

A state-of-the art learning environment in palliative care is proving useful for rural health professionals

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Abstract

Purpose

The following paper illustrates an education resource that was developed following a needs assessment to fill a gap in resources in the area of pastoral care, counselling and support for rural health professionals. Interviews with eight health professionals working in community palliative care preceded the authoring, designing and development of the learning environment produced on DVD. In rural areas, access to services is often difficult and knowledge of the range of needs of palliative care clients and their families, mostly the primary caregivers may be overlooked, along with the knowledge of ways to meet these needs.

Method

Following a needs assessment, a multimedia learning resource was developed on pastoral care, counselling and support for rural health professionals. The education resource consisting of a comprehensive learning environment is produced on DVD with a multidisciplinary focus. The health professionals who participated in the needs assessment were experts with knowledge of the rural palliative care context. The interviews were subsequently transcribed and analysed to determine the content for the learning environment. The authoring and the design of the learning environment were undertaken by the authors of this manuscript.

The content of the learning environment presents a story of a young man with brain cancer and his journey in dealing with the illness. The end of life care provided by family, health professionals and others is portrayed in a moving story, resulting in an empowering experience for the patient and his family. Embedded in this story using a case-based reasoning (CBR) pedagogy is an up to date, engaging learning environment which consists of reflective exercises, a library of full text resource materials and a repository of real-life expert cases for the user to interact with in making critical judgments in decision making.

Outcomes

The product discussed herein was subjected to an iterative process, prior to the final production of the DVD. Since its release in 2009, we have received requests for the DVD resource from numerous hospitals and health services offering palliative care including the Royal Flying Doctor Service, universities, TAFE and private colleges offering education in palliative care in South Australia, New South Wales, Victoria, Queensland and Northern Territory. Some of these organisations have integrated the DVD resource in their undergraduate education while others have integrated the resource in their professional development programs in palliative care.

Conclusion

The purpose of the paper is to report the development of a learning resource for rural palliative care professionals. Early reactions from the user evaluations revealed that the DVD learning resource is 'versatile, comprehensive and engaging'. It is interactive and can be used as stand-alone and/or in support of other resources in palliative care. The product represents the real world practice of community palliative care and is at the forefront of current thinking in psychosocial care. It complements evidence base practice in palliative care which illustrates the strong effect of psychosocial interventions on the patient and his family. The genesis of this learning environment is proving to be highly useful.

Background

As the incidence of life-limiting diseases and conditions increase there is a strong need for palliative care especially at the end stages of life. The literature on life limiting disorders revealed that the leading causes of death in Australia are coronary heart diseases, cancers, other heart diseases and dementia and related disorders. Life-limiting diseases such as cancers increase as people age. Cancer is the major cause of death for females aged between 25 and 44 years of age, accounting for 35.5% of female deaths. Cancers account for 57.3% of deaths for females aged between 45 and 64 years of ages. Figures are similar for males with cancers accounting for 42.5% of deaths in males between the ages of 45-64 and 38.1% of deaths between the ages of 65-84. The rate of cancer decreases in the population over the age of 85 (Australia's health 2008). Other life-limiting illnesses such as cardiovascular diseases as well as respiratory diseases such as chronic obstructive pulmonary disease (COPD) also increase with age. All of these life-limiting diseases and conditions increase the probable need for palliative care.

Although life-limiting diseases and conditions occur across the generations and sexes, the increase of an aging population does affect the use of medical care, services and facilities. Hospitalisation rates for example for people aged between 65 and 84 years are double the rate for those aged between 25 and 64 years of age. For those people over 85, the rate triples (Australia' health 2008, p. 265). Total allocated health expenditure increases five times over the age range with costs increasing sharply after the ages of 64 years (p. 412).

A study of hospital costs of older people in New South Wales in the last years of life found that the number of days spent in hospital and inpatient costs increased sharply in the three months before death (Kardamanidis, Lim, Da Cunha, Taylor & Jorm 2007). The authors confirmed that a major part of the end-of-life morbidity burden was carried shortly before death. The study concluded that, "Population ageing is likely to result in a shift of the economic burden of end-of-life care from the hospital sector to the long-term care sector, with consequences for the supply, organisation and funding of both sectors".

