STANDARDS

STANDARDS AND MEDICAL PROCEDURES FOR PEDIATRIC PALLIATIVE HOME CARE IN HOSPICES FOR CHILDREN

STANDARDS FOR PERINATAL PALLIATIVE CARE

The Warsaw Hospice for Children Foundation
2019

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The report hereby was written for the Polish Ministry of Health. It was developed *pro bono* by a team of independent experts cooperating with the Warsaw Hospice for Children Foundation (NGO). The authors' goal is to introduce in Poland consistent standards of pediatric palliative home care and perinatal palliative care, which would guarantee to sick children and their families an optimal quality of services and would constitute effective protection against a life-prolonging treatment referred to as futile medical care.

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Perinatal palliative care

Foreword

Pediatric and perinatal palliative care are new branches of medical science. Accordingly, theoretical models and approaches used in contemporary medicine are hardly applicable to them. The evidence based medicine (*the EBM*) tends to consider randomized epidemiological studies and clinical trials using biostatistics as the only credible source of evidence.

The ubiquitous use of the *EBM* methodology is the reason why the description of particular clinical case studies and small groups of patients are considered unreliable. We do not agree with such an approach. The experience of the Warsaw Hospice for Children, gained during twenty-five years of taking care of children facing death and their families, has provided essential and meticulous clinical observation of individual cases as well as the necessity of taking into account the whole psychosocial context of the process of dying. The present *Standards of pediatric and perinatal palliative care* were developed based on that approach.

How to love a child? This fundamental question was asked by a pediatrician, Dr. Janusz Korczak, as the title of his book published in 1918. Answering it he formulated three crucial child's rights: (1) the right to die, (2) the right to live the present day, (3) the right to be what he or she is, and – in addition – the right to express his or her thoughts and to actively participate in our reflection and decisions regarding his or her life.

We suggest that pediatric and perinatal palliative care be developed, analyzed, studied and described in accordance with these four principles that we have called "the Korczak's paradigm".

A contemporary application of this paradigm is visible in two documents: "The Charter of the Rights of the Terminally Ill Child at Home" issued by the Polish Ombudsman, and "Cessation and withdrawal of futile medical care in children" the guidelines for physicians issued by the Polish Pediatric Society.

In the latter of the above mentioned documents, we wrote: *Speaking about the cases of terminally ill children, the right to life must not be analyzed separately from the right to die. The medicine considered exclusively as serving the right to life and fighting with death is reduced to actions aiming at prolonging life at all costs and in any case. Such a one-sided approach may lead to paternalism, iatrogenic effects, medical experiments and futile medical care.*

We believe that the present publication is well rooted in this "Korczakian" way of thinking about sick children and their needs.

Authors

Pediatric palliative home care

Introduction

I. Need for pediatric palliative care

Based on the data collected by the organization *Children's Hospice International,* it is estimated that in 2008, only 7 million children worldwide had access to pediatric palliative care (PedPC).[1] The fact that 2 out of 3 countries had no activity in the area of PedPC shows clearly the need of establishing international cooperation aiming at an exchange of experience and establishment of palliative care teams.[2] Poland should join such an initiative.

The need for PedPC in the children 0 - 19 years old has been estimated between 20 per 10 000 in the United Kingdom and 113 per 10 000 in Zimbabwe.[3] In 2017, the population of children 0 – 19 years old in Poland was 7 689 900.[4] Applying the UK ratio, the need for PedPC in Poland could be estimated at the level of 15 380 children 0 – 19 years old.

In the years 1999 – 2015, in Poland, 15 epidemiological studies on pediatric palliative home care (PedPHC) were conducted.[5,6] According to their results, in 2013, 53 home hospices took care of 1 368 children 0 - 17 years old and of 130 patients over 18 years old, that in total gives the amount of 1 488. Unfortunately, there is no more recent data because neither the National Health Fund nor the Ministry of Health makes it available. Assuming that nowadays home hospices take care of about 2 000 children per year, this group would constitute only 13% of all children who need PedPC. That means that the remaining 87% (about 13 000 children) need to receive pediatric palliative care services in hospitals or other facilities. A part of them are probably provided with services of long-term care, but we do not have data regarding their number.

In 2013, 970 children 0 - 17 years old died because of incurable diseases; 729 died in hospitals, 209 at home, and 32 in other places. The biggest group consisted of children who died because of congenital heart defects (320 cases – 285 in hospitals, 28 at home, 7 in other places). The second big group consisted of children who died of malignancies (196 – 112 at hospitals, 78 at home, 6 in other places).[7]

[1] Children's Hospice International: Resources: an unmet need. Children's Hospice International 2008. Available from: http://www.chionline.org

[2] Knapp C, et al. Pediatric palliative care provision around the world: a systematic review. Pediatric Blood & Cancer; 2001. 57: 361-368. Available from: https://dokumen.tips/documents/pediatric-palliative-care-provision-around-the-world-a-systematic-review.html

[3] Connor SR, Downing J, Marston J. Estimating the global need for palliative care for children: a cross-sectional analysis. JPain Symptom Manage 2017; 53: 171-177. Available from: https://www.jpsmjournal.com/article/S0885-3924(16)30493-6/pdf

[4] Data from Statistics Poland, Rocznik Demograficzny (Demographic Yearbook) 2018. Available from: https://stat.gov.pl/obszary-tematyczne/roczniki-statystyczne/roczniki-statystyczne/rocznik-demograficzny-2018,3,12.html

[5] Kozera K, Murawska M, Marciniak W, Dangel T. Pediatryczna domowa opieka paliatywna w Polsce (Pediatric palliative home care in Poland) (2012). Medycyna Paliatywna 2014; 6: 19-54. Available from: https://hospicjum.waw.pl/pliki/Artykul/1107_pediatryczna-domowa-opieka-paliatywna-w-polsce-2012.pdf

[6] Kozera K, Wojciechowska U, Marciniak W, Tokarska E, Dangel T. Pediatryczna domowa opieka paliatywna w Polsce (Pediatric palliative home care in Poland) (2013); Medycyna Paliatywna 2015; 7: 19-44. Available from: https://hospicjum.waw.pl/pliki/Artykul/1109_pediatryczna-domowa-opieka-paliatywna-w-polsce-2013.pdf

[7] Ibid. p. 25, table 17.

II. Models of pediatric palliative care

There are different models of PedPC, depending on dominant diseases (for example, in Africa, the majority of patients are children with AIDS), geographical, demographic and economic characteristics of a country, as well as on its healthcare and health insurance systems. The data collected in 24 countries, published in the study *Pediatric Palliative Care: Global Perspectives*, led to a couple of general conclusions.[8] There are three main models of palliative care dedicated to children with incurable diseases: (1) home care, (2) hospital care, (3) inpatient hospice care. According to the study, home hospices functioned only in 6 out of 24 analyzed countries (Uganda, Singapore, Ireland, the USA, Argentina, and Poland).[9] The majority of countries base on hospital care. Specialized expert teams are established mainly in intensive care or oncological hospital units.[10] Another popular solution, especially in the United Kingdom, is the third one, which means the care offered by inpatient hospice facilities, referred to as the respite care. Inpatient hospices may be established as hospital units or independent facilities. They are the most expensive form of PedPC. It is not clear whether inpatient hospices for children operating in Poland act as centers of palliative or long-term care.[11]

III. Polish model of pediatric palliative home care

The Polish model of PedPHC was introduced in 1994 at the Institute of Mother and Child (Warsaw), and named the Warsaw Hospice for Children (WHC). Its organizational assumptions and principles of activity were generated from the results of a study conducted in the United Kingdom on the needs of the children with life-threatening conditions and their families.[12] The ethical principles were inspired by the guidelines issued by the World Health Organisation,[13] whereas the hypothesis regarding the need of establishing WHC was based on the following assumptions:

1. The children with life-threatening or terminal conditions suffer from pain and other symptoms whose treatment requires high expertise, clinical experience, and appropriate equipment. Those who stay at home do not have access to this kind of professional care.
2. Polish healthcare institutions, including hospices for adults, are not able to provide children and their families with adequate palliative care at home.

[8] Knapp C, Madden V, Fowler-Kerry S, Pediatric Palliative Care: Global Perspectives. Springer 2012. Available from: http://midnurse.umsha.ac.ir/uploads/Pediatric_Palliative_Care_Global_Perspectives.pdf

[9] The study did not include such countries as Belarus, Latvia, Romania and Slovakia, where home hospices for children had been present for many years.

[10] In Poland, a project for establishing such team was developed in 1992 in Centrum Zdrowia Dziecka (The Children's Memorial Health Institute) by Tomasz Dangel, but it has never been implemented.

[11] The rules of functioning of hospices for children are specified in the standards of the Polish National Forum of Pediatric Palliative Care and of the Polish Pediatric Society (2016). Available from: http://ofpop.pl/wp-content/uploads/standardy-ofpop-i-ptp-2016.pdf

[12] The ACT Charter for Children with Life-threatening Conditions and their Families. Association for Children with Life-threatening or Terminal Conditions and their Families, Institute of Child Health, Royal Hospital for Sick Children, Bristol; 1994.

[13] World Health Organization Expert Cemmittee. Cancer pain relief and palliative care. Geneva; 1990. Available from: https://apps.who.int/iris/bitstream/handle/10665/39524/WHO_TRS_804.pdf?sequence=1&isAllowed=y

3. In hospital, a child is exposed to futile medical care and medical experiments which aim to prolong life in the situation where there is no chance to cure the ongoing disease.
4. Probably a majority of sick children would prefer to spend the last part of their life at home.
5. The majority of parents can take care of their child better than hospital personnel.
6. In Poland, there is a need for home palliative care for adults. A hospice movement which revealed this need was born spontaneously, based on the British model, outside of the state healthcare system.
7. In the United Kingdom, there is a need for home palliative care for children.

In the beginning, WHC team (primarily consisting of 1 physician, 3 nurses and 1 social worker) offered a 24-hour care to children staying at home within the boundaries of Warsaw, and since 1995, it has offered these services to children living within a radius of 100 km from the city. In May 1995, WHC launched a program of bereavement support. In 2000, the team consisted of 3 physicians, 6 nurses[14], 3 social workers, 1 physiotherapist, 1 psychologist, 1 pedagogue, 1 priest, 3 administration employees (an accountant, a public relations officer, an administrator of the database of hospice's sponsors), and a group of about 80 volunteers. At that time, WHC had a legal status of an association (NGO) and acted on the medical services' market under the label of a non-public healthcare institution.

Patients were admitted based on a referral from a physician who had taken care of the child before, and after an interview with the parents who were supposed to give their informed consent for the treatment.[15] The referral had to include a diagnosis, information that the disease was incurable, and that the therapy aiming at the cure or the prolongation of life had been discontinued.

Permanent care was offered by an individually assigned nurse to every family; the nurse/family ratio was 1:4 and a social assistant was responsible for seven families. The personnel was in permanent phone contact with the families. Those who did not have a phone received a cell phone from the hospice which also helped them to get a regular phone line at home. The parents could be in touch with the nurse on duty at any time, day and night, reachable through paging system. The visits at home were scheduled between 9 a.m. and 3 p.m. The whole team met twice a day (at 8 a.m. and 3 p.m.) to discuss the needs of the patients and their families, and to divide the tasks. One physician and one or two nurses were on duty between 4 p.m. and 8 a.m. every day, and for 24 hours on weekends and holidays.

The intensity of pain and other symptoms was evaluated with the use of simple clinical scales. The treatment of pain and other symptoms was conducted in accordance with the WHO standards.[16]

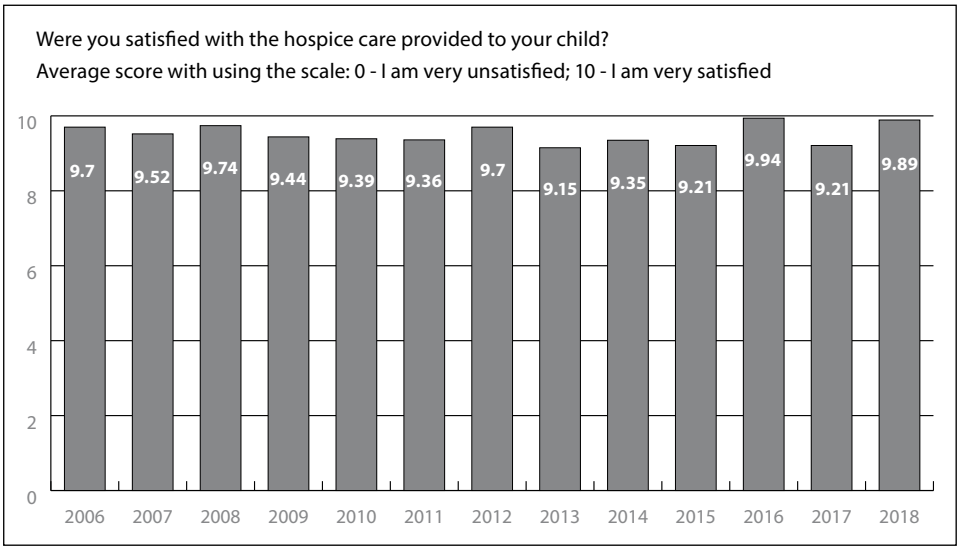
WHC covered the territory of 21 districts of the Mazovian voivodeship (Garwolin, Grodzisk, Grójec, Kozienice, Legionowo, Mińsk, Nowy Dwór, Otwock, Piaseczno, Płońsk, Pruszków, Pułtusk, Siedlce, Sochaczew, Warszawa, Warszawa Zachód, Węgrów, Wołonin, Wyszków, Żyrardów, and Siedlce). In 1999, the population of this territory was 3 514 094 inhabitants.

[14] Between 1994 and 2000, only two nurses quit because of the burnout syndrome.

[15] Dangel T, Przyjęcie dziecka pod opiekę hospicjum – rozmowa z rodzicami (Admission of a child in the hospice, interview with parents). In: Dangel T, editor. Palliative Care for Children. Warsaw: Instytut Matki i Dziecka & Warszawskie Hospicjum dla Dzieci; 1999. p. 40-43.

[16] World Health Organization. Cancer pain relief and palliative care in children. International Association for Study of Pain. WHO. Geneva; 1998.

In 1994 – 2019, WHC took care of 733 patients (children and young adults). In 1995, a program was launched aiming at promoting WHC model in Poland. The program included courses and internships for physicians and nurses, individual consultations, papers and a quarterly journal published by WHC and articles in scientific journals, lectures and public education initiatives. The program was developed in cooperation with the Institute of Mother and Child where in 1996 a Department of Palliative Care was established. In 1998, a list of physicians offering PedPHC in Poland was published, and WHC started monitoring nationwide the situation in that area.



In 2000, a methodology of evaluating the quality of PedPHC services was developed, and implemented by WHC.[17] The evaluation continued in 2006-2018. The indicator of "parents' satisfaction with the hospice's services" was between 9.15 and 9.94 on a scale from 0 to 10 (see the chart below).[18]

In 2003, David Clark and Michael Wright published the results of their study conducted in 28 countries of Eastern Europe and Central Asia. The authors identified only five leading centers ("beacons") of palliative care. Among them, they mentioned four centers for adults and WHC as the only pediatric center.[19] The study was quoted in the guidelines of the Committee of Ministers of the Council of Europe regarding palliative care in the member states.[20] David Clark and Michael Wright published a report from an audit conducted in WHC, in which they described in detail Polish standards of pediatric palliative home care that they evaluated positively.[21]

[17] Dangel T, Fowler-Kerry S, Karwacki M, Bereda J. An evaluation of a home palliative care program for children. Ambulatory Child Health. 2000; 6: 101-114.

[18] The Warsaw Hospice for Children Foundation. Annual reports. See also: Appendix 9.

[19] Clark D, Wright M. Transitions in end of life care: hospice and related developments in Eastern Europe and Central Asia. Buckingham: Open University Press. 2003.

[20] Committee of Ministers of the Council of Europe. Recommendation no. R (03) 24. 12 November 2003. p. 30, item 15. Available from: https://rm.coe.int/0900001680910b78

[21] Clark D, Wright M. The development of pediatric palliative care in Warsaw, Poland. European Journal of Palliative Care 2003; 10(3): 120-123. Available from: https://hospicjum.waw.pl/pliki/Artykul/1076_thedevelopmentofpaediatricpaliativecareinwarsaw-poland-2003.pdf

In 2004, professor Jacek Łuczak, the national consultant for palliative medicine, also positively assessed the WHC model.[22]

In 2012, the Polish model of PedPHC was presented on an international forum by Marek Karwacki.[23] Thanks to WHC's international cooperation home hospices for children were established in East-Central Europe: in Belarus, Czech Republic, Latvia, Russia, Romania, Slovakia and Ukraine.

The authors of the present document propose to implement the WHC model in Poland via appropriate legal acts issued by the Ministry of Health.[24]

IV. Obstacles for organizing and developing pediatric palliative care

The quality of palliative care and its acceptance by the public depends on many factors. The most significant have cultural roots such as a denial of death, which is particularly strong in Western civilization, especially when it comes to death of a child. The belief in an unlimited power of medicine for prolonging life is an important factor. The nonacceptance of the finiteness of life has a considerable impact on legal solutions and healthcare policy adopted in a given country, and strongly shapes public opinion and the attitudes of medical circles regarding the care offered to terminal patients.

A survey carried out in 2012 by the Polish Public Opinion Research Center came to the following conclusions:

- 36% of respondents had no conception of the phrase "giving up futile medical care." Only 22% of respondents interpreted this phrase to mean the discontinuation of treatment and 9% as practicing euthanasia. The authors conclude that *the notion of "giving up futile medical care" raises confusion. A relatively large number of people is not able to name any situation associated with that term, and a small group of respondents has a very general understanding or confuse it with euthanasia.*
- The most controversial opinions were given when questions were asked about *disconnecting life support equipment from a patient who suffered an accident; the patient has been unconscious for many weeks; his/her brain has been damaged, and it is obvious that he/she will not come back to normal life anymore, and his/her family gave consent.* Close to one half (47%) of respondents interpreted such situation as euthanasia, but a quite large group (35%) was of the opinion that in such circumstances we should rather speak about discontinuation of futile medical care.
- Close to one half (48%) of respondents expressed the opinion that *when it comes to a person dying of an incurable illness, treatment should be ceased if it is clear that it cannot be successful, but only increases patient's suffering and prolongs his terminal phase.* 38% of respondents expressed the opposite opinion.

[22] Łuczak J. Geneza działalności Warszawskiego Hospicjum dla Dzieci na tle ruchu hospicyjnego w Polsce i Europie (Origins of the activity of the Warsaw Hospice for Children compared to the hospice movement in Poland and Europe). In: Dangel T, editor. Opieka Paliatywna nad Dziećmi (Palliative Care of for Children), Warsaw: The Warsaw Hospice for Children, Institute of Mother and Child; 2004. p. 8-16. Available from: https://hospicjum.waw.pl/pliki/Artykul/1143_genezadzialalnosciwarszawskiegohospicjumdladziecinatleruchuhospicyjnegowpolsceieuropie-2004.pdf

[23] Karwacki M. Pediatric palliative care in Poland. In: Knapp C, Madden V, Fowler-Kerry S. Pediatric Palliative Care: Global Perspectives. Springer 2012. Available from: http://midnurse.umsha.ac.ir/uploads/Pediatric_Palliative_Care_Global_Perspectives.pdf

[24] The solutions described in the present document have not been implemented yet through legislative acts (e.g. regulations).

- Only 22% of respondents supported the idea of stopping futile medical care, and concomitantly they were against euthanasia (this attitude is consistent with the stance of the Roman Catholic Church). Regularly practicing Catholics were more often against than for abandoning futile medical care (46 vs. 38%), but 29% of them supported euthanasia.[25] It proves limited influence of the Roman Catholic Church in shaping public opinion in that area. The authors of the survey conclude that *the stance of the Catholic Church in that matter is little known to the public, including religious people.*
- 60% of Poles accepted the idea of implementing an advanced healthcare directive (in Poland called *Testament of Life*) via legislation.

The above mentioned survey was inspired by a bill which included new legislative solutions such as an advanced healthcare directive and a healthcare proxy. Both aimed at guaranteeing the patient's right to die with dignity, and introducing a civil liability for a culpable violation of this right. The authors of the bill argued that *unclear legal regulations as well as physicians' anxiety about being liable for the death of their patient caused by witholding of treatment are the reason why in Poland many terminally ill patients are subjected to futile medical care*.[26] In 2012, the bill was handed over to the President of the Republic of Poland who refused to forward it to the Parliament. The bill was evaluated by Catholic ethicists who stated that *the proposal goes in the right direction, but it needs to be refined to prevent the use of it for justifying euthanasia*.[27]

The results of the survey, as well as the fate of the bill, confirm the argument that the law and healthcare policy are both strongly influenced by cultural factors.

