Palliative Care in Australia

Submission to Senate Standing Committees on Community Affairs

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Palliative care is an exemplar of a complex area of healthcare provision. It is provided in a variety of settings such as hospices, in-patient wards and residential aged care facilities as well as supporting community care in patients' homes. Many different health professionals are involved including palliative care physicians, specialist and generalist nurses, general practitioners, and allied health providers such as physiotherapists, social workers and occupational therapists. Co-morbidities are common and care needs can change over time, in accordance with the underlying disease. Palliative care also recognises the role and needs of the family and carer(s) as well as the patient. In this area, as in other areas of complex care needs, information and knowledge is critical for palliative care providers and for patients, their carers and their families.[1-4]

However, knowledge needs in this field can be complex. Different amounts and types of information are likely to be needed by patients and their families at different time points.[3-10] While patients and partners may meet and discuss issues and concerns with their health professionals, there may be unanswered questions across the extended family. As most patients prefer to be cared for at home for some or all of their illness, carer involvement is crucial.[11] Carers themselves can have specific and unique information needs relating to services, resources or care practices.[12-16] Most health professionals involved in providing palliative care do not work full time in specialist services. General Practitioners, community nurses, aged care workers and those from allied fields such as oncology or cardiology may have a partial but ongoing, or only an intermittent, involvement with patients with palliative care needs.[1, 17] Ensuring that timely, relevant and trustworthy information is readily available when it is needed by these different participants within the palliative care community, is challenging.[4, 18] A rapidly expanding literature and evidence base [19] means that the ongoing currency of information is also an important consideration.

Given the diversity of the information needs of health professionals and health consumers, and the diversity of the care settings, the online environment offers a powerful avenue to enable dissemination and maintain information currency as well as encourage engagement with the knowledge base.[20-24] The web has changed how health information can be made available to clinicians and to consumers. It offers new avenues for information providers to store and disseminate materials. It enables unprecedented accessibility to vast amounts of health information by health professionals and by health consumers as, and when, information is needed. It provides new opportunities for initial and ongoing learning and for professional development. It is powerful because of its reach, its relative cost advantages and its immediate availability.

According to the Australian Bureau of Statistics in 2008-2009, 72% of Australian households had home Internet access and 78% of households had access to a computer. Between 1998 and 2008-09, household access to the Internet at home more than quadrupled from 16% to 72%, while access to computers increased from 44% to 78%.[25] Rates of internet access for those with serious illness of those caring for people with a serious illness are not dissimilar to those of the general Australian population.[26] Importantly, of those with Internet access, 28% of seriously ill people and 23% of those caring for someone with a serious illness felt that the Internet was very useful in helping them make health decisions, and 29% of seriously ill people and 26% of those caring for those with a serious illness felt that access to the Internet was very important.[26]

For palliative care patients and their families, having access to information when it needed is a major benefit given the tensions and uncertainties around communication at the end of life.[5, 27-28] Attention and comprehension of information can be particularly difficult when discussions around death and dying first begin. The opportunity to revisit some of these issues can help patients to better understanding the issues to be considered and decisions to be made. Patients and carers may only be ready to examine or seek further information at some period after the first conversation. Therefore, availability of relevant and quality information at the point of readiness, is crucial. However, it is not sufficient to have access to the Internet; trustworthy, current and palliative care relevant resources need to be available and easily retrieved. These resources need to be developed and promoted to ensure that they can be found, and that their content can be absorbed and used.