The aim of our study was to establish the need for an education resource on psychosocial care underpinning pastoral care, counselling and support as well as accessibility of resources for rural palliative care professionals.

The impetus for this study was the Commission for Health Improvement (2001) that declared a decade ago that patients' psychological symptoms are often not recognised with the result that they are not offered access to needed services (Commission for Health Improvement/Audit Commission December 2001), while the World Health Organization (WHO) describes palliative care as:

... an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO 2010)

Likewise, Australia's National Palliative Care Strategy (Commonwealth Department of Health and Aged Care, 2000, p. 4) recognised palliative care as an integration of "the physical, psychosocial, social, emotional and spiritual aspects of care, with coordinated assessment and management of each person's needs" while having a "support system to help the family cope during the person's illness and in their bereavement". Further, the 2006 Declaration of Venice on palliative care research in developing countries included a recommendation for: "A concentration on palliative care research that considers the needs and preferences of individual patients and their families, which takes into account physical, psychological, social and spiritual dimensions of suffering and which makes use of multidisciplinary approaches." (<http://www.hospicecare.com/dv/english.html>).

There is increasing attention in the literature given to psychosocial aspects of palliative care. Hermsen and ten Have (2004) highlighted the marked increase in the number of journal articles exploring psychosocial concepts such as pastoral care, spirituality and religion from 1984 to 2001. While the holistic view of health is acknowledged as the focus of health care practice today, many professionals are still missing the real essence of such awareness, and struggle with offering appropriate help including pastoral care to clients, especially at the end-stage of life.

Smith and Bellemare (1998) contend, at the very root of pastoral care is the discernment of emotional and spiritual issues central to patients and their families while seeking to empower them as they face situations by engaging in activities of guidance, sustenance, reconciliation and healing (cited by Hermsen and ten Have, 2004). In addition, Kirkwood (2002, p.109) points out that pastoral care may also include gestures of touch, presence, words of comfort, counsel, plain interest and concern; while intervention to enable physical distress to be dealt with, adds Swan (2006). Kirkwood's insights (1995) on pastoral care from a Christian perspective in hospitals could transfer easily to health professionals operating from a secular base in the rural setting. Pastoral care is understood to be non-discriminatory and unconditional involvement, a relationship of 'mutual sharing' and empathising with the person who is hurting (Kirkwood, 2002, p. 108; Nouwen, 1998). It is about sensitivity to and assessment of the salient unspoken spiritual, emotional and psychological needs, proffer Kuebler, Davis & Moore (2005) and the very essence of end of life care.

Psychosocial care in palliative care

The National Council for Hospice and Specialist Palliative Care Services (1997) was concerned about the lack of awareness of psychosocial care in palliative care and declared that psychosocial care relates to the psychological and emotional wellbeing of the patients and their families and other caregivers and includes issues of self-esteem, insight into adaptation to the illness and its consequences, communication, social functioning and relationships. Integral to psychosocial care is the wellbeing of the individual experiencing a life-limiting condition and the many challenges faced by the patient, family and their caregivers (Oliver, 2010). While accessibility to palliative care services has increased across the world, there is consensus about the importance of delivering palliative care services that integrates patients' psychosocial needs. But, not all patients have access to such services (Ward, Jemal, Cokkinides, Singh, Cardinez & Ghafoor, 2004). It is our contention that palliative care services do not adequately meet the needs of all patients and has failed more broadly to address the psychosocial needs of these patients (Skillbeck & Payne, 2005; Ward, Jemal, Cokkinides, Singh, Cardinez & Ghafoor 2004).

There is mounting evidence to suggest that the provision of a psychosocial and holistic service provided by multidisciplinary professionals achieve outcomes that are more positive for patients and caregivers. Psychosocial care designed to help the patient and family cope with the illness and its treatment during all stages of the illness, however such care has mainly focused on patients with cancer. O'Connor and Payne (2010) caution, in palliative care family care is central because family members are both partners in the care of the dying person and may themselves require support from health professionals to address their own concerns.

In summary, there is an overwhelming need for education resources to be made available especially on psychosocial care for multidisciplinary health professionals engaged in community palliative care and dealing with end-of-life issues.