A polarization amongst public opinion regarding the prolongation of life of a terminally ill child by using a ventilator vs. discontinuation of mechanical ventilation (discontinuation of futile medical care) was visible in the case of Alfie Evans. The Expert Team on Bioethics of the Polish Bishops Conference came up with the following statement: *Taking into consideration a predictable effect, removing him [Alfie Evans] from the mechanical ventilation was synonymous with killing the child and not with morally and legally acceptable discontinuation of futile medical care*.[28]

The opposite stance was taken by the physicians Marcin Rawicz[29], Zbigniew Żylicz,[30] and Tomasz Dangel[31]. That debate revealed vastly different interpretations and ethical assessments of the sentence of the British court and of the stance taken by physicians from the Alder Hey Hospital in Liverpool.

[25] Centrum Badania Opinii Społecznej. Zaniechanie uporczywej terapii a eutanazja (Withdrawing futile medical treatment vs. euthanasia). 2013. Available from: http://www.hospicjum.waw.pl/pliki/Artykul/1370_1101-k003-13.pdf

[26] Andruszkiewicz P, Dangel T, Grenda R, Kurkiewicz A, Rawicz M, Strus-Wołos M, Szeroczyńska M, Szymkiewicz-Dangel J. Projekt ustawy o zmianie ustawy o prawach pacjenta i Rzeczniku Praw Pacjenta oraz niektórych innych ustaw (The bill amending the law on patient's rights and on Commissionaire for Patient's Rights, and other laws). Warsaw; 2013. Available from: https://hospicjum.waw.pl/pliki/Artykul/1100_proj-ust-o-zm-ust-o-prawach-pacjenta-i-rzeczniku-praw-pacjenta.pdf

[27] Łoziński B. Godne umieranie czy eutanazja (Death with dignity or euthanasia). Gość Niedzielny. 2012; 48. Available from: http://gosc.pl/doc/1374459.Godne-umieranie-czy-eutanazja

[28] Expert Team on Bioethics of the Polish Bishops Conference, Stanowisko w sprawie Alfiego Evansa (Stance on Alfie Evans's case). Available from: https://episkopat.pl/stanowisko-zespolu-ekspertow-kep-ds-bioetycznych-w-sprawie-alfiego-evansa/

[29] Rawicz M. Żeby była mama i żeby nie bolało. W sytuacjach krańcowych trzeba dać dziecku spokojnie umrzeć (I wish my mom was here and I didn't feel pain. In terminal conditions we should let the child die in peace). 2018. Available from: https://zdrowie.dziennik.pl/aktualnosci/artykuly/573520,rigamonti-wywiad-dr-marcin-rawicz.html

[30] Żylicz Z, Nie było szans na uratowanie Alfiego Evansa (Alfie Evans could not be saved). Plus Minus. 2018. Available from: https://www.rp.pl/Plus-Minus/305109929-Zbigniew-Zylicz-Nie-bylo-szans-na-uratowanie-Alfie-Evansa.html

[31] Dangel T, Czy sędzia Hayden zabił Alfiego Evansa? (Did Mr Justice Hayden kill Alfie Evans?). Hospicjum. 2018; 84: 30-32. Available from: https://hospicjum.waw.pl/pliki/Artykul/1471_informator-hospicjum-nr-84-czerwiec-2018.pdf

The authors of the present Standards are of the opinion that in our society the attitude supporting the prolongation of life of terminally ill children prevails and is an obstacle for the development of PedPC. This situation will not change until protection against futile medical care has not been established by law (e.g. by implementing the above mentioned bill).

Stefan Friedrichsdorf and Eduardo Bruera distinguish four stages of implementing a PedPC program in a children hospital, which need a "cultural adaptation".[32] They are as follows:

1. Denial by clinical colleagues and hospital executives. Other physicians and the hospital leadership reject the project.
2. Palliphobia. Physicians, nurse practitioners and other health professionals may feel their professional competence is being questioned or even threatened by the new PPC team.
3. Pallilalia.[33] A relentless repetition of absurd opinions regarding palliative care leads to burnout syndrome among the members of the PedPC team. The team does not receive proper support from the hospital leadership. Pediatricians refer only a few patients – usually with terrible psycho-social-medical and/or mental health problems – to their fellow physicians from the PedPC team.
4. Palliactive. The PedPC program is accepted, recognized, and funded as well as other hospital units. Hospital physicians refer their patients to the PedPC unit and encourage their colleagues to do the same.

The first project of establishing an in-hospital PedPC unit in Poland was proposed in 1992 by Tomasz Dangel in the Children's Memorial Health Institute. Unfortunately, it was not accepted. That experience corresponded to the above mentioned stage "denial."

At present, in Polish hospitals for children there are neither teams nor units of palliative care. It shows how much the need of palliative care has been ignored within Polish hospitals. We insist on establishing PedPC units in all hospitals having pediatric intensive care units.

Some hope that a process of cultural adaptation in our country has started can be raised by a number of initiatives undertaken by different circles, such as:

1. Publishing of the British guidelines *Withholding and Withdrawing Life Saving Treatment in Children*.[34]
2. Publishing by the Polish Pediatric Society (PPS) of the guidelines for physicians *Withholding and withdrawal of futile life-sustaining treatment in children*.[35]
3. Publishing of the document *Guidelines regarding the ineffective maintenance of organ functions (futile therapy) in ICU patients incapable of giving informed statements of will.*[36]

[32] Friedrichsdorf SJ, Bruera E. Delivering pediatric palliative care: from denial, palliphobia, pallilalia to palliactive. Basel: Children. 2018; 5: 1-13. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6162556/pdf/children-05-00120.pdf

[33] The neologism derived from the word "palilalia" which means a language disorder characterized by the involuntary repetition of syllables, words, or phrases.

[34] Royal College of Pediatrics and Child Health. Zaniechanie i wycofanie się z leczenia podtrzymującego życie u dzieci – zarys praktyki medycznej (Withholding and Withdrawing Life Saving Treatment in Children). Polish translation by Tomasz Dangel and Marek Wichrowski. Pediatria Polska. 1999; 74: 821-837. Available from: https://hospicjum.waw.pl/pliki/Artykul/1135_zaniechaniewycofaniezleczeniapodtrzymujacegozycieudzieci-zaryspraktykimed-1997.pdf.

[35] Zaniechanie i wycofanie się z leczenia podtrzymującego życie u dzieci – wytyczne dla lekarzy (Cessation and withdrawal of futile medical care in children: guidelines for physicians). Dangel T, editor. Polish Pediatric Society. Warsaw; 2011. Available from: https://hospicjum.waw.pl/pliki/Artykul/1333_1134-zaniechanieiwycofaniezleczeniapodtrzymujacegozycieudzieci-wytyczneptp-2011.pdf

[36] Kübler A, Siewiera J, Durek G, Kusza K, Piechota M, Szkulmowski Z. Wytyczne postępowania wobec braku skuteczności podtrzymywania funkcji narządów (terapii daremnej) u pacjentów pozbawionych możliwości świadomego składania oświadczeń woli na oddziałach intensywnej terapii (Guidelines regarding the ineffective maintenance of organ functions (futile therapy) in ICU patients incapable of giving informed statements of will). Anestezjologia Intensywna Terapia; 2014; 46: 229-234. Available from: https://www.ptpaio.pl/dokumenty/19.pdf

4. The above mentioned bill.
5. Publishing by the Ombudsman of the *Charter of the Rights of the Terminally Ill Child at Home* (**Appendix No 8**).
6. Publishing by the Expert Team on Bioethics of the Polish Bishops Conference of the document *Futile medical treatment in patients subjected to intensive care*.[37]
7. Debates within the Polish Bioethical Society.[38,39] The first of the above mentioned debates was summed up by Kazimierz Szewczyk as follows:
    - It is essential to amend the present regulations because they are unclear and complicated, and destroy mutual trust and respect of physicians and patients.
    - A number of sensational news regarding "death hastening practices" trigger irrational reactions and distract from the substance.
    - Freedom is constrained by anxiety caused by ubiquitous and unjust accusations of physicians of euthanasia.
    - Such accusations based on the "Dr. Mengele argument" could be alleviated or eliminated if clear definitions of euthanasia and futile medical care were formulated and implemented in the legal system.
    - Euthanasia is the deliberate active shortening of life motivated by desire to relieve suffering, executed by a physician on the voluntary request of a competent patient. Euthanasia, as defined above, would be illegal.
    - Wish of withholding active treatment expressed by a competent patient, as well as his/her advance healthcare directive, should not be equated with euthanasia.
    - It is difficult to define futile medical care for cultural reasons (a strong death denial characteristic for Western civilization).
    - However, such a definition would considerably increase the sense of security of physicians by protecting them against accusations of euthanasia.
    - No physician should undertake or continue futile treatment because of the probability of survival or cure.
    - Physicians' path through the land of suffering is set by their patients' rights and their individual hierarchy of values, but this path is always narrowed down by the medical know-how (awareness of the futility of treatment), and by the prohibition of euthanasia (in the cultural and economic context of our country). These two conditions constitute the spine of the moral integrity of health professionals.[40]

The success of the cultural adaptation is eventually a result of decisions taken by the healthcare authorities, including the Ministry of Health, and professional medical organizations, such as the PPS.

[37] Expert Team on Bioethics of Polish Bishops Conference, O terapii daremnej (uporczywej) chorych poddawanych intensywnej terapii (Futile [persistent] medical treatment in patients subjected to intensive care). Available from: https://episkopat.pl/zespol-ekspertow-kep-ds-bioetycznych-zaprzestanie-terapii-daremnej-nie-moze-byc-utozsamiane-z-eutanazja/

[38] Polish Bioethical Society. Czym jest uporczywa terapia? (What is futile medical care?. Available from: http://www.ptb.org.pl/opinie_uporczywa.html

[39] Polish Bioethical Society. O terapii daremnej (About futile medical care). Available from: https://www.ptb.org.pl/opinie_archiwum.html

[40] Polish Bioethical Society, Czym jest uporczywa terapia? (What is futile medical care?). Available from: http://www.ptb.org.pl/opinie_uporczywa.html

V. Standards for pediatric palliative home care – historical background

The first edition of standards of PedPHC, dedicated to the Ministry of Health, was published in 1999 by the Department of Palliative Care of the Institute of Mother and Child.[41] The document was based on the experience of WHC. The authors set the minimal requirements (less demanding that those met by WHC) necessary for ensure a 24-hour palliative care at home for 1-12 children.

Based on the above mentioned standards, a questionnaire was designed that in October 1999 was sent to physicians 39 from hospices'. Those physicians had previously graduated from a course on palliative care for children conducted by the Centre of Postgraduate Medical Education (CPME). They declared their readiness to provide palliative home care for children in the area of their activity and agreed to publish their personal data in the Internet to allow other physicians to refer patients to them. None of these hospices, except WHC, met the minimal requirements. The lacking requirements were mostly the following:

- the physicians had not completed a one-month internship at WHC;
- the hospices were not equipped with pulse oximeters and pagers, and could not provide patients' families with cell phones.

Only two hospices (in Warsaw and in Płock) were fully equipped according to the minimal requirements set in the Standards (see the table below).[42]

List of equipment necessary for home palliative care for children according to standards (1999). Prices from 2000

Equipment used by WHC	Price in PLN	Total in PLN
1 Fiat Seicento	20 400	20 400
4 cell phones – yearly prepaid	4 x 4800	19 200
1 pager – yearly prepaid	1000	1 000
2 oxygen concentrators Puritan Bennett 590i	2 x 8500	17 000
1 pulse oximeter Nellcor Puritan Bennett NBP-295	10 000	10 000
4 Laerdal Suction Units (LSU)	4 x 4000	16 000
2 anti-bedsore mattresses ROHO (2 x 4 segments)	2 x 8500	17 000
4 infusion pumps Graseby MS26	4 x 3700	14 800
2 inhalers Voyager	2 x 450	900
4 electronic blood pressure monitors NISSEI DS-157	4 x 350	1 400
Total		**117 700**

[41] Dangel T, Januszaniec A, Karwacki M. Standardy domowej opieki paliatywnej nad dziećmi (Standards of Palliative Home Care for Children). Nowa Medycyna 6: 43-50; 1999.

[42] Dangel T. Domowa opieka paliatywna nad dziećmi w Polsce. Model, potrzeby możliwości i ich ocena. Praca habilitacyjna. (Palliative Home Care for Children in Poland. Model, needs, capabilities, and their assessment. Habilitation thesis.) Wydawnictwo Naukowe Scholar, Warsaw; 2001.

In 2008, the second edition of PedPHC Standards was published, and it was referred to the Ministry of Health as a draft regulation.[43]

In 2006 – 2015, PedPHC Standards were submitted to a two-year validation in eight other home hospices for children in Poland (Białystok, Gdańsk – 2, Kraków, Opole, Rzeszów, Szczecin, Tychy). In that period, those hospices were co-financed and monitored by the WHC Foundation which spent for that purpose 10.7 million PLN.[44] Based on that co-operation, a methodology of calculating PedPHC costs was developed (**Appendix No 11**).[45]

In 2014, the Section of Pediatric Palliative Medicine was established within the PPS, whose team worked on standards and medical procedures for PedPHC in home hospices for children. Unfortunately, the authors could not reach consensus with the General Board of the PPS regarding the final version of the document.[46] Hence, the WHC Foundation published it in 2015 as the third edition of PedPHC Standards.[47] The document was translated to Russian and Ukrainian.[48]

In 2016, after having rejected the above mentioned document, the Management Board of the PPS and the Polish National Forum of Pediatric Palliative Care (PNFPPC) published their own project of standards. Many norms and requirements were far less demanding that those contained in the project of the WHC Foundation.[49] Furthermore, the document published by the PPS and the PNFPPC included quotations from the document published by the WHC Foundation without any reference to the original source.[50] A comparison of selected norms and requirements included in the Standards published by the WHC Foundation and by the PPS and the PNFPPC is presented in the table below.

The present 4th edition of the "Standards and Medical Procedures for Pediatric Palliative

[43] Dangel T, Strus-Wołos M, Boszko K, Iwaszkiewicz M, Szymborski J. Projekt rozporządzenia w sprawie standardów postępowania i procedur medycznych z zakresu pediatrycznej domowej opieki paliatywnej w zakładach opieki zdrowotnej (Draft regulation on standards and medical procedures in pediatric palliative home care in healthcare facilities). Fundacja Warszawskie Hospicjum dla Dzieci. 2008. Available from: https://hospicjum.waw.pl/pliki/Artykul/1093_standardypostepowaniaiprocedurmedycznychzzakresupediatrycznejdomowejopiekipaliatywnej-projektrozpmz-2009.pdf

[44] During the 2 first years, these hospices were financed by the Warsaw Hospice for Children Foundation. Based on the agreement signed with the hospices, the Foundation controlled the fulfilment of the requirements set by the Standards.

[45] Kozera K, Wojciechowska U, Marciniak W, Tokarska E, Dangel T. Pediatryczna domowa opieka paliatywna w Polsce (2013) (Pediatric palliative home care in Poland). Medycyna Paliatywna. 2015; 7: 9-44. Available from: https://hospicjum.waw.pl/pliki/Artykul/1109_pediatryczna-domowa-opieka-paliatywna-w-polsce-2013.pdf

[46] The discrepancies regarded, i.a., the relation between the number of nurses employed in the hospice and the number of patients, or the list of life-prolonging procedures which should not be applied in the PedPHC.

[47] Boszko K, Dangel T, editors, Grenda R, Januszaniec J, Karwacki M, Kurkiewicz A, Rawicz M, Sawicka E, Strus-Wołos M, Szeroczyńska M, Szymborski J, Szymkiewicz-Dangel J, Świetliński J, Wichrowski M. Standardy i procedury medyczne w hospicjach domowych dla dzieci (Standards and medical procedures in home hospices for children). 3rd ed. Fundacja Warszawskie Hospicjum dla Dzieci. 2015.

[48] Available from: https://hospicjum.waw.pl/pliki/Artykul/1457_Standarty-raboty-i-medicinskie-procedury-v-domashnih-detskih-hospisah.pdf; https://hospicjum.waw.pl/pliki/Artykul/1474_Standarti-roboti-ta-medichni-proceduri-u-domashnih-dityachih-hospisah.pdf

[49] Korzeniewska-Eksterowicz A, Buczyński F, Muszyńska-Rosłan K, Ciupiński R, Andrzejewski W, Hermanowicz A, Dobrzańska A, Jackowska T, Peregud-Pogorzelski J. Standardy prowadzenia pediatrycznej opieki paliatywnej Ogólnopolskiego Forum Pediatrycznej Opieki Paliatywnej i Polskiego Towarzystwa Pediatrycznego (Standards of Pediatric Palliative Care of the Polish Forum of Pediatric Palliative Care and the Polish Pediatric Society). Przegląd Pediatryczny. 2016; 45: 64-72. Available from: http://ofpop.pl/wp-content/uploads/standardy-ofpop-i-ptp-2016.pdf

[50] [A scientific researcher] can use printed documents only upon condition that he indicates the source and clearly makes distinction between his own achievements and those of other scientists. Quoting scientific publications of other authors is acceptable exclusively for the purpose of briefly and accurately informing about the authorship. Any handwritten texts or drafts can be used exclusively with a previous written consent of the author and with indication of the source. Source: Kodeks Etyczny Polskiej Akademii Nauk (Ethical Code of the Polish Academy of Science). 2001. Available from: http://www.paleo.pan.pl/documents/Kodeks_Etyczny_PAN.pdf

Home Care in Hospices for Children" is a supplemented version of the 3rd edition from 2015 ("Standards and medical procedures in home hospices for children).

Comparison of selected norms and requirements included in the Standards published by the WHC Foundation and by the PPS / PNFPPC

Norm / requirement	WHC Foundation 2015	PPS/PNFPPC 2016
Number of patients vs. number of nurses	4	6
Time of nurse's visit (minutes)	90	-
Social workers	1	-
Chaplain	1	-
Maximal number of patients	30	-
Maximal distance (km)	100	-
Team briefing	2 times a day	-
Obligatory professional training for physicians (course registered in CPME)	every 2 years	-
Evaluation of services	yes	-
DNR form according to the guidelines of the PPS	yes	-
List of diseases	open	closed
Cooperation with a family court	yes	-
Use of a cough assist machine	yes	-
Use of botulinum toxin	yes	-
Number of oxygen concentrators / number of patients	1 for 2	1 for 4
Number of suction units / number of patients	4 for 5	1 for 4
Number of anti-bedsore mattresses / number of patients	4 for 5	1 for 6
Number of cough assist machines / number of patients	1 for 5	-
Number of electric power generators / number of patients	1 for 2	-
Cars	5	3

VI. Regulation of the Minister of Health

None of the above mentioned documents was implemented by the Minister of Health. Therefore, the norms and requirements for PedPHC enforced by the National Health Fund are defined in the regulation of the Minister of Health on guaranteed healthcare services in palliative and hospice care.[51] The regulation contains serious and substantial errors and inner contradictions. Furthermore, the requirements defined in that regulation do not guarantee an adequate quality of PedPHC.[52]

[51] Poland. Ministry of Health. Information notice of the Minister of Health from 28 March 2018 on the publication of the consolidated text of the regulation of the Minister of Health on guaranteed healthcare services in palliative and hospice care. Official Journal of the Republic of Poland from 17 April 2018, item 742. Available from: http://prawo.sejm.gov.pl/isap.nsf/download.xsp/WDU20180000742/O/D20180742.pdf

[52] We pointed it out on several occasions in our correspondence with the Ministry of Health, and we proposed our own draft regulation which was not accepted.

The regulation establishes two contradictory norms regarding the work of nurses:

1. "Ratio of 1 job position [of a nurse] per 12 beneficiaries."
2. "Frequency of nurse's visits – depending on needs, but at least than twice a week."

The controls carried out in the WHC Foundation by the National Health Fund (2015) and the Supreme Chamber of Control (2018) demonstrated that nurses could not visit all patients twice a week, although WHC employed 10 nurses per 30 patients, that means four times more than defined in the above mentioned regulation. The National Health Fund received detailed explanations from the Foundation specifying why it had not been able to meet that requirement, but it neither engaged in a substantial discussion with the Foundation nor undertook steps aiming at amending the above mentioned norm.

