).

Alignment between national campaigner and voice perspective priorities can be summarised as follows:

1. Dignity, respect and rights aligned with local campaigners, people with dementia and social work professionals;
2. Increasing understanding and interaction skills aligned with views among professional groups and carers; and
3. Normalising dementia aligned with people with dementia and service professionals.

### Table 3 Campaign drivers for national and local initiatives

<table>
<thead>
<tr>
<th>National-level campaigners (n = 10)</th>
<th>Local-level campaigners (n = 9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raising general awareness to improve understanding and support</td>
<td>Creating dementia-friendly communities through initiatives with local councils, care and support services, parks and amenities, businesses, shopping centres and the public</td>
</tr>
<tr>
<td>Aligning the aims of national, other dementia strategies and public health priorities with the activities of dementia-focused organisations</td>
<td>Training and education activities to improve care services and interactions in public</td>
</tr>
<tr>
<td>Gaining the support and commitment of national and state or local political representatives for particular policy goals</td>
<td>Promoting local events on the human rights and dignity of people with dementia</td>
</tr>
<tr>
<td>Empowering people with dementia through advocacy and public information</td>
<td>Providing a platform for people with dementia and their supporters to advocate for themselves</td>
</tr>
</tbody>
</table>

### Figure 1 Campaigners’ priorities for campaign: percentage of mentions within group. ___ National level campaigners (n = 10), ___ Local level campaigners (n = 9)
While there were areas of congruence, three areas stood out as being valued by voice perspective groups that were not given the same degrees of emphasis by either national or local campaigners. These included the following:

1. Awareness-raising was most emphasised by health professionals and carers. Carers were concerned with increasing general awareness of what living with dementia was like and what were its consequences, and health professionals focused on awareness from a public health perspective.

2. Increasing mutual understanding and how to interact with people with dementia were important for all professional groups and carers. While both national and local campaigners recognised the priority for a normalising agenda, which was also the concern of people with dementia, there was relatively little emphasis being given to these carer and professional priorities.

3. National and local campaigners gave some emphasis to health-care systems and services, together with social work professionals. Otherwise, there was an unexpected lack of emphasis on this topic.

4 | DISCUSSION

In this paper, we have examined the overlap between priorities expressed by representatives from national (within Australia and internationally) and local campaigning organisations (Australia) with the views of people with dementia, carers, and health-care, social work and service professionals living in Australia.

We found that national- and local-level campaign priorities showed distinctive priorities and methods of facilitation, as well as considerable overlap in their objectives. When compared to voice perspectives, campaigning aligned with specific voices on particular issues. Overall, when comparing campaigning organisations and voice perspectives, social factors such as normalising relations in communities and skills...
for interaction between groups were given greater emphasis than those related to health. There was a general consensus that dignity, respect and rights were an important priority, with national and particularly local campaigning organisations giving greatest priority to seeing people with dementia as a normal part of society, as did people with dementia themselves and service professionals. Professional groups’ and carers’ emphasis on skills for increasing mutual understanding and how to interact with people with dementia was only partially reflected in the priorities of campaigning organisations. While national priorities included health-care systems and services to some extent, this was not a priority for other groups.

4.1 What does this all say about campaigning?

Our findings evidence some forms of mismatch between the priorities of the senders of messages and those of the recipients, when compared both to the academic literature on campaign effectiveness and to the WHO 2016 guidelines, and to a lesser extent in the contemporary priorities of campaigning organisations.

In order to address possible ways forward, three issues have been identified:

First, an area that stands out is the new finding that carers and professionals want more initiatives on how to interact with people with dementia in the public domain, indicating public inhibition and a lack of appropriate social skills, and more awareness raising about the effects of living with dementia. An absence of these, rather than the effects of stigma, is perceived to be an important barrier to normalising dementia. Our results would suggest, somewhat unexpectedly, given the numbers of carers and professionals engaged in campaigning organisations, that carer and professional concerns may be under-represented in campaign priorities. This may reflect a certain altruism and contemporary respect for the views of the person with dementia as the end-user. However, if lasting solutions to social aspects of dementia are to rely on negotiated perspectives, then these particular voices should not be missed. Professionals’ and carers’ attention to public attitudes, plus their increased awareness of the importance of interpersonal communication, would be important factors in creating a positive social environment for people with dementia and those close to them. Normalising alone is unlikely to generate lasting solutions, but if normalising agendas and a desire to communicate are seen as two sides of the same coin, the essentially interactive nature of social exchange and the possibilities for enduring social engagement would be enhanced. At a practical level, training for helping professionals and others who come in contact with people with dementia as part of their daily work should be prioritised, particularly in the areas of interpersonal communication and mutual understanding.

