

Special Edition
**"Palliative Care and Oncology:
 Time for Increased Collaboration
 and Integration"**

Commentary

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Delivering Palliative Care Education where there is Little Concept of Palliative Care: The Cultural Challenges

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ABSTRACT

Volunteering to teach abroad in a country where palliative care is not well-established, either as a concept or service, is professionally stimulating and challenging. It provides an opportunity to learn about other social and healthcare cultures and challenges one's own views and attitudes. Sharing knowledge and skills with others, is a two way experience that enriches one's practice and provides motivation for change. It is also an opportunity for reflection and re-focusing for the busy professional and to be recommended. In this paper we seek to describe some of the challenges you may face and ways around them. We look at subjects such as the need to know and respect the culture we will travel to, explore ideas around truth-telling, concepts of honour and shame and training in countries where there are limited resources and opioids. We shall also comment on introducing new methods of teaching and making them relevant for different subjects. This is drawn from over 20 years of experience by volunteer educators working under the auspices of PRIME (Partnerships in International Medical Education), a UK charity.

KEY WORDS: Palliative care; Education; Teaching; Culture; Developing countries; Volunteer; Multi-disciplinary team.

INTRODUCTION

There are significant inequalities in the provision of basic healthcare in the world. Over a billion people worldwide lack access to even the most basic facilities, often because there are no trained workers. Palliative care and end-of-life care is recognized as an integral part of provision of good healthcare in many countries. However, where resources are limited it is often seen as a fringe benefit or not recognized at all.¹ Whilst delivering education in these circumstances is challenging, the transferable skills learnt can have far-reaching benefits in other areas of healthcare service provision. With sensitivity and humility, palliative care education can be delivered that is both culturally sensitive and relevant. In 2016 PRIME (Box 1) supported more than 100 tutors visiting 25 different countries and teaching over 4300 healthcare workers in a variety of topics.² You may find yourself in a position to be able to travel abroad to teach and this short paper seeks to share some of the cumulative knowledge that PRIME tutors have acquired over the years, beginning with:

Box 1

PRIME (Partnerships in International Medical Education) is an international network of professional healthcare volunteers, who deliver healthcare education. This education is based on the concept that the effects of illness impact on the whole person - mind, body and spirit - and attention to all aspects of the person are taught. PRIME tutors are Christian, however all the teaching is accessible and relevant to those of all faiths or none. The tutors fund their own travel and attend at the invitation of the host organisation.

Recognizing Where We are Coming from

We may live in a culture where palliative care has been established for a number of decades. Most of our colleagues and many of our patients embrace the benefits of palliative care in advanced symptomatic disease. Indeed society respects palliative care. We see advances in diagnosis and treatment leading to prolonged survival. We teach about palliative care happening 'early in the course of illness, in conjunction with other therapies that are intended to prolong life'.³ We recognize that we do not have all the answers and may therefore hesitate to volunteer. Maybe we are questioning how transferable our models of care and education are?

Having Some Understanding of What We are Going to: What We Need to Know

There are numerous pitfalls for the progression of palliative care for the unwary and uninformed. Here are some of the important questions we need to consider. Some may not be answerable until we have arrived. Many appear obvious and others less so.

What is the healthcare system, who delivers it and is it free? If not free, are people insured or do families incur debt to pay for expensive investigations and treatments, which may or may not have health value? What is the level of trust between the patient and doctor where healthcare is not free? How are the practitioners licensed and governed and what are their codes of conduct? What is the legal status of withdrawing life-sustaining treatments?

We operate in a society where choice, autonomy and individualism are highly valued. How is the diagnosis or bad news shared and with whom? What are the attitudes to nutrition and hydration, and how do people talk about life-prolonging treatments and stopping them? Can patients and families demand treatments? What are the societal and family rituals around death and bereavement? How do people make sense of pain? What are their expectations of confidentiality and privacy?

In many of the countries we have visited, we may become aware that honour and shame is of greater significance than truth-telling and guilt. This plays out in a wide variety of situations in which both parties will make cultural assumptions. Breaking bad news, place of death, classroom behavior and treatment of visitors, to name but a few, may all be affected.

Which palliative care drugs are available? When there is no morphine, teaching needs to be adapted to what is locally available. What are the beliefs and expectations regarding routes of drug administration? Are injections viewed as 'better treatment'?

