



In this section, European palliative care organisations are invited to explain their goals, express their hopes and voice their concerns

Sweden: the SFPM battles to make palliative care a medical specialty

The Svensk Förening för Palliativ Medicin (SFPM, the Swedish Association for Palliative Medicine), founded in 1997, has helped to ensure substantial changes in the provision of palliative care and has instigated formal educational courses. Now it is determined to get palliative care recognised as a medical specialty



Eva Thoren Todoulos, Chairman, SFPM

Palliative care in Sweden has its roots in home-care services. The first palliative day-care team was set up in Linköping, Östergötland, in 1963, operating from Monday to Friday. Inspired by the home-care idea, the first comprehensive home-care team with 24-hour access to doctors and nurses began in 1977 in Motala. The pioneer behind these initiatives was Barbro Beck-Friis, 'the grand old lady' of palliative care in the country.

The home-care team model soon spread, becoming the role model for palliative care in many areas of the country. The biggest problem was the lack of 'back-up beds' for patients who could no longer stay at home. The first hospices or palliative inpatient units developed independently of the home-care teams, but it soon became obvious that palliative beds were a necessary part of palliative care. More comprehensive units were developed.

Development of research

Initially, Östergötland county council was the driving force behind palliative home care, and it was on its initiative that, in 1997, the first professorial chair in palliative medicine was established at Linköping University. Peter Strang was appointed to the post. In 2001, a further chair was established at the Karolinska Institute in

Stockholm to promote research and Peter Strang moved to take up this position. Today, there are several professors of palliative nursing care.

Since the 1990s, when Barbro Beck-Friis wrote the first Swedish medical thesis on palliative medicine, clinical research has burgeoned; several doctoral theses have been completed by physicians, nurses and social workers. Today, more than 500 Swedish publications can be identified in PubMed with 'palliative' as a key word.

Palliative care in public health

In 1979, a governmental committee published a report on 'end-of-life issues', bringing palliative care on to the public healthcare agenda for the first time. The recommendations were quite modern, but little happened until 1995, when new guidelines formally recognised palliative care. The same year, the first palliative care adviser was appointed to join other medical specialists on the National Board of Health and Welfare.

In 1998, a governmental committee began a new inquiry into end-of-life care, reporting back in 2001. There was broad parliamentary consensus on its conclusions, one of which being that palliative care of equal standard should be accessible to all people at the end of life, wherever

they died. It also emphasised the need for education, research and organisation. The hope was that comprehensive palliative care would be available within five years.

In reality, this has proved difficult. Swedish healthcare is, to a great extent, a local business. There are 20 county councils, which fund healthcare through local taxation. The result is that access to palliative care depends on where you live.

There are more than 100 palliative care teams, most of which are home-care or consultant teams. About 16 are hospices/palliative inpatient units with more than ten beds. Most teams are contracted to work exclusively for the public health authorities. Seven of the hospices are run by non-profit private organisations or foundations – something highly unusual in Swedish healthcare. But it is not just the organisation that varies. Guidelines and standards also differ across the 20 counties. An initiative has been launched to draw up national guidelines for the organisation, levels of care, standards of, and education in, palliative care.

The Swedish Association for Palliative Medicine

Svensk Förening för Palliativ Medicin (SFPM, the Swedish Association for Palliative Medicine)¹ was founded in 1997 and, since 2000, has been an associate member of both the Swedish Medical Association and the Swedish Society of Medicine. It is also a collective member of the European Association for Palliative Care (EAPC). Its members are all medically qualified because, when the SFPM was founded, the overriding need was for a meeting place for doctors scattered throughout the healthcare system who wanted to be identified as ‘palliative doctors’. The main aims of the association were – and still are – to promote palliative medicine as a recognised medical specialty and to foster education and research at all levels.