Developing standards or regulations in the matter of PedPHC requires an in-depth knowledge of principles of operation of the WHC model, including the policy of maximum efficiency.[53] The most important element of this model is a nurse and 3-4 patients he/she takes care of. Nurses work 7 hours 35 minutes 4 days a week, and she has one on-call duty, which is compensated by one day off. The call time extends from 3.35 PM till 8.00 AM during working day and from 8 to 8 during weekends and holidays. If the duty falls on a holiday, the nurse visits her patients according to a previously made schedule. The patients can live close or far away. Within one day, a nurse can pay 2 visits to patients living close, or 1 visit to a patient living far away. That means that over 4 working days she can pay 8 visits to patients living close, or 4 visits to patients living far away. That leads us to four possible scenarios:

1. The nurse takes care of 1 patient who lives far away, and 2 who live close. In that case, she uses 2 days for 2 remote visits, and 2 days for 4 visits given to patients who live close. The average number of visits per patient per week is 2.
2. The nurse takes care of 2 patients who live far away, and 1 who lives close. In that case, she can make 3 remote visits, and 2 visits given to patients who live close. The average number of visits per patient per week is 1.67.
3. The nurse takes care of 2 patients who live far away, and 2 who live close. In that case, she can make 2 remote visits, and 4 visits given to patients who live close, or 3 remote visits, and 2 visits given to patients who live close. The average number of visits per patient per week is respectively 1.5 or 1.25.
4. The nurse takes care of 1 patient who lives far away, and 3 who live close. In that case, she can make 2 remote visits, and 4 visits given to patients who live close, or 1 remote visit, and 6 visits given to patients who live close. The average number of visits per patient per week is respectively 1.5 or 1.75.

The first scenario allows the hospice to meet the norm included in the regulation upon condition that none of the patients requires an additional visit.

The quality of services of a home hospice depends on the work of the whole team, and not only nurses and physicians whose minimal number of visits was defined in the regulation. The table below presents an average number of visits of WHC employees to patients in 2015-2018.

[53] No human team, and especially a team of nurses taking care of terminally ill children, should work with maximum efficiency because of an increasing risk of a burnout syndrome which leads to poorer quality of services and a more frequent absence from work. The quality of palliative care does not depend on a given number of visits, but on the adjustment of this number to the needs of the patient and his caregivers, which has been proven by our analysis of the quality of services.

Year	Average number of weekly visits (nurses)	Average number of monthly visits (physicians)	Average number of visits (all employees)	
			weekly	monthly
2015	1.57	2.82	3.50	15.18
2016	1.65	2.90	3.55	15.38
2017	1.70	2.50	3.68	15.95
2018	1.78	1.94	3.45	14.95

The table below presents the evaluation scores of the frequency of the visits made by the employees of WHC. The evaluation was done by the parents of deceased patients, and the majority of them considered the frequency adequate.

How do you evaluate the frequency of visits?	2015	2016	2017	2018
Adequate	26	16	24	35
Too frequent	0	1*	0	0
Too rare	0	1**	0	0

* During 116 days of care 52 visits of nurses and 18 visits of physicians were made. The total number of visits of all employees was 108.

** During 305 days of care the employees made 144 visits.

The regulation of the Minister of Health also includes other provisions which do not guarantee an adequate quality of services, namely the requirement of 1 oxygen concentrator per 10 patients, or 1 electric suction device per 10 patients.

The authors of the present document propose to the Ministry of Health designing a new regulation based on the standards developed by our team.

VII. Refunding

It is essential to adopt a relevant methodology of calculating the costs of services provided by a home hospice for children. Such methodology was developed by WHC (**Appendix 11**). At present, these services are refunded by the National Health Fund to a minimal extent. The person responsible for this situation is the President of the Agency for Health Technology Assessment and Tariff System, who in 2016 set out the tariff for hospice services. He named it a "man-day" to represent the work carried out at a home hospice for children, and assigned it a value of 1.60 points.[54] Since one point has been given a value of 56.19 PLN, the services of WHC are reimbursed by the National Health Fund in amount of 89.9 PLN per one man-day.

[54] Poland. Agency for Health Technology Assessment and Tariff System. Information notice of the President of the Agency for Health Technology Assessment and Tariff System on tariffs of guaranteed healthcare services such as palliative and hospice care. Available from: http://www.aotm.gov.pl/www/wp-content/uploads/2016/09/20160629_Obwieszczenie_Prezesa_OPH_AW.pdf

However, according to our methodology, in 2019 the minimal cost of services provided by a home hospice for children is 249 PLN per a man-day (see the **Appendix 11**).[55] That means that the National Health Fund refunds only 36% of costs of services meeting the standards described in the present document. An inadequate reimbursement impairs the quality of services, especially in the hospices which do not have other sources of income or do not want to spend it for home care.

VII. Training of physicians and nurses

In Poland, postgraduate training of physicians and nurses in the matter of PedPC was launched in 1996 by Tomasz Dangel.[56] A study was carried out with the aim to analyze the influence of training on physicians' and nurses' attitude towards dying children.[57] In 1996 – 2009, 15 nationwide courses were conducted, each of them accompanied by a subsequent volume of a monography "Palliative Care for Children".

In 2010, a curriculum was developed for a course "Pediatric palliative home care" dedicated to the Center of Postgraduate Education for Nurses and Midwives. In 2010 – 2015, the WHC Foundation organized 4 such courses which were graduated by 93 nurses from home hospices for children. Subsequent interest for this course faded.

Since 2016, the WHC Foundation has conducted professional improvement courses for physicians under the name "Palliative care in pediatrics". Their goal has been to provide physicians working in hospitals with basic knowledge on pediatric and perinatal palliative care.[58] In 2016 – 2019, 265 physicians graduated from 11 courses.

In 2018, a curriculum for a two-day course "Palliative care" was developed for the Centre of Postgraduate Medical Education with the purpose of including it in the curriculum of pediatric specialty training (**Appendix 12**). We propose that a similar course be included in the curriculum of other medical specialties training dedicated to children's health.

The regulation of the Minister of Health sets the following requirements regarding education and training of physicians and nurses working in home hospices for children:

1. "Physician specialist in either pediatrics, neonatology, pediatric neurology, pediatric oncology and hematology, anesthesiology and resuscitation, anesthesiology and intensive care, pediatric surgery, palliative medicine, family medicine; physician in the course of a specialty training in pediatrics, neonatology, pediatric neurology, pediatric oncology and hematology, anesthesiology and resuscitation, anesthesiology and intensive care, pediatric surgery, palliative medicine, family medicine; physician with certificate of graduation from a course whose curriculum covers the curriculum of specialization in palliative medicine, in treatment of pain, and somatic and psychological symptoms, from a course in palliative care for children carried out by the Centre of Postgraduate Medical Education, a medical school entitled to conduct undergraduate or postgraduate trainings for physicians, or by an institution accredited to conduct specialization in palliative medicine";

[55] In 2018, the cost of a man-day in WHC amounted to 596 PLN. The National Health Fund refunded only 18% of the costs borne by WHC for pediatric palliative care services.

[56] Dangel T. Kształcenie lekarzy i pielęgniarek (Training of physicians and nurses). Hospicjum. 2018; 85: 15-19. Available from: https://hospicjum.waw.pl/pliki/Artykul/1473_Informator-Hospicjum-nr-85-wrzesien-2018.pdf

[57] Dangel T. Domowa opieka paliatywna nad dziećmi w Polsce. Model, potrzeby możliwości i ich ocena. Praca habilitacyjna (Palliative Home Care for Children in Poland. Model, needs, capabilities, and their assessment. Habilitation thesis). Warsaw: Wydawnictwo Naukowe Scholar; 2001.

[58] This course does not prepare for working in a home hospice for children.

2. "Nurse having either:
    a) graduated from a specialization in nursing and palliative care, or is in the course of such training, or
    b) graduated from a specialization in pediatric nursing and a specialization course in pediatric palliative home care, or graduated from specialization in pediatric nursing, and is in the course of specialization in pediatric palliative home care, or
    c) graduated from a qualification course in palliative nursing, or is in the course of such training, or
    d) graduated from a qualification course in pediatric nursing, and a specialization course in pediatric palliative home care, or graduated from a qualification course in pediatric nursing, and is in the course of a specialization course in pediatric palliative home care, or
    e) graduated from or is in the course of a specialization course in palliative care, or graduated from or is in the course of a specialization course in pediatric palliative home care".

According to those prescriptions, physicians and nurses who have not been trained in pediatric palliative medicine can work in home hospices for children. There is no specialization program for physicians or nurses, which would provide them with practical training (such as an internship) in a home hospice for children. Furthermore, no hospice for children has been accredited to conduct such training.

Therefore, it is necessary to implement in Poland a new model of professional training for physicians and nurses who work in home hospices for children, administered by a training center accredited by the Minister of Health, director of the Centre of Postgraduate Medical Education, and director of the Center of Postgraduate Education for Nurses and Midwives.

The responsibilities of the Centre of Postgraduate Medical Education include, but are not limited to, training and qualifying physicians in defined areas of medicine and in particular healthcare services, as well as providing them lifelong professional learning. The Centre conducts its teaching activity using resources of healthcare institutions, based on agreements signed between those institutions and the Centre.[59]

[59] Poland. Ministry of Health. Ordinance of the Minister of Health from 21 December 2018 on conferring statutes to the Centre of Postgraduate Medical Education. Official Journal of the Minister of Health, 28 December 2018; item 125; Available from: https://www.cmkp.edu.pl/wp-content/uploads/2019/01/Zarz%c4%85dzenie_MZ_w_sprawie-nadania_statutu_CMKP.pdf

Definitions and recommendations

Pediatric palliative care (PedPC) provides children with incurable diseases, at high risk of premature death or suffering from symptoms difficult to control, with a seven days a week and round-the-clock medical and nursing care. Its goal is to preserve child's dignity, to improve the quality of his/her life, and to protect her/him against futile medical care and iatrogenic treatment. It includes symptom management in the child, as well as psychological, social, and spiritual support provided to the whole family, also in form of bereavement care.

- Physicians and nurses taking care of such children must be qualified in PedPC.[60]
- A physician who refers a child to PedPC treatment must determine the procedure which should be carried out in the case of cardiac or respiratory arrest. That means he has to decide whether resuscitation should be undertaken or not (**Appendix 3)**.[61]
- The risk of premature death and the effectiveness of the symptom management have to be assessed every month. Based on such assessment, a decision on continuation or discontinuation of PedPC treatment should be taken. The children in whom the risk of premature death has decreased and is assessed as low, and whose symptoms can be effectively controlled by a general practitioner and a family nurse, do not need PedPC treatment and should be referred to a long-term care facility.
- PedPC should be provided, if possible, at home (a home hospice for children), or in exceptional and justified cases, in an inpatient hospice or in a hospital unit of palliative care.
- The team of home hospice for children consists of physicians, nurses, psychologists, social workers, chaplains, physiotherapists, and volunteers.

Pediatric hospital: The decision on (1) introducing resuscitation and intensive care, or (2) the withdrawal from resuscitation and intensive care is taken by a local intensive care specialist, or a specialist physician in charge. Then, a relevant physician fills in a document specifying the procedure in the case of cardiac or respiratory arrest (**Appendix 3**). The decision on the withdrawal from resuscitation and intensive care obliges a physician in charge to provide the child with PedPC (e.g. by referring the child to a hospice, or a palliative care unit, or by consulting a hospice physician). In particularly difficult cases which do not require an immediate decision, a physician sets up a case conference or consults a clinical ethics committee.

General hospital: The decision on (1) the application of resuscitation and intensive care, or (2) the withdrawal from resuscitation and intensive care is taken by a specialist physician in charge. Then, a specialist physician fills in a document specifying the procedure to be applied in the case of cardiac or respiratory arrest (**Appendix 3**). The decision on the withdrawal from resuscitation and intensive care obliges a physician in charge to provide the child with PedPC (e.g. by referring the child to a hospice or to a palliative care unit, or by consulting a hospice physician).

[60] Professional improvement course conducted by the Centre of Postgraduate Medical Education (physicians); specialization course conducted by the Centre of Postgraduate Education of Nurses and Midwives (nurses).

[61] Dangel T, editor. Zaniechanie i wycofanie się z uporczywego leczenia podtrzymującego życie u dzieci – wytyczne dla lekarzy (Cessation and withdrawal of futile medical care in children: guidelines for physicians). Warsaw: Polish Pediatric Society; 2011; p. 103-104. Available from: https://hospicjum.waw.pl/pliki/Artykul/1134_zaniechanie-iwycofaniezleczeniapodtrzymujacegozycieudzieci-wytyczneptp-2011.pdf

Pediatric long-term care (PedLTC) provides medical and nursing care to children with incurable diseases at low risk of premature death or suffering from symptoms esasy to control. The care is provided by general practitioners and community nurses, or physicians and nurses from chronic medical care homes for children and youths. Particular forms of PedLTC are assisted ventilation applied to children with a chronic respiratory failure, treatment of children in a coma, and enteral and parenteral nutrition.[62]

Criteria for distinguishing long-term and palliative care in pediatrics

Criteria	Long-term care	Palliative care
Risk of premature death	low	high
Control of symptoms	easy	difficult
Obligatory monthly verification of medical indications for continuing services (criteria 1 and 2)	no	yes
Obligation of previous determination of procedures in the case of cardiac or respiratory arrest (Appendix 3)	no	yes
Physician accessible 24/7	no	yes
Nurse accessible 24/7	no	yes
Personnel qualified in PedPC	no	yes
Support provided to family	no	yes
Bereavement care	no	yes

Pediatric palliative medicine (PedPM) is a so-called narrower area of medicine. It is often confused with an actual specialty of palliative medicine. Therefore, it is necessary to implement by the Centre of Postgraduate Medical Education a particular curriculum for training physicians working in hospices for children and in hospital palliative care wards for children (if such units are established) in the PedPM.

[62] It is desirable that more and more pediatric services be provided at home. Home hospices for children has been just a beginning of a larger trend in Poland.

Standards and medical procedures for pediatric palliative home care in hospices for children – general remarks

I. Patients

1. PedPC is provided to children younger than 18 years old, without prejudice to the provisions of section 2 below.
2. PedPC can be also continued in patients being older than 18 years old, under patient's or patient's legal guardian's consent.
3. Children with incurable diseases and with a high risk of premature death, regardless the disease, receive equal access to PedPC services, if they meet the requirements specified in the **Appendix 1** paragraph I hereto.

II. Personnel

Pediatric palliative home care (PedPHC) services are provided by:

1. Physician
   a) with a certificate of graduation from the course "Pediatric palliative medicine" for physicians working in home hospices for children, registered by the Centre of Postgraduate Medical Education and conducted by a reference center;
   b) obliged to graduate from a two-year course of professional improvement "Advanced pediatric palliative medicine" for physicians working in home hospices for children, registered by the Centre of Postgraduate Medical Education and conducted by a reference center.
2. Nurse with a certificate of graduation from a specialty course "Pediatric palliative home care" registered by the Centre of Postgraduate Medical Education and conducted by a reference center.
3. Other medical and non-medical personnel employed in home hospices for children, with profiled education, as well as volunteers.

III. Home hospices

1. PedPHC is provided by home hospices for children who meet the standards and follow the procedures defined by the Minister of Health.
2. PedPHC is provided by home hospice for adults who meet the standards and follow the procedures defined by the Minister of Health only if there is no home hospice for children in a given territory.
3. Home hospices providing services in PedPHC are supervised by consultants in pediatrics or another relevant pediatric subspecialty.
4. The Minister of Health shall implement obligatory professional training for physicians and nurses (see the paragraph II, section 1 and 2).
5. The Directors of the Centre of Postgraduate Medical Education and the Center of Postgraduate Education for Nurses and Midwives shall appoint an education center for training physicians and nurses and they shall sign appropriate agreements with this center.

IV. Hospital wards of palliative care and inpatient hospices

1. The Minister of Health shall implement separate standards for inpatient PedPC, including those regarding the withdrawal of futile medical care, and especially withdrawal of mechanical ventilation.
2. The national consultants in pediatrics, other relevant pediatric subspecialties and the Director of the Centre of Postgraduate Medical Education shall set the requirements of professional training for physicians.

Appendixes

1. Standards and medical procedures for pediatric palliative home care in hospices for children – details.
2. Medical procedures in the field of PedPHC.
3. Form defining the procedure of treatment in the case of cardiac or respiratory arrest in the child.
4. Referral form to home hospice.
5. Qualification for home hospice for children.
6. Consent of parents (legal guardians) for providing a child with pediatric palliative home care.
7. Consent of a patient being over 16 years old for being submitted to pediatric palliative home care.
8. Charter of the Rights of the Terminally Ill Child at Home published by the Polish Ombudsman.
9. Familiy satisfaction questionnaire.
10. Primary, secondary and direct cause of death – list for physicians working in home hospices for children [not included in the English edition].
11. Costs of services provided by a home hospice for children in 2019, according to the minimum standard defined by the Warsaw Hospice for Children Foundation.
12. Draft curriculum for professional training in palliative care as a part of specialization in pediatrics.

Appendix 1

Standards and medical procedures for pediatric palliative home care in hospices for children – details

I. Qualification for pediatric palliative home care

1. PedPHC is provided if all the following conditions are jointly fulfilled:
   1) The disease is incurable and associated with high risk of premature death; if a disease is not progressive, the qualification is based on an analysis of individual needs of the child and his/her family, made by the physician in charge and a hospice physician.
   2) The parents, or legal guardians, the patient older than 16 years old and the physician referring to hospice jointly agree that the best interest of the child requires withdrawing from hospital treatment and undertaking palliative care at home; the opinion of a child younger than 16 years should be taken in consideration.
   3) The physician of a home hospice deems that it is necessary to submit the child to symptom management; the symptoms (see the section 4 below) are difficult to treat, which means they can't be effectively controlled with long-term care.
   4) The parents or other cargivers are able to provide the child with round-the-clock care at home.
   5) The principal guardian can effectively communicate by phone in Polish with hospice employees.
   6) The family lives within the area of hospice's operation.[63]
   7) The living conditions of the patient meet basic sanitary and technical requirements; they must be assessed by an employee of a home hospice before the patient is admitted; if the habitation requires renovation works, the admission to a home hospice should be postponed.
   8) The referral form to a home hospice is signed by a physician from the hospital where the child was treated, a general practitioner or an appropriate specialist physician; the referral form should contain a diagnosis and the statement that the disease is incurable and that life-prolonging treatment was ceased (**Appendix 4**).
   9) The physician referring to a hospice fills in the document "Procedures in the case of cardiac or respiratory arrest in children" (**Appendix 3**), and attaches its copy to the referral form.
   10) A physician from a home hospice fills in the document "Qualification for home hospice for children" (**Appendix 5**).
   11) The parents or legal guardians and the patient being over 16 years old agree on a treatment by a home hospice, commit to follow the orders of hospice physicians, and accept that the hospice employees will not apply methods aiming at prolonging life specified in the **Appendix 2** section 3 (**Appendixes 6 and 7**).
2. If uncertainty persists whether a child is qualified for PedPHC or not, an opinion of a regional consultant in pediatrics or other relevant pediatric subspecialities should be requested.

[63] The distance between the patient's place of residence and the hospice headquarters should not be more than 100 km.

