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## **The Impact of Public Health Awareness Campaigns on the Awareness and Quality of Palliative Care (Accepted version)**

**Jane Seymour, Professor of Palliative and End of Life Care, University of Sheffield**

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### **Abstract**

The right to health includes a right of access to good quality palliative care, but inequalities persist. Raising awareness is a key plank of the public health approach to palliative care but involves consideration of subjects most of us prefer not to address. This review addresses the question: ‘do public health awareness campaigns effectively improve the awareness and quality of palliative care?’

The evidence shows that public awareness campaigns can improve awareness of palliative care and probably improve quality of care, but there is a lack of evidence about the latter. A comprehensive public awareness campaign about palliative care (including advance care planning and end-of-life decision making) should be based on clear and shared terminology, use well piloted materials and the full range of mass media to suit different ages, cultures and religious/ spiritual perspectives. Arts and humanities have a role to play in allowing individuals and communities to express experiences of illness, death, and grief; and encourage conversation and thoughtful reflection. There is evidence about key factors for success: targeting, networking, use of SMART objectives; continuous evaluation and complementarity to national and international policy. Campaigns should be located within the framework of public health promotion and the synergy between short national mass media campaigns and longer term local community action initiatives carefully considered. National and local projects to raise awareness should identify and address any barriers at the level of individuals, communities and systems of care e.g. literacy skills and unequal access to resources.

## **Introduction**

In the last few years, the links between palliative care, social justice and human rights have been strengthened, with international recognition right up to the level of the World Health Organisation, that the right to health includes a right of access to good quality palliative care. However, international research (presented in a previous article of this supplement) shows that members of the public are rarely familiar with the meaning and availability of palliative care and that the majority have not taken steps to anticipate their own future care through the use of advance care planning. This is in spite of rapid increases in ageing, multiple morbidity and family care-giving responsibilities. Raising awareness has the potential to enable people to ask for palliative care and to take action in their own families and communities to improve the quality of palliative care provided, but means engaging people in topics they often find challenging to consider. Moreover, public awareness campaigns require significant funding and may not be effective. This review looks at public awareness campaigns of relevance to palliative care internationally and within Canada. We define public awareness campaigns as: organised communication activities designed to raise awareness, induce behaviour change and improve quality outcomes for individuals and populations.<sup>1</sup>

The methods of this review are discussed in a previous article of this supplement. This review identifies the various types of campaign addressing palliative care issues, before addressing four primary questions:

1. What techniques are effective in raising public awareness and promoting engagement in general health issues?
2. What techniques are effective in raising public awareness of palliative care issues and helping people talk to their families?
3. What are the best ways of raising awareness of advance care planning and what is the impact on quality of care?
4. What are the key features of successful campaigns?

## **Types of Campaign**

Internationally, there have been a wide range of campaigns which involve at least some attempt to raise public awareness of palliative care issues and related subjects. A review published in 2009<sup>2</sup> found four categories of campaign focusing on the following topics: 1) death, dying and bereavement; 2) end of life care; 3) preparing for older age; 4) consent and organ donation.

Some campaigns relate to locally bounded activities, whereas others take the form of cross national collaborations. Some of the campaigns primarily take on an advocacy role, whereas others primarily take on a monitoring role, examining and tracking views about their key issue. Some actively lobby political opinion as pressure groups. The degree of politicization of the groups/campaigns varies greatly, with some selling a particular approach or stance

such as the importance of choice or being completely open about death and dying. A number of international networks are emerging with common goals, including public awareness.<sup>3</sup> Most campaigns operate by bringing networks of people and organizations into contact with each other, and making strong links to the press and other types of media. Some international examples are given below before describing key national campaigns in Canada.

### **International Campaigns**

In the USA, the 'Project on Death in America' (PDIA) in the USA was a large scale programme seeking to change the culture and character of dying funded by Mr George Soros and located in the Open Society Institute from 1994-2003.<sup>4</sup> It was an important driver for large-scale innovation in relation to death, dying and bereavement across the state, entrepreneurial and voluntary sectors in the USA. Despite this, its outcomes on quality of care have been difficult to establish at the level of the whole programme of work. The PDIA supported:

- a wide ranging conventional research and practice/ service development programme,
- a programme of literary, visual, and performing arts projects to identify and convey meaning in facing illness, disability and death, and
- community initiatives about bereavement and grief.