Aims of the project

- The aim of this study was to examine the psychosocial aspects of care as determined by multidisciplinary health professionals engaged in community palliative care;
- Through a needs assessment determine the nature and gap in education resources available to health professionals in palliative care;
- Author, design and develop a learning environment using expert practice in psychosocial aspects of care to address the gaps identified;
- Facilitate up-skilling of rural health professionals through accessibility of the learning environment.

Research process

A needs assessment with eight multidisciplinary health professionals working in palliative care preceded the development process of the learning environment. Ethics approval was obtained from the Human Ethics Committee of the research institution prior to the needs assessment and interviews being conducted with the health professionals. The health professionals that participated in the needs assessment were considered to be experts in palliative care by their peers. They were asked the following four questions during interview.

1. In your opinion, why is psychosocial care important to be incorporated in palliative care for patients diagnosed with a life limiting condition?
2. How are the patients' psychosocial needs met by the palliative care service/s?
3. What gaps do you perceive exist in palliative care services in offering patients, family and caregivers' pastoral care counselling and support?
4. How do you envisage these gaps could be overcome?

These health professionals believed that it was crucial to incorporate psychosocial care for all palliative care patients and especially for those diagnosed as having a life limiting condition. They discussed what was considered as psychosocial care which included pastoral care, counselling, and support for the patient, family and caregiver including spiritual care. Their understanding of spiritual care was holistic and secular and incorporated the unique needs and wishes of individuals. They believed while health professionals were committed to delivering holistic care, many had not received education and training specifically on what might constitute psychosocial care and how best to include patients, family and caregivers in providing such care. They overwhelmingly believed that learning resources should be developed with authentic content that was engaging to support health professionals. Moreover, they indicated their willingness to be involved in developing the content, if such a resource were to be produced.

A consultative approach was used involving multidisciplinary health professionals to develop the content for the learning resource which resulted in the storyboard for the short film. Revisions and iterations to the storyboard were undertaken prior to commencing work on the learning environment. Professional actors were cast in the patient and family roles while health professionals were involved in their normal role of caring and supporting the patient and the family.

The case-based reasoning approach

Case-based reasoning (CBR) is a problem solving technique that originated in the United States through the work of Schank and Abelson (1977), which refers to both a cognitive and a computational method of reasoning by analogy with past cases. A basic premise in CBR is that many problems that decision makers encounter are not unique, but rather they are variations of a problem type. The process of solving new problems is based on the solutions of similar past problems. Schank and Abelson (1977) postulated that peoples' general knowledge about situations recorded as scripts allow them to set up expectations and perform inferences and the individual solves new problems by adapting solutions that were used to solve old problems (Riesbeck & Schank, 1989). This is particularly evident in the way experts make decisions and solve problems. As Aamodt and Plaza (1994) cogently put it, CBR is a cyclical process comprising of four REs;

- RETRIEVE the most similar case(s);
- REUSE the case(s) to attempt to solve the problem;
- REVISE the proposed solution if necessary, and
- RETAIN the new solution as a part of a new case (Watson & Marir, 1994).

The CBR approach illustrated in our project is primarily an academic learning tool implemented to illustrate certain aspects of CBR through the experiences of palliative care experts embedded within an online environment. Today, CBR software tools are available as commercial applications and employed by many sectors, such as industry, business, engineering and commerce. The repository of cases presented in our learning environment are contextualised pieces of knowledge representing experts' experiences (Kolodner,

1993; David, 1991; Alterman, 1989). Inherent in these experiences are past lessons which represent the case content and the context within which the case is used. Thus, a typical case would represent a problem as it unfolds and present the derived solution to a specific problem illustrating the outcome of the situation (after the case occurred). The case of the young man with a brain cancer is presented as a typical case in our learning environment with a sequence of events manifesting in a desirable outcome for the patient, family and the caregiver/s.

Application of CBR in palliative care

The CBR approach has provided the conceptual framework for creating the pastoral care, counselling and support learning resources for multidisciplinary health professionals produced on DVD. This is a rich environment constructed as a complex scenario which encompasses decision making on psychosocial issues and in particular involving pastoral care, counselling and support. The scenario in this instance unfolds as unstructured complex problems that are embedded within this scenario that the health professionals (the user) are required to work through. The user is also provided with reflective activities and additional resources in the way of expert narratives, full-text library including URLs which they can easily access.

