

'We are not alone' - Expanding knowledge through international learning within children's palliative care.

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Abstract

Educational opportunities for practitioners working with children requiring palliative care are central to future development within the speciality across countries. International educational initiatives involving a range of professionals, **seen** opportune in affording learning with and from others working within the field. This paper examines one such initiative, the use of an international asynchronous discussion forum with students in two countries (Australia and Belfast UK) who themselves work with children and families. The innovation is examined and student perspectives of the forum's value are presented. Students endorsed the value of the forum, identifying three main areas of learning 'Differences across locations within countries'; 'respecting different views and being open' and 'need for continued learning within children's palliative care'. The overarching theme 'We are not alone' supported the idea that participation in the international discussion forum enabled students to see a broader perspective. Ideas for future developments of similar forums are also explored.

150 words (max)

Keywords

International, children's palliative care, asynchronous discussion forum, interprofessional, continuing education.

Paper 3024 words

Introduction

Children's Palliative Care has developed as a small yet distinct area of practice in recent years locally, nationally and internationally (Liben et al, 2008). Brought about as a result of advanced care and technology, increased numbers of children with life limiting conditions and their families require sustained support and services, throughout the child's life and beyond (Price and McNeilly, 2009). Strategy across countries highlights the centrality of education both for the undergraduate and continuing education student (ACT,2009; DoHC, 2010). Further, international collaboration has been identified as key in future developments within the field (ACT, 2009; ICPCN, 2010). Given that the numbers of children requiring a palliative approach to care are much smaller than those within the adult population, the resultant numbers of professionals providing the care are similarly fewer. Consequently, providing education for those who need it can be challenging, particularly around affordability and accessibility, geographical diversity and numbers of people requiring such courses (Downing and Ling, 2012). Given such challenges, opportunities for using technologies and for international educational collaborations are therefore immense. This paper will explore an innovative online collaboration between professionals working with children who have palliative care needs and their families in Australia and Northern Ireland as they undertake continuing education studies within this area of care (see table 1 for an outline of each programme).The practicalities of setting up this type of learning initiative will be outlined, highlighting the influence on student learning and exploring the implications for future educational practice..

Table 1: Background to programmes

Queens University Belfast

The 'Palliative care for children and families' educational initiative at Queen's University Belfast commenced in 2004 following the early development of specialist children's palliative care services within Northern Ireland, including the first children's hospice (Price and McNeilly, 2006). The module runs over the course of the academic year from September to May and comprises one afternoon session per week with the aim of building on students' existing knowledge and experience. Students are trained staff from various disciplines who currently work with children and young people requiring a palliative approach to care in the hospital, hospice or home setting. Over the years, the module has been updated to respond to the needs of practitioners, student evaluations, innovations within higher education along with local and national policy directives. Most recently it has also been aligned with the Royal College of Nursing Competencies for palliative care for children and young people (Royal College of Nursing, 2012). Thus the ongoing development of the module is a dynamic and cyclical process from needs assessment to outcomes (see Peyton, 1998) for practitioners as well as the families they care for. However, the overall core content has remained generally consistent and includes issues such as the development and principles of palliative care for children and families, supporting children and families, communicating with families, including breaking significant news, spiritual care, symptom assessment and management, the provision of respite care, ethical and legal issues, care of the dying child and their family and bereavement care. Key educational principles of the module include the need for student centred (as opposed to teacher centred) learning, an interactive and facilitative approach within the classroom, the incorporation of self-directed learning in order to foster a deeper sense of learning and the inclusion of a reflective approach in order to link theory, research and practice in a meaningful way.

The University of Melbourne

The University of Melbourne Paediatric Palliative Care pathway established in 2011, aims to enable health professionals to develop and consolidate skills when caring for children with life limiting conditions. Similarly to the course in Belfast, the Melbourne course focuses on palliative approaches to care, the diversity of diagnostic groups, symptom management, psychosocial and ethical issues for palliative children and their families. Throughout the course work, students have the opportunity to participate in a variety of teaching methods including; workshops, seminars, tutorials and role playing with much emphasis placed on adult /group learning and sharing.

The Paediatric Palliative Care course is an elective subject of the University of Melbourne's Specialist and Graduate Certificates in Palliative Care. Coordination and curricula development and management are provided by the Victorian Paediatric Palliative Care Program, Royal Children's Hospital. Targeting clinicians working in both hospital and community settings attendees on the course include doctors, nurses, social workers, physiotherapists, occupational therapists, pastoral care workers and music and art therapists. The course curriculum includes completing an online module - Evidence Based Palliative Care and attending four study days; Illnesses Encountered in Paediatric Palliative Care, Symptom Management in Paediatric Palliative Care, Psychosocial and Spiritual Aspects and Ethics. In addition, each student is assigned a clinical mentor who is an experienced paediatric palliative care clinician. Students are required to complete [a](#) self-directed clinically focused learning activity, in consultation with this clinical mentor.