3. The diseases which, in the case of high risk of premature death, may qualify a child for PedPHC, are in particular:
   1) malignancies;
   2) infectious diseases and their consequences:
      a) AIDS;
      b) complications of post-infectious encephalopathy with severe course;
      c) severe complications of bacterial meningitis;
      d) diseases caused by lentiviruses;
      e) syndromes occurring as a result of intrauterine infection;
   3) damages of the central nervous system caused by hypoxia, hemorrhages, venous thrombosis, injuries or intoxication:
      a) perinatal injury,
      b) intrauterine hypoxia,
      c) perinatal asphyxia,
      d) hypoxic ischemic encephalopathies,
      e) cerebral palsy,
      f) posttraumatic encephalopathies,
      g) toxic encephalopathies;
   4) metabolic diseases:
      a) genetically determined disorders of amino acid metabolism,
      b) genetically determined disorders of purine metabolism,
      c) genetically determined disorders of lipid metabolism,
      d) genetically determined disorders of carbohydrate metabolism,
      e) genetically determined disorders of metal metabolism,
      f) lysosomal diseases,
      g) mucopolysaccharidoses;
   5) degenerative diseases of the nervous system (genetically determined, and of unknown etiology):
      a) amyotrophic lateral sclerosis,
      b) progressive sclerosis of the grey matter,
      c) spongy degeneration,
      d) mitochondrial diseases;
   6) genetically determined neuromuscular diseases:
      a) muscular dystrophies,
      b) myotonic dystrophies,
      c) spinal muscular atrophy;
   7) genetically determined progressive diseases characterized by a considerable shortening of lifespan:
      a) cystic fibrosis,
      b) tuberous sclerosis and other phacomatoses,
      c) skeletal disorders, certain bone dysplasias diagnosable in neonates,
      d) connective tissue diseases;

8) chromosomal aberrations:
    a) Edwards syndrome (trisomy 18),
    b) Patau syndrome (trisomy 13),
    c) Down syndrome (trisomy 21) in end-stage of disease,
    d) other;
9) congenital disorders and complications of their course and treatment:
    a) congenital heart defects,
    b) congenital abnormalities of the central nervous system,
    c) congenital malformation syndromes;
10) incurable congenital malformation syndromes accompanied by end-stage failure of kidneys, liver, heart, or lungs;
11) irreversible multiple organ dysfunction while awaiting transplantation, or resulted from post-transplatn severe and non-reversible complications (that means that a patient who was qualified for transplantation or retransplantation developed irreversible complications that exclude further transplantation effort);
12) chronic respiratory or cardiac failure in the course of other than the abovementioned diseases, including bronchopulmonary dysplasia, cardiomyopathy, pulmonary hypertension;
13) other rare and exceptionally rare or undiagnosed diseases with uncertain or unknown prognosis, associated with chronic multiple organ dysfunction.

The above list is not complete. It is impossible to establish a closed catalogue of diseases qualifying patients for PedPHC, based on the ICD-10. Despite the diagnosis, other criteria are necessary which are not specified in that classification.

4. The symptoms that need to be treated by PedPHC are in particular:
    1) pain;
    2) symptoms of respiratory and cardiac dysfunction, such as dyspnea, hypoxia, edema;
    3) persistent cough;
    4) dysphagia;
    5) symptoms of malnutrition, such as cachexia, bedsores, fractures;
    6) urine retention;
    7) muscle tension disorders, such as spasticity, hypotonia;
    8) convulsions, epilepsy;
    9) extrapyramidal movement disorders;
    10) sleep disorders;
    11) restlessness, depression, behavioral disorders,
    12) nausea, vomiting;
    13) diarrhea;
    14) constipation;
    15) pruritus;
    16) hypersalivation;
    17) adverse symptoms of inflammation;
    18) weakened cough reflex.

II. Criteria for discharge of patients from a home hospice for children[64]

1. A hospice physician states that the condition of the patient has improved and symptom management can be continued in long-term care. The physician assesses on a monthly basis the risk of premature death as well as the effectiveness of symptom management, and validates the recommendations regarding continuation of PedPHC. The children in whom the risk of death has decreased and has been assessed as low, and whose symptoms can be effectively controlled by a general practitioner and a community nurse, don't need to be provided with PedPHC and should be referred to a long-term care facility.
2. Parents, guardians, or patients older than16 years old disagree on the treatment proposed by a hospice physician, which, in physician's opinion, has a significant influence on patient's condition. In such case, the physician should inform a family court and a regional consultant in pediatrics or another appropriate healthcare specialty for children.
3. Parents, guardians, or patient older than16 years old change their decision regarding undertaking experimental or life-prolonging treatment.
4. In justifiable cases, a child can be temporarily referred by a home hospice physician to a hospital for interim treatment. The necessity of hospitalization has to be justified by hospice physician in the referral form as well as in patient's hospice records. Along with the referral, the document "Procedures in the case of cardiac or respiratory arrest in children" is attached (**Appendix 3**).
5. Parents, guardians, or patient older than16 years old decide on their own on a temporary hospitalization. Discharge of a child from the hospital does not automatically mean admission to the home hospice, and a new agreement on principles of the care has to be concluded.
6. Parents, guardians, or patients being over 16 years old, implement at home a treatment commissioned by a physician not employed in the hospice without notifying a hospice physician, and without his acceptance.[65]
7. A patient who reached the age of legal majority, and has been treated at a hospice for children, wants to move to a hospice for adults, or his/her insurance company does not agree on the continuation of the treatment in a hospice for children (refusal of refunding).
8. A patient moves outside the area of activity of the hospice.
9. Parents or guardians are not able to adhere recommendations of a hospice physician.[66] In such case, a hospice physician should notify a family court and a regional consultant in pediatrics or another relevant pediatric subspecialty.

[64] A discharge from a hospice is a routine procedure. The decision is taken by the hospice. Parent's or guardian's disagreement is not binding (Law from 5 December 1996 on professions of physician and dentist, article 38).

[65] Any medical decision has to be taken in agreement with the hospice. See: Appendixes 6 and 7.

[66] The most common reasons are alcoholism, exhaustion, depression, or other mental disorders. In such cases the child should be immediately placed in a hospital or in an inpatient hospice.

III. Minimal operational requirements for home hospice for children

1. The home hospice for children ensures 24/7 care with a physician and a nurse. Waiting time for an emergency visit may not exceed 2 hours.[67]
2. The home hospice for children employs at least:
   1) two full-time physicians; one physician is available 24 hours per day; maximum 15 patients per physician;
   2) four full-time nurses; one nurse is available 24 hours per day; maximum 4 patients per nurse;
   3) one full-time psychologist;
   4) one full-time physiotherapist;
   5) one full-time chaplain.
3. The home hospice for children is equipped at least with the following devices (owned or leased):
   1) five cars; each nurse should be provided with a car, and one car should be available for the physician on duty;
   2) mobile phones for all physicians and nurses;
   3) one pulse oximeter per nurse and one for the physician on duty;
   4) one oxygen concentrator per 2 patients;
   5) one cough assist machine per 3 patients;
   6) four suction units per 5 patients;
   7) four anti-bedsore mattresses per 5 patients;
   8) one syringe pump per 5 patients;
   9) one inhaler per 2 patients;
   10) one sphygmomanometer per nurse and one for physician on duty;
   11) one multi-position hospital bed for each patient with body weight over 30 kg;
   12) one electric power generator per 2 patients;
   13) one scale and one tape for body measurement;
   14) one glucometer;
   15) one CRP fast analyzer;
   16) one patient bedside lifting device per 8 patients.
4. The home hospice has to meet the following minimum requirements regarding the premises:
   1) an office provided with a telephone, automatic responder, fax and Internet connection;
   2) a storage room for medicines, dressing materials and medical equipment;
   3) a conference room for team briefings.
5. The home hospice functions under the following rules:
   1) the family of every sick child has a telephone and is in touch with the nurse on duty via a mobile phone;
   2) each patient has an assigned nurse who coordinates all actions of the hospice team related to that patient;
   3) each nurse takes care of no more than 4 patients simultaneously;
   4) every 6 months a rotation of nurses takes place, so they get other patients;[68]

[67] Therefore the distance between the patient's place of residence and the hospice headquarters should not exceed 100 km.

[68] It prevents building routine and too strong emotional bonds.

5) a visit of a nurse takes on average 90 minutes;
6) twice a day on working days, and once a day on holidays, briefings of the whole team on duty take place to discuss patients' and families' needs, to sum up and to assign task;
7) the number and the schedule of the visits is determined by the hospice's medical director or his deputy, based on current patients' needs (and not on norms defined by officers of the Ministry of Health or the National Health Fund);
8) to guarantee an adequate quality of services, a home hospice for children should not admit more than 30 patients.[69]

IV. Other requirements

1. The home hospice provides families with bereavement care in support groups for parents and siblings. Their meetings should take place at least once a month, and be available up to 2 years after a child's death.
2. The home hospice evaluates the quality of its services using the methodology described in the **Appendix 9**.

[69] A bigger number of patients makes time of briefings longer and time of visits too short. Moreover, physicians are not able to remember relevant information about a bigger number of patients.

Appendix 2

Medical procedures in PedPHC

1. Diagnostic procedures include, in particular:
   1) physical examination;
   2) medical history;
   3) identification of medical indications and the scope of symptom management;
   4) monitoring of the effectiveness of symptom management;
   5) non-invasive measurements: oxygen saturation, heart rate, blood pressure, body temperature, weight and length of the body;
   6) blood sample collection (venous or capillary);
   7) urine sample collection;
   8) collection of respiratory trackt secretion for a microbiological test;
   9) fluid balance;
   10) blood sugar level measurement;
   11) ketone bodies measurement in urine;
   12) CRP measurement.
2. Therapeutic procedures include, in particular:
   1) preparing and administering oral or enteral medication;
   2) preparing and administering of rectal medication;
   3) preparing and administering of inhalation medication;
   4) preparing and administering of percutaneous medication;
   5) preparing and administering of medication by subcutaneous, intramuscular, intravenous injection or infusion;
   6) placement of a needle into subcutaneous central venous access ports;
   7) placement of subcutaneous cannula;
   8) local anesthesia of skin;
   9) handling of syringe pumps;
   10) handling of feeding pumps;
   11) oxygen therapy**;**
   12) maintenance and changing of tracheostomy tube;
   13) treatment of mouth ulcerations and inflammatory states;
   14) placement of a stomach tube;
   15) treatment of gastrostomy complications;
   16) enteral nutrition (by tube or gastrostomy);
   17) designing and monitoring of a ketogenic diet, or another balanced diet;
   18) catheterisation and lavage of the bladder;
   19) bedsores treatment;
   20) respiratory physiotherapy with use of cough assist machine;
   21) injection of botulinum toxin into muscles and salivary glands;
   22) enema administration.

3. PedPHC does not include the following life-prolonging medical procedures:[70]
   1) cardiopulmonary resuscitation;
   2) intravenous hydration;[71]
   3) parenteral nutrition;
   4) transfusion of blood and blood products;
   5) mannitol transfusion;[72]
   6) mechanical ventilation;
   7) intravenous or intramuscular administration of antibiotics;[73]
   8) chemotherapy.

[70] The goal is to protect the child against the futile medical care and iatrogenic effects. Such attitude is in accordance with the definition of pediatric palliative care. Some procedures, such as mechanical ventilation or parenteral nutrition, can be implemented at home, but as a part of other service (that means not as a part of services of a home hospice for children). Children whose gastrointestinal tract is damaged by chemotherapy, and who are still provided with oncological treatment, should not be admitted to a home hospice. Intravenous therapy should be conducted in a hospital. See: Dangel T, editor. Zaniechanie i wycofanie się z uporczywego leczenia podtrzymującego życie u dzieci – wytyczne dla lekarzy (Cessation and withdrawal of futile medical care in children: guidelines for physicians). Warsaw: Polish Pediatric Society; 2011. Available from: https://hospicjum.waw.pl/pliki/Artykul/1134_zaniechanieiwycofaniezleczeniapodtrzymujacegozycieudzieci-wytyczneptp-2011.pdf

[71] Risk of a pulmonary edema and a hastened death.

[72] At home, there is no means to monitor intracranial pressure, or electrolyte concentration, which is necessary for treatment with the use of mannitol.

[73] Enteral antibiotic therapy is an effective and sufficient method of treatment upon condition that a bacteriological test (quantitative test, antibiotic susceptibility test) and a CRP have been performed. An intramuscular administration should not take place in children because of pain. Intravenous administration is not possible at home for practical reasons – a nurse should visit the child several times a day, which is not realistic given the norm of one nurse per 4 patients during the working day, and one nurse per 30 patients after 4 p.m.

Appendix 3

Procedures in the case of cardiac or respiratory arrest in the child

Name and surname of patient: _____

Diagnosis: _____ Date of birth: _____

IN CASE OF CARDIAC OR RESPIRATORY ARREST

ATTEMPT RESUSCITATION ☐

Date: _____

Physician's name: _____

Physician's signature: _____

IN CASE OF CARDIAC OR RESPIRATORY ARREST

DO NOT ATTEMPT RESUSCITATION ☐

Date: _____

Physician's name: _____

Physician's signature: _____

Decision has been consulted among the team:	YES/NO	
Decision has been discussed with patient:	YES/NO	☐ doesn't concern
Patient has accepted decision:	YES/NO	☐ doesn't concern
Decision has been discussed with parents:	YES/NO	
Parents have accepted decision:	YES/NO	

Date: _____

Physician's name: _____

Physician's signature: _____

Caution: The document must be validated by a specialist physician.

Appendix 4

Institution referring to hospice Stamp of the healthcare institution

Date _____

Name of home hospice Address Fax No

Referral to home hospice

I kindly request to admit our patient to home hospice.

Name and surname: _____

ID Number / Date of birth: _____

Adress: _____

_____

Telephone No: _____

Diagnosis: _____

ICD-10: _____

The disease is incurable. All treatment options for the child have been exhausted, and life-prolonging treatment has been ceased.

Referring physician: _____

Telephone: _____

_____

stamp, signature, date

Head of the unit: _____

_____

stamp, signature, date

Additional data for National Health Fund

National Official Business Register No ☐☐☐☐☐☐☐☐☐☐

Ministry of Health Registration Code, part VII ☐☐☐

Ministry of Health Registration Code, part VIII ☐☐☐☐

Referring physician's number
from the Central Register of Physicians ☐☐☐☐☐☐☐

Appendix 5

Qualification for home hospice for children

Patient's name and surname: _____

Criteria	YES ✓	Remarks
Disease is incurable and with **high risk** of premature death.		
Prenatal diagnosis. Did the prenatal consultation with psychologist take place?		
Disease is progressive.		
Disease is not progressive, but patient's condition is serious, and symptoms involve a risk of death.		
Disease is not progressive, patient's condition is stable, and symptoms do not involve a risk of death. Patient has been admitted to hospice because of: ☐ need to support parents in period of adaptation to home care ☐ difficult social situation ☐ prenatal qualification ☐ _____ _____		
Hospice physician states that **the child requires symptom management in palliative care** (not long-term care).		
Parents, child, and referring physician agree that the best interest of patient requires discontinuation of hospital care and starting of palliative care at home.		
Parents and child odler than 16 years accept the decision on withdrawal from a life-prolonging treatment (resuscitation, oncotherapy, dialysis, etc.).		
If life-threatening symptoms occur, parents will call an ambulance and transport the child to a hospital.		
Parents or guardians are able to assure round-a-clock care to the child at home, and to observe the hospice physician's orders.		
Family lives in the area of activity of home hospice, and their living conditions meet basic sanitary and technical requirements.		

Referral has been signed by a hospital physician, a general practitioner, or an relevant specialist physician.		
Parents and child older than16 years agree on treatment by home hospice, commit to observe hospice physician's orders, and accept that hospice employees will not apply life-prolonging methods.		
Patient is admitted ☐ for an indefinite period ☐ for …….. months		
Patient's admission has been postponed in order to conduct additional tests, treatments, legal steps, or renovation of house/apartment/flat.		
Patient has not been qualified for home hospice for children.		

Date: _____ Hospice physician's signature: _____

Appendix 6

Consent of parents (legal guardians) for providing a child with pediatric palliative home care

Name and surname of patient: _____

ID Number / Date of birth: _____

Address: _____

_____

We hereby declare that we have been informed that the disease of our child is incurable. We have also got explanation of the rules of the palliative home care as described in the document "Standards and medical procedures for pediatric palliative home care in hospices for children" whose copy we received.

We have been informed that the hospice's employees will not apply life-prolonging treatment, referred to as futile medical care, such as cardiopulmonary resuscitation, intravenous hydration or nutrition, transfusion of blood and blood products or mannitol, mechanical ventilation, intravenous or intramuscular administration of antibiotics or chemotherapy.

From now, only symptom management will be applied, aiming at the relief of suffering of the child. Appropriate diagnostic and therapeutic procedures are listed in the appendix 2.

Any medical decisions will be taken in agreement with hospice physician. We are committed to strictly observe the orders of the hospice physician and to abstain from any consultation with other healthcare institutions without the previous agreement with the hospice physician. Any treatment requiring hospitalization of our child should be undertaken based on a referral, signed by the hospice physician. Concerning reimbursement, the National Health Fund refunds simultaneously the following healthcare services: (1) outpatient specialist care; (2) outpatient psychiatry; (3) dental care; (4) outpatient palliative radiotherapy; (5) outpatient palliative chemotherapy.

We have been informed that the continuation of palliative home care for our child will be subjected to a monthly validation by a team of physicians, nurses, psychologists, and social workers. If for medical, psychological, or social reasons, or for the benefit of our child, our child cannot be treated by a home hospice, the matter will be discussed with us, and the hospice physician will decide on discharging our child from the hospice and referring her/him to an inpatient healthcare facility or to a general practitioner's care. We have also been informed about the criteria for discharge for patients (appendix 1).

We give our consent for submitting our child to pediatric palliative home care in a home hospice for children.

Parents' (legal guardians') signatures: _____

Hospice's representative's signature: _____

Place and date: _____

Appendix 7

Consent of patient over 16 years old for providing him/her with pediatric palliative home care

Name and surname of patient: _____

ID Number / Date of birth: _____

Address: _____

_____

I hereby declare that I have been informed that my disease is incurable. I have also got explanation of the rules of the palliative home care set up in the document "Standards and medical procedures for pediatric palliative home care in hospices for children" whose copy I received.

I have been informed that the hospice employees will not apply life-prolonging treatment referred to as futile medical care, such as cardiopulmonary resuscitation, intravenous hydration r nutrition, transfusion of blood and blood products or mannitol, mechanical ventilation, intravenous or intramuscular administration of antibiotics, chemotherapy.

From now, only symptom management will be applied, in order to relieve my suffering. Appropriate diagnostic and therapeutic procedures are listed in the appendix 2.

Any medical decisions will be taken in agreement with the hospice physician. I am committed to strictly observe the orders of the hospice physician and to abstain from any consultation with other healthcare institutions without the previous agreement with hospice physician. Any treatment requiring my hospitalization should be undertaken based on a referral signed by the hospice physician. As for patients of a hospice the National Health Fund refunds simultaneously the following healthcare services: (1) outpatient specialist care; (2) outpatient psychiatry; (3) dental care; (4) outpatient palliative radiotherapy; (5) outpatient palliative chemotherapy.

I have been informed that the continuation of palliative home care will be subjected to a monthly validation by a team of physicians, nurses, psychologists, and social workers. If for medical, psychological, or social reasons, or for my own benefit, I cannot be treated by a home hospice, the matter will be discussed with me, and the hospice physician will decide on discharging me from the hospice and referring me to an inpatient healthcare facility or to a general practitioner's care. I have also been informed about the criteria for discharge for patients (appendix 1).

I give my consent for submitting me to pediatric palliative home care in a home hospice for children.

Patient's signature: _____

Hospice's representative's signature: _____

Place and date: _____

Appendix 8

Charter of the Rights of the Terminally Ill Child at Home published by Dr. Janusz Kochanowski, Ombudsman[74]

Acknowledging the need for providing terminally ill children with complete care at home, after having analyzed the current legal situation as well as the present financial and organizational framework of this care, the Ombudsman presents the Charter of the Rights of the Terminally Ill Child at Home. All provisions of the Charter refer to the Constitution and to the Convention on the Rights of the Child. The Ombudsman states that in Poland a model system for palliative home care for children and their families has been developed. Until the above mentioned system becomes a part of the healthcare policy of the state, the Charter may constitute a moral, legal and substantial point of reference for institutions and organizations responsible for and involved in providing terminally ill children with complete care at home.

1. Every terminally ill child staying at home, regardless of the the disease and the psycho-physical condition, has the right to dignity, respect and intimacy.
2. A sick child maintains the right to education at home, in a scope which is adjusted to the child's condition.
3. Terminally ill children have the right to active and complete care provided by a home hospice which ensures palliative treatment adequate to the child's needs and aiming at improving child's quality of life.
4. Sick children should be protected against pain, suffering and unnecessary medical treatments and tests.
5. Care for a terminally ill child is mainly shouldered by parents whom the medical personnel should consider as partners. Parents have the right to a complete information and they are allowed to take all decisions being in accordance with the best interest of the child.
6. Every sick child has the right to information and to participation in decisions regarding his/her care, in accordance with the child's maturity and understanding.
7. The personnel of a home hospice should be professionally qualified in order to meet child's and family's physical, emotional, social, and spiritual needs.
8. The parents should be given the possibility to consult a pediatrician specialized in their child's disease.
9. The parents have the right to take an informed decision regarding hospitalization of their child in a unit adapted to needs of terminally ill children.
10. The mourning family has the right to receive support as long as it is necessary.

