

The development of paediatric palliative care in Warsaw, Poland

In this final part of a series on palliative care in Eastern Europe, **Michael Wright** and **David Clark** present the paediatric situation in Poland since 1994

At present, 29 palliative care services provide home care for children; two of these services have paediatric inpatient units

In Poland (population 38.7 million) around 1,200 children aged one to 19 years with life-limiting conditions died each year between 1985 and 1996, making a rate of 10.4 deaths per 100,000 children. Seventy-four per cent of these child deaths occurred in hospital, while 26% occurred at home; around half of the children died from cancer. At present, 29 palliative care services (five independent, 24 attached to adult services) provide home care for children; two of these services have paediatric inpatient units.¹

Key palliative care developments

Tomasz Dangel, an anaesthesiologist, founded the Warsaw Hospice for Children in 1994, 13 years after Poland's first adult palliative service was registered in Cracow. After discussions with Jacek Luczak and Robert Twycross, Dangel visited hospices in England and returned to Poland with the intention of establishing a



Warsaw is prominent in ensuring that paediatric palliative care obtains the recognition that it deserves politically and nationally

hospital-based service. After two attempts proved unsuccessful, he developed an alternative vision based on home care. As the hospice developed and grew, Artur Januszaniec was appointed executive director, taking responsibility for management and personnel issues. Tomasz Dangel is now the medical director and leads the department of palliative care at the National Research Institute for Mother and Child.² The hospice currently seeks to raise public awareness about the needs of children with life-limiting conditions and provides the following services:

- A paediatric home care service
- Bereavement support for parents and siblings
- Pain management
- Teaching programmes
- Research.

The hospice is located in a residential district of Warsaw and was purchased in 1998. Artur Januszaniec had major input into the design and furnishing of the building, which covers several floors: the upper floor houses an education centre, study bedrooms and staff accommodation; the middle level incorporates a

Key points

- In Poland (population 38.7 million) around 1,200 children aged one to 19 years with life-limiting conditions died each year between 1985 and 1996, making a rate of 10.4 deaths per 100,000 children.
- The Warsaw Hospice for Children provides a paediatric home care service, bereavement support for parents and siblings, pain management, teaching programmes and performs research into paediatric palliative care.
- Poland has made substantial attempts to integrate palliative care into the national healthcare system, although formative influences have previously stemmed from adult services.
- The Warsaw Hospice for Children has made remarkable progress and become widely recognised as a beacon of paediatric palliative care.

doctors' room and library and on the ground floor is a dental surgery and recovery room. In 2002, the neighbouring house was purchased. This provides accommodation for children requiring dental surgery who travel to the hospice, with their families, from outside Warsaw. It also accommodates trainees.

Levels of service provision

A multidisciplinary team provides paediatric palliative care 24 hours a day in an area that covers a radius of up to 100 km from the hospice and includes around 3.5 million people. The nurses have a caseload of four patients each and visit children between the hours of 9 am and 3 pm. After 4 pm, a doctor and a nurse are on-call. Any child in the district who is diagnosed by hospice doctors as having an incurable disease and is in need of palliative care can be admitted to the programme. After referral, a meeting is arranged between the hospice staff, the child and family and the child's physician. Difficult questions surrounding the cessation of life-prolonging treatment and choice of the place of death frequently arise at this time.³ In some circumstances, patients are admitted to the programme for a period of three months, which is renewable after review.

The multidisciplinary team meets twice a day (8 am and 3 pm); a practice which demonstrates the commitment of the hospice to communication and teambuilding. Full-time staff include three doctors, eight nurses, three social workers, two bookkeepers, a psychologist, a chaplain, a physiotherapist, a public relations manager and a computer specialist. Part-time staff include four dentists, two anaesthetists and 50 volunteers. Morning meetings begin with the prayer of St Francis followed by a blessing from the chaplain. Mass is said once a week.

To date, 216 children and young people have been cared for – 118 patients with cancer and 98

patients with other diseases (see Table 1). In 2001, the average number of patients at any one time was 24.5.

