Tomasz Dangel Oral History.

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Dr. Tomasz Dangel initially began his career as a pediatric anesthesiologist and oversaw Pain Management at the Memorial Hospital Children’s Health Centre in Warsaw, Poland. During his time working in the in the pediatric intensive care unit, he witnessed many children die while receiving aggressive and “inadequate life-prolonging treatment” where he thought it would be more appropriate to offer an option for end-of-life support.

Through a course he attended in 1991 and several pediatric hospice visits abroad, Dr. Dangel discovered adult palliative care practices and pediatric hospice practices, thus beginning his advocacy for a specialized pediatric palliative care practice at his home institution. Dr. Dangel envisioned a palliative service that would complement his in-patient pain management department. Unfortunately, his home institution and several others in Poland rejected his vision and failed to recognize the medical and spiritual need for a pediatric palliative service.

Dr. Dangel consciously chose to “splendid[ly] isolate[e]” himself from “inhumane hospital medicine,” and continued to work on gathering support and evidence for pediatric palliative medicine. He eventually established the first pediatric hospice in Poland.

Dr. Dangel has since successfully initiated pediatric and perinatal palliative care in Poland, established multiple children’s hospices in Poland, opened an educational centers, conducted and published 15 epidemiological studies on pediatric palliative home care in Poland, co-authored the Polish standards of Pediatric Palliative Home Care and Perinatal Palliative Care, established the first committee of clinical ethics, and continues to research pregnancy and perinatal nutritional needs. He retired from the Warsaw Hospice for Children in 2020 after 25 years of medical work.

Interview Abstract

Dr. Dangel begins the interview describing his experiences as a pediatric anesthesiologist witnessing children dying while receiving unnecessary aggressive treatment during the end-of-life. He also describes several pivotal experiences learning about and seeing other countries develop pediatric hospices. When he brought back his experiences to his home institution, he was not well received and consequently left to seek an environment to nurture his vision for pediatric palliative and hospice care.

Dr. Dangel comments that this was not his first time bringing new ideas into Polish medicine since he “introduced the modern techniques of regional anesthesia and analgesia in children,” in the 1980s. He then mentions that he was more than comfortable making the “conscious choice” to have his own “splendid isolation from the inhumane hospital medicine.”

He then describes the barriers he faced and overcame, such as lack of funding, training gaps for clinicians, no transportation for his staff, failing personal health, a research block from the ethical committees in Poland, and “single case of malpractice at the medical court for using the ketogenic diet, which I designed for my hospice patient”.
Dr. Dangel goes on to describe his work in leading Polish medicine to establishing pediatric palliative and hospice care through his work in policy, peer-reviewed studies, publications, and books, public outreach, and coaching of other professionals. He also describes some of his biggest challenges today being lack of cooperation from the Polish government, lack of official accreditation, and government blocks on some palliative practices.

He then also describes the strengths of the current Polish practices of pediatric palliative and hospice to be the establishment of the Warsaw Hospice for Children Foundation who provide supportive services and organizational outreach as well as Polish societal values.

Finally, Dr. Dangel describes his vision for the future of pediatric and hospice care to be recognized as a branch of medicine in Poland, increase clinician knowledge and competency of palliative practices, increase the awareness and palliative training of other disciplines, such as gynecologists and obstetricians, establish a national research center, establish a journal of pediatric and perinatal palliative care, and to increase pediatric palliative and hospice consults with experts and ethics committees.

Glossary of Acronyms

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<td>Intensive Care Unit</td>
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Interview Roadmap

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1) When and how did you become interested in pediatric palliative care?

In 1991 I attended my first course of adult palliative care for physicians, organized in Poland by Professor Jacek Łuczak from Poznań and Dr. Robert Twycross from Oxford. At that time, I was employed as a pediatric anesthesiologist in charge of pain management in the Memorial Hospital Children's Health Centre in Warsaw. I witnessed children dying while on duty as a doctor at our pediatric ICU since 1980. I felt the ICU is not the right place to die for them because of aggressive treatment, which we applied to them at the end of life.

In 1993 I visited children's hospices in the U.K. in Oxford and Birmingham, and I met Professor David Baum in Bristol. Since the inception, I was convinced that in Poland we need palliative home care for children, not inpatient hospices.

2) When you started out, did you find a community of similar minds?

If yes - How did you come together around this work?

If no - What was it like to be relatively alone in this? When did you start to find others who cared about this work?

Not at all. In the early 90s nobody understood the idea and the need for pediatric palliative care in Poland. I was isolated in my hospital. My boss at that time, Professor Tadeusz Szreter in 1992 rejected my project of in-hospital pain management and palliative care service. Therefore, I decided to quit that hospital.

I failed again in the next pediatric hospital in Warsaw at Kopernika Street, because its Director took the funds, which I had received to start the hospice there.