Soon after the foundation of the SFPM, it became evident that there was a need for a broader coalition with other professionals in the field, so as to speak with one voice in the public debate. The Nationella Rådet för Palliativ Vård (NRPV, the National Council for Palliative Care)² was founded in 2004. It has members from 13 organisations and networks, representing physicians, nurses, social workers, clergymen, physiotherapists, occupational therapists and researchers. The SFPM is an important driving



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force in the council. Some issues, such as that of palliative medicine as a specialty, are dealt with mainly by the SFPM, rather than by the NRPV. The first national conference on palliative care took place in Stockholm on 12–13 April 2010. It was organised by two non-profit organisations involved in palliative care and research – Ersta and Stockholms Sjukhem Foundation – in collaboration with the NRPV.

Education is an important area for the SFPM. The British curriculum for palliative medicine was translated into Swedish in 2001 and became the basis for a diploma in palliative medicine launched by the SFPM in 2005. The criteria for the diploma are such that they should fulfil the requirements of a future specialty. So far, 37 physicians fulfil the requirements. University courses for physicians in palliative medicine have been held at both the Karolinska Institute in Stockholm and at Umeå University. Education in palliative medicine for medical students is sparse and has received little attention, but efforts are under way to change this.

Based on the Swedish curriculum, the SFPM has created a Nordic specialist course in palliative medicine³ in co-operation with the associations for palliative medicine in Denmark, Finland, Iceland, Norway and Sweden. Twenty Swedish students have graduated from this course, which is also thought to fulfil the requirements for a future specialty in each of the countries.⁴

A district nurse in Stockholm cycles off to visit a patient at home

The debate about definitions, referral criteria and how to measure outcomes has been predominant in the development of palliative care in Sweden. In 2004, the SFPM initiated efforts to set up a web-based national quality register in end-of-life care.⁵ Now publicly funded, the register has helped to raise awareness of palliative care in different sectors of society. It currently collects data from more than 20% of all deaths in Sweden and the coverage is growing, especially among palliative care units and nursing facilities.

Current challenges

Our most urgent challenge, and one that has been on the agenda since the start, is to make palliative medicine a recognised medical subspecialty. Most of our efforts are concentrated on this, as we feel that it is crucial for the survival of palliative care as an entity. Many of the doctors engaged in palliative care, either at a clinical or a research level, are those who pioneered it and they will soon reach retirement age. There is an interest among young doctors, but they have so many choices, and palliative medicine, not even being a specialty, is not at the top of their list.

Arguments in favour of a subspecialty are that:

- Palliative care is becoming an integrated part of the healthcare system and requires unique skills and knowledge
- The scientific basis of knowledge required for a specialty is at hand
- The capacity to educate new doctors exists
- Research in palliative care is growing.

A recent debate about pain treatment in end-of-life care revealed a lack of basic knowledge, even among doctors who deal with death and dying on a daily basis. It is remarkable that there are still no palliative care teams to consult in acute hospitals, or even in the university hospitals.

One consequence of the fact that palliative care grew from the home-care concept is the gap between clinical activities and research. Palliative care is recognised and sought after by health authorities in the clinical practice, but the interest in research and scientific evaluation is still low and needs encouragement. Some initiatives have been taken, which are outlined below.

- In Östergötland, 'the cradle' of palliative home care in Sweden, a Palliative Education and Research Centre has been set up. In the past four years, 7,000 healthcare workers have attended a three-hour, case-based discussion led by palliative medicine specialists. The aim is

Peter Strang (bottom right) at the annual meeting of the Svensk Förening för Palliativ Medicin (SFPM) in 2006, with the first doctors to receive diplomas in palliative medicine



to educate them in the basic principles of palliative end-of-life care.

- The Stockholm Sjukhem Foundation and Ersta Sköndals University College in Stockholm both have research and development units.
- A clinician-based palliative research network (PANIS) was created in 2002; it now includes more than two-thirds of all specialised palliative care units in Sweden.⁶

Still, there are no plans to establish new regional or national centres for palliative research and evaluation, or to co-ordinate the ones that exist. The SFPM strongly promotes the idea of formalised centres for research, evaluation and development of palliative care, like those for all other medical specialties that are recognised in clinical practice. National guidelines would make an important contribution to this concept.

A lot has been achieved during the past 15 years, but there is still much to be done! ■

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