Second, and equally surprising, is the underemphasis given to health-related priorities. This may be partly because participants believed they had already been given significant attention, perhaps reflecting a tacit view that this priority was already in the public domain. The key messages of the Lancet Commission on “dementia prevention, intervention and care” include exhortations to be ambitious about prevention, to individualise dementia care and to reduce the risks to family carers. Research evidence from large-scale observational cohort studies and preventive intervention trials has shown that relatively small changes to lifestyle-related risk factors can prevent or stall cognitive impairment and dementia. However, these findings stand beside enduring evidence that the uptake of public health messaging is at most patchy. Such findings may indicate that while public health campaigning is not unaware of targeting, it may be preoccupied with “getting a message across” rather than taking the position of the “receivers” of messaging into account. Our results would indicate that making needs identification appropriate within specific target groups might make the issue more visible and serious at the personal level, if it is made compatible with the holders of specific voice perspectives. For example, the increased visibility of people with younger onset dementia may both draw attention to those more able to articulate their needs and to make changes at an earlier age. It may also highlight the evolution of need as the condition progresses and allow more nuanced distinctions to be made between the experience of younger and later onset dementia.

At a practical level, this means generating effective, accessible and available options for action that engage with different voices at the level of their own everyday priorities.

Third, these points invite us to revisit the questions of “how” and “what then?” raised in our introduction. Comparing national and local approaches indicates their complementary functions as change agents and the potential for greater collaborative strategising and feedback. A closer and complementary relationship would respect the priorities and skill sets of each organisation and provide an integration of attempts at global attitude change with initiatives embedded in local circumstances. A key component here would be to elaborate the practical meaning of a “normalising agenda.” Normalising dementia, not to be mistaken with dementia as a normal part of ageing, nor with dementia as demographically connected to later life, suggests the social (re)engagement of people affected by dementia. For many, dementia is the radical other hiding within the otherness of older age, with negative constructions of the condition filling the vacuum of meaningful contact and social understanding. Positive othering—recognising distinctiveness as a basis for finding shared solutions—may be particularly difficult given perceptions of dementia in popular culture. Practically this may mean closer integration of national and local interventions at least three levels: interpersonal interaction, community networks...
and wider social attitudes, suggesting a cumulative role in reducing the otherness of the condition in the public mind.

4.2 | Limitations

Our study has certain limitations. First, while the percentage of participants from culturally and linguistically diverse backgrounds (CALD) in our study paralleled Australian population statistics, the number of participants was too small to allow a CALD-based analysis. Aboriginal and Torres Strait Islander people were not part of the study. Future research should be undertaken to include these perspectives. Second, national campaigns represented primarily English-speaking and European perspectives. This study did not extend to looking at the growing number of initiatives in other parts of the world. Third, sampling included an element of self-selection which may have skewed participation in favour of people who already had some connection with dementia. Family connection has been explored elsewhere. Fourth, our sample comprised predominantly women, except for people with dementia who were predominantly men. Again this may reflect an element of self-selection and gender expectations, plus ratios in the helping professions, and that people with dementia were occasionally recruited through their partners. Fifth, because we wanted people with dementia to answer for themselves rather than through a third-party advocate, we restricted interviews to people who could undertake the interview themselves and provide signed informed consent. Future research should attempt to access the views of people with more advanced stages of the condition.

Strengths of the paper are (a) collaboration between disciplines (social gerontology and public health education); (b) inclusion of five different voice perspectives on their priorities with respect to dementia; (c) inclusion of people with dementia and service industry professional who are under-represented in contemporary research in this area; and (d) comparison of national and local campaign initiatives in terms of their responsiveness to user needs and the distinctiveness of each organisational approach.

5 | CONCLUSION

Our findings have contributed to the question of how to increase public understanding of dementia through an integration of normalising agendas and interaction skills. This proposes a shift away from general awareness-raising in relation to dementia to promoting strategic communication at local and national levels, increasing skills aimed at changing and influencing behaviours through interpersonal connections, plus negotiated advocacy plus broader social influence to promote a climate where change can occur.

ACKNOWLEDGEMENTS

We would like to thank all our interviewees for giving their time and sharing their stories and insight with us. We are also thankful to the research network coordinating organisation, the CDPC, members of Dementia Australia’s National Consumer Network, Carers Victoria, the Brotherhood of St Laurence and the funding organisations for their support and for facilitating the recruitment process in five Australian states. This project was funded through the CDPC (https://cdpc.sydney.edu.au/) receiving support from the NHMRC Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People known as the Cognitive Decline Partnership Centre (CDPC) (grant number GNT9100000) and partners, including Brightwater Care Group, Dementia Australia, Hammond Care and Helping Hand Aged Care.

The study was approved by the University of Melbourne Humanities and Applied Sciences Human Ethics SubCommittee (HESC 1647136).

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

ORCID

Irja Haapala https://orcid.org/0000-0001-5624-3018
Ashley Carr https://orcid.org/0000-0003-1557-4018
Simon Biggs https://orcid.org/0000-0002-2808-8134

REFERENCES