The Open Society has also funded smaller projects in Eastern Europe.<sup>5</sup>

In England and Wales, the 'Dying Matters' campaign<sup>6,7</sup> was funded in the wake of the first national strategy to improve end of life care in England in 2008. It supports and promotes activities to raise awareness and promote change in attitudes towards the discussion of death and the preparation for end of life care. It emphasises the importance of talking about 'end of life' wishes.

In Australia, there is an annual day of action to generate discussions about death.<sup>8</sup> This is part of wider international 'death literacy' movement,<sup>9</sup> which often involves what are known as 'death cafes' where people gather to talk about related issues and experiences (e.g. <http://deathcafe.com>). This movement is related to palliative care but has a wider purpose.

In Ireland (both Northern Ireland and the Republic of Ireland), a wide ranging public awareness campaign was launched as part of the All Ireland Institute for Hospice and Palliative Care. They have a 'palliative care' week, which aims to raise greater awareness and deeper understanding of palliative care across the Island of Ireland and has some simple key messages.<sup>10</sup>

### **The Canadian Experience**

In Canada, three main national initiatives can be identified that focus on public awareness raising in palliative care. There also are many related regional ones.<sup>11</sup>

1. The Canadian Virtual Hospice: Online since 2004, the website aims to provide a reputable source for finding information and support, whenever people need it and wherever they live, although it is not a campaign in the usual sense of the word. It includes discussion forums for people in need of support.<sup>12,13</sup>
2. The ‘Speak up’ Campaign: This is part of Advance Care Planning in Canada, a larger initiative. It is overseen by a National Advance Care Planning Task Group. Its members are individuals representing a spectrum of disciplines, including health care, law, ethics, research and national non-profit organizations.<sup>14</sup>  
  
In turn, it sits under an organisation called ‘Quality of End of Life Coalition in Canada’, which has links to an inventory of stakeholders and educational resources.<sup>15</sup>
3. The ‘Just Ask’ Campaign is focused on goals of care planning: While this is accessible to members of the public, its target audience is clinical practitioners who wish to talk to their clients/ patients about these issues.<sup>16</sup>

## **Results from Research Evidence**

On the whole, studies evaluating interventions to raise public awareness do not relate to the campaigns identified above, although some projects sit underneath the wider umbrella of the campaign. For example, the All Ireland Institute published an evaluation of their national campaign, described below. What the studies do relate to are discrete planned interventions aimed at one local or several local communities. The evidence is useful for informing planned and strategic mass media campaigns, as well as identifying those interventions that may be transferable and possible to scale up.

*What techniques are effective in raising public awareness and promoting engagement in general health issues?*

### **a. Social marketing or ‘mass media’ campaigns**

Reviews of research on social marketing campaigns, including online campaigns, suggest that they can influence people to change their behaviour<sup>17,18</sup> and can also influence policy-makers.<sup>19</sup> Shorter interventions (in terms of time) have been shown to have larger impacts on voluntary behaviour change.<sup>17</sup>

An important condition for the success of any campaign is that individuals must feel able to trust the information given. In Canada, an evaluation of TV advertisements about health promotion aimed at older adults showed that recipients were generally distrustful of the information if they perceived that it had been provided by the ‘government’. Professionals such as doctors, or celebrities (e.g. Olympic stars) were seen as more trustworthy.<sup>20</sup>

Younger people prefer to receive health information via the internet or other electronic means, while older people prefer the newspapers. In the future, preferences may be angled

towards online options across a range of age groups.<sup>21</sup> For the time being, a mixed approach is advised based on prior assessment of community preferences. One important consideration is that online campaigns can achieve higher reach at comparatively low cost.<sup>17</sup>

On the whole, there is little evidence on ‘outcomes’ for quality of care from social marketing. However, one fairly old but high-quality review shows that targeted mass media campaigns (i.e. aimed at particular groups) can lead to those groups making better use of health services, i.e. being more likely to use health services with proven cost-effectiveness.<sup>22</sup> Screening choices might be one example.