What do our hosts expect from us? What do they want us to teach, and to whom? Are they doctors, nurses, allied healthcare professionals or volunteers and where are they

working? Perhaps they work in community clinics or people's homes or hospitals. How many will attend and is it in a lecture theatre, classroom, or around a patient's bed? Is the seating in the room fixed or can the room be changed to accommodate different styles of teaching? Perhaps we may find ourselves sitting outside under a tree in the shade.

What is the status and autonomy of nurses and other healthcare practitioners? Is multidisciplinary team working a concept that is understood or practised?

What language is spoken and read? Sometimes people will be able to read English but they would prefer teaching in their own language. A translator will need to understand medical terminology and we need to allow time for translation in our teaching. How will we get our slides translated? It can be helpful to have the English alongside the translated words on the same slide, keeping words to a minimum. What is the availability of teaching aids including the reliability of electricity supply and internet access? We must be culturally aware when using illustrations and photographs.

Finally, we need to be respectful in the way we dress and interact with our colleagues. Check about use of head cover for female visitors to Muslim countries.

As you can see these preparations are more than just finding out about the ethnicity, demographics and religion of the country. Without spending time answering these questions, we run the risk of our teaching being at best well-received but irrelevant, and at worst insulting. Remember hosts don't know what they don't know and polite enquiry and suggestion is better than proceeding in ignorance. We are now going to consider how we approach the education.

How to Teach About Relationships between the Healthcare Professionals, the Patient and their Carers

The palliative care concept of physical, psychological, social and spiritual suffering is promoted in teaching and the patient might be asked about their ideas, concerns and expectations. This involves respectful exploration of attitudes and gentle demonstration that there are alternative ways of working with the patient such as in partnership. This is in stark contrast to the biomedical model with the doctor or nurse knowing the 'answer' and the patient being required to simply listen and comply. In seeking to teach an holistic, compassionate approach to patient care this may be counter to both the professional's and the patient's and families' expectations. 'Why should anyone want to be interested in where I live, my family or that I have recently lost my job?' asks the patient. By recognizing the difference between patient and professional relationship and the power and prestige that is afforded the professional, we can sensitively explore alternative ways of providing care.⁴

We are frequently asked to provide communication

skill training and it may be framed as ‘Teach us how to tell the patient the bad news. Actually, normally we don’t tell the patient, we tell the family.’ You may be told, ‘When you are well you belong to yourself but when you are ill you belong to your family’.⁵

These apparent contradictions need to be approached with respect, great care and understanding of culture and the local financing of healthcare. The following story from a PRIME teaching session illustrates this:

When Mr A handed his doctor the slip of paper from the oncologist in the capital city, Dr M knew that her suspicions had been correct and that he had carcinoma of the larynx.

Then Mr A, who had not been ill before he noted his hoarse voice a few weeks earlier, asked her, ‘What’s wrong with me?’ Time stood still for them both.

What would Dr M do? A multitude of conflicting thoughts went flashing through her mind:

If Mr A knew the truth would he kill himself?

Would his family be angry and threaten her?

Would the oncologist feel that he had lost face in the eyes of the patient?

Was it against the law to tell him?

Dr M was prepared as she told him, gently, step by step with time for him to ask questions and to indicate if he had heard enough.

Two weeks later at a training meeting a few of us go with Dr M to visit Mr A and his wife.

What might we find? We had heard that his wife had indeed been angry.

We enter their backyard with trepidation. They are expecting us. There are smiles all round! Mr A’s wife is particularly warm to us and explains that initially she had been angry. However, when she saw how much calmer and at peace her husband was and that he now had hope she knew that it had been right to tell him.

We return to the training meeting and Dr. M shared the full story.

The initial response was... SILENCE....followed by:

“How could you?” “What if someone asked me?” “What would I do?”

Truth Telling

When a situation such as this arises during a training, we might create a safe discussion of pros and cons of truth-telling or perform a role play where the family’s view is respected, in order to explore these issues. Some attendees will recognize that there are times where telling the truth is beneficial to the patient and

family and carefully start to practice this way. Understanding the barriers is wise before launching into any discussion of the ethics of autonomy, or models of truth telling.⁶ Whilst truth telling is often cited as a difficulty, the ease with which spiritual or faith-based conversations occur may surprise the tutor, particularly in countries where openly practising one’s faith is the norm. Also, where family relationships are strong and there are large families it is usual that the family will provide the care at home.