Educational Strategies in Palliative Care

The education landscape is constantly changing with an ever increasing array of innovative tools aimed at engaging students with learning. Methods implemented to respond to palliative care health professionals' teaching and learning needs have expanded over the last twenty years and now include; the use of technology for online learning, case based learning, bedside teaching and reflective practice (Kidd et al., 2010). A mixed modality model for delivering education is consistent with the broad range of student learning styles and has the potential to engage students in a variety of ways and assists in transferring the learning into a meaningful experience for each individual (Merriam 2001). Moreover, most universities currently integrate blended teaching models that incorporate face to face teaching complemented by an interactive online component. Online learning is just one design methodology employed to stimulate students' participation in the learning process. However, it should be noted that there is a distinct lack of rigorous empirical data to guide the use of online teaching and learning. Importantly, it is acknowledged by both students and teachers that online interaction promotes a sense of connectedness between learners; and learners and teachers by creating a sociable learning culture (Goodyear, 2005).

A plethora of online palliative care education courses have been developed over the past ten to fifteen years, primarily in the United Kingdom, United States and Australia, with a target audience dominated by doctors and nurses (Kavanaugh et al., 2009). The content and priorities for informing the agendas of palliative care education have largely been developed by national and international standards that guide best practice within palliative care. For example, the World Health

Organisation provides a definition of palliative care for adults and children, which requires health professionals to be able to respond to "... 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, 2014). Thus currently, there is a focus on the skill required by palliative care health professionals to be able to respond competently to the needs of patients and families. A more recent advent in online learning platforms has been the emergence of interactive collaborations, including providing students with the opportunity to participate in guided discussions with peers (Wearne et al, 2011).

Online programs including the use of on line platforms offer flexibility, are accessible to a larger student cohort than is possible with face to face teaching and are thus considered to be a cost effective way of responding to a learning need as well as having a greater geographical reach and being accessible to students internationally. Access to the internet is considered the norm for health professionals working in developed countries around the world. However, it is important to consider strategies that will enhance the experience for online learning. Chickering&Ehrmann (1996) developed seven principles (see table 2) that provide a check list for online learning.

Comment [JC1]: Table added

Despite the explosion of technologies and their utilisation within education in the intervening years, the principles still appear very relevant and were of great use within the international on line discussion forum examined here.

Table 2: Chickering & Ehrmann (1996) Seven Principles for on line learning

1. Ensuring interaction between student and teacher, with both contributing to the learning direction and process
2. Ensure learning is collaborative and social to promote engagement
3. Encourage reflection and self-identification of learning opportunities
4. Teachers should strive to provide prompt, regular feedback to the students to maintain the momentum of interest
5. Time management both in terms of student commitment to complete tasks and teacher commitment to ensuring the workload is reasonable and relevant
6. Encourage high expectations and students will respond appropriately
7. Recognise strengths in students and encourage the sharing of skills for the benefit of all students.

Children's palliative care is a relative new specialty and has likely benefited from the experience gained by other more established specialties with regard to successful teaching styles including palliative care teaching focused on care for the adult population. Little however has been written about the development of on-line educational initiatives within children's palliative care to date, which is surprising given the centrality of education within strategic future directions of this fledgling speciality. This paper aims to part way readdresses such gaps in knowledge by examining students views of the use of an on line platform instigated internationally between practitioners caring for children with palliative care needs within 2 developed countries in Northern Ireland and Australia.

The Initiative

A virtual learning environment was created for students undertaking an educational programme in children's palliative care whereby students in Australia and Northern

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Ireland could learn with, from and **about each other** through a moderated discussion

forum. **It is important to recognise that despite the geographical and cultural differences between the 2 countries, configuration of services for children with palliative care needs and their families in both locations are free at the point of use and share other common features. These features include: ongoing partnership working between hospital, community and hospice sectors, the care of children with both malignant and non-malignant or degenerative conditions, a key emphasis on quality of life for the child and family and the provision of care led by teams of specialists with responsibility for supporting and building capacity in others.**

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Chickering and Ehrhamm's, (1996), seven principles were integral to the decision making involved in planning the initiative, providing invaluable guidance to educators in maximising student learning (as evidenced below).