CBR draws on prior knowledge and is well suited for the on-going education of health professionals. The repository of expert narratives presented as stories is a powerful resource with which they can interact and learn. Therefore, the structure of a program using CBR is quite different to traditional learning materials where the user is provided with print based information and readings. The content of this program incorporates multidisciplinary roles of professionals as advocated by Auty (2005) in pastoral care, counselling and support to engage the user in learning activities on issues that palliative care clients, caregiver/s and their family experience.

The following image presents the organisation of the learning environment presented on DVD. The users navigate the folders and subfolders that open up on the left side of the image which seamlessly integrate graphics as well as text files with which the user interacts.

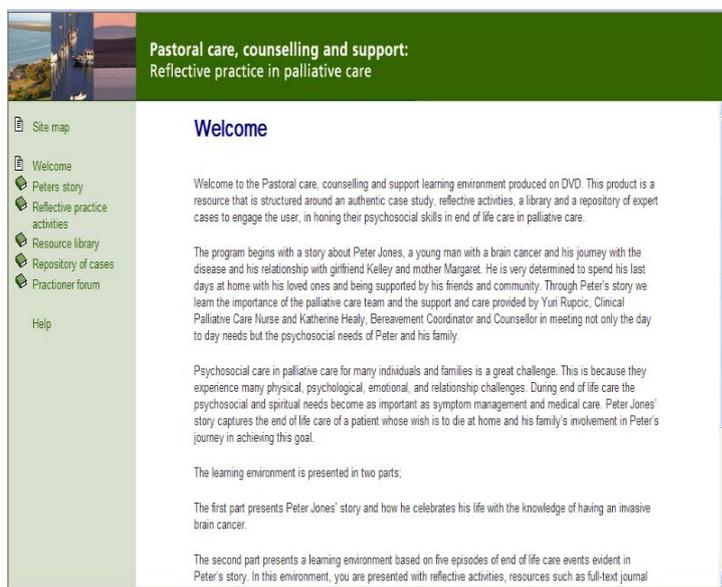


Figure 1 Screenshot from the CBR learning environment

Art as expression of coping with end of life

In the repository of cases we have presented art as an expression of coping with end-of- life issues which is a relatively new concept in palliative care. A narrative accompanies the art displayed as a gallery.

The gallery of paintings presented is a personal expression of a palliative care client who is an artist and their experiences of the palliative care journey, a way of coping with end-of-life issues. The water colour paintings represent the emotions of the artist and how through art she was able to cope with the daily challenges of

living through her condition. Each painting accompanied by a narrative depicts the emotional upheaval and how the artist came to terms with the situation. The use of art in various forms including music, painting, dance, meditation, guided visualisation and so forth as a means of expression in times of existential crisis have been explored by Romo and Gifford (2007), Crow and Banks (2004), Mackinlay (2004), Dossey, Keegan, Guzetta and Kolkmeier (1995). The gallery of paintings presented in our learning environment is unique, as it is a complete body of work by an artist depicting their vulnerability in coping with end of life issues.

Adoption of the product

The product discussed in this paper has received much attention and widely taken up by health services, private service providers for up-skilling staff, universities and TAFE colleges in several Australian States and used in the education of health professionals working in palliative care. The wide adoption of this state-of-the-art learning environment by end users suggests that there is a pressing need for similar products to be made available for up-skilling health professionals because at present such opportunities are limited.

Although the literature revealed other learning programs developed in palliative care using the World Wide Web for practitioners around the world to contribute to an ever growing body of expertise in palliative care (Gavrin, 2009), a combined program of participants self-study utilising a multimedia CD-ROM and 'train-the-trainer' seminars followed a curriculum entitled Education in Palliative and End-of-Life Care for Oncology (EPEC™-O) with American Indian and Alaskan Native Cultural Considerations (Arenella, Finke, Domer, Kaur, Merriman, Ousley 2010) is proving to be useful. The product discussed in this paper is distinct from those others as this provides a seamless learning environment in psychosocial aspects of palliative care integrated with a full-text library, reflective activities and a repository of expert cases.