How to Teach About Relationships between Ourselves (the Visitors), and Those We are Working Alongside

In order for our teaching to be acceptable and relevant, we need to adapt our teaching styles to the country we are visiting. A lecture is likely to miss the mark. An interactive, learner-centred session will be more likely to work for student and educator, providing the teacher has done the necessary homework and planning. PRIME not only promotes whole person care but also interactive teaching. This is often new in cultures where the didactic model predominates from primary school to university, where teacher is right and to be honoured and the learner is probably wrong and should listen and take notes. Experience has shown, particularly with the truth-telling issues that clinical case-histories, role play, quiz games, people’s stories and discussion will communicate best. Indeed, admission of fallibility in the educator may win credibility with the audience. This leads us onto looking at how we might introduce the concept of multi-disciplinary team-working.

The World Health Organization (WHO) states that palliative care ‘uses a team approach to address the needs of patients and their families’.³ In countries where palliative care is well established it may or may not be the doctor who leads care. We may find ourselves in a culture where there are pre-existing gender-based, academic, professional and educational level hierarchies. The best approach is to explain the role of the multidisciplinary team and then to illustrate this with a complex case that could only be palliated with the input of multiple professions acting on an equal footing. Simultaneously, the visiting teachers should role model multi-disciplinary respect and interactions within their team in front of their host audience. We will have succeeded when we get suggestions and questions from students and all professions present. You should not be surprised if you have to work to establish professional, clinical and educational credibility even if you have a degree or diploma in palliative care in your own country that has equal standing with other healthcare qualifications. Another model of education is mentoring as in the Integrate Project in Africa⁷ and is best described by Lao Tsu from 700 BC: “Start with what they know, build with what they have and work with the best leaders so when the work is done, people can say ‘We did this ourselves.’”

How to Work with Competition for Limited Resources

One must be aware that palliative care education may not be the highest priority for funding. When resources are limited we

may only reach a very small nucleus of motivated health professionals in the first instance. We are not discouraged! We may not be able to demonstrate an improvement in key performance indicators, but we will have shown that we care about the people enough to volunteer, and that matters. Feedback confirms that attitudes and practices have changed. Don't underestimate the value of going and being 'present'.

How to Take Account of Restricted Access to Medication and Opiophobia

Our own practice is likely to be in a culture where drugs for control of symptoms and strong opioids are freely prescribed. Opiophobia (fear of morphine) and a complete lack of any strong analgesic can be immensely frustrating. Whilst morphine is on the WHO essential drug list,⁸ there are still some countries where the government does not have a developed drug regulatory system to allow safe storage, transport and prescribing and it is not available.⁹ Where morphine has limited availability there may also be fear of prescribing it, or it is poorly prescribed, resulting in reduced clinical effectiveness. People may be reluctant to use it believing they will become addicted and that morphine promotes an early death. Most other drugs are usually available. If you are teaching away from main centres then delivery methods such as infusion pumps may not be available and you may be requested to teach how to use donated equipment. One needs to be mindful of the lack of servicing and consider the risk *versus* benefit principle of providing training for this.

SUMMARY

In summary, palliative care is universally important and there are good reasons for teaching, mentoring and educating in other countries. The key is to stop for a moment, be aware of our assumptions and the limitations of our 'western' model. PRIME provides training in interactive teaching with minimal resources. The whole person approach is not exclusive to palliative care and should be indicated in any healthcare encounter. We should be flexible and patient when our ideas of teaching timetables and topics change, time keeping is not what we expect, or a logistical situation frustrates us. It is unlikely that after our input there will be immediate changes in nationwide palliative care policy or that the government will suddenly divert large resources to this. Rather, we may be sowing a seed with one or two individuals who may become national palliative care champions in time.

CONCLUSION

When approaching an educational initiative in a country where we believe palliative care is unknown or poorly understood, it

behooves us to reflect upon our prejudices and assumptions. We need to be open-minded and attend with a willingness to share and learn together.

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CONFLICTS OF INTEREST

All the authors are volunteer tutors for PRIME.

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