[74] Kochanowski J. Gdy dziecko umiera w domu (When a child dies at home). Więź. November-December 2007, 11-12 (589-590), p. 60-65 and 66. Available from: https://www.hospicjum.waw.pl/pliki/Artykul/1118_gdydzieck-oumierawdomu-2007.pdf

Appendix 9

Family satisfaction questionnaire

The method of evaluation of the quality of home palliative care provided by the hospice for children was developed based on our research.[75]

The following questionnaire should be sent or handed over to the parents or other legal guardians (to each one separately) of the deceased child one month after the child's death. The questionnaire should not be filled in if the time of care provided to the child was shorter than 7 days.

The questionnaires which were filled in should be discussed during the meeting of the hospice team. It is important to pay attention to the issues pointed out by the parents. The remarks made in the item 36 should be discussed and taken into consideration as for the proposals of new solutions.

The questionnaires have to be kept in the documentation of deceased patients (in order to allow the regional consultant in pediatrics or other specialty in medicine for children to analyze them).

The questionnaires in Polish, English, Russian or Ukrainian are available here:
https://hospicjum.waw.pl/pliki/Artykul/1238_ocena-jakosci-opieki-whd.pdf
https://hospicjum.waw.pl/pliki/Artykul/1070_family-satisfaction-polish-hospice-questionnaire.pdf
https://hospicjum.waw.pl/pliki/Artykul/1457_Standarty-raboty-i-medicinskie-procedury-v-domashnih-detskih-hospisah.pdf
https://hospicjum.waw.pl/pliki/Artykul/1474_Standarti-roboti-ta-medichni-proceduri-u-domashnih-dityachih-hospisah.pdf

[75] Dangel T, Fowler-Kerry S, Karwacki M, Bereda J. An evaluation of a home palliative care program for children. Ambulatory Child Health 2000; 6: 101-114.

Dear Sir or Madam,

We kindly ask you to complete the form provided below. You will be asked to evaluate the care your child received from our hospice. Your evaluation is of great value for us to learn about your most important needs and to adjust our care system adequately.

The questionnaire is anonymous. From the information you provide, neither you or your child's identity will be revealed.

The results will be analyzed and published by us in a scientific journal/magazine/paper, as well as presented in the form of lectures for physicians and nurses.

Each form is meant to be filled out by one person on their own without the assistance of any other people. Please put an X in the appropriate boxes □ .

Please complete and send us back the form, using the enclosed envelope, as soon as possible.

Thank you.

QUESTIONNAIRE – Evaluation of the hospice care

1. How did you learn about the hospice?
   - □ from your doctor
   - □ from parents of other ill children
   - □ from friends
   - □ from press or TV
   - □ from psychologist during prenatal consultation
   - □ other source (please state what)

   .....

2. Why did you decide to take the child home? (you may choose more than one answer)
   - □ my child wanted to be at home
   - □ we understood that further hospital care is not beneficial
   - □ the conditions at the hospital ward were difficult
   - □ we wanted the whole family to be together
   - □ other reasons (please state)

   .....

3. Did you have any concerns about the hospice care? (you may choose more than one answer)
   - ☐ my child would not receive medical treatment
   - ☐ my child would die sooner
   - ☐ my child would find out the truth about his/her illness
   - ☐ strangers would be coming to visit
   - ☐ we would not cope with home care
   - ☐ the hospice would create a depressing atmosphere
   - ☐ the neighbors would think negatively of us
   - ☐ other (please explain)

   .....

4. How would you evaluate the preliminary conversation with the hospice staff? (you may choose more than one answer)
   - ☐ the information about the hospice was given in a clear manner
   - ☐ the information about the hospice was not clear
   - ☐ I was too upset and I cannot remember that conversation
   - ☐ I felt relieved
   - ☐ my anxiety increased
   - ☐ other reaction (please state)

   .....

5. How would you evaluate the materials/information received from the hospice? (you may choose more than one answer)
   - ☐ it helped me understand the hospice care
   - ☐ it was not clear
   - ☐ it raised my anxiety
   - ☐ it helped me with future co-operation with the hospice
   - ☐ I did not need it
   - ☐ other (please state)

   .....

6. What were your expectations about the hospice care? (you may choose more than one answer)
   - ☐ my child would not suffer any more
   - ☐ my child would feel safe
   - ☐ our helplessness as caretakers would decrease
   - ☐ we would receive medical assistance
   - ☐ we would receive psychological support
   - ☐ we would receive spiritual support
   - ☐ we would receive financial support
   - ☐ the hospice would help make formal arrangements after my child's death
   - ☐ other expectations (please state)

   .....

7. How would you evaluate the frequency of home visits by hospice staff?
   - ☐ visits were too frequent
   - ☐ visits were too rare
   - ☐ frequency of visits was adequate

8. How would you evaluate the training concerning your child's care from the hospice doctors and nurses?
   - ☐ adequate
   - ☐ not adequate

   Comment: .....

9. How would you evaluate financial costs during your child's home care?
   - ☐ home care did not negatively affect our budget
   - ☐ costs of home care exceeded our budget, adequate care was possible due to hospice financial support
   - ☐ costs of home care exceeded our budget, adequate care was not possible in spite of hospice financial support

   Comment: .....

10. What was most difficult for you during the home care of your child (please choose the **three** most important options from the list or add your own choices and number according to importance: 1, 2 and 3).
    - ☐ ..... my own physical exhaustion
    - ☐ ..... my own emotional exhaustion
    - ☐ ..... spiritual crisis
    - ☐ ..... fear
    - ☐ ..... helplessness
    - ☐ ..... co-operation with the hospice
    - ☐ ..... co-operation with my spouse
    - ☐ ..... co-operation with other family members
    - ☐ ..... talking with my ill child
    - ☐ ..... talking with other children
    - ☐ ..... controlling pain and other symptoms
    - ☐ ..... my own inability to provide care
    - ☐ ..... organization of family life
    - ☐ ..... feeling of imprisonment at home
    - ☐ ..... making decisions (what decisions?)
    - ☐ ..... other (please state)

    .....

11. Name the problems mentioned in question 10 which the hospice **was able** to help you with.

    .....

12. Name the problems mentioned in question 10 which the hospice **was not able** to help you with.

.....

13. Did any decisions made by hospice doctors or recommendations by hospice staff were hard to agree with or did not meet your expectations?
    - ☐ yes
    - ☐ no

    If yes, please state.....

    .....

14. Could your child speak?
    - ☐ yes
    - ☐ no

    If yes, please answer the questions 15, 16 and 17. If not, please ignore those questions.

15. Did you speak honestly with your child about their approaching death?
    - ☐ yes
    - ☐ no

16. If you answered „yes" to question 15, was this decision influenced by your contact with the hospice?
    - ☐ yes
    - ☐ no

17. If you have answered „no" to question 15, please explain why.

.....

18. Did you feel prepared for your child's death?
    - ☐ yes
    - ☐ no

19. If you have answered 'yes' to question 18, please describe the role of the hospice.

.....

20. If you have answered 'no' to question 18, please explain why.

.....

21. Which symptoms caused your child's suffering? Please list.

.....

22. How would you rate the management of symptoms listed in question 21 by hospice physicians and nurses? (you may choose only one answer)
    - ☐ my child suffered very often because symptoms were not treated properly
    - ☐ my child suffered most of the time, occasionally the treatment resulted in relief
    - ☐ my child suffered rarely, occasionally symptoms increased, but were relieved when medications were provided
    - ☐ my child never suffered because the symptoms were managed successfully

    Comment: .....

23. How would you describe the last hours of your child's life? (you may choose more than one answer)
    - ☐ my child was quiet
    - ☐ my child did not suffer
    - ☐ my child did suffer
    - ☐ my child was unconscious
    - ☐ my child was conscious
    - ☐ my child was afraid
    - ☐ my child did not want to die
    - ☐ my child accepted his/her death
    - ☐ other (please state) .....

24. Did you want a person from the hospice to be present at your child's death? (you may choose more than one answer)
    - ☐ yes, a nurse
    - ☐ yes, a doctor
    - ☐ yes, a chaplain
    - ☐ yes, another person from the hospice (who?) .....
    - ☐ no

25. How would you evaluate the presence of the hospice staff in the last moments of your child's life and immediately after his/her death?
    - ☐ it was helpful
    - ☐ it made me feel uncomfortable
    - ☐ I did not need it
    - ☐ does not apply (if the hospice staff were not present)

    Comment: .....

26. How would you evaluate the assistance of the hospice staff with the formal arrangements following your child's death?
    - ☐ positive
    - ☐ negative

    Comment: .....

27. Did you take part in the meetings of the bereavement support group?

 yes

If yes, please state how you benefited from these meetings:

.....

 no

If no, please state why:

.....

28. Were you satisfied with the hospice care your child received?
 yes
 no

Please, rate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark: .....

29. How would you evaluate the assistance of the hospice doctors?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark: .....

30. How would you evaluate the assistance of the hospice nurses?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark: .....

31. How would you evaluate the assistance of the hospice social workers?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark: .....

32. How would you evaluate the assistance of the hospice chaplain?

Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

Your mark: .....

33. How would you evaluate the assistance of the hospice psychologist?

    Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

    Your mark: .....

34. How would you evaluate the assistance of the hospice physiotherapist?

    Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

    Your mark: .....

35. How would you evaluate the assistance of the hospice volunteers?

    Please, evaluate giving a mark from **0** (very disappointed) to **10** (very satisfied)

    Your mark: .....

36. What would you change in our hospice care?

    Comment: .....

    .....

Date of completing this form:.....
Period of time under hospice care:.....
First and last name of child:.....
Age of child:.....
Sex of child:.....
Type of illness:.....
Personal data of the person completing this form:
Relationship:
□mother □father □grandmother
□grandfather □other.....
Place of living:
□Warsaw □other town □village
Education:
□primary school □high school □vocational □college

Appendix 11

Costs of services provided by a home hospice for children in 2019 according to the minimum standard defined by the Warsaw Hospice for Children Foundation

Employees

	16 patients	30 patients
Nurses	4	8
Physicians	2	2
Social worker	1	1
Psychologist	1	1
Physiotherapist	1	1
Chaplain	1	1

Wages (PLN)

		Gross	Net	Total employer's cost
Nurses	Employment contract + duties	10 000	7 200	12 000
Physicians	Contract (100 PLN/h)	16 000	12 960	16 000
Social worker	Employment contract	5 000	3 500	6 600
Psychologist	Employment contract	6 000	4 250	7 200
Physiotherapist	Employment contract	4 500	3 250	5 400
Chaplain	Employment contract	4 000	2 850	4 800

Wages fund (PLN)

		Employer's cost 16 patients	Employer's cost 30 patients
Nurses (4/8)	Employment contract	48 000	96 000
Physicians (2)	Contract	32 000	32 000
Social worker	Employment contract	6 600	6 600
Psychologist	Employment contract	7 200	7 200
Physiotherapist	Employment contract	5 400	5 400
Chaplain	Employment contract	4 800	4 800
TOTAL		**104 000**	**152 000**

Medical equipment (PLN)

Device	Price per unit	16 patients	30 patients
Oxygen concentrator	2 300	(8) 18 400	(15) 34 500
Cough assist machine	22 000	(5) 110 000	(10) 220 000
Pulse oximeter	300	(5) 1 500	(9) 2700
Suction unit	4 100	(12) 49 200	(24) 98 400
Mattress (1 section)	800	(48) 38 400	(96) 76 800
Syringe pump	2 600	(5) 13 000	(10) 26 000
Inhaler	300	(8) 2 400	(15) 4 500
Sphygmomanometer	90	(5) 450	(9) 810
Bed	4 000	(5) 20 000	(10) 40 000
Power generator	1 700	(8) 13 600	(15) 25 500
Patient lift	5 500	(2) 11 000	(4) 22 000
Glucose meter	120	(2) 240	(2) 240
CRP device	3 100	(1) 3 100	(1) 3 100
Physician's kit	500	(2) 1 000	(2) 1 000
Nurse's kit	300	(4) 1 200	(8) 2 400
TOTAL		**283 490**	**557 950**

Office equipment and vehicles (PLN)

Office equipment and vehicles	16 patients	30 patients
Office furniture*	5 000	5 000
Storage room furniture	2 000	2 000
Computer and printer	2 500	2 500
Telephone, fax, automatic responder	1 200	1 200
Car Fiat Panda	(5) 185 500	(10) 371 000
TOTAL	**196 200**	**381 700**

* Furniture: desk, 10 chairs, 2 computer desks, 2 closets

Disposables (PLN)

Disposables	Monthly expenditure per patient	16 patients	30 patients
Disposable devices	350	5 600	10 500
Hygiene products	450	7 200	13 500
Dressing and antiseptic products	300	4 800	9 000
TOTAL	**1 100**	**17 600**	**33 000**

Fixed costs (PLN)

	16 patients	30 patients
Rent	1 000	1 000
Accounting services	1 000	1 000
Exploitation of vehicles*	1 695	3 390
Fuel**	8 347	16 695
Telephones, Internet***	705	965
Personal liability insurances****	800	800
TOTAL	**13 547**	**23 850**

* One car exploitation costs: insurance (2 000 PLN/year, 167 PLN/month), winter tiers (800 PLN/3 years, 22 PLN/month), disposables and other exploitation costs (windscreen washer fluid, car wash, small repairs – 150 PLN/month). Total cost – 339 PLN/month.

** Average daily mileage per car – 150 km. Fuel consumption – 7 l per 100 km. Cost of 1 l of fuel – 5,3 PLN. Monthly cost of fuel per vehicle – 1 669 PLN (150 x 30 x 7/100 x 5,3).

*** Telephones: one desk telephone – 70 PLN; mobile phones – 9/13 x 65 PLN; Internet – 50 PLN.

**** Employer's and medical personnel's personal liability insurance required by the National Health Fund.

Monthly expenditures' balance (PLN)

	16 patients	30 patients
Wages fund	104 000	152 000
Depreciation 25%*	7 827	15 654
Disposables	17 600	33 000
Fixed costs	13 547	23 850
TOTAL	142 974	224 504

***** 25% is the most widely used depreciation rate. The depreciation applies to all assets with a unit price of more than 3 500 PLN. Fully depreciated assets can still be exploited. Depreciation cost changes every 4 years, assuming that every 4 years a new equipment is purchased.

Cost of a man-day (PLN)

	16 patients	30 patients
Actual cost of a man-day	298	249

Tables developed by:
Tomasz Dangel, Artur Januszaniec, Ireneusz Kalisiak,
Katarzyna Jaworska-Marcjaniak, Wojciech Marciniak

Data updated: 19 February 2019

Appendix 12

Draft curriculum for professional training in palliative care as a part of specialization in pediatrics

25. Palliative care

A physician who graduated from the basic module in pediatrics should be qualified in the following matters:

1) ethical principles regarding the withdrawal of futile medical care and introducing palliative care;
2) qualification of a patient for a hospice;
3) epidemiology and classification of incurable diseases involving risk of premature death;
4) needs of children and their families – models of palliative care;
5) palliative procedures before referring a child to a hospice;
6) standards and procedures for home hospice for children;
7) evaluation of the quality of services;
8) analgesic pharmacology;
9) palliative sedation;
10) ketogenic diet;
11) palliative treatment in oncological, neurological, cardiovascular diseases, and in lethal congenital anomalies.

A physician who graduated from the basic module in pediatrics should have the following skills:

1) completing a DNR form and a death certificate;
2) referring a patient to a hospice;
3) informing parents on difficult situation of their child.

Course "Palliative care"

Objective of the course:
A physician who graduated from the course is expected to be able to stop life-prolonging treatment and to qualify a patient for palliative care.

Scope of the course:
Day I. Ethical principles, clinical matters:

1) discontinuation and withdrawal of futile therapy prolonging life – guidelines of the Polish Pediatric Society;
2) decision-making by a physician in a hospital;
3) pharmacology of certain analgesics (paracetamol, tramadol, morphine, methadone);
4) oncological diseases;
5) neurological diseases: encephalopathies, muscle diseases;
6) palliative sedation;
7) ketogenic diet.

Day II. Referral of a patient to a hospice, neurology, perinatology:

1) standards and procedures;
2) qualification for palliative care and referral to a home hospice;
3) cardiovascular diseases;
4) perinatal palliative care;
5) informing parents about the difficult situation concerning their child;
6) filling of a death certificate.

Duration of the course: *2 days (16 lecturing hours)*

Requirements for graduation: *certified attendance and successful completion of a test checking knowledge of the course matter, conducted by the head of the course.*

The bibliography (2018) – obligatory manuals published in Polish - https://www.cmkp.edu.pl/wp-content/uploads/akredytacja2014/0723-program-5.pdf - has to include:
Tomasz Dangel [Ed.] *Zaniechanie i wycofanie się z uporczywego leczenia podtrzymującego życie u dzieci – wytyczne dla lekarzy* (*Discontinuation and withdrawal of futile therapy prolonging life of children – guidelines for physicians*), Polskie Towarzystwo Pediatryczne, Fundacja Warszawskie Hospicjum dla Dzieci, 2011
http://www.hospicjum.waw.pl/pliki/Artykul/1134_zaniechanieiwycofaniezleczeniapodtrzymujacegozycieudzieci-wytyczneptp-2011.pdf

Developed for the Centre of Postgraduate Medical Education:
Tomasz Dangel, MD, PhD
Prof. Joanna Szymkiewicz-Dangel, MD, PhD
31 October 2018

Perinatal palliative care

Introduction

I. Need for perinatal palliative care

In 2017, in Poland, 1136 neonates[76] died, and 1039 abortions were performed because of a high probability of a severe and irreversible malformation of the fetus, or an incurable, life-threatening disease[77], confirmed by prenatal tests or other medical circumstances.

The number of intrauterine deaths may be estimated at 1889, which means 0.47% live births[78] whose number in 2017 was 401 982.[79]

The total number is 4 064 (1 136 + 1 039 + 1 889), which allows us to estimate the need for perinatal palliative care (PerPC) in Poland.

Another important indicator is perinatal mortality, or the number of stillbirths or neonatal deaths up to 6 days postpartum, which in 2017 was 1957.[80] This indicator, combined with the number of abortions, allows us to compare the need for PerPC in different voivodships (see the table below).

Voivodship	Perinatal mortality	Abortions	Total
dolnośląskie	163	68	231
kujawsko-pomorskie	103	44	147
lubelskie	100	6	106
lubuskie	47	11	58
łódzkie	149	53	202
małopolskie	170	90	260
mazowieckie	274	319	593
opolskie	47	25	72
podkarpackie	99	0	99
podlaskie	59	27	86
pomorskie	145	125	270
śląskie	196	102	298
świętokrzyskie	41	21	62
warmińsko-mazurskie	84	20	104
wielkopolskie	194	71	265
zachodnio-pomorskie	86	53	139
Poland 2017	**1957**	**1035***	**2992**

* In addition: 4 in the hospitals of the Ministry of Interior

[76] Data from Statistics Poland.

[77] Poland. Report of the Council of Ministers form 2017, impact assessment of the law from 7 January 1993 on family planning, protection of human fetus and admissibility conditions for termination of pregnancy. Warsaw: 2018. Available from: http://orka.sejm.gov.pl/Druki8ka.nsf/0/6F82FBB36BAA945CC125839200434FC7/%24File/3185.pdf

[78] Zaręba-Szczudlik J, et al. Analiza czynników ryzyka zgonów wewnątrzmacicznych płodów (Analysis of risk factors of stillbirths). Perinatologia, Neonatologia i Ginekologia. 2009; 2: 203-207. Available from: https://pdfs.semanticscholar.org/e7d2/01a72fd59e306eeb255af6262f1d1d146fdc.pdf

[79] Data from Statistics Poland.

[80] Ibidem.

This data shows that the greatest need for PerPC services exists in the mazowieckie, śląskie, pomorskie, wielkopolskie, małopolskie, dolnośląskie, and łódzkie voivodships.