#### b. Public deliberation methods

A literature review,<sup>23</sup> cited in a larger Canadian literature review<sup>11</sup> found benefits from public deliberation methods (e.g. citizen panels and juries, consensus conferences) in:

- bringing insights into social values;
- improving understanding of complex issues (particularly ethical and social dilemmas); and
- enhancing civic-mindedness.

#### c. eHealth interventions and social media

As noted above, younger people are more likely to favour ‘e’ interventions. A representative survey in Australia found that people preferred to receive eHealth information via the device that they were most familiar with.<sup>24</sup> There is likely to be a range of inter-relating factors affecting how eHealth interventions work, including: design features, social support, peer pressure and information sharing practices. Little is understood about these factors or to what extent any changes observed are sustained,<sup>18,25</sup> although simple interventions that are easy and quick to use appear to be more effective at changing behaviour.<sup>26</sup>

Social media has the potential to increase engagement with health care issues and enable debate and discussion, as well as create virtual social networks.<sup>27</sup> However, there may be unintended consequences and risks. One commentary provides some useful pointers to safe use of Twitter for communication and knowledge exchange in medicine that have wider applicability(22). Generally, challenges include evaluation of social media based interventions in diverse communities with different concerns(23) and uncertainties about how to design features to sustain engagement and behaviour change (21).

### *2. What techniques are effective in raising public awareness of palliative care issues and helping people talk to their families?*

The existing research often talks about ‘end-of life’ care issues, which can often refer to a broader category of concerns than ‘palliative care’. Sallnow and Paul present a useful spectrum of community engagement in end-of-life care, from informing at one end through consultation, co-producing, collaboration and empowerment at the other end.<sup>30</sup> Sallnow and

Paul claim that projects focusing on collaboration and empowerment are more likely to result in sustained improvements in care although, as we see below, there is only a small body of research examining this. Researchers' positions on this continuum are usually informed by their philosophical, political or theoretical stance or by what it is they are seeking to achieve from their project.

A systematic review focusing particularly on methods of helping people raise end of life care issues within their families<sup>31</sup> found 5 studies, three suggesting positive effects (all from the UK) and two suggesting less positive effects (one from the UK and one from Japan):

- A peer education programme on end- of- life planning for older people, which could be seen as being at the empowerment end of the spectrum. The programme featuring small workshops was positively appraised by participant since it allowed them to make sense of issues in their own terms. It made use of information materials co-written by researchers and older people.<sup>32</sup> Volunteer peer educators, who received a three-day training programme, were most effective when they were closely linked to a community group. This gave them a sense of social identity and access to social capital.<sup>33</sup> Impacts on the recipients of peer education are not known, although some small scale evaluations suggest this approach works in different contexts.<sup>34</sup>
- An arts project bringing hospice users and school pupils together appeared to help normalise death for school pupils.<sup>35,36</sup>
- A public information roadshow engaged people using an informal questionnaire survey and eased conversations between those who participated.<sup>37</sup>
- A module on end-of-life planning delivered as part of 'expert patient' education programme on the management of chronic illness was not well received by participants.<sup>38</sup>
- In Japan, public lectures by physicians intending to promoting home death as a possibility were unsuccessful in changing public attitudes among 607 people across 11 areas at six months follow-up, although they had short term impact on the percentage of people who perceived that a home death was feasible (9% to 34%).<sup>39,40</sup>

Looking more generally at raising awareness of palliative care issues, the Japanese team of researchers referred to above conducted a large scale study in 4 areas involving distribution of information about palliative care (leaflets, posters, booklets and talks) to cancer patients, their bereaved relatives and the general public.<sup>41</sup> This was preceded by a survey showing very low levels of awareness.<sup>42</sup> 'Before and after' surveys over three years showed positive effects on perceptions of the public and bereaved relatives about palliative care over time. Impact on patients' perceptions was less clear. The study showed that sense of security with care improved in all three categories: public, relatives and patients.<sup>41</sup>