Between 1994 and 2002, the average length of time that a patient received hospice care was 180 days (average length of care for patients with cancer = 49 days, average length of care for patients with other diseases = 368 days). During the period from 1995 to 2002, 160 patients died, giving an average death rate of 20 per annum – that is, 5.7 per one million people. This suggests that the hospice provides an 18.6% coverage of its 'at risk' population. Among the children who received hospice care, 93% died at home as opposed to 26% nationally.

Income and expenditure

The hospice's total income in 1994 came from a government subsidy of around 52,600 zloty (about €12,530). By 2001, its annual income had risen to 3.25 million zloty (around €774,205). In the same period, private donations rose from nil to around 80% and government subsidies decreased to around 20% of the total. Since 1995, daily home care costs per patient have risen from 150 zloty (€35.73) to 270 zloty (€64.32).

The hospice has been successful in its efforts to obtain funding. During the last five years, grants have been awarded to:

- Train staff from the Belarusian Children's Hospice (Stefan Batory Foundation, 1998)
- Sponsor a new European course (Open Society Institute [OSI], 1999)
- Develop paediatric palliative care in Poland (Johnson and Johnson, 2000)
- Establish a resource centre (OSI, 2001).

An anaesthetic dental surgery has been founded to provide a broader service for children and to obtain a parallel income from health insurance. In 2001, 266 dental procedures were performed; 185 under general anaesthesia. After surgery costs have been deducted, surplus funds are directed to the hospice.

A multi-disciplinary team provides paediatric palliative care 24 hours a day in an area that covers a radius of up to 100 km

Table 1. Patient details from the Warsaw Hospice for Children (1994–2002)

| | 1994* | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 |
|--------------------------------|-------|------|------|------|------|------|------|------|------|
| Total patients | 7 | 25 | 32 | 32 | 39 | 52 | 46 | 51 | 57 |
| Cancer patients | 3 | 15 | 22 | 15 | 9 | 20 | 15 | 11 | 21 |
| Non-cancer patients | 4 | 10 | 10 | 17 | 30 | 32 | 31 | 40 | 36 |
| Patient deaths | 3 | 17 | 24 | 18 | 14 | 28 | 16 | 17 | 26 |
| Bereavement meetings (parents) | 0 | 14 | 22 | 22 | 24 | 28 | 27 | 23 | 22 |

*From 1 Sept 1994

National viewpoint

Four marketing campaigns have been organised since December 1998 using strategies that include billboard advertising, radio and television commercials, a mail shot sent to all Warsaw addresses and leaflets in banks and post offices. By the end of the third campaign, hospice support had risen from 1,300 to 13,000 donors – and 1.4 million zloty (around €333,507) was credited to the hospice bank account. Tomasz Dangel writes, *'The secret of effective fundraising is that the donor and recipient benefit. The organization only helps to facilitate the exchange. So receiving and giving are two sides of the same coin; in other words, they are inseparably linked and experienced by all parties in the form of gratitude and satisfaction'*.⁴

Polish standards of paediatric palliative care

The document 'Standards of palliative home care for children'⁵ was published in 1999 and outlines a comprehensive range of standards for a home care service that deals with up to 12 children. These standards include:

- A minimum staffing requirement of 1.5 physicians and three nurses
- A total of five days' training on a postgraduate palliative care course and one month's training at the Warsaw Hospice for Children
- Periodic access to paediatricians of different specialties and the availability of a paediatric ward
- Multidisciplinary team meetings at least once per day.

Evaluation

After the death of a child, parents complete a questionnaire to evaluate the quality of care provided by the hospice. These questionnaires were used in a cross-sectional survey that evaluated the care of 87 children who died under the auspices of the programme from inception until 2000.⁶ Eighty (59%) questionnaires were returned and responses indicate a high level of parental satisfaction.

Each marketing campaign has been evaluated to determine public awareness of the hospice brand. After the 1999–2000 campaign, the hospice's aided brand awareness rose from 35% to 41%; while unaided awareness rose from nil to 3%. The 1999 billboard campaign was the best recognised of all displays during the month of December 1999, remembered by 67% of all respondents.