User feedback

The feedback received from users has been highly positive. The following excerpts are unsolicited:

Thank you for forwarding me a copy of the video/DVD on Reflective Practice in Palliative Care – I have just watched the video and gone through the supporting lecture/tutorial material. The format is excellent and the teaching goals clearly identified and delivered. The use of a younger person as the clinical study will, in my opinion, enhance the impact on students studying this material as it brings home the fact that younger people do die young and do have unique needs. I think the authors should be congratulated on this resource. Thank you again for the opportunity to review this product.
(Director Royal Flying Doctor Service)

The DVD learning package is “versatile, comprehensive and engaging. It is interactive and can be used as standalone and or in support of other resources on palliative care” (Palliative care practitioner).

The DVD resource is “firmly grounded in the real world of practice of multidisciplinary palliative care health professionals. The DVD package is at the forefront of current thinking in pastoral care, counselling and support and complements evidence base practice in palliative care” (University lecturer).

Moreover, “the DVD resource has had a profound impact on the practice of regional and rural health professionals that generally do not have access to high quality learning resources and who have reported a highly positive experience in using the DVD resource and learning about providing pastoral care, counselling and support for patients requiring end of life care” (Health professional).

Reports indicate that the DVD resource has been used to teach palliative care in the undergraduate nursing program, as well as in the post-graduate program. It has been utilised by individual practitioners, regional TAFE Colleges and service providers to up-skill palliative care professionals.

Discussion

Palliative care education discussed in the literature included pain and non-pain symptom management, communication skills, ethics and law and psychosocial care. The overarching perspective is one of seeing human beings as bio-psychosocial spiritual entities (Fitch 2005). There are education resource materials available to support classroom and experiential palliative care training (Weissman & Blust 2005). The types of educational resources available included a psycho-educational intervention for family caregivers of dying patients (Hudson, Aranda & Hyman-White 2005); model of end-of-life curricula for continuing educational

programs for social workers (Csikai & Raymer 2005); an intensive mode cancer-nursing education for rural and remote area nurses (Dewar, Steginga, Dunn, McCarthy, Yates, Beadle and Lancaster (2003) and postgraduate palliative medicine programs (Gwyther & Rawlinson 2007).

Previously health care professionals were able to enhance their knowledge in palliative care, skills and attitudes by utilising these educational resources. However, Bruera, Willey, Cohen and Palmer (2008) contend that there are limited resources addressing psychological and emotional support. Current approaches of specialist palliative care may not be the most appropriate for addressing the complex psychosocial problems of patients, families and caregivers.

Moller, Amadori, Bellos, Cancian, et al., (2002) developed an interactive training program produced on CD-ROM to help general practitioners play a more active role in the management of breast cancer. The program is based on case method, self-test and an encyclopedia. In another product, case-based reasoning was applied in improving pain and symptom management for advanced cancer patients via a user-friendly web-based CBR system to improve decision making for end-of-life patients (Elvidge 2008). Earlier, Tamang, Kopec, Shagas and Levy (2005) developed a computer based program for palliative information systems used by community-based palliative care program.

The learning environment discussed in this paper is distinctive. Our program situates the user within a case-based reasoning environment with reflective activities, supplemented by a full-text library and a repository of expert cases underpinned by a gallery of paintings within which users interact and learn.

Conclusion

There is a pressing need for easy access to contemporary learning resources in palliative care capturing the psychosocial and spiritual dimensions of care to be made available especially for rural health professionals who work in isolation due to distances from urban centres. Early reactions from the user evaluations reveal that the learning resource is authentic in its content, comprehensive and engaging. It is interactive and can be used as, stand-alone and or in support of other resources in palliative care. Importantly, the product represents the real world of practice of multidisciplinary palliative care health professionals. It is at the forefront of current thinking in psychosocial care, complements best practice in palliative care. The paper discussed the impact of a project on psychosocial care by multidisciplinary health professionals engaged in community palliative care and the genesis of a state-of-the-art learning environment that is proving to be valuable.

Currently a large scale evaluation of the product is being undertaken with the end users completing a questionnaire on the educational merit, relevance, authenticity of content, aesthetics, navigation and presentation. The evaluation questionnaire is presented as an appendix in this paper.

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