In Ireland, a one week social marketing campaign to raise awareness and understanding of palliative care had national coverage and involved advertisements, interviews and talks on TV, radio and online and a dedicated website. An evaluation showed that radio had the most reach in the Republic of Ireland, which is more rural than the rest of the country. An impact survey showed that 46% of people in the Republic of Ireland were aware of the campaign, compared to 26% in Northern Ireland. Those who were aware had a better understanding of palliative care.<sup>43</sup>

Social marketing campaigns that make use of media stories such as the death of Terri Schiavo in the USA<sup>44</sup> or the death of David Bowie (38), provide an opportunity to open up awareness of potentially difficult issues. EHealth and social media campaigns in palliative care are emerging, often as an outreach aspect of an online network aimed at professionals.<sup>43,45-47</sup> These make it possible to use a range of innovative techniques for teaching and learning (such as simulation), as well as providing targeted and potentially good quality information and support to patients, families and the public: the Canadian virtual hospice is one example.<sup>13,48</sup>

One innovative review examined 42 studies reporting clinical outcomes on leading contemporary social media use (ie, Facebook, Twitter, Wikipedia, YouTube) in 10 chronic diseases, many giving rise to palliative care needs.<sup>49</sup> Its findings suggest that, overall, the impact of social media on chronic disease is variable, with 48% of studies indicating benefit, 45% neutral or undefined, and 7% suggesting harm. The authors recommend using social media to provide social, emotional, or experiential support in chronic disease.

Community based interventions to develop compassionate communities are reported in the literature<sup>50</sup> and are at the empowerment end of the continuum of community engagement described above.<sup>51</sup> They often involve maximisation of social capital, sometimes called 'community assets', to enable local communities to learn about palliative care. These communities can then develop their own solutions to palliative care issues, working in partnership with professional agencies.<sup>52-55</sup> They put forward a socially oriented alternative to medical models of palliative care. They refer to 'persons' with an illness rather than 'palliative care patients' and see the person at the centre of concentric 'circles of care'.<sup>56</sup> This area of activity is often called health promoting palliative care, a concept that originated in Australia from the work of Kellehear and colleagues.<sup>57-61</sup> It is in line with the framework presented by Ottawa Charter on Health Promotion.<sup>55</sup>

Another related term is 'the public health approach to palliative care',<sup>60,63</sup> with an international network of partners dedicated to promotion of this.<sup>64</sup> Conceptual clarity is lacking in this whole area of work, with different terms meaning different things in various contexts.<sup>51,65</sup> There is as yet little research based evidence of impact on quality of care from community projects, although research projects are underway to look at impact and a systematic review looking at 8 projects identifies positive outcomes for family carers' well-being and support.<sup>65</sup> There are also reports of projects in resource poor countries involving

community volunteers in identifying people who need care, planning and providing some aspects of palliative care. For example, in Kerala, India there is a neighbourhood network of many years standing that has reached over 60% of people in need, in spite of lack of statutory resources.<sup>66; 67</sup>

3. *What are the best ways of raising awareness of advance care planning and what is the impact on quality of care?*

Existing evidence suggests that engagement with advance care planning improves the quality of end-of-life care, and reduces life sustaining therapies that are out of step with individuals' wishes and preferences or that are futile.<sup>68</sup> Early engagement means that people can be better prepared for making decisions when they are ill, as well as ensuring that their wishes are known by staff and relatives who might have to make decisions on their behalf. Some key messages come through from the existing research:

a. Ensure materials to raise awareness are culturally appropriate and piloted.

One detailed study involving community representatives of different cultural and aboriginal groups in Canada highlights the importance of tailoring attempts to raise awareness and use of advance care planning to cultural perspectives.<sup>69</sup> Some groups may find engagement completely counter cultural. One review of the research on African- Americans' perspectives on similar issues recommends tailoring interventions to ensure that they are culturally appropriate through consultation and piloting.<sup>70</sup> Similarly, a detailed research study looked at the acceptability of two brochures to provide information about advance care planning. That study recommends involving community representatives in writing such materials.<sup>71</sup>

Gauvin and Lavis<sup>11</sup>, in a Canadian review of interventions, highlight that particular groups need special attention: frail older people; first generation immigrants; and minority groups, which should be broadly defined. Minority groups may include not only ethnic minority groups but also LGBT communities for example. Structured conversation guides help patients and clinicians talk to one another<sup>72</sup> and may have relevance in public awareness raising.

b. Start young.