Any child in the district who is diagnosed by hospice doctors as having an incurable disease and is in need of palliative care can be admitted to the hospice programme

Research

Tomasz Dangel and Marek Karwacki hold research posts as Assistant Professor and Senior Lecturer respectively at the National Research Institute for Mother and Child (which is part of the Polish Ministry of Health). These posts allow them to work on some significant projects in terms of paediatric palliative care that include the following:

- The development of a tool to measure quality of care in paediatric hospice home care programmes⁵
- The determination of demand for palliative care for children with life-limiting conditions¹
- An evaluation of the impact of education on the attitudes of physicians and nurses towards children in the terminal stage of cancer.⁷

Education

The hospice's core education team is made up of Tomasz Dangel, Marek Karwacki and Agnieszka Chmiel-Baranowska, who each make contributions to local, national and international programmes. Marek Karwacki has a comprehensive legal knowledge and plays a central role organising international conferences. The appointment of Agnieszka Chmiel-Baranowska has added teaching experience to the education programme and has provided insight into the psychological aspects of care – as Tomasz Dangel explains, *'Agnieszka is responsible for all trainees because of her good English and Russian and experience in education. She is used to working with Professor Rubén Bild from Spain and with Professor Luczak from Poznan, and she is experienced in teaching and managing workshops, communication, and all the psychological aspects of palliative care'*.⁸

The document 'Standards of palliative home care for children' was published in 1999 and outlines a comprehensive range of standards

Education and training at the Warsaw Hospice for Children fall into four main categories:

- In-house training that is designed to meet the training needs of healthcare professionals and volunteers associated with the hospice
- Intern training of one month's duration supported by the OSI and the Stefan Batory Foundation
- National courses on pain management and paediatric palliative care; 729 participants have attended eight courses held between 1996 and 2002
- International courses – the first of which was held in partnership with Bethesda Children's Hospice (Budapest 1999), the second of which was held in partnership with the National Research Institute for Mother and Child (Warsaw 2001). The third occurred in May 2003 in Warsaw.

The dissemination of information

The hospice disseminates its work in numerous ways. Its website (www.hospicjum.waw.pl) gives details of the hospice and its history. The website also includes a downloadable library of 13 papers in English and 24 papers in Polish and gives information on topics ranging from dyspnoea to opioids and the fear of death to the future of paediatric palliative care. The in-house *Hospice Journal* is published four times a year and has a circulation of 5,000 copies. The hospice has also become a rich source of monographs and papers: the curriculum vitae of Tomasz Dangel lists 24 peer-reviewed publications (including one book) while that of Marek Karwacki lists 36 scientific papers, 16 chapters in medical books and 46 published abstracts.

Influence upon national policy

Poland has made substantial attempts to integrate palliative care into the national healthcare system, although formative influences have previously stemmed from adult services. There are now indications that paediatric palliative care is making an impact at the level of policy and discussions on standards and plans for a national policy are currently taking place between Tomasz Dangel and Marius Lapinski, Poland's Minister of Health.

Achievements

The Warsaw Hospice for Children has made remarkable progress and become widely

recognised as a beacon of paediatric palliative care.⁹ Since the founding of the service in 1994, leaders of outstanding vision have conveyed the meaning of the children's hospice to large sections of the Warsaw population and harmonious relationships have been developed with a range of political, professional and commercial partners, leading to widespread support. Values that relate to teamwork and communication are expressed in the hospice's service standards, which incorporate a low caseload for nurses and twice-daily meetings of the multidisciplinary team. A culture of evaluation and research gives the hospice a critical edge that is underpinned by publications in the academic press and conference presentations, while strategic approaches to education have ensured that a multilevel, cross-professional curriculum is in place to meet international, national, and hospice-based needs.

The hospice's challenges for the future now relate to securing acceptance of the Polish standards of paediatric palliative care by the Polish Ministry of Health, establishing a broader coverage of the paediatric 'at risk' population, and – in the absence of paediatric palliative care being recognised as a medical specialty – ensuring that the hospice service remains within the specialty of paediatrics rather than becoming an offshoot of adult palliative care.

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