Finally, I met Professor Zdzisław Rondio, a pediatric anesthesiologist and director of the Institute of Mother and Child in Warsaw, who accepted my project, and due to his decision I established the Warsaw Hospice for Children home care team in 1994 at this Institute.

It was a radical switch in my life at the age of 40. I left the hospital and my former medical career and become a hospice physician. The background of my decision was spiritual (Catholic). I felt that I must change my life and use my skills and knowledge in a different way and setting.

At that time, I was supported by two other people: Dr. Marcin Rawicz, a pediatric anesthesiologist, and Dr. Joanna Dangel, a pediatric cardiologist, and my wife.

a. What was it like to be relatively alone in this?

It was my conscious choice, kind of splendid isolation from the inhuman hospital medicine. I was sure that I was on the right path, which pediatricians cannot avoid in the future. Somebody must start and establish a standard.

Long before in the 80s I introduced in Poland the modern techniques of regional anesthesia and analgesia in children. Due to this experience, I was aware of how it feels to be “different” or “strange” in medicine. It is not a bad feeling – merely a different perspective.
3) Whom did you learn from early on?

In 1978-1979 I was taught the principles of anesthesiology by Professor Jaime A. Wikinski and Professor Juan Armando Nesi at the University Hospital in Caracas, Venezuela. They had a considerable impact on my personality as a very young physician. Then I was supervised by Professor Tadeusz Szreter at the Memorial Hospital Children's Health Centre in Warsaw in 1979-1983 as a junior anesthesiologist and ICU physician. Since 1983 I have been a specialist in anesthesiology and intensive care.

In 1991-1994 I completed four courses of palliative care for physicians. The basic education in palliative care I owe to Professor Jacek Łuczak and Dr. Robert Twycross.

In 1993 I received from Professor David Baum the Charter of the Association for Children with Life-Threatening or Terminal Conditions and Their Families, which I translated into Polish and used as our benchmark how to establish the hospice.1 2

In 1992-1993 I worked as editor of the journal Medicus in which we published articles on palliative care, pain management, bioethics, and medical law. At that time, I had the opportunity to learn a lot from Polish philosophers, theologists, and lawyers.

The specialty in palliative medicine that I obtained in 2003 placed me among the first group of physicians in Poland.

4) When you were beginning your work, what were the biggest challenges in caring for children suffering from serious illnesses?

In 1994 I was not sure if we would receive patients referred from hospitals to home care. We did not have sufficient funds, the staff was inexperienced, and we had no cars. After 1.5 years, I got sick with pulmonary mycobacteriosis, probably due to stress, and I had to stop working for the next eight months.

5) What were the biggest challenges you faced as you forged your career in pediatric palliative care?

Our projects establishing standards on pediatric and perinatal palliative care were rejected by the Ministry of Health since 1999 until now. However, they were plagiarized and deformed. My research was blocked in the Institute of Mother and Child by the ethical committee in 2004.3

I failed to establish a department of pediatric palliative care in the Children's Memorial Health Institute in Warsaw in 2005.

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1 https://www.researchgate.net/figure/Association-for-Children-with-Life-threatening-and-Terminal-Conditions-and-their-Families_fig1_12873617
2 https://www.hospicjum.waw.pl/d/fcf90c0cc62813b3c7766f2d318c328d
Once I was accused of a single case of malpractice at the medical court for using the ketogenic diet, which I designed for my hospice patient.

6) **How much did the adult hospice movement affect the development of pediatric palliative care?**

Since the beginning, I taught my colleagues from the adult hospices that they should not treat children because of their incompetence in pediatrics, neonatology, perinatal medicine, et cetera. We trained some physicians and nurses from the adult hospices at the beginning, when we did not have enough children's hospices in Poland.

7) **Over your career, what have been the biggest changes in the care provided to children suffering and dying from serious illnesses?**

   a. How has your work contributed to these changes?
   
   b. What would you say are the biggest challenges facing the field now?
   
   c. Where does the field need to grow?
   
   d. In what areas is the field the strongest?

During the last 25 years, the network of pediatric palliative home care has been developed in Poland. There are also some in-patient hospices for children. In my opinion, still too many children die in hospitals receiving inadequate life-prolonging treatment.

We introduced into pediatric palliative care in Poland: cough assistor, methadone, intranasal fentanyl, PCA, cannabinoids, palliative/terminal sedation with propofol or thiopental, botulinum toxin, ketogenic diet, quality of care measurement, bereavement support for parents and siblings, and teaching methods.

Moreover, we introduced perinatal hospice, and school of parenthood after prenatal diagnosis of lethal defect.

**a. Contribution:**

From 1996-2005, I was Department head of Palliative Care at the Institute of Mother and Child in Warsaw.

