Palliative care in Poland – the Warsaw Hospice for Children

Stefan Friedrichsdorf, **Sandra Brun**, **Boris Zernikow** and **Tomasz Dangel** report on

epidemiological data and describe Warsaw's paediatric hospice home care programme

Only a few European countries provide professional paediatric palliative care,[1] and even fewer have a paediatric hospice home care programme. Poland is fortunate to have such a service. This article reports epidemiological data on paediatric palliative care in Poland and describes the Warsaw Hospice for Children.

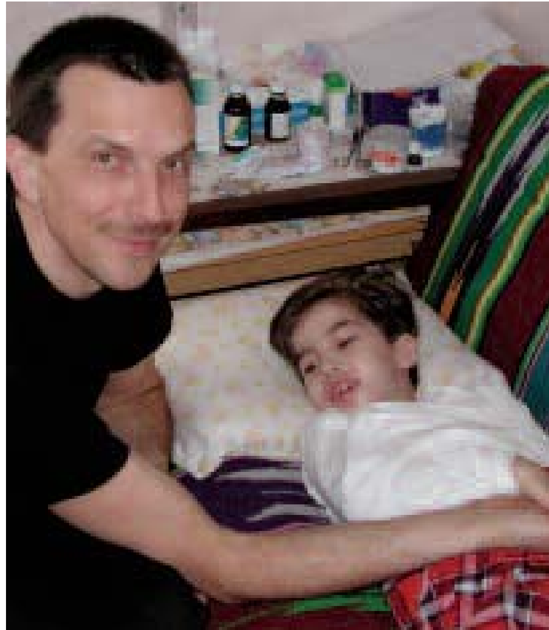
Proportion of children dying at home

Parents of terminally ill children wish for home care,[2] and data from several studies suggests a high correlation between the availability of comprehensive home care and the number of children with life-limiting conditions dying at home.[3–5] At Great Ormond Street Hospital for Children, in London, only 19% of children with cancer died at home before the establishment of a Symptom Care Team by Ann Goldman in 1987. Within two years of establishing the team, more than 75% of paediatric oncology patients were dying at home.[6,7] Long-term problems of bereaved parents and siblings seem to be reduced when they have been involved in caring for the dying child at home.[8]

Situation in Poland

In Poland, nearly 1,200 children and adolescents (aged one to 19) die from a life-limiting disease every year.[9] The mortality rate of 1.04/10,000 closely matches British and German figures.[10,11] Polish numbers from 1985–1996 indicate that 14,243 children died from a life-limiting condition, of whom 26% died at home, and the rest died in hospital.[9] Most available data refers to children with cancer; in Washington State in the USA, the number of children with cancer dying at home is as low as 20% per cent,[12] in Germany 40%,[13] and in England and Wales 52%.[14]

The first children's hospice in Poland was founded in the capital, Warsaw, in 1994. Since then six more children's hospices have been



established in the cities of Lódz, Lublin, Poznan, Torun, Myslowice and Wroclaw. Each hospice covers a population of between one and four million inhabitants. All provide home care, but no inpatient or respite care, with the exception of the one in Myslowice, which offers inpatient care occasionally. There are an additional 24 adult hospices in Poland, which provide paediatric palliative home care when needed. The seven children's and 24 adult hospices cover 79% of the Polish population; 69% of all paediatric palliative patients will be cared for by the children's hospices. The data from six consecutive national surveys is presented in

Key points

- To increase the standard of care for dying children, the first children's hospice in Poland was founded in the capital, Warsaw, in 1994. It was the first dedicated children's hospice programme in Europe outside the UK.
- Long-term problems of bereaved parents and siblings seem to be reduced when they have been involved in caring for the dying child at home.