The table below shows the mortality of neonates (0 – 27 days) and infants (28, 29 days – 11 months) in 2016, in Poland, according to selected causes.[81]

Diagnosis	ICD-10	Age		Total
		0-27 days	28, 29 days – 11 months	
Certain conditions originating in the perinatal period	P00-P96	720	108	828
Disorders related to short gestation and low birth weight	P07	578	78	656
Congenital malformations, deformations and chromosomal abnormalities	Q00-Q97	336	193	529
Congenital malformations of the nervous system	Q00-Q07	29	9	38
Congenital malformations of the circulatory system	Q20-Q28	106	127	233
Chromosomal abnormalities	Q90-Q99	45	22	67

II. Models of perinatal palliative care

The first description of a perinatal hospice was published in 1996. The concept of *perinatal hospice* was introduced by Byron C. Calhoun and Nathan J. Hoeldtke, as a Christian alternative to the termination of pregnancy.[82] An appropriate program was implemented in 1989, in a military hospital in Tacoma where the pregnancy was not terminated because of lethal malformations. The hospital's perinatal team consisted of obstetricians, neonatologists, anesthesiologists, labor and delivery nurses, neonatal intensive care nurses, chaplains/pastors, and social workers. All of them ensured mothers of children with lethal malformation a supportive environment during the prenatal diagnostics, pregnancy, and in the perinatal period.[83]

In 2010, the British Association of Perinatal Medicine published a framework for clinical practice in PerPC.[84] In 2015, in Australia, a description of a model of perinatal care was published.[85]

[81] Data from Statistics Poland.

[82] The notion of "perinatal hospice" is a metaphor which raises some confusion in Poland by equating prenatal consulting with activity of hospices for children. See: Definitions – perinatal hospice.

[83] Calhoun BC, Hoeldtke NJ. Perinatal hospice. Journal of Biblical Ethics in Medicine. 1996; 9 (1): 20-23. Available from: http://www.biblicalworldview21.org/bmei/jbem/volume9/num1/calhoun_hoeldtke_the_perinatal_hospice.pdf

[84] Murdoch E, et al. Palliative Care (Supportive and End of Life Care). A Framework for Clinical Practice in Perinatal Medicine. British Association of Perinatal Medicine. 2010. Available from: http://www.icpcn.org/wp-content/uploads/2018/06/Palliative_care_final_version_-Aug10.pdf

[85] Australia. Department of Health, State of Western Australia. Perinatal Palliative Care. Model of Care. 2015. Available from: https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Networks/Palliative%20care/Perinatal-Palliative-Care-Model-of-Care.pdf

A review of the bibliography regarding models of PerPC provides very general information which leads to an important conclusion that no empirical, evidence-based research was published, indicating the best model of care.[86]

In 2019, the organization "Perinatal Hospice & Palliative Care" published a list of 300 organizations providing PerPC services, including 233 organizations from the USA, and 7 from Poland.[87]

In 2016, in 30 US states, a survey was published on 75 programs of PerPC, which disclosed a large variety of settings and forms of care.[88]

It is undoubtedly possible to distinguish two major streams of PerPC – one, traditional, rooted in the neonatology, and a more recent one, connected to prenatal diagnostics and therapy. Although they both concern different stages of a child's life, they should become integrated.

III. Polish model of perinatal palliative care

The Polish model of PerPC, also referred to as the perinatal hospice, was implemented in 1998 as an original solution (at that time, the authors were not familiar with the above mentioned publication of Calhoun and Hoeldtke from 1996).[89] In contrast to the in-hospital model launched in the USA, the Polish model relied on close cooperation between prenatal diagnostics and a home hospice for children. PerPC was presented as an alternative to the termination of pregnancy, infanticide, and futile medical care.[90]

In 1998-2005, perinatal consultation was provided only by Joanna Szymkiewicz-Dangel, a physician specialized in ultrasound diagnostics of congenital malformations. She developed a PerPC system in cooperation with obstetricians, geneticists and neonatologists. A few children with prenatal diagnosis who survived an early neonatal period became patients of the Warsaw Hospice for Children.

[86] Balaguer A, et al. The model of palliative care in the perinatal setting: a review of the literature. BMC Pediatrics. 2012;12:25. Available from: https://bmcpediatr.biomedcentral.com/track/pdf/10.1186/1471-2431-12-25

[87] USA. Perinatal Hospice & Palliative Care. List of programs. Available from: https://www.perinatalhospice.org/list-of-programs Last reviewed: 14.03.2019.

[88] Wool C, et al. Provision of Services in Perinatal Palliative Care: A Multicenter Survey in the United States. Journal of Palliative Medicine. 2016; 19: 279-285.

[89] Dangel T, Szymkiewicz-Dangel J. Hospicjum perinatalne – polski model (Perinatal hospice. Polish model). Available from: http://www.hospicjum.waw.pl/phocadownload/hospicjum-perinatalne/hospicjum-perinatalne-polski-model.pdf

[90] Dangel T. Lethal defects in fetuses and neonates: palliative care as an alternative to eugenic abortion, eugenic infanticide, and therapeutic obstinacy. In: International Textbook of Obsteric Anesthesia and Perinatal Medicine. Kuczkowski KM, Drobnik L, editors. MED-MEDIA. 2009. p. 137-144. Available from: https://hospicjum.waw.pl/pliki/Artykul/1068_lethaldefectsinfoetusesandneonatespalliativecareasalternativetoeugenicabortion.pdf

In 2006, an Ultrasound Clinic was opened within the Warsaw Hospice for Children Foundation in Warsaw, at Agatowa Street in Warsaw, headed by Joanna Szymkiewicz-Dangel. Thereby, a clinical, scientific and didactic center was born, which for the first time in Poland integrated perinatology and palliative care.

The fact that Agnieszka Chmiel-Baranowska, a psychologist employed by the WHC, became a consultant at the Ultrasound Clinic Agatowa, meant that a new model of perinatal hospice was born based on integrated consultations of physicians and psychologists. The crucial components of this model are as follows:

- consultation with the physician who makes a diagnosis;
- filling in of a DNR form by a physician (**Appendix 14**);
- referral to a pathology of pregnancy outpatient clinic;
- a psychologist is present during the consultation with a physician;
- a psychologist stays with the parents following physician's consultation and gives PerPC consultation;
- availability of the physician after the psychological consultation (if the parents need additional information);
- availability of phone contact with a psychologist during pregnancy and after labor;
- a hospice physician and a hospice chaplain available for parents;
- possibility of meeting with parents of another hospice patient with similar condition;
- parenting school (a course for the parents);
- scheduling of the labor in a tertiary referral obstetric and neonatology center or in any other hospital chosen by parents;
- cooperation contracts signed with 9 hospitals in Warsaw;
- program of bereavement care (specifically designed for PerPC).

In 2002-2009, 197 lethal malformations were prenatally diagnosed, including 100 cases which were diagnosed before 24 weeks of gestation (in 55 cases, the parents decided to terminate the pregnancy). In 44 cases, an intrauterine death occurred, 75 neonates were born alive, and 55 died in a neonatology unit soon after the birth (resuscitation was not performed). In one case, the parents did not agree to forego resuscitation or other life-prolonging treatment. Therefore, a neonate with Edwards syndrome and the esophageal atresia was provided with a salivary gland fistula and a gastrostomy. The infant died after a 2-month stay in an intensive care unit.[91]

In 2006-2017, the Ultrasound Clinic Agatowa took care of 133 unborn children with Edwards syndrome (trisomy 18) by providing their parents with 190 medical and 157 psychological consultations. The dispensary obtained information about 96 children: 13 terminations of pregnancy (in 48 cases, the diagnosis was made before 24 weeks of gestation), 30 intrauterine deaths, 3 stillbirths, and 50 live births. Among the children born alive 4 died within the first hour after birth, 30 died later in hospital, and 16 were discharged from hospital and referred to a hospice (including 12 who were referred to WHC). The infants referred to hospices constituted 16% of those prenatally diagnosed, and 32% of the children born alive.[92]

[91] Dangel J. Zasady podejmowania decyzji na podstawie diagnozy prenatalnej ze szczególnym uwzględnieniem postępowania okołoporodowego w przypadkach prenatalnego rozpoznania nieuleczalnej choroby płodu (Decision making proces in cases with prenatal diagnosis, especially in case of prenatal diagnosis of fetus's lethal disease). Standardy Medyczne/Pediatria. 2011; 8, 1, 60-69. Available from: https://hospicjum.waw.pl/phocadownload/Etyka/Zasady_podejmowania_decyzji_na_podstawie_diagnozy_prenatalnej.pdf

[92] Ślązak M. Opieka paliatywna nad 42 dziećmi z zespołem Edwardsa (Palliative care in 42 children with Edwards syndrome). Master thesis, Medical University of Warsaw. 2018.

In 2018, two groups of women under 24 weeks of gestation, whose children had been diagnosed with a lethal malformation, were provided with psychological consultation at the Ultrasound Clinic Agatowa. When a diagnosis was given at a hospital, the rate of abortion was 91%. When the information was given at the Ultrasound Clinic Agatowa, the rate of abortion was 14% (see the table below).

The place where the information on diagnosis was given	Mothers' (parents') decisions		No data	Total
	Abortion	Continuation of pregnancy		
Hospital	113 (91%)	6 (5%)	5 (4%)	124
Ultrasound Clinic Agatowa	25 (14%)	137 (78%)	13 (8%)	175

In 2018, the psychologists of the Warsaw Hospice for Children Foundation provided 727 consultations in 431 cases where a lethal malformation had been diagnosed by the Ultrasound Clinic Agatowa, which means 1.7 consultations per family. In that period, only 5 children prenatally diagnosed were treated in WHC, which proves that the role of hospices for children providing PedPC services is infinitesimal.

At present, the Ultrasound Clinic Agatowa is the biggest national reference center in prenatal cardiology, and the headquarters of the Department of Perinatal Cardiology and Congenital Anomalies of the Centre of Postgraduate Medical Education.

The Polish idea of perinatal hospice was presented for the first time in 1999, in Budapest[93], at the European Course on Palliative Care for Children.[94] The first article in Polish was published in 2005[95], and the next one in 2007[96].

In 2007, Tomasz Dangel took part in the meeting of the Committee for Family and Women's Rights of the Polish Parliament where he gave the lecture "Palliative care in perinatology as an alternative to eugenic abortion".[97] The main conclusions were as follows:

1. In Poland, pediatric palliative care is not considered a valuable method of treatment of incurable diseases prenatally diagnosed. Therefore, it is not available for a majority of sick neonates.
2. Obstetricians suggest termination of pregnancy more often than childbirth and palliative care for the child and the family.
3. Palliative care may be a worthwhile alternative for families who, for ethical reasons, do not accept abortion.

[93] Data of the Warsaw Hospice for Children Foundation.

[94] Szymkiewicz-Dangel J. Ethical problems in perinatal medicine. 1st European Course on Palliative Care for Children. Budapest; 1999. Abstract.

[95] Dangel T, Szymkiewicz-Dangel J. Opieka paliatywna w perinatologii (Palliative care in perinatology). In: Opieka Paliatywna nad Dziećmi. Dangel T, editor. Warszawskie Hospicjum dla Dzieci, Instytut „Pomnik – CZD". p. 27-30. Warsaw; 2005. Available from: https://hospicjum.waw.pl/pliki/Artykul/1281_opiekapaliatywnawperinatologii-2005.pdf

[96] Szymkiewicz-Dangel J. Perinatalna opieka paliatywna – czy możliwa jest współpraca położników i neonatologów z hospicjami domowymi dla dzieci? (Perinatal palliative care. Is cooperation between obstetricians and neonatologists from home hospices for children possible?). In: Opieka Paliatywna nad Dziećmi. Dangel T, editor. Fundacja Warszawskie Hospicjum dla Dzieci. p. 25-28, Warsaw; 2007. Available from: http://www.hospicjum.waw.pl/phocadownload/Etyka/PerinatalnaOpiekaPaliatywna-CzyMozliwaJestWspolpracaPoloznikowINeonatologowZHospicjamiDomowymiDlaDzieci_2007.pdf

[97] Poland. Polish Parliament (The Sejm). Newsletter of the Chancellery of the Sejm. No 1751/V. p. 8-13. Available from: http://orka.sejm.gov.pl/Biuletyn.nsf/0/D7B94DE49CDDBE27C12572B30031304C/$file/0175105.pdf

4. Palliative home care protects the incurably sick child against futile therapy, and the parents against moral criticism from medical personnel.
5. Palliative home care is far less expensive than the hospital treatment.
6. Centers of prenatal diagnostics and neonatology hospital units should cooperate with home hospices for children.
7. The parents of a sick fetus should be provided with guaranteed consultation on palliative care.
8. Prenatal pro-life diagnostics is impossible without the development of pediatric palliative care.

In 2007, Janusz Gadzinowski and Aleksandra Jopek wrote an article "Neonatologia – między etyką a pragmatyzmem" (Neotanology: ethics versus pragmatism) where they stated among others: *The present technology enables us to prolong the life of neonates with lethal anomalies, which actually means prolonging the dying process. Thanks to available means, the length of life of the children with the trisomy 18 can be extended until one year, while without any medical intervention, these children would live little more than a few weeks. It has become obvious that although the benefits of the development of medicine cannot be overestimated, the side effects of its successes are so terrifying that they require a deep reflection. […] We decide to abstain from the resuscitation only if we are sure that the anomalies of the neonate will not let him/her survive. Any doubt aroused in the delivery room makes us undertake standard life-saving procedures. We withdraw the procedures only if a lethal anomaly has been diagnosed. Similarly, we provide every neonate with the so-called comfort care which means feeding, analgesic treatment, and nursing. Such an approach respects the sanctity of life doctrine, and its practical implications enable us to take decisions in unambiguous situations where we have no doubts that the neonate has a lethal anomaly and the chances of survival are close to zero. However, in less obvious cases which are much more frequently faced by neonatologists, traditional ethical norms are not always able to ease a physician's conscience. Especially if a patient in whom a lethal anomaly was not diagnosed, is in critical condition which might justify the withdrawal from the treatment prolonging the dying process. The difficulty with an unequivocal recognition of such condition results from a lack of specific i.e. undoubtful and unquestionable symptoms. Such cases cause the most common dilemmas, because they force us to take decisions based only on high probability conditions, our experience, other physicians' experience, and statistics.*[98]

A survey conducted in 2008 in 309 hospital units of neonatology or of pediatric intensive care in Poland showed that DNR decisions were taken in 146 units (47%).[99] Moreover, in 76 units, DNR decisions led to limitation or withdrawal of other forms of treatment, such as:

- renal replacement therapy (dialysis) (66 cases; 87%);
- surgery (e.g. correction of congenital heart defects) (64 cases; 84%);
- catecholamines (63 cases; 83%);
- increase of mechanical ventilation parameters (55 cases; 72%);
- intubation (54 cases; 71%);
- transfusion of blood products (45 cases; 59%)
- intravenous nutrition (33 cases; 43 %);

[98] Gadzinowski J, Jopek A. Neonatologia – między etyką a pragmatyzmem (Neotanology: ethics versus pragmatism). Nauka. 2007; 3: 21-30. Available from: http://cejsh.icm.edu.pl/cejsh/element/bwmeta1.element.ojs-issn-1231-8515-year-2007-issue-3-article-446/c/446-441.pdf

[99] Dangel T, Muśalik-Świetlińska E, Brożek G, Świetliński J. Praktyka powstrzymania się od resuscytacji u dzieci w Polsce (The practice of abstaining from resuscitation in children in Poland). Standardy Medyczne – Pediatria. 2009; 6: 1044-1051. Available from: https://hospicjum.waw.pl/pliki/Artykul/1130_praktykapowstrzymaniasieodresuscytacjiudzieciwpolsce-2009.pdf

- antibiotic therapy (29 cases; 38%);
- ventilator disconnection (24 cases; 32%);
- enteral nutrition (11 cases; 14%);
- oxygen therapy (10 cases; 13%);
- other (3 cases; 4%).

The teams of physicians who took part in the survey drew up a ranking list of criteria which should be taken into consideration while deciding on abstaining from resuscitation (by choosing 5 the most important ones):

- prognosis regarding the cure of the disease (79%);
- attitude of the parents (65%);
- prognosis regarding remission (relative improvement of the patient's condition; patient's ability of staying out of the hospital) (62%);
- prognosis regarding patient's quality of life (53%);
- unanimity of physicians (53%);
- karyotype (53%);
- child's suffering related to hospital treatment (38%);
- technical means of life prolonging (available equipment) (24%);
- ability of using surgery (results of surgical treatment) (20%);
- attitude of the child (if the child is able to express it) (16%);
- life expectancy (13%);
- costs of the treatment (2%);
- other (2%).

A DNR decision was taken by:

- head of the hospital unit, physicians' team and parents (73 cases; 51%);
- head of the hospital unit and physicians' team (41 cases; 29%);
- chief physician or physician on duty (8 cases; 6%);
- case conference (6 cases; 4%);
- chief physician and parents (6 cases; 4%);
- head of the hospital unit (3 cases; 2%);
- other (6 cases; 4%).

In the case of a dying child a prior DNR decision was fully respected in 75 hospital units (53%), and not always respected in 66 units (47%).

The majority of respondents (201; 65%) were of the opinion that in cases of lethal anomalies and chromosomal aberrations (e.g. trisomy 13, or 18) a decision on abstaining from resuscitation may be taken before the child's birth, based on prenatal testing (ultrasound, karyotype). Alternatively, 78 respondents (25%) expressed the opposite opinion, and 30 (10%) had no opinion at all. The highest percentage of the opponents of the DNR decision taken based on a prenatal testing (30%) came from primary referral neonatology units.

In 102 units (72%), a DNR decision was also taken when a ventilator was not yet connected to the child. In the other 39 units (28%), such decision was taken only when mechanical ventilation had been implemented.

When a DNR decision was taken regarding a child without mechanical ventilation, it was theoretically possible to discharge the child from the hospital and to continue palliative care at home with the assistance of a home hospice. Such an approach was used in 55 analyzed health centers (42%), while it was not implemented in the other 76 (58%) centers for the following reasons: (a) no home hospice was available (50 centers) or (b) the physicians found

such an approach wrong (26 centers). A statistically significant difference was noticed between units of intensive care which cooperated with home hospices for children, and neonatology units which did it far less often (88% vs. 32%, p value = 0,000001). Likewise, such difference was noticed between various neonatology units. Children were most often discharged and referred to a home hospice from tertiary referral units, less often from secondary referral units, and the least often from primary referral units (53% vs. 35% vs. 10%, p value = 0,004). The highest percentage of opponents of home palliative care after the DNR decision (32%) came from primary referral neonatology units.

The notion of palliative care was officially introduced to the Polish neonatology in 2011 by the Team for Ethical Recommendations in Perinatology. However, the authors of the Recommendations did not define that notion, and they did not explain what "palliative actions" meant in practice.[100]

In 2012, several types of decisions taken in a perinatal hospice were defined, together with rules for decision-making.

Types of decision:

- continuation vs. termination of pregnancy;
- resuscitation vs. abstaining from resuscitation;
- intensive care vs. palliative care;
- corrective surgery of a defect vs. no surgical treatment;
- hospital treatment vs. home care;
- death at hospital vs. death at home.

Rules and art of decision-making:

1. The ultimate value is the benefit of the child. Termination of the pregnancy or futile medical care should be both considered as activities contradictory to this value. The former is legal, based on provisions of law. The latter, despite interpretational issues, should be considered a medical error.
2. The types of decisions listed above should be taken by parents (legal representatives) on the basis of information provided by physicians. The exception is decision on abstaining from life-prolonging treatment – the physician can take such decision against parents' will. Consequently, in most cases, the role of the physician is limited to providing parents with appropriate information, and not decision-making.
3. The way of providing parents with the information on diagnosis, prognosis, and further treatment, belongs to the art of medicine.
4. In the decision-making process the parents may be assisted by a psychologist familiar with medical circumstances, or other qualified advisor, who will help them to figure out possible options and their impact on future life of the family.
5. The diagnosis of fetus's complex malformations, and especially heart's malformations, require particular qualifications. Such diagnosis should be validated by a specialist at a reference center of prenatal cardiology.