From 1996-2009, I organized annual courses on pediatric palliative care for physicians and nurses, and I edited periodic monograph, the XVII volumes.

From 1996-2000, I researched pediatric palliative care in Poland, and I published a book in 2001 as habilitation for my post-doctoral degree. Only one chapter was published in English. ⁴ ⁵

Since 1996, we have published 88 issues of the hospice journal (recently printed in 15,000 copies). ⁶

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⁵ https://www.jpsmjournal.com/article/S0885-3924(02)00461-X/pdf

⁶ https://hospicjum.waw.pl/biblioteka/informator,s-1
In 1998, we initiated perinatal palliative care in Poland.\(^7\)

From 1998-2018, I supervised an individual one-month training in pediatric palliative care (in our hospice) of 399 professionals from Poland and other countries.

In 1999, we translated and published a British document *Withholding and withdrawing life sustaining treatment in children.*\(^8\)

In 1999, 2001, and 2003, we organized three international courses within my project *Development of Palliative Care for Children in Europe.*\(^9\)

In 2001, we translated and published WHO guidelines *Cancer pain relief and palliative care in children.*

From 2001-2015, we conducted and published 15 epidemiological studies on pediatric palliative home care in Poland.\(^10\)

From 2006-2015 our Foundation spent $10,710,578 zł to establish eight new children's hospices in Poland.

In 2006, I initiated the first committee of clinical ethics in Poland in the Children's Memorial Health Institute in Warsaw.

In 2011, we published Polish guidelines on withholding life-prolonging treatment in children.\(^11\)

In 2016, we started elective course *Pediatric and perinatal palliative care. Communication with the patient and his family* for medical students.

In 2017, I published a book on low carbohydrate nutrition and supplementation in pregnancy.\(^12\)

In 2018, we opened a new educational center in Warsaw.

In 2019, we published the 4\(^{th}\) edition of Polish standards of pediatric palliative home care and the 1\(^{st}\) edition of Polish standards of perinatal palliative care.\(^13\)

**b. Biggest challenges:**

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\(^7\) https://perinatalne.pl/


\(^9\) https://www.jpsmjournal.com/article/S0885-3924(02)00466-9/fulltext


\(^12\) http://tomaszdangel.pl/

\(^13\) https://hospicjum.waw.pl/pliki/Artykul/1520_Standards.pdf
Lack of cooperation between our Foundation and the governmental administration. The Ministry of Health has never accepted our projects of standards in pediatric and perinatal palliative care.

Lack of official accreditation for our Foundation for teaching physicians and nurses.

Lack of palliative care units in pediatric hospitals.

Lack of intravenous methadone in Poland.

Our articles on pediatric and perinatal palliative care have been rejected by international journals (except one).  

We need to implement changes into the Polish law. In 2012 we wrote a bill, which was rejected by the President of Poland.

**c. Need to grow:**

We have too many children's hospices in Poland (66 contracted pediatric home care in 2020 for 1336 patients). They must be reviewed in accordance with the established standards.

We need to increase the level of medicine in those institutions through better education of physicians and nurses.

Our method to measure the quality of care should be introduced.

We need small palliative care units or teams in every pediatric hospital where is an ICU.

We need to educate gynecologists/obstetricians, geneticists and neonatologists in perinatal palliative care.

**d. Areas of strength:**

The Warsaw Hospice for Children Foundation (25 years of experience, teaching and research center).

The catholic ethical background with an emphasis on respect for life.

The concept of children's rights by Janusz Korczak (Dr. Henryk Goldszmit).

A traditional society based on families that create the possibility of home care.

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17 https://hospicjum.waw.pl/
18 http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html
19 https://www.cyc-net.org/cyc-online/cycol-0504-korczak.html
20 https://hospicjum.waw.pl/pliki/Artykul/1491_Informator_2_2019_czerwiec.pdf (pp. 24-25)
Volunteers.

Financial support from Polish society.21

8) Lastly, I would love for you to dream aloud: If budget and politics were no obstacle, what would you want care for these children to look like in 10 years?

Pediatric and perinatal palliative care officially recognized as branches of medicine.

Consultants of pediatric and perinatal palliative care involved in the process of decision-making in hospitals.

Difficult decisions are discussed openly and consulted with committees of clinical ethics.

Every pediatric hospital, which has an ICU, must also own a palliative care unit or team.

Children dying in hospitals are protected against life-prolonging treatment and suffering. Home care is an optimal option.

Physicians and nurses working in children's hospices and palliative care units must attend continuous education.

There is a national center of education, consultation, and research.

There is an international journal of pediatric and perinatal palliative care (open access, without charging fees from authors).

The terms "children's hospice" and "perinatal hospice" are not overused and defined precisely according to the standards.

Tomasz Dangel, MD, PhD
Interview for the Becker Medical Library of Washington University in St. Louis
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