Most research on advance care planning involves people over the age of 65. There is now a trend towards involving and educating much younger people, so that they are better prepared to deal with the issues in their families and communities. One study looks at university students in the USA and recommends that an important aspect of public health is providing reliable information about advance care planning to all young people.<sup>68</sup>

c. Involve the community and build coalitions.

There are examples of how communities can be empowered to engage at a deep level with advance care planning and to develop plans to raise awareness in their own networks and localities. These fit in with the empowerment model described above and usually involve different groups coming together for a common purpose.<sup>33,53</sup> On a larger scale, the Respecting Choices programme is one example of a complex intervention for advance care planning across a health care system where involvement and awareness raising in the local community has been shown to be essential to success.<sup>71</sup>

4. *What are the key features of successful campaigns?*

There are models in existence providing a conceptual framework for the development and organization of successful campaigns in palliative care. For example, Professor Allan Kellehear<sup>73</sup> advises that public health programmes and activities can be addressed through the following questions:

1. In what way do they prevent social difficulties around dying death, loss or care?
2. In what ways do they seek to minimize harm or difficulties?
3. In what ways can activities be seen as early interventions?
4. In what ways do activities alter or change a setting or an environment?
5. In what ways are the proposed activities participatory?
6. How sustainable will these activities be without your future input?
7. How will you evaluate their success or usefulness?

Of broader relevance, a systematic review commissioned by the European Literacy Policy Network<sup>1</sup> suggests that the following 9 features characterise successful awareness raising campaigns in health:

1. Definition of the goal, current situation and the gap that needs to be closed;
2. Clear goals in line with policy and using the SMART approach: (specific, measurable, achievable, realistic, time-bound);
3. Target group(s) identified
4. Tailored messages that engage the target audience(s);
5. Networking to involve stakeholders and draw on their expertise;
6. Enabling participants/ stakeholders to feel part of the campaign;
7. Identification of communication channels appropriate to the target audience(s)
8. Management of funds and continuous monitoring and evaluation;
9. Planned to be complementary to national or international goals.

## **Conclusion**

This review shows that public awareness campaigns can improve awareness of palliative care and probably improve quality of care, but there is a lack of evidence about the latter. A comprehensive public awareness campaign about palliative care (including advance care

planning and end-of-life decision making) should be based on clear and shared terminology, use well piloted materials and the full range of mass media to suit different ages, cultures and religious/ spiritual perspectives (e.g. print, radio, TV, web based, social media). There is evidence about key factors for success: targeting, networking, use of SMART objectives; continuous evaluation and complementarity to national and international policy. Campaigns should be located within the framework of public health promotion and the potential synergy between national mass media campaigns and local community action initiatives carefully considered.

Opportunities for community engagement and action to improve palliative care at local, regional and national levels, based on evidence of what works and for whom, can be built into complex interventions to improve uptake of advance care planning or the quality of palliative care. Particular groups need special attention: frail older people; first generation immigrants; ‘minority’ groups broadly defined: this may include not only ethnic minority groups but also LGBT communities for example. Barriers should be identified at the level of individuals, communities and systems of care, and may include: literacy skills; misunderstandings (for example about ‘death panels’) and unequal access to resources.<sup>74</sup>

Learning vicariously from experiences and stories of others features in many of the campaigns examined for this review, whether using traditional modes of engagement or new social media. Story telling may alleviate the reluctance of some people to engage with the material and illustrates the important role of the arts and humanities initiatives in supporting individual and community expression of experiences of illness, death, and grief and to encourage conversation and thoughtful reflection. Difficulties in evaluating ‘outcome’ of such initiatives need to be creatively addressed.

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