There are already some specific Australian online palliative care resources. These resources include the CareSearch website (www.caresearch.com.au) which acts as a “one-stop” shop for quality appraised information and evidence for the palliative care community. It provides a significant range of resources for palliative care researchers, for health professionals in all settings of health care, and for those affected by the need for palliative care, namely patients, carers, family members, and friends and colleagues. The site’s web metrics demonstrate the interest in, and use of, this online resource. Each month around 40,000 people visit this site and over 200,000 pages are viewed. However, there are great opportunities to enhance the range and type of web based resources to support palliative care patients and their families and health professionals. This approach would support the goals of awareness and understanding outlined in the National Palliative Care Strategy.[29]

Some examples of the growing set of online tools and resources for patients and carers that may be relevant to palliative care include patient decision aids such as the Ottawa Personal Decision Guide [30], carer managed networks such as My lifeline [31] , Lotsa Helping Hands [32] or iHealth Space [33], and information resources such Health Talk Online's Living with Dying [34]. There is also the opportunity to explore new initiatives that may have specific applicability within palliative care. There are already examples of mental health programs being delivered through the web.[35-36] Such approaches could be considered for new areas such as bereavement by offering ongoing support for those who have lost a family member, or by enabling ongoing bereavement surveillance of those at risk of complicated grief in the community. This could build on preliminary research that is already underway on the role of online support in bereavement.[37-38] These directions would also recognise the potential of the web as a platform for health care interventions, not merely as a repository for health information.

Health professionals will also need to manage changing technologies and applications. Health services and health systems are increasingly using the web to distribute information and deliver resources, and health professionals will be expected to be able to engage with this environment. Health professionals themselves may adopt new technologies and seek to incorporate these benefits into their professional lives. They may also be able to utilise this avenue to undertake and maintain professional certification. These factors will create a professional environment where professional practice is influenced by the changing nature of web technology. Moreover, given health consumers value the knowledge of health professionals above other sources[39-41], health professionals have an important role in being able to direct health consumers to trustworthy online resources. However, to take on this role those working in palliative care will need to acknowledge and accept the growing use of online health information by health consumers, and understand the needs of their patients in relation to these resources. As the government initiatives in eHealth records, national health reform and a national broadband network gather momentum, there is an increasing need for the health system to prepare health professionals to understand the changing resources, and be able to support their clients in using them.

There are opportunities to invest in online resources to enhance continuing education of health professionals by providing sustainable continuous access to learning modules. There are already some examples of resources to support continuing professional development, such as the Community Pharmacy Training module [42] or the end-of-life learning modules developed by the National Health Service in the UK.[43] Incidental learning and professional practice is also by access to bibliographic resources such as PubMed or CINAHL. But a more integrated approach to online education and training covering the needs of all of the different groups involved in palliative care such as careworkers in residential aged care or allied health providers working with palliative care clients in the community should be considered. Building the capacity of all relevant sectors to provide quality palliative care has been recognised as a goal in the National Palliative Care Strategy.[29]

Point of care clinical support and health informatics resources could enhance bedside and remote patient care.[44-47] The value of these technological advancements supporting new models of care and supporting generalist providers should be explored. Similarly, the capacity to conduct research requires access to and experience in using a range of technologies and applications. For palliative care, multisite trials are often needed to ensure sufficient power of sample sizes. In turn this requires web based solutions to enable data collection across sites.[48]

To enhance the provision of palliative care in Australia, the actual and potential role of the Internet and health informatics needs to be considered. This should include

1. Continued support for quality online palliative care resources that meet the information and evidence needs of health professionals and palliative care patients, their families and friends,
2. An expanded suite of online resources for the palliative care community including innovative online carer supports, interactive web-based learning modules for generalist providers and careworkers, and virtual collaborative spaces for health professionals and researchers,
3. A review of the role that informatics and web based applications could play in supporting and sustaining community care of palliative care patients and their carers,
4. Piloting of point of care clinical evidence on patient outcomes and clinical decision making, and

5. A program to develop and enhance the informatics competencies of the palliative care workforce.

Patients, carers and health professionals are already using the web, and this use is likely to expand and change as new technologies and applications are made available. How the palliative care sector makes use of the web and health technologies will influence how care is provided, how patients and families manage care at home, the continuing professional competency of the palliative care workforce, and the research and evidence base for palliative care practice in Australia.

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