Students (n=14) from **a cross both countries -range of professions-** were **invited asked** to discuss current and future challenges within children's palliative care strategically and within their own practice. **Twelve students participated, including 9 nurses, 2 medics and 1 social worker.** The discussion forum was open for two weeks to permit students the freedom to participate at a time which suited them and allowed flexibility given the time difference across the countries. This time frame seemed reasonable and manageable for students given the other workload within the module but ensuring enough time for permit flexibility was permissible (principle 5). Students were required to draw up a "pen portrait" which acted as an on-line professional

profile to provide insights into the roles and profession of each participant. This was provided to enable clarity amongst students regarding individual's roles, experiences and strengths. The on line educational initiative enabled students to explore current models of service provision across two countries while promoting student awareness as to the challenges and issues in providing palliative care from an international perspective. Students in each institution were provided with an introduction by their respective course tutor regarding the aim of the learning activity. The moderation was undertaken by educators from both institutions and in keeping with the facilitative approach of the programmes and directives suggested by Chickering and Ehrhamm, (1996), the course team facilitated deeper learning during moderation, prompting them to for example think of another aspect of care or reflect deeper on an issue raised (principle 3). Such interaction between students and teachers, helped as principle indicated in giving the learning direction and process (principle 1).

Encouraging the students to link theory and practice, students were asked to draw on literature and policy within their discussion, citing these appropriately. Consistent documents were provided to both student cohorts, including guidelines for accessing the discussion forum and rules of using the discussion forum. Such guidance included issues around confidentiality, the importance of not using identifiable names, respecting the opinions of other students. All students accessed the forum through the University of Melbourne portal and all members of the teaching teams from both institutions also had portal access. Given that this was a new initiative, it was viewed as essential that feedback was collected from the students that had taken part. Their insights were seen as crucial to future usage and potential developments of such learning strategies in the future.

Collecting student perspectives

The questionnaire for collecting feedback was designed specifically for this activity and used a likert scale to enable students to rank certain aspects of their experiences with the discussion forum. In addition they were asked to list their three most meaningful areas of learning, that resulted from participation in the discussion. The questionnaire comprised of three sections (See table 3).

Table 3: areas examined in the questionnaire

Section Heading	Information Sought
Section 1: General Issues	Previous experiences of using on line discussion forums
Section 2: Participating in the discussion forum	About the practical issues around taking part in the discussion.
Section 3: International Online Discussion Forums as a means of learning	Views around engaging in on line discussion forums with international colleagues.

Fourteen students were invited to take part across both institutions, two did not participate. The 12 who did take part all responded to the questionnaire. Questionnaires were collected within two weeks of the forum closing by each respective university and collated. Ethics approval for evaluating this new initiative was sought and granted from both universities. Students were aware that the

information shared should they chose to participate could be used in publications and presentations in the future.

Findings

. Six of the 12 students who took part in the discussion forum had participated in similar forums previously. Despite this only one expressed feeling anxious prior to participation and this rose from fear of navigating the system. No students had difficulty logging on and only one student reported technical difficulties using the forum and that related to posted responses (which they found a bit confusing). All students agreed that the pre-instruction was clear and relevant.

Comment [JC2]: This sentence was changed to make the point clearer

Overall, all students endorsed the value of the discussion forum in relation to gaining international perspectives regarding children’s palliative care. The students indicated the learning activity created a more meaningful and memorable learning experience when compared with reading international policy documents or undertaking a classroom based activity in their own institution about global issues related to caring for children with palliative care needs and their families. Varying degrees of value were indicated by the students (See table 4).

Table 4: Overall value ratings indicated by students

Rating	Number
Excellent	2
Very Good	7
Good	3
Fair	0
Poor	0

With regards to the free text [responses in Section 3 of the evaluation](#), ~~in response to the question encouraging~~ students ~~were required~~ to name ~~three~~3 things that they learnt through participating in the discussion forum. ~~a number of recurring points~~

~~were listed. Overall~~ the overarching theme that ~~appeared to capture~~ students' perspectives of what they learnt was 'We are not alone'.

"The same issues were experienced locally as internationally ie challenges re resources — we are not alone" ~~(do you have a professional eg nurse to identify who said this?)~~

Students indicated that the discussion enabled them to ~~importantly~~ consider the broader context of care, recognising that whilst at times they felt isolated in their struggle to provide best care to children and families that many of the issues experienced were similar regardless of their country. A number ~~of~~ other themes arose which contributed to the overarching theme, those being:

- ~~'Similarities across countries and professions';~~
- ~~'Differences across locations within countries';~~
- ~~'respecting different views and being open' and~~
- ~~'Need for continued learning within children's palliative care'.~~

~~Practitioners~~ ~~Students expressed that the discussion about~~reported that the challenges and future developments regarding palliative care for children helped them explore common issues such ~~as~~ parental reluctance to accept 'palliative care' services, barriers such as resources, recruitment of staff if a child is suddenly sent home, concerns about knowledge and rarity of symptoms.

What also was made clear was that within each country there were differences within the same country dependent on location. These differences led to what was described as inequitable services, for example some rural areas had better access to equipment than others, creating particular challenges for practitioners.

