

DEVELOPING A LIBRARY OF EDUCATIONAL RESOURCES FOR THE PALLIATIVE CARE COMMUNITY



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Provision of effective palliative care is a globally important issue. This article describes the journey of ecancer, specialist providers of oncology education, from developing an e-learning course in palliative care to recognizing the importance of palliative care education on a long-term basis and striving to create a comprehensive library of resources.

Initially, ecancer, through their Founder and Chair Professor Gordon McVie, worked in partnership with the Cardiff University palliative care team led by Dr Fiona Rawlinson and with The African Palliative Care Association, through their Executive Director Dr Emmanuel Luyirika, to develop a 20 module course in palliative care. This article describes the processes the collaboration undertook to develop the content, the format of the modules as well as feedback from learners. These resources are available for free for African health-care professionals through ecancer's open-access educational platform (www.ecancer.org). This article also describes other initiatives in palliative care education, which include video interviews with leading figures, the publication of a special issue dedicated to palliative care and future plans to develop a new e-learning course in partnership with the Indian Association of Palliative Care for health-care professionals in their country.

Supporting the global palliative care community is extremely important through education and awareness to help recognize its importance within health care. There are many organizations and individuals working on this vital issue and ecancer hopes to be able to leverage its resources to contribute in any way possible.

In early 2013, ecancer was commissioned by the Programme of Action for Cancer Therapy (PACT) to develop an e-learning course in palliative care for health-care professionals in Africa. As a not-for-profit oncology channel that is committed to improving cancer communication and education with the goal of optimising patient care and outcomes, ecancer had always published information and education on palliative care when possible, but it had not been a main focus of our activity (www.ecancer.org). Over the next couple of years as we discovered more and more about palliative care education this changed and ecancer is now actively engaged in becoming one of the leading global resources for online palliative care education.

Education in palliative care is a hugely important issue as

sparing terminally ill patients unnecessary pain and allowing them to die with dignity is seen as critical by the UN Committee on Economic, Social and Cultural Rights (1) as well as being identified as a fundamental human right by a number of other leading organizations.

According to WHO Global Health Estimate, in 2011 20.4 million people were in need of palliative care at the end of their lives, with 9% of those in Africa, and the *Global Atlas of Palliative Care at the End of Life* recognizes that "the need for palliative care has never been greater and is increasing at a rapid pace due to the world's ageing population and increases in cancer and other noncommunicable diseases" (2) so the global need is on the rise. Palliative care is also an extremely important issue in the field of oncology as cancer accounts for 34% of the adult palliative care needs in the world (3).

E-learning project

ecancer are specialists in oncology education and communication and therefore sought additional expertise in palliative care to ensure that we were able to deliver the best e-learning course possible. We felt the particular importance of delivering an excellent end product as palliative care is such an important area and “the vast majority of health professionals have little or no knowledge of the principles and practices of palliative care” (4).

To ensure the e-learning course was developed to the highest international standards ecancer partnered with the palliative care team at Cardiff University which has been providing a distance learning course in palliative medicine and palliative care since 1987. The team is led by Baroness Ilora Finlay and Dr Fiona Rawlinson, who has experience of teaching in Africa and has a good understanding of the complexities of palliative care delivery in Africa. Professor Finlay has been on the board of the Diana Fund advising on the provision of funding to palliative care service development across Africa and research into effective patterns of service delivery, which provided her with insights that proved invaluable to the success of this project.

Regional expertise was also sought and collaborations were formed with the African Palliative Care Association (APCA), through their Executive Director, Dr Emmanuel Luyirika, and the University of Cape Town (UCT) through their Head of the Palliative Care Unit, Dr Liz Gwyther, to help provide expert insight and support throughout the project alongside a pre-existing network of leading figures in African health care known as the “VUCCnet Focal Points” which PACT has created.