Table 1. Number of children aged 0–18 admitted to Polish paediatric home care programme (seven children's and 24 adult hospices)

Year	Total number of children	Children with cancer	Children with non-malignant diseases	Number of deaths
1999	171	99 (58%)	72 (42%)	83
2000	186	92 (49%)	94 (51%)	80
2001	214	85 (40%)	129 (60%)	83
2002	252	90 (36%)	162 (64%)	82
2003	329	111 (34%)	218 (66%)	102
2004	373	103 (28%)	270 (72%)	104

Table 1 and Figure 1. There was an marked increase in the numbers of children with non-malignant diseases referred over time.[15,16]

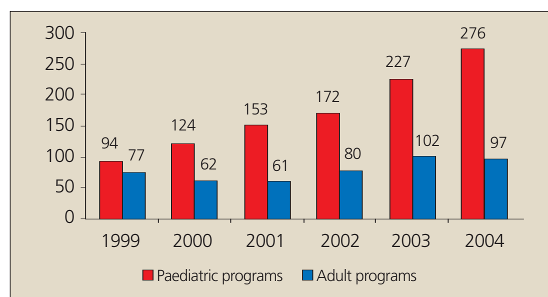


Figure 1. The number of children (<18 yrs) treated by palliative home care programs

The Warsaw Hospice for Children

The Warsaw Hospice for Children was established by Dr Tomasz Dangel in 1994 and was the first dedicated children's hospice programme in Europe outside the UK. Notably, the Children's Hospice in Minsk, Belarus, was established in the same year.[17] The Warsaw Children's Hospice covers a region of 3,830,000 inhabitants. Comprehensive home care is provided by a multidisciplinary team comprising three doctors, eight nurses, two social workers, a clinical psychologist, a physiotherapist, a Catholic chaplain, two book-keepers, a manager for fund-raising and public relations, a computer specialist and 50 volunteers. All services provided by the hospice are free of charge to the families and are financed by fund-raising (79%), health insurance (19%) and the City Council (2%).[18]

Home care

Home care is nurse-led and provided 24 hours a day, seven days a week. Regular home visits by an allocated primary nurse take place between 9 am and 3 pm, daily or weekly, according to need. A nurse and a doctor are on call the rest of the time. At regular intervals, and whenever necessary, the children are visited by one of the three doctors who work full-time in the hospice. A physiotherapist provides regular physiotherapy at home if appropriate. All team members have use of one of the 13 hospice-owned cars. In 2004, each patient received on average 13.6 visits a month by different members of the home care team.[18] The mean duration of a visit was two hours.

Hospice as a service centre

As well as providing medical palliative home care, the Warsaw Hospice for Children also offers several other services. Bereavement support is given to parents through a weekly self-support group led by the clinical psychologist and the chaplain. At irregular intervals, weekend or week-long trips for bereaved families are offered. A weekend trip for bereaved siblings takes place once a month with a social worker, a nurse and the chaplain.

The hospice incorporates a busy dental clinic that provides dental care especially for severely disabled children who have no other means of dental care because of lack of compliance. Four dentists and two anaesthetists work part-time in this part of the service.

As a post-communist country, Poland is experiencing great turmoil in its welfare and healthcare system. The finance provided by the government and local authorities to families with sick children does not even cover basic needs, and parents have to pay for many medications and equipment themselves. Therefore the hospice covers all expenses for medication and medical equipment, and will provide a bathroom with running water if there is not one available. It also helps the parents to find a job if both of them are unemployed. These expenses amounted to 13% of the hospice budget in 2004.[17]

Admission and discharge criteria

Children are admitted to the hospice programme if their physician considers that

they are incurably sick, require palliative care, and live in the region. Other criteria include that life-prolonging treatment has been discontinued, the child wants to be at home, the parents and other family members wish to care for the child at home and there are no parental risk factors.

Young adults with congenital diseases are also accepted for admission, as there is currently no other programme looking after them. Oral medications are usually effective, so there is rarely a need to provide intravenous drugs or patient-controlled analgesia (PCA) pumps. Usually, the hospice does not care for children on a home ventilator, as this is seen as life-prolonging treatment. Paediatric patients and their families who choose this option have access to the national home ventilation programme. Admission criteria vary, however, the Poznan children's hospice looked after eight children on a home ventilator during 2002.