[100] Poland. Team for Ethical Recommendations in Perinatology. Rutkowska M, editor. Rekomendacje dotyczące postępowania z matką oraz noworodkiem urodzonym na granicy możliwości przeżycia z uwzględnieniem aspektów etycznych (Recommendations on dealing with the mother and the neonate born on the edge of survival, including ethical aspects). Medycyna Wieku Rozwojowego. 2011; 15: 259-269. Available from: https://www.ptgin.pl/sites/default/files/page-2019/Post%C4%99powanie%20z%20matk%C4%85%20oraz%20noworodkiem%20urodzonym%20na%20granicy%20mo%C5%BCliwo%C5%9Bci%20przе%C5%BCycia%20z%20uwzgl%C4%99dnieniem%20aspekt%C3%B3w%20etycznych.pdf

6. If an anatomical malformation of a fetus is diagnosed, which could possibly be corrected, the parents should be given a possibility to consult a pediatric surgeon, and to receive credible information on actual results of such surgery in a particular health center.
7. Before a decision regarding the continuation or termination of the pregnancy is taken, the parents should be given a possibility to consult a perinatal palliative care center.
8. The parents' decision on abstaining from a life-prolonging treatment in the case of an incurable disease with a high risk of premature death should not be criticised or questioned by physicians.[101]

The above statement was a voice in a debate conducted by the Polish Bioethics Society "For rational decisions in neonatal care."[102] The debate was summarized in the article "Should parents have the right to decide on life and death of critically ill neonates?"[103] written by Kazimierz Szewczyk. The same author, in another publication, presents a broad analysis of critical decisions in neonatology.[104]

In 2018, the monography "Palliative treatment in perinatal care – clinical practice, ethics, law, psychology" edited by Magdalena Rutkowska and Sławomir Szczepaniak[105] was published. Therein, Marcin Rawicz set out five principles of palliative treatment, which should be implemented in a unit of intensive care for neonates:

1. There will be no pain.
2. There will be no dyspnea.
3. There will be no cold.
4. There will be no hunger.
5. There will be no fear.[106]

[101] Dangel T. Decyzje dotyczące dzieci z nieuleczalnymi chorobami prowadzącymi do przedwczesnej śmierci w perinatologii (Decision-making regarding children with incurable diseases leading do hastened death in perinatology). Polish Bioethics Society; 2012. Discussion „O racjonalne decyzje w opiece neonatalnej" (Toward rational decision-making in neonatal care). Available from: http://www.ptb.org.pl/pdf/dangel_neonatalna.pdf

[102] Polish Bioethics Society. O racjonalne decyzje w opiece neonatalnej (Toward rational decision-making in neonatal care). Available from: http://www.ptb.org.pl/opinie_neonatalna.html

[103] Szewczyk K. Czy rodzice powinni mieć prawo do decydowaniu o życiu i śmierci krytycznie chorych noworodków? (Should parents decide about life and death of terminally ill neonates?). Diametros 2012; 34: 154–178. Available from: www.diametros.iphils.uj.edu.pl/index.php/diametros/article/download/504/620

[104] Szewczyk K. Decyzje krytyczne w neonatologii i standardy ich podejmowania (Critical decisions in neonatology, and decision-making standards). Diametros 2010; 26: 96-135. Available from: https://www.diametros.iphils.uj.edu.pl/serwis/pdf/diam26szewczyk.PDF

[105] Rutkowska M, Szczepaniak S, editors. Postępowanie paliatywne w opiece perinatalnej – praktyka kliniczna, etyka, prawo, psychologia (Palliative treatment in perinatal care – clinical practice, ethics, law, psychology). PZWL; 2018.

[106] Ibid. Rawicz M. Opieka paliatywna na oddziale intensywnej terapii noworodka (Palliative care in intensive care units for neonates). p. 231-243.

IV. Discussion with neonatologists

In 2017, the Polish Neonatal Society (PNS) published "Principles of decision-making regarding palliative care in neonatology, taking into consideration ethical reasons."[107] In that document, the principles of treatment of premature neonates born at 22-25 weeks of gestation were defined. Although the recommendations do not regard premature neonates born as the result of the termination of the pregnancy[108], they include a couple of important statements:

1. The care of a neonate born before 23 weeks of gestation should be limited to palliative treatment.
2. It is recommended that neonates born at 23-24 weeks of gestation receive palliative care, unless circumstances improving prognosis occur.
3. Neonates of the same gestational age can significantly vary regarding biological maturity.
4. If life-prolonging treatments are ceased, all possible measures should be taken in order to let the neonate die with dignity.

We took part in a public debate on that document and presented our position.[109] The main distinct opinions were as follows:

1. **Children with lethal malformations, born at 20 - 23 weeks of gestation as a result of the pharmacological termination of the pregnancy.** Those children can still manifest symptoms of life. In such cases, the cause of death is lung immaturity. The child can live up to several hours.
   PNS's stance: *This document does not refer to abortion. Therefore, we do not define the treatment of neonates born as the result of artificial abortion.*
   Our stance: *For humanitarian reasons, it should be assumed that such neonates suffer because of dyspnea. Therefore, in accordance with medical ethics, the neonate should be provided with palliative care, just like older children who feel dyspnea in the terminal phase of their life. The child can be protected against dyspnea and stress by an intravenous administration to the mother of a strong opioid (e.g. fentanyl) which is transported across the placenta, and simultaneously provides her with analgesia, or by intranasal administration of fentanyl to the child after the artificial abortion* [*Intranasal fentanyl in palliative care of newborns and infants. Harlos MS et al. J Pain Symptom Manage 2012*].
2. **The prenatal decision "to undertake or to abstain from resuscitation" in the case of a neonate with a lethal malformation diagnosed prenatally.**
   PNS's stance: *The decision is taken by an interdisciplinary team at a university hospital or a scientific and research institute.*

[107] Rutkowska M, et al. Zasady postępowania w neonatologii przy podejmowaniu decyzji o objęciu opieką paliatywną uwzględniające racje etyczne. Standardy opieki medycznej nad noworodkiem w Polsce. Zalecenia Polskiego Towarzystwa Neonatologicznego (Rules of decision-making on providing palliative care, taking into consideration ethical reasons. Standards of medical care in neonate in Poland. Recommendations of Polish Neonatal Society). 2nd ed. 2017.

[108] In Poland, termination of the pregnancy because of genetic malformations is permitted until 24 weeks of gestation. (Supreme Court judgment from 13 October 2005; docket number: IV CK 161/05). Available from: https://www.saos.org.pl/judgments/163611

[109] Open letter to Polish Neonatal Society and its reply. Standardy Medyczne (Medical Standards). 2017. Available from: http://www.standardy.pl/newsy/id/169

Our stance: *If a lethal malformation of the fetus is diagnosed, and the parents decide to continue the pregnancy, a physician specialized in prenatal diagnostics who is aware of the prognosis in the case of a diagnosed pathology, will:*

1) *validate the diagnosis by consulting it with a reference center;*
2) *complete a form specifying the procedure to be implemented in the case of cardiac or respiratory arrest (***Appendix 14***);*
3) *forward the above mentioned form to obstetricians and neonatologists;*
4) *refer the parents to a perinatal hospice.*

3. **Administration of opioids in the delivery room to the neonate – when it is decided to abstain from resuscitation.**
   PNS's stance: *If the administration of analgesics is necessary, it can be done orally (morphine) or intravenously by an umbilical vein catheterization or a peripheral vein cannulation.*
   Our stance: *Fentanyl should be administered through the nose. Intravenous cannulation should be avoided.*
4. **Mechanical ventilation in neonates with lethal malformations.**
   PNS's stance: *If a neonate was intubated and mechanically ventilated, we primarily recommend to decrease the ventilation to a basic level, which does not exclude an extubation within several hours.*
   Our stance: *The above recommendation should be included in the "Standards" of the PNS, accompanied by the statement that such an approach is ethically justified because it follows the principles of discontinuation of futile medical care. It would be useful if the PNS developed and published a protocol of ventilator disconnection and extubation understood as a palliative procedure. Mechanical ventilation applied in children with lethal malformations is a superfluous procedure, and cannot be considered a form of palliative care.*
5. **Parenteral nutrition of neonates with lethal malformations.**
   PNS's stance: *A neonate's brain is particularly vulnerable to hypoglycemia and hypocalcemia, possibly resulting in convulsions. Similarly, prolonged hypoglycemia can damage the brain. Since we are not able to predict how long palliative care will last, and we do not hasten death, we recommend restricted parenteral nutrition (glucose with calcium products) in order to protect the neonates from convulsions, or additional suffering, and brain damage.*
   Our stance: *For children with lethal malformations total parenteral nutrition is an unjustified procedure which cannot be considered a form of palliative care. However, parenteral nutrition should not be confused with treatment of hypoglycemia. The administration of water, glucose, and calcium (without amino acids) certainly cannot be considered nutrition. Neonates, in the first days of life, metabolize mainly their own fat, and not glucose. Consequently, they are in a state of a moderate ketosis which has an anticonvulsant and neuroprotective effect. Gluconeogenesis and glycogenolysis are the processes by which glucose is produced. Temporary hypoglycemia in a neonate is a physiological state, and routine intravenous administration of glucose to the neonates with lethal malformations is unjustifiable. Neonates with lethal malformations born prematurely may suffer from metabolic disorders resulting in hypoglycemia, but in such cases, intravenous administration of glucose in order to avoid convulsions also raises doubt. The correct anticonvulsant treatment is the administration of phenobarbital. Pathological hypoglycemia can be treated with a glucose infusion in children who do not die immediately after birth, but only if it is correctly diagnosed.*

V. Epidemiological data

A child born at 20-23 weeks of gestation may manifest signs of life (a child in the age of 20-22 weeks has no chance for survival, while at 23 weeks the probability is minuscule). The direct cause of death is the lung immaturity, i.e. respiratory distress syndrome (RDS). Survival time can be up to several hours (see the table below).[110]

Gestation age (weeks)	Signs of life (%)	Survival time
20	12	80 (38 – 122) minutes
21	20	
22	37	
23	56	6 (2 – 10) hours

The table below shows the distribution of decisions taken by parents who could choose palliative care or intensive care for premature neonates born at 23-25 weeks of gestation. Palliative care was provided to all premature neonates born at 22 weeks of gestation, and intensive care to all premature neonates born at 26 weeks of gestation.[111]

Gestation age (weeks)	Palliative care (%)	Intensive care (%)	Survival on the intensive care (%)	Significant long-term neurological disability* (%)
22	100	0		
23	63	37	21	~ 40-60
24	27	73	59	~ 30-45
25	4	96	78	~ 25-35
26	0	100	87	~ 20

**Intelligence quotient <70, or cerebral palsy, or a severe visual or hearing deficit.*

[110] Macfarlane PI, Wood S, Bennett J. Non-viable delivery at 20-23 weeks gestation: observations and signs of life after birth. Arch Dis Child Fetal Neonatal Ed. 2003; 88: F199-202. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1721558/pdf/v088p0F199.pdf

[111] Kaempf JW, Tomlinson MW, Tuohey J. Extremely premature birth and the choice of neonatal intensive care versus palliative comfort care: an 18-year single-center experience. J Perinatol. 2016; 36:190-195. Available from: https://www.ncbi.nlm.nih.gov/pubmed/26583942

VI. Perception of pain and dyspnea

There is no consensus on the week of gestation at which the child can experience pain.[112] Kanwaljeet Anand, an expert in that area, states that the nervous system is mature enough to feel pain at 20 weeks.[113] His opinion has been questioned by other scientists for whom a conventional barrier is 24 weeks of gestation.[114] Nonetheless, there is a view according to which at 15 weeks of gestation, the nervous system becomes mature enough to perceive pain.[115]

The question if a fetus or a premature neonate feel pain is important if we consider performing surgical abortion accompanied by tissue damage. In contrast, if a pregnancy is terminated with medications, the premature neonate dies because of the lung immaturity and respiratory failure. The same situation takes place after non-viable delivery at 20-23 weeks of gestation. Therefore, it is necessary to take into consideration the child's ability to experience dyspnea, stress, and suffering.

Polish experts, Wojciech Walas and Andrzej Piotrowski, expressed the following view: *Another issue is the analgesia of fetuses subjected to abortion at the end of the second trimester of the pregnancy. The fact that the fetus is nonviable does not mean that it does not sense pain or other forms of suffering. Then, it is highly justified to apply a pain treatment in the pregnant woman, which also provides fetal analgesia (e.g. the administration of opioids).*

The authors also stress a particular perception of pain by the neonates *who have fully developed structures responsible for pain sensation, but have not developed defence mechanisms against it,* and *in comparison with older children, neonates are distinguished by a stronger hormonal and metabolic response to pain stimuli*. (**Appendix 15**).[116]

It is certain that premature neonates born at 20-24 weeks of gestation cannot survive because of lung immaturity that manifests as respiratory distress syndrome (RDS). That term has been translated into Polish as "zespół zaburzeń oddychania noworodka" (neonatal respiratory disorders syndrome), but the translation does not reflect the meaning of the word *distress*, which is a synonym of suffering. The Polish word *dystres* which means a detrimental reaction of the organism to stress, would be more suitable. In that context, this term seems more appropriate because in the RDS, hormonal, oxidative, and detrimental stress responses were demonstrated.[117, 118]

Since dyspnea in a dying neonate is a subjective experience, it cannot be confirmed by any existing measurement methods. However, based on the hormonal and metabolic response to stress, we should assume that fetuses and neonates born alive

[112] Lowery CL, Hardman MP, Manning N, Hall RW, Anand KJ, Clancy B. Neurodevelopmental changes of fetal pain. Semin Perinatol 2007; 31: 275-282. Available from: https://pdfs.semanticscholar.org/7443/6ab1cdedf6e9f6ff8d8ee0b847e91def52e4.pdf

[113] Anand KS. Expert report 2004. Available from: https://www.nrlc.org/uploads/fetalpain/AnandPainReport.pdf

[114] Kosińska-Kaczyńska K, Wielgoś M. Czy płód może odczuwać ból? (Can fetus feel pain?). Ginekol Pol 2011; 82: 133-136. Available from: https://journals.viamedica.pl/ginekologia_polska/article/download/46375/33162

[115] Sekulic S, Gebauer-Bukurov K, Cvijanovic M, Kopitovic A, Ilic D, Petrovic D, Capo I, Pericin-Starcevic I, Christ O, Topalidou A. Appearance of fetal pain could be associated with maturation of the mesodiencephalic structures. Pain Res 2016; 9: 1031-1038. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5115678/pdf/jpr-9-1031.pdf

[116] Walas W, Piotrowski A. Ocena bólu i jego leczenie w perinatalnej opiece paliatywnej (Pain assessment and treatment in perinatal palliative care). In: Postępowanie paliatywne w opiece perinatalnej - praktyka kliniczna, etyka, prawo, psychologia (Palliative treatment in perinatal care – clinical practice, ethics, law, psychology). Rutkowska M, Szczepaniak S, editors. PZWL 2018.

[117] Quinn MW, et al. Stress response and mode of ventilation in preterm infants. Arch Dis Child Fetal Neonatal Ed 1998; 78: F195–F198. Available from: https://fn.bmj.com/content/fetalneonatal/78/3/F195.full.pdf

[118] Negi R, et al. A novel approach to study oxidative stress in neonatal respiratory distress syndrome. BBA Clinical 2015; 3: 65-69. Available from: https://www.researchgate.net/publication/276107567_A_novel_approach_to_study_oxidative_stress_in_neonatal_respiratory_distress_syndrome

(also at 20-23 weeks of gestation) react to hypoxia (lack of oxygen).[119] Therefore, we cannot exclude that a child suffers from dyspnea. Therefore, in accordance with medical ethics, we suggest providing such children with palliative treatment, as we do with older children who are subjected to intensive care or are in the terminal phase of an illness, and suffer from dyspnea.

In extremely premature neonates who are subjected to intensive care, methods aiming at decreasing distress, which means a hormonal and metabolic response of the hypothalamus, the pituitary gland and the adrenal glands, should be used. In such cases, strong opioids, e.g. morphine or fentanyl, are administered.[120, 121]

During termination of pregnancy, a child can be protected against dyspnea and stress by intravenous administration of fentanyl to the mother, which is transferred across the placenta and produces analgesia for both mother and child.[122] The same medicine (fentanyl) may be administered intranasally to a child after nonviable delivery, if the child manifests signs of life.[123]

A patient-controlled analgesia (PCA) used during the termination of pregnancy has been reported.[124] The method consists in a self-controlled administering of fentanyl by the mother who triggers an automatic syringe or an infusion pump by pushing a button. The analgesic is immediately injected intravenously. The woman adjusts the dose herself, adequactely to the level of pain, and a part of the medicine crosses the placenta and produces anaglesia to the child.

In 2016, the state of Utah (USA) introduced a law imposing an obligatory use of anesthesia or analgesia of an unborn child during abortion performed from 20 weeks of gestation.[125, 126]

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[121] Lago P, et al. Randomised controlled trial of low dose fentanyl infusion in preterm infants with hyaline membrane disease. Arch Dis Child Fetal Neonatal Ed 1998; 79: F194–F197. Available from: https://fn.bmj.com/content/fetalneonatal/79/3/F194.full.pdf

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[123] Harlos MS, Stenekes S, Lambert D, Hohl C, Chochinov HM. Intranasal fentanyl in palliative care of newborns and infants. J Pain Symptom Manage. 2013 Aug;46(2):265-74. Available from: https://www.ncbi.nlm.nih.gov/pubmed/23017621

[124] Smith RL, Siddiqui N, Henderson T, Teresi J, Downey K, Carvalho JC. Analgesia for medically induced second trimester termination of pregnancy: a randomized trial. J Obstet Gynaecol Can 2016; 38: 147-153. Available from: https://www.jogc.com/article/S1701-2163(15)00037-7/pdf

[125] USA. Utah Code Title 76. Utah Criminal Code § 76-7-308.5. Administration of anesthetic or analgesic to an unborn child. A physician who performs an abortion of an unborn child who is at least 20 weeks gestational age shall administer an anesthetic or analgesic to eliminate or alleviate organic pain to the unborn child caused by the particular method of abortion to be employed. Available from: https://codes.findlaw.com/ut/title-76-utah-criminal-code/ut-code-sect-76-7-308-5.html

[126] In 2017, dr. Tomasz Dangel asked His Eminence Oskar A. Solis, the bishop of the Catholic Diocese in Salt Lake City (Utah), and His Eminence archbishop Henryk Hoser, the chairman of the Polish Episcopal Conference's Team of Experts on Bioethics, for an ethical interpretation of this regulation, in the context of the Canon Law of the Catholic Church, but he did not receive any answer. On 21 September 2018, the Polish Episcopal Conference's Team of Experts on Bioethics, chaired by His Eminence bishop Józef Wróbel, took a negative stance on Tomasz Dangel's proposition of providing mother and child with analgesia and dyspnea alleviation during medical abortion.

The authors of the present publication are not competent to discuss moral aspects of reducing dyspnea after medical abortion by using fentanyl, and of providing maternal analgesia for terminantion of pregnancy. Consequently, they present solely legal and medical arguments which may be useful for further considerations.

From the Law on patient's rights and on Commissionaire for Patient's Rights (articles 20 and 20a) it follows that:

- The patient has the right to privacy and dignity, especially while being provided with healthcare services.
- The right to dignity includes the right to die in peace and dignity.
- The patient has the right to be provided with pain management.

The above mentioned law neither excludes nor restricts those rights in the case of the women who terminate their pregnancy, or children who are born as the result of the termination of pregnancy.

VII. Regulation of the Minister of Health

In 2016, a project called "Proposal of life protection program in the case of the prenatal diagnosis of lethal malformations" was developed and handed over to the Prime Minister of the Republic of Poland.[127] The project was rejected by the government which accepted another project submitted by the Polish National Forum of Pediatric Palliative Care. Based on that project, on 31 January 2017, the Minister of Health issued a regulation amending the regulation on guaranteed healthcare services in palliative and hospice care.[128]

VIII. Refunding

In 2018, which was the first year of refunding of PerPC services,[129] the National Health Fund allocated only 409 000 PLN for that purpose, that means 10% of the total budget planned for such services (4 million PLN).[130] The reimbursement of the services provided by PerPC Dispensary Agatowa of the Warsaw Hospice for Children Foundation amounted to 339 493 PLN, or 83% of the whole amount spent by the National Health Fund on that purpose. That means that the Warsaw Hospice for Children Foundation provides a high accessibility to PerPC services, whereas the solutions developed by the Polish National Forum of Pediatric Palliative Care and the Ministry of Health offer an accessibility which may be considered inadequate.

[127] Dangel T, Szymkiewicz-Dangel J. Propozycja programu ochrony życia w przypadku rozpoznania wady letalnej w badaniach prenatalnych (Proposition of pro-life program in the case of lethal malformation diagnosis in prenatal tests). Available from: http://perinatalne.pl/pliki/Artykul/1034_propozycja-programu-ochrony-zycia-13-10-2016.pdf

[128] Draft amedment to that regulation has been published only in the Polish edition of the present publication.

[129] In 2017, the Ministry of Health refused to refund PerPC services offered by the Warsaw Hospice for Children Foundation.

[130] Klinger K, Szczepańska A. Hospicja perinatalne są, a jakby ich nie było (Perinatal hospices hardly exist). Dziennik Gazeta Prawna 13 March 2019, No51 p. A7.