Content development

The first stage of the e-learning course development involved reviewing existing educational materials to ensure the content created was complementary to these existing resources. Throughout this process the existing educational material, which formed Cardiff University’s “Short Course in Palliative Care” was constantly being refreshed to ensure that it was appropriate for health-care professionals in Africa and that the latest regional guidelines and best practice were incorporated. The content was reviewed to ensure its suitability for the African environment in alignment with key documents including the *INCTR Palliative Care Handbook* and *Developing e-learning in palliative care education in sub-Saharan Africa: Ideas and examples for the selection of appropriate media and technology* (a document produced by the Diana Princess of Wales Memorial Fund, the Sobell House Hospice and the African Palliative care

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Association). The next stage in the process was a meeting of all of the key stakeholders which was hosted in Cape Town by UCT and involved a review of the plans as well as laying out a framework that would allow the course to be developed and published in time for the African Organisation for Research and Training in Cancer (AORTIC) Conference in 2013 which was held in Durban, South Africa. Once the draft curriculum was finalized, the course was divided into 20 modules:

- Basic principles of palliative care;
- Overview of malignant disease;
- Medication;
- The role of chemotherapy, radiotherapy and surgery;
- Pain management;
- Palliative care emergencies;
- Symptom management: Confusion and delirium;
- Symptom management: Constipation and bowel obstruction;
- Symptom management: Nausea and vomiting;
- Symptom management: Respiratory symptoms;
- Symptom management: Skin and mouth care;
- Symptom management: Weakness, fatigue and loss of appetite;
- Paediatric palliative care;
- Communication and counselling skills;
- Ethics in palliative care;
- Spiritual care;
- Psychosocial care;
- End of life care;
- Grief and bereavement;
- Resources.

Module development

Through consultation with the project partners, it was decided that the educational elements of the project would be most effectively delivered in a video lecture format broken down into manageable one to two minute digestible

sections, with supporting written slides that reinforce the key educational points. Due to limited bandwidth availability across Africa, a text-only version of the course was also developed with the same materials presented without the need for videos. The content was created to highlight clinical best practice with a key focus on developing long-term improvement in behaviours and each module followed the same format, with an introduction involving educational aims and objectives as well as a pre-module quiz to identify existing knowledge. The educational content of the module was then presented with interactive elements and continuous evaluation to help ensure key elements are fully understood by the learners. The key educational points of each module were then reinforced at the end of the module and learners complete the post-module quiz to demonstrate knowledge gain. The conclusion contains extra resources, an opportunity for feedback as well as an opportunity to reflect on what they had learnt and make a pledge on how they were going to implement

what they had learnt and what changes they were going to make to their clinical behaviours when they saw patients in the future.

Filming of the educational content took place at multiple locations across the United Kingdom and Africa over several months and involved producing footage of 41 leading experts in the various different elements of palliative care and patients who were happy to share their experiences.

Testing and peer-review

The first drafts of the modules were produced for testing at the APCA 2013 Conference in Johannesburg, South Africa. During the testing period 32 African health-care professionals with varying levels of knowledge of palliative care were invited to test the modules, their feedback was collected, analysed and guided the creation of additional resources which were produced in collaboration with

leading experts who were attending the conference. These additional materials were then incorporated into the modules which were peer-reviewed in collaboration with the VUCCnet Focal Points as well as contacts provided by APCA.

Launch and dissemination activity

The modules were launched at the AORTIC conference in Durban, South Africa in November 2013 with a poster presentation, distribution of promotional materials, inserts in the delegate's bags and a presentation to the VUCCnet stakeholders.

Additional promotion took place in association with APCA, AORTIC and hospice organizations across Africa. This included promotion of the modules through the e-newsletters and on the websites of organizations including:

Figure 1: Content for a typical module

The introduction includes learning objectives that are explained to ensure learners have clear goals

Pre- and post-learning quiz to demonstrate existing knowledge

Education is delivered in multiple formats including video lectures

Interactive diagram educational format

Key educational points are reinforced at the end of the module

Learner evaluation to feed further course design

Table 1: The post-module survey

1. How would you say your clinical behaviour has changed as a result of this module?				
Considerably worse	Worse	Neither	Improved	Improved considerably
0%	0%	0%	67%	33%
2. I feel more confident in treating patients as a result of this module				
Strongly disagree	Disagree	Neither	Agree	Strongly agree
0%	0%	16%	56%	28%
3. Do you think that you will continue to use your new skills in the future?				
Very unlikely	Unlikely	Neither	Likely	Very likely
0%	0%	0%	17%	83%
4. Would you recommend this module to your colleagues?				
Very unlikely	Unlikely	Neither	Likely	Very likely
0%	0%	0%	56%	44%

