

Approaches to end-of-life care: a comparison between the UK and Albania

Authors: Helen Organ^A and Rudina Rama^B

ABSTRACT

The charity Sue Ryder has been delivering hospice- and community-based palliative care in the UK since the mid-1950s and prides itself in its approach to person-centred care. Shared care and support for self-management are the norm, with each patient having their own person-centred care plan, which deals with the whole person and enables any carer/professional to 'see' the person and not just the condition. The culture in the UK around dealing with life-limiting illnesses is in sharp contrast to that seen in some other parts of the world. This article compares these cultural differences by looking at the approach to end-of-life care in Albania, where Sue Ryder has provided significant financial and managerial support aimed at improving and developing modern approaches towards palliative care.

KEYWORDS: Person-centred, palliative, culture, communications, hospice

Sue Ryder and palliative care in the UK

Sue Ryder, who later became Baroness Ryder of Warsaw (Lady Ryder), opened her first care home in the UK in 1952 and worked tirelessly throughout her life to care for disadvantaged people across the world. Lady Ryder's interest in developing services overseas was considerable, and as each country became self-financing, the UK charity was able to move away from providing financial support to all the overseas projects, with the exception of Ryder Albania and the Sue Ryder Foundation in Malawi.

Today, the Sue Ryder charity is a major provider of palliative and neurological care in the UK through its hospices and neurological centres. As well as being a care provider, Sue Ryder campaigns tirelessly to promote 24-hour-a-day support for every person at the end of their life.

When providing palliative and end-of-life support, care options are always discussed with the patient and their families. Care can be provided in the person's own home through our community services and also in our hospices, where symptoms are brought under control so that the person can be as

comfortable and pain-free as possible, enabling both quality of life and a good death. The charity's mission and values state:

We start with the person as an individual with their strengths, characteristics, preferences and aspirations. Then we help them to be at the centre of the process of identifying their needs. We do this so they're enabled to make choices about how and when they're supported to live their lives.

Each person has their own person-centred care plan, which deals with the whole person and enables any carer/professional to read the plan and 'see' the person, not just the condition.

The involvement of patients in their own care allows for transparency and open and honest conversations about the future. This is a vast improvement on the days when the patient did not have a right to know and the family often kept a relative's terminal diagnosis and prognosis to themselves. Today, of course, it is the patient's decision who should know; this might mean that family members do not know the patient's diagnosis and prognosis.

This approach reflects the culture that is prevalent in palliative care in the UK's largely independent hospices. Everyone in the UK is entitled to end-of-life care and the medication to control their symptoms, although some of the specialist hospice support can be difficult to access in some parts of the country. A good death, in the patient's place of choice, is the aim of all hospices.

Ryder Albania Association and palliative care in Albania

Ryder Albania Association (RAA) was established in Tirana, Albania, in 1993 through financial support from Sue Ryder in the UK. In 1996, RAA opened a branch in the city of Durrës through a financial contribution from the European Community and Sue Ryder. RAA is the pioneer organisation for the delivery of palliative care in Albania, providing a free home service for terminally ill patients and elderly people with chronic disease. With a team of 19 people, mainly physicians, nurses and social workers, RAA supports around 500 patients a year and their families.

RAA has played an active role in developing the national strategy for palliative care and its 5-year action plan, as well as producing publications around standards of palliative care, clinical guidelines and care protocols. RAA staff have also produced the first standardised basic training manual for

Authors: ^Acompany secretary and legal counsel, Sue Ryder Care, London, UK; ^Bproject manager, Ryder Albania, Tirana, Albania

palliative care staff, developed a 1-year palliative care university course for doctors and helped to set up the first three palliative care units in public regional hospitals.

There is currently limited healthcare provision for patients suffering from cancer in Albania – in our experience, the regional hospitals have few, if any, oncology specialists and the National Oncology Service, which is the only specialist service in the country, has overworked physicians and inadequate facilities, equipment and medication. There are two private hospitals in Tirana which provide a multidisciplinary specialist oncology service but very few people can afford to pay for these services.

Even when patients are able to access the oncology services – whether in the private or public sector – and have had surgery or chemotherapy, they still need to be referred to the family doctor to be prescribed pain relief. However, GPs are generally not trained in this and are not comfortable prescribing morphine. Indeed, the community teams are only legally able to prescribe morphine to someone diagnosed with cancer. If a patient is fortunate enough to live in Tirana or Durres they can be referred to RAA for palliative care in the community.