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The other commonality across student responses was how ~~students felt~~ the discussion forum enabled them to realise the importance of ~~seeing~~ different perspectives and being open to different viewpoints:-

'Broadens the pool of knowledge/information and gathering/sharing experiences to beyond my immediate setting' ~~needs to be assigned to a responder~~

For example, the inter-professional aspect of forum participants seemed to be an influencing factor regarding this broader perspective.

The areas of learning identified throughout student responses was that students felt that the forum highlighted to them the need for continued learning and education within children's palliative care for themselves and for other colleagues. Many students indicated that they experienced exposure to children with palliative care needs on a less frequent basis, thus it was difficult for them to develop and maintain skills and confidence. Attending educational programmes and learning with/from others enabled sharing experiences and thus increased knowledge.

Discussion

The student perspectives raised following contributing to the online discussion endorse the value and potential power of an international on line discussion forum whilst undertaking an educational programme in children's palliative care. Consistent with the literature, students reported that the small group online forum provided them with a meaningful learning opportunity that was enhanced by an awareness of the experiences of other students internationally (Kim, 2013).

Despite the different geographical locations students undoubtedly identified many similarities in experiences with some subtle differences noted, for example differences in availability of services within countries and also the roles of other

professions within their teams. The ~~online discussion learning experience created for students through this educational approach~~ enhanced the learner's experience whilst creating learning that was meaningful, memorable and enabled students to obtain a much broader, more global perspective of care and service provision within children's palliative care.

From a teacher's perspective setting up the discussion forum took much time and commitment as it involved overcoming challenges for example getting all participants ~~to access to the online~~ platform in one university. Further the different configuration of the academic ~~teaching~~ terms in both countries meant that the Australian students had only recently commenced their programme whilst students on the UK course were coming to the end of their programme. The different ~~academic~~ stages of students meant that the subject under discussion had to be quite broad and based on their practice rather than specific scenarios related to learning on their respective programmes.

A problem occurred with the pen portraits in that these were not displayed to all students from the commencement of the discussion forum, this was noticed and rectified during the ~~two~~ week period but all students did not use them. Those that were unaware of their existence felt they would have been useful in giving them some insight into the professional background and experience of those that they were talking to. ~~These~~ students who did use the ~~pen portraits~~ found them very beneficial, ~~this which~~ is something we need to correct in the future.

Whilst this initiative was with a ~~reasonably~~ small group of students, ~~it is apparent that~~ on line learning and technology provides a potent means of enhancing student learning within a speciality where numbers are relatively small, and ~~as a where~~

~~consequence~~ providing viable education programmes can be difficult. Given student suggestions and lecturer views, future developments of this type of forum could usefully ~~include~~ explore the potential for students undertaking to undertake an education programme observational clinical placement in children's palliative care at an institution from a different country, ~~to wider the discussion further and potentially the learning for students. It was suggested by students~~ Such a programme would enhance the learning of both institutions while providing an enticing incentive to students.

Students suggested that a case scenario (observing confidentiality) could be ~~used~~ facilitate discussion in the second week of the program. giving ~~This would provide~~ them an opportunity to explore the care of a particular child and family, to apply decision making and problem solving strategies, whilst examining how care may be different and also similar depending across countries.

Comment [JC3]: Expanding the implications for practice as identified by reviewer 2.

Lecturers from both organisations moderated the forum and close moderation was viewed by the team as central to the success of the forum in that they kept the discussion on track. The lecturers who moderated were aware of the centrality of their role in that failure of moderators to guide discussions can result in less student learning and lead to student frustration which in turn can lead students to lose purpose (Keengwe & Kidd, 2010). The lecturers were able to keep the discussion developing using a variety of techniques which included encouraging thinking, posing questions to extend the conversation further to develop student thinking and; give praise and encourage those participants who may be more reserved about ~~the~~ contribution (Keengwe & Kidd, 2010).

Children's Paediatric palliative care is likely to continue to be an important but small specialty area of clinical practice. Therefore, creative ways of ensuring professional development opportunities are viable are critical to the survival of the speciality. Online forums and moderated discussions are one strategy that once they are established can support clinician learning, collegial discussion and improve practice awareness. However, the technological requirements for an online discussion forum obviously limit the relevance of this type of learning program to countries with education programmes and reliable internet access. This is recognised as a limitation of the program to the broader international children's paediatric palliative care field.

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Conclusion

This paper has outlined a pilot international educational online discussion learning initiative that was used successfully to enhance students' undertaking continuing understanding of education programmes in children's palliative care.

Learning with, from and about others on a moderated on line discussion forum, enabled participants to see perspectives of other professional groupings and learn of challenges in other countries. Whilst this initiative only gave the perspectives of a small group student cohort in two countries, there is no doubt about the potential scope for extending this to other institutions and other topics. The initiative indicates that there is relative merit in using on line forums in small specialities such as children's palliative care to enhance student learning.

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