- promotion through the APCA newsletter and on their website;
- over 350 cancer organizations, hospitals and hospices in collaboration with AORTIC;
- promotion to ecancer’s registered users;
- social media marketing campaign.

Course impact

Two hundred and ninety-one African health-care professionals have engaged in learning through the course with over 649 completed modules.

Geographical spread of learners

The learners who have taken the modules through ecancer represent a good spread of different countries across Africa as represented in this diagram (learners are from the countries in red).

The five most popular countries were:

- Kenya – 44;
- Nigeria – 38;
- South Africa – 31;
- Uganda – 31;
- Zimbabwe – 26.



Sample learner reflections

- “I will encourage the greater availability of pharmacological medications and will try to get the policy changed on this” – Doctor, Mozambique
- “Delirium is a very important factor when treating patients” – Doctor, Zimbabwe
- “I will use the FICA tool for patients’ spiritual care” – Nurse, Tunisia
- “Don’t forget to assess what is normal bowel routine for

- patients” – Doctor, Madagascar
- “The importance of body language and play language when communicating with children” – Nurse, Sudan

The resources developed as part of this initiative are available free for health-care professionals through www.ecancer.org/education and PACT’s Virtual University for Cancer Control (VUCCnet).

Outcomes measurement

The ultimate aim of all of ecancer’s educational resources is to impact on clinical care and patient outcomes. Reliable measurement of this as a result of e-learning activity is extremely challenging but also extremely important to demonstrate effectiveness and to justify continued support in this area.

To help measure the effectiveness of our resources, ecancer has a communication and feedback system where learners are asked to reflect on their new knowledge once any module has been completed. Learners are asked to pledge how they will use their new knowledge to improve their clinical practice next time they treat a patient. We then contact the learners one and three months after completing any module by email to evaluate if they have been able to put this practice change into action. Learners are invited to complete a survey which contains four questions which are quick and easy to complete, the responses are measured on a five-point Likert scale and we currently have a 2.8% response rate with the following results shown in Table 1.

Future plans

Now that the valuable resource has been developed and is available for African health-care professionals, ecancer is in

the process of making this available to other regions of the world with a focus on low- and middle-income countries (LMICs). This is particularly important as 78% of adults and 98% of children in need of palliative care at the end of life live in LMICs (4). The first step in this process is already in place through collaboration with the Bangalore Hospice Trust, Karunashraya, and the Indian Palliative Care Association through their Chairman, Dr Nagesh Simha. Review of the existing materials has already begun, the course began production alongside the 22nd International Conference of Indian Association of Palliative Care in Hyderabad, India, February 2015 (<http://iapcon2015hyd.com>). The course is being tailored to the needs and resources available to Indian health-care professionals and will be made available for free through ecancer.org with the launch scheduled for September 2015. Additional funding is also being identified that will allow the course to be translated and tailored for the Francophone African community as well as being made available in Spanish and Portuguese for the Latin American audience. This project and the additional opportunities that are now in progress have offered an exciting opportunity for [ecancer](http://ecancer.org) to be able to establish itself as a leading global resource for palliative care education and to hopefully improve the quality of palliative care offered across the world.

Additional library of resources

During the development of the e-learning course, it became apparent to [ecancer](http://ecancer.org) that there is a great deal of high quality work being done in the field of palliative care and oncology in Africa. As a not-for-profit organization that aims to improve education and communication in the field of oncology, we wanted to embrace the contacts and impetus that had been created throughout the e-learning development process. In order to develop the course we visited Africa a number of times, and had many conversations with leading figures in the world of palliative care that were keen for [ecancer](http://ecancer.org) to assist in improving the dissemination of the latest research and developments.