The ‘right to know’

In contrast to current practice in the UK, based on our experience of treating patients in Albania, we estimate that 75–80% of people diagnosed with cancer don’t know they have the disease, and of those who do know, many are not aware of the prognosis. The few who are aware of both are generally highly educated and have received their diagnosis and treatment outside of Albania.

Interestingly, there are conflicting instructions about the ‘right to know’ in two government documents that regulate the relationship and standards of communication between physician and patient. Article 5 of the ‘Patient’s Rights Card’, states that:

The patient has the right to be informed about the disease, has the right to have a summary of the medical chart, has the right to receive a qualitative and standardised health service.

In contrast, article 25 of the ‘Code of Ethics’ states that it ‘is up to the physician either to inform the patient or not, judging upon the impact this information will have on the mental wellbeing of the patient’.

In our experience, neither of these documents carries much weight as the practice is that the doctor will initially inform a family member – usually the patriarch – of the diagnosis, and then be guided by the views of the family. Family ties and values are generally stronger in Albania than in the UK. Usually, a patient is accompanied by a family member when going to the doctor to receive a diagnosis, but when the patient goes alone, the doctor will ask for a meeting with the relatives. This approach varies significantly from that described in UK guidance around sharing information with family and carers.

Doctors and family members are often concerned that if the patient is told the truth he or she may become aggressive, may not want to receive any treatment, or may even become suicidal. Consequently, the doctor could be said to be acting in accordance with article 25 of the ‘Code of Ethics’. This could also explain why the doctor seeks permission from the family before revealing a diagnosis or prognosis to the patient. The lack of training that doctors have around end-of-life conversations means they feel ill-equipped to have these discussions.

This approach is partly explained by the widespread myths, superstitions and religious beliefs prevalent in some sections of Albanian society that cancer is a ‘curse’ or a punishment for something wrong or bad they have done in their lives. Cancer is similarly equated with death, body and face deformity and extreme suffering and pain. This, of course, is exacerbated by the fact that very often when people feel unwell they will initially seek a cure through folk medicine and only when their health seriously deteriorates will they seek help from a qualified doctor. Albanians have an old saying: ‘for each illness there is a plant to treat it, and each plant is useful for treating an illness’. This tradition is still very much alive in the country and towns and, in the homes of many families, there is every likelihood of finding chamomile, lime, garlic, onion, St John’s wort, and many other medicinal plants.

Generally, doctors in the oncology services and those at RAA do believe that it is better for the patient to be aware of the diagnosis and prognosis because it affects the quality of the communication and relationship with the patients. If they are not told the truth, the family members then play a role to convince the patient that he/she is going to recover; and if the patient is able to get access to morphine, which relieves the pain, this can reinforce the patient’s belief that they are recovering. While the doctors at RAA prefer to tell the truth to patients, they will still seek agreement from the family as they are the ones caring for their relatives. Even when doctors try to explain why telling the truth is so important, some families will not allow it, as it is very difficult to change attitudes for the reasons already alluded to in this article. Consequently, doctors face an extremely difficult situation. While they will not go against the wishes of the family, the medical team will make it clear to the patient that they are specialists in pain relief only, and they do not cure or treat the illness.

Conclusion

Changing the culture around how palliative care is viewed by patients and family members in Albania will take time. Education is needed for both health professionals and the general public if the philosophy of good palliative care, as seen in the UK, is to be embedded within Albanian society. There is a low awareness of health issues in Albania and people do not have regular check-ups – only seeking help when they have a problem – and they often have to pay, as the public healthcare provision is limited.

The palliative care services in Albania face enormous challenges if they are to embrace a philosophy of care that is truly person centred. Some of these challenges are being addressed, including through the work that RAA is doing. Clearly, there is a need for massive investment in the infrastructure of the health service in Albania and hopefully palliative care will feature as a priority in the country’s future health strategy. Albania can pride itself on the kind of family support and family values that are less common in the UK, but on the other hand their attitudes towards terminal illnesses need to adapt to embrace the philosophy of palliative care as we know it in the UK. ■

Address for correspondence: Ms Helen Organ, Sue Ryder, 1st Floor, King’s House, King Street, Sudbury CO10 2ED, UK. Email: helen.organ@suerydercare.org