Recently, some children have been discharged from the hospice programme, mostly because of a significant improvement in their health status, such that palliative care was no longer required. Children with potentially life-limiting non-malignant conditions, in whom the prognosis is not clear, are admitted to the hospice programme for three months then re-evaluated and sometimes discharged. Occasionally, the hospice has been unable to establish a working relation with the parents; for instance, when the parents' motive for contacting the hospice was based solely on financial interests, when round-the-clock nursing care was expected, when parents continuously failed to comply with drug regimes, or repeatedly demanded that the hospice cover the costs of treatment or consultation outside Poland.

Ethical guidance

Poland has no national guidelines. However, Dr Dangel translated and edited the British guidelines.[19] His team strongly believes in the necessity of definitions[20,21] in paediatric palliative care and the need to define curative treatment and palliative care. The Warsaw Children's Hospice pursues the following principles based on the ACT Charter[22] and the ethical considerations published in a WHO report about palliative care:[23]

- Decisions about treatment are difficult but inevitable
- Cessation of curative treatment represents a change of philosophy where prolonging life is no longer the objective; the goal is to improve the quality of the remaining lifetime
- Withholding life support is appropriate for children dying of life-threatening or life-limiting conditions
- Parents' and children's decisions should be supported.

Teaching and evaluation

The Warsaw Hospice for Children organises annual national courses on palliative care in children. Approximately 900 participants have attended the ten courses held since 1996. Moreover, three European courses were organised in Budapest in co-operation with the Bethesda Children's Hospital (1999), and in Warsaw (2001, 2003). As a consequence of the teaching programme, hospice care for children is available in 30 regions in Poland.

The hospice itself has been evaluated by foreign professionals.[24,25] The quality of hospice care is also evaluated by parents after the child's death using a questionnaire.[26]

Table 2. Diagnoses of 249 children at the Warsaw Children's Hospice (1994–2004)

Diagnosis	No. of children	Per cent
Solid tumour	66	27
Brain tumour	39	16
Leukaemia	28	11
Neurodegenerative disease	24	10
Neuromuscular disease	21	8
Chromosomal aberration	18	7
Indefinite congenital defect	13	5
Cerebral palsy	10	4
Other	30	12
Total	249	100

Experiences at the Warsaw Hospice

Between 1994 and 2004, 249 children were looked after by the Warsaw Hospice for Children; 53% suffered from cancer, 47% had non-malignant life-limiting diseases. The number referred with non-malignant disease has risen steadily over time. The range of diagnoses was wide (Table 2). The mean age was 10.2 years. The mean time that the patient received hospice care was 216 days (range 1–2621). The average time for patients with cancer was 50 days; for patients with other diseases, it was 447 days.[17] Ninety-three per cent of the hospice patients died at home;[9] the most common symptoms are listed in Table 3.

According to the bereaved parents, 68% of the children died peacefully and only 1% were full of fear, 59% did not suffer, and 19% did suffer during their last hours of life.[25]

Table 3. Most frequent symptoms during palliative care

Symptom prevalence	(%)
Pain	84
Restlessness	71
Vomiting	63
Constipation	59
Insomnia	54
Dyspnoea	50
Fever	43
Dysphagia	41
Anxiety	36
Loss of consciousness	35
Cough	33
Apnoea	33
Spasticity	31

A comprehensive progamme

The Warsaw Hospice for Children offers an excellent example of a comprehensive paediatric palliative home care programme. Dr Dangel and his team are convinced that the last period of a child's life can and should be lived with dignity, without fear, separation and unnecessary procedures. The hospice has changed the shape of care for dying children in Poland. The majority of children in Europe with life-limiting conditions have no access to palliative care.[1] The hope is that many more countries will implement dedicated paediatric palliative care to improve the care for dying children.

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