[ecancer](http://ecancer.org) has a library of over 3000 videos covering a whole range of oncology topics and we were keen to add palliative care resources as well as some specifically focused on cancer in Africa. We published a number of interviews with leading experts from conferences including AORTIC 2013 and the African Palliative Care Association 2013 Conference; these videos have been viewed over 70,000 times in total.

In addition to this, [ecancer](http://ecancer.org) published articles in its peer-reviewed journal with an editorial titled "Collaboration across continents to produce e-learning for palliative care

education in sub-Saharan Africa" and a special issue of our journal called *Palliative care in Africa* which was guest edited by Professor Anne Merriman who was a founder member of the African Palliative Care Association and was recently nominated for the Nobel Peace Prize. The special issue contains five articles covering varying topics in African palliative care, it was published for free and is available open-access.

Conclusion

[ecancer](http://ecancer.org) was originally commissioned to develop an e-learning course for health-care professionals in Africa. By leveraging the wide-ranging expertise available to us in the field of online education, we are able to expand the lifetime of that project to develop a whole range of additional resources which are available for free to the oncology and palliative care community. We are now tailoring the e-learning course to make it suitable for health-care professionals in India and beyond, with a key focus on ensuring we are able to maximise the educational opportunities these new networks and interactions bring. All of this has been done with patients at the core; the aim is for the education and information we have developed in collaboration with our many partners to assist the global health-care community with our shared goal of improving patient care. ●

Acknowledgements

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Danny Burke is Head of Education at ecancer.org, the free educational platform for the oncology community. He has a Postgraduate Certificate in online education and has worked at a number of oncology and education charities in fundraising, business development and resource development. Danny has a passion for demonstrating the effectiveness of online educational interventions and, together with [ecancer](http://ecancer.org), is leading the way in recognizing its importance.

Dr Fiona Rawlinson is a Consultant in Palliative Medicine in South Wales, UK, and Course Director for the Palliative Care Education Department at Cardiff University. Supporting creative and innovative education in palliative care underpins her work. The most recent project was a collaboration with [ecancer](http://ecancer.org) and African Palliative Care Association, which has resulted in 20 open-access online learning modules for palliative

care in sub-Saharan Africa. This work is being further developed for Indian palliative care education.

Professor Gordon McVie is widely regarded as a leading international authority in the research and treatment of cancer. He is currently Senior Consultant to the European Institute of

Oncology, Milan, and is founding editor of *ecancer.org*, *ecancerpatient.org* and *ecancerLatinoAmerica* – open access free educational websites for the global oncology community.

He is a visiting professor at Kings College London, the University of Milan and the University of Wales.

References

1. Committee on Economic, Social and Cultural Rights (CESCR) General Comment 14, para. 25.
2. Baxter S et al. *Global Atlas of Palliative Care at the End of Life*. Worldwide Palliative Care Alliance: 2014.
3. Jemal A, Vineis P, Bray F, Torre L, Forman D (Eds). *The Cancer Atlas*. Second Ed. Atlanta, GA: American Cancer Society; 2014.
4. Baxter S et al. *Global Atlas of Palliative Care at the End of Life*. Worldwide Palliative Care Alliance: 2014.

Library of resources

- Palliative care e-learning course for health-care professionals in Africa (text only version): <http://ecancer.org/education/course/4-text-only-version-of-the-palliative-care-e-learning-course-for-healthcare-professionals-in-africa.php>
- AORTIC 2013 Conference interviews: <http://ecancer.org/conference/349-aortic-2013.php>
- African Palliative Care Conference 2013 interviews: <http://ecancer.org/conference/678-african-palliative-care-association-conference.php>
- Editorial – Collaboration across continents to produce e-learning for palliative care education in Sub Saharan Africa: <http://ecancer.org/journal/editorial/36-collaboration-across-continents-to-produce-e-learning-for-palliative-care-education-in-sub-saharan-africa.php>
- Special issue – Palliative Care in Africa: <http://ecancer.org/special-issues/6-palliative-care-in-africa.php>