Definitions

Perinatal palliative care (PerPC) consists in:

1. Providing support for parents of children with incurable lethal malformations whose treatment is possible, however, carries high risk of complications in the prenatal period, and especially in the period when the termination of pregnancy is allowed, in the form of medical and psychological consultation.
2. Providing a sick child with a postnatal care consisting of keeping the child in comfort and protecting him or her against futile medical care. That means providing the neonate with symptom control, and the parents with psychological, social and spiritual support. If the child is born alive and survives next hours, he or she can be taken care of in a neonatology hospital unit or at home (by the parents and a hospice). PerPC is provided for the neonates with incurable diseases with a high risk of premature death, and for premature neonates born before 24 weeks of gestation.
3. Providing aborted children with comfort, and alleviating dyspnea if they manifest signs of life.
4. Providing parents with bereavement care, regardless of the fact if the child has died before or after the birth.

Perinatal hospice is not an entity (e.g. a hospice or a clinic), but a model of perinatal medicine based on respect for life and dignity of an incurably sick child in the fetal and neonatal period. It provides pregnant women with comprehensive care if a prenatal diagnosis of a lethal malformation has been made and validated by a reference center. It includes a complex prenatal care – medical, psychological and spiritual, as well as bereavement care, regardless of the time of the child's death. After the labor, it consists of neonatal palliative care, palliative home care, and long-term care. It is an alternative to the termination of pregnancy and futile medical care.

Lethal malformation (lat. *letalis*) in a child in the fetal or neonatal period is: (1) a developmental disorder resulting in spontaneous abortion or intrauterine death; (2) a developmental disorder resulting in premature death of a child born alive, regardless of the treatment applied; and (3) a developmental disorder allowing to terminate pregnancy in accordance with law. The disorders of the third category may or may not belong to the other two previous ones. But in all three situations, the malformation directly or indirectly results in fatality.

Standards of perinatal palliative care

I. Clinical circumstances

1. The diagnosis of a lethal malformation is made and validated before 24 weeks of gestation, and a decision on continuation or termination of pregnancy can be taken. A physician informs the parents about options regarding the medical treatment of the unborn child and the prognosis, as well as the predictable medical consequences for the mother. A psychologist discusses with them probable consequences of both decisions. The physician and the psychologist do not suggest to the mother (parents) any of the alternative solutions, leaving them a free choice.
2. The diagnosis of a lethal malformation is made and validated after 24 weeks of gestation.
3. The diagnosis of a lethal malformation is made and validated after the birth of the child.
4. Due to spontaneous or medical abortion a nonviable neonate is born before 24 weeks of gestation, who still manifests signs of life.
5. Intrauterine death takes place.

II. Service providers

1. In the circumstances described in sections 1 and 2 above, PerPC should be provided in centers of prenatal diagnostics, prenatal cardiology, or genetics. The first consultations of a physician and a psychologist should be integrated and executed in the same place and time. If it is not possible, the consultation of a psychologist should take place within 24 hours from the moment when the information on the diagnosis of a lethal malformation has been given to the parents.

   Prenatal diagnostics

   If a lethal malformation is diagnosed prenatally, and the parents decide to continue the pregnancy, a physician specialist in prenatal diagnostics, aware of prognosis:
   1) verifies the diagnosis by consulting a reference center;[131]
   2) fills in the document "Procedures in the case of cardiac or respiratory arrest in neonate" (**Appendix 14**);
   3) forwards the above mentioned document to obstetricians and neonatologists;
   4) refers the parents to a perinatal hospice;
   5) refers the pregnant woman to a dispensary for pregnancy pathology in a reference center or in a regional hospital, close to the place of residence;
   6) assists the pregnant woman to find a place of labor in a reference center or in a regional hospital, taking into consideration the woman's preferences and the pathology diagnosed in the fetus.

2. In the situations 1, 2, 3, 4, and 5, PerPC should be provided in centers of neonatology, obstetrics and gynaecology.

[131] It is necessary to establish a center of reference for pediatric and perinatal palliative care which would provide validation of diagnosis, consultations, and education.

Postnatal diagnostics

In the case of a postnatal diagnosis of a lethal malformation, a physician specialist in neonatology:

1) fills in the document "Procedures in the case of cardiac or respiratory arrest in neonate" (**Appendix 14**);
2) implements palliative care in a hospital unit of neonatology;
3) refers the neonate and his/her parents to a hospice for children (**Appendix 4).**

3. In the case of intrauterine death and stillbirth, the parents are provided with psychological consultation and the possibility of taking part in a program of bereavement care.
4. A program of bereavement care is led by a psychologist.
5. The hospices for children start providing PedPC (as a continuation of PerPC) if the neonate survives and is discharged from hospital. The hospice physicians have no qualifications for providing prenatal consultations.

III. Personnel

1. A specialist physician with either two years work experience in a center of prenatal diagnostics, a reference center for prenatal cardiology, a center of genetics, or a tertiary center of obstetrics and neonatology, and with a certificate of graduation from the professional improvement course "Perinatal palliative care" conducted by the Centre of Postgraduate Medical Education.
2. A psychologist with a certificate of graduation from a training organized by a reference center for pediatric and perinatal palliative care appointed by the director of the Centre of Postgraduate Medical Education. The psychologists providing consultation in PerPC should be employed in either a reference center for prenatal diagnostics or prenatal cardiology, a center of genetics, a center of neonatology, a tertiary center of obstetrics and gynaecology, or in a hospice for children, upon the condition that they are available within 24 hours.
3. A physician employed in a dispensary for pathology of pregnancy.
4. A midwife preparing the mother for the labor.

IV. Indications

1. The medical indications before the beginning of perinatal palliative care are validated by a specialist physician in a center for prenatal diagnostics, or in a center of prenatal cardiology, or in a center of genetics, or in a tertiary center of obstetrics and neonatology, and in the postnatal period by a specialist physician in a neonatology center.
2. In doubtful cases, a particular validation of the diagnosis and indications for implementation of perinatal palliative care is necessary; such validation should be done in a reference center for pediatric and perinatal palliative care, appointed by the director of the Centre of Postgraduate Medical Education.

3. Lethal malformations:[132]
   1) trisomies (e.g. 13 or 18);
   2) triploidy syndrome 69XXX, 69XXY;
   3) monosomy X with the presence of hydrops fetalis;
   4) renal agenesis;
   5) anencephaly, holoprosencephaly, other malformations of the central nervous system with poor prognosis;
   6) body stalk anomaly;
   7) some bone dysplasias;
   8) heart defects withe severe circulatory insufficiency;
   9) complex congenital malformations with fetal hydrops;
   10) conjoined fetuses sharing a heart or other organs, if a separation surgery is not possible;
   11) congenital high airway obstruction syndrome;
   12) Smith-Lemli-Opitz syndrome;
   13) other rare genetic syndromes with poor prognosis;
   14) other malformations, potentially lethal, if they meet the criteria allowing the parents to terminate the pregnancy.

V. Additional regulations

1. The Minister of Health shall commission a reference center to develop a methodology of evaluating the quality of PerPC services.
2. The director of the Centre of Postgraduate Medical Education shall appoint a PerPC training center where the training of physicians and psychologists will take place, and he shall sign an appropriate agreement with it.

Appendixes

13. Draft amendment to regulation on perinatal palliative care [not included in the English edition].
14. Form defining the procedure of treatment in the case of cardiac of respiratory arrest in the neonate.
15. Pain assessment and treatment in perinatal palliative care.

[132] It is not possible to make a closed catalogue of diseases, in accordance with the ICD-10, qualifying for PerPC.

Appendix 14

Procedures in the case of cardiac or respiratory arrest in the neonate

Name and surname of mother: _____

Prenatal diagnosis: _____

Name and surname of neonate: _____

Date of birth: _____

IN CASE OF CARDIAC OR RESPIRATORY ARREST

ATTEMPT RESUSCITATION ☐

Date: _____

Physician's name: _____

Physician's signature: _____

IN CASE OF CARDIAC OR RESPIRATORY ARREST

DO NOT ATTEMPT RESUSCITATION ☐

Date: _____

Physician's name: _____

Physician's signature: _____

Decision has been consulted with obstetricians: YES/NO

Decision has been consulted with neonatologists: YES/NO

Decision has been discussed with parents: YES/NO

Parents have accepted decision: YES/NO

The reasons of the decision: _____

_____

Date: _____

Physician's name and surname: _____

Physician's signature: _____

Caution: The document must be validated by a specialist physician.

Appendix 15

Pain assessment and treatment in perinatal palliative care

Wojciech Walas, MD, PhD,[133] Professor Andrzej Piotrowski, MD, PhD[134]

The International Association for the Study of Pain defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage (1). Any limitations in perinatal palliative treatment aiming at avoiding futile medical care must not include pain management or treatment of other unpleasant sensations. On the contrary, our objective should be to ensure the maximum comfort to the child. The World Health Organization lists pain relief treatment first among the methods of palliative care. Such an approach has also been present in the Recommendation of the Council of Europe on protection of the human rights and dignity of the terminally ill and the dying, the World Medical Association's Declaration on Child Health, the report on palliative care publishedby the Council of Europe, the Code of Medical Ethics, the Charter of the Rights of the Terminally Ill Child at Home[135], and in the law on patient's rights and on Commissionaire for Patient's Rights. A group of experts from the Polish Pediatric Society published guidelines for physicians entitled "Cessation and withdrawal of futile medical care in children" where they recommend pain relief treatment to be used in pediatric palliative care. The need for pain relief in neonates undergoing palliative care has also been emphasized by the Polish Neonatal Society in its publication "Standards of medical care of neonate in Poland" where it has been considered a priority in treatment of such patients.

Pain in fetuses, premature neonates and full-term neonates

The opinion that newborns, premature neonates, or in particular, fetuses, do not feel pain or feel it less than more mature children, has been rejected in the light of the evidence. The first nociceptors emerge at 7 weeks of gestation in the mouth area, and by 20 weeks of gestation, they cover the whole skin of the fetus. The first synaptic connections between the sensory nerves and the neurons of the anterior horn of the spinal cord form at 7-8 weeks of gestation, and at 13-32 weeks the layered structure of the spinal cord and the interneuron connections develop. By 34 weeks of gestation approximately, the cerebral cortex becomes fully mature concerning sensory functions. Although the myelination of the thalamocortical nerve fibres ends no earlier than in the age of one year, it does not mean a slower transmission of pain stimuli to the brain. The reason is a smaller distance between the nodes of Ranvier, and a smaller distance that must be travelled by the pain stimuli, which is caused by the neonate's small size.

[133] University Hospital in Opole, Unit of Anesthesiology and Intensive Care for Children and Neonates.
[134] Medical University in Łódź, II Department of Pediatrics, Clinical Unit of Intensive Care and Anesthesiology, Children's Memorial Health Institute in Warsaw.
[135] Appendix 8

From the early stages of fetal development, neurotransmitters related to nociceptive transsmission come into existence in brain: at 8-10 weeks somatostatin and substance P, at 12-16 weeks – glutamine and met-enfkephalin, at 34 -38 weeks – dopamine and norepinephrine, and in the postinfant period – serotonin. The fact that the last three neurotransmitters form relatively late is probably caused by a delayed maturation of descending pain supression pathways. That means that the neonates have fully developed structures responsible for pain sensation, but they have not yet developed defence mechanisms against it.

In comparison with older children, the neonates are distinguished by a stronger hormonal and metabolic response to pain stimuli. Prolonged exposure to pain stimuli causes an increased release of nerve growth factor, and consequently, a nerve fibre overgrowth. The sensory neuronal system expands, and the fibres which in normal conditions do not take part in pain transmission are involved in that process. Consequently, the skin area close to the damaged tissue is over-represented in the central nervous system. This leads to hyperalgesia and the lowering of the pain threshold and its tolerance, as well as to the allodynia responding by a burning sensation or pain to a simple touch stimulus. Because the above mentioned pathological mechanisms, the newborns (the premature neonates in particular) and the fetuses have a heightened sensitivity to pain and require particular protection from it (2,3).

Treatment of pain in the prenatal period

Although it is difficult to delimit the gestational age at which pain management should be implemented, it certainly concerns the fetus starting from 20 weeks of gestation. Pain management is necessary in the case of fetal intrauterine and open surgery (such as vesicoamniotic shunting, tracheal balloon dilation, surgery of spina bifida). This also applies to pain related to bone fractures in fetuses with osteogenesis imperfecta.

Protection of fetus from pain during intrauterine or open fetal surgery should depend on the type of anesthesia applied to the pregnant woman. A more detailed discussion of this topic is beyond the present paper. Nonetheless, the authors want to emphasize the importance of the phenomenon of pain in an operated fetus. The options regarding the treatment of pain resulting from fetal broken bones are limited. Caesarean delivery should be considered, and in the case of a natural childbirth an opioid should be administered via umbilical vein or intramuscularly when the cervical opening expands wide enough.

Another issue is the anesthesia of fetuses subjected to abortion in the end of the second trimester of the pregnancy. The fact that the fetus is nonviable does not mean that it does not sense pain or other forms of suffering. In such cases, it is highly justified to apply pain treatment in the pregnant woman, which results in fetal analgesia (e.g. the administration of opioids).

Classification of pain

"WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses" contain a classification of pain based on its etiology, pathophysiology, duration and location. (4)

The etiological classification is based on the underlying disease accompanied by pain, e.g. cancer, post-injury or inflammatory pain. In perinatal palliative care, one must take into account the pain of diverse etiology.

The pathophysiological classification:

- nociceptive pain occurs when an injury activates nociceptors, in other words, receptors sensitive to chemicals released from the tissues in response to oxygen deficiency, damage, inflammation, heat, cold, vibrations, or stretching; it includes:
  - somatic pain regards either surface tissues (skin or mucosa) or deep structures, such as joints, bones, muscles, or connective tissue; an example of somatic pain is different kinds of procedural pain (e.g. resulting from intravenous cannulation or blood sampling) and the pain related to bone fractures in children with osteogenesis imperfecta;
  - visceral pain regards the internal thoracic and abdominal organs; it can occur due to inflammation, distension from fluid or gas, stretching or compression; the visceral pain is caused by different pathologies of internal organs (inflammatory or proliferative);
- neuropathic pain results from neuronal damage and dysfunction; it can be peripheral (due to peripheral nerve or dorsal root lesion or disease process) or central (due to central nervous system lesion or disease process); it is caused by spinal cord injuries related to congenital spina bifida, nerve injuries caused by tumor or abscess compression, or congenital degenerative neuropathies; the neuropathic pain is associated with diverse sensory dysfunctions, such as allodynia, hyperalgesia, paresthesia, hyperesthesia, or hypoesthesia;
- mixed pain – nociceptive pain coexisting with neuropathic pain; it may be caused by nerve or other tissue infiltration in the course of malignant or inflammatory process.

Classification based on pain duration:

- acute pain is of sudden onset, is felt immediately following noxious stimulus, is severe in intensity, but is usually short-lasting and generally disappears after noxious stimulus cessation; an example of acute pain is procedural pain;
- chronic pain is continuous or recurrent, e.g. the pain caused by solid tumour compression;
- episodic or recurrent pain occurs intermittently over a long period of time, and the child can be pain free between each painful episode; an example of episodic pain is pain accompanying successive bone fractures in children with osteogenesis imperfecta;
- breakthrough pain is characterized as a temporary increase in the severity of pain over and above the pre-existing baseline pain level;
- incident pain or pain due to movement has an identifiable cause, such as walking, coughing or urination;
- end-of-dose pain results when the blood level of the analgesic falls below the minimum effective level.

Classification based on pain location. Pain that may be superficial or deep, and may have different locations: in the periosteum, muscles, joints or inner organs.

Pain experienced by neonates provided with perinatal palliative care may have a diverse character as for its etiology, pathophysiology, duration, location or intensity. Chronic pain may be frequently faced, and since it results from an interaction of many different factors, it implicates a holistic approach to the child.

Pain assessment

In order to treat pain effectively, it is necessary to assess its intensity. The American Pain Society recognised pain as the fifth vital sign, and as such, it should be monitored (5). Pain assessment in neonates and infants is challenging due to the lack of verbal communication. Common pain indicators, such as motor agitation, continuous screaming, grimacing, tachycardia, or increased blood pressure, may either not occur or occur to a limited extent, depending on the general condition of the patient. Some of them may also be a consequence of anxiety resulting from other reasons, such as dyspnea. The assessment of pain intensity is essential in order to implement an appropriate treatment – on one hand, to avoid analgesics if they are not necessary, and on the other hand, to administer them if needed.

Behavioral and physiological scales

An effective method of pain assessment in neonates and infants is the use of scales based on pain-related behaviors and changes in vital signs. They have been elaborated mostly for assessment of postoperative pain and procedural pain (the pain related to performance of different medical procedures). Given the lack of an appropriate scale for pain assessment in neonates and terminally ill infants, the above mentioned scales may be useful and applicable with some limitations to those patients. The choice of a given scale may be dictated by preferences of the medical team, nonetheless it is recommendable to use relatively simple methods that may be also used by the patient's parents. The use of a given scale requires some experience. Therefore, one scale should be used consistently. The fact that the parents take part in pain assessment with the use of a given scale may not mean that they master it totally, but that they can more easily assess pain in their child at home.

There are different scales of pain assessment in neonates. In the view of the authors of the present paper the most useful ones are the following:

- Neonatal Facial Coding System (NFCS) – is based on the assessment of behavioral facial reactions (grimacing). It is applicable in neonates born after 25 weeks of gestation. Ten parameters are assessed [table 1]. Premature neonates may receive from 0 to 10 points, and the full-term neonates – from 0 to 9 points. Patient who receives 0-2 points usually does not need any analgesic treatment. Since this scale is based on the observation of the patient's face, its advantage is that it may be used for children held in their parents' arms (6).

Table 1. Neonatal Facial Coding System

Facial actions	Score	
	Does not occur	Occurs
Brow bulge	0	1
Eyes squeeze	0	1
Deepening of nasolabial furrow	0	1
Open lips	0	1
Vertical mouth stretch	0	1
Horizontal mouth stretch	0	1
Tongue teutening	0	1
Chin quiver	0	1
Lip purse	0	1
Tongue protrusion*	0	1

* Only in premature neonates; in the full-term neonates the tongue protrusion does not indicate pain.

- Neonatal Infant Pain Scale (NIPS) – is based on the assessment of behavioral reactions. It is applicable to the full-term and premature neonates born after 27 weeks of gestation. Six parameters are assessed [table 2]. Patient who receives 0-2 points usually does not need any analgesic treatment. If the score is between 3 and 4 points, non-pharmacological methods of analgesia are applied, and if the score is between 5 and 10 points, a pharmacological treatment is introduced (7).

Table 2. Neonatal Infant Pain Scale

Category	Score		
	0	1	2
Facial expression	Relaxed	Grimace	
Cry	No cry	Whimper	Vigorous crying
Breathing pattern	Relaxed	Change in breathing	
Arms	Relaxed	Flexed, extended	
Legs	Relaxed	Flexed, extended	
State of arousal	Sleeping or awake	Fussy	

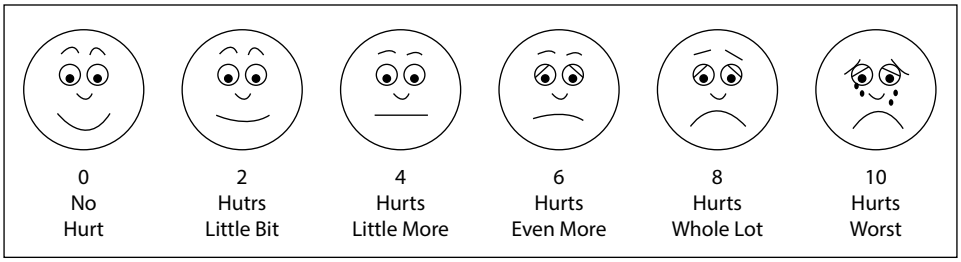
- Faces, Legs, Activity, Cry, and Consolability Scale (FLACC) – is based on the assessment of behavioral reactions. Five parameters are assessed [table 3]. A patient who receives between 0 and 3 points usually does not need any analgesic treatment. If the score is between 4 and 6 points, non-pharmacological methods of analgesia or non-opioid analgesics are applied, and if the score is between 7 and 10 points, opioids are used (8).

Table 3. Faces, Legs, Activity, Cry, and Consolability Scale (revised)

Category	Score		
	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested, sad, appears worried	Frequent to constant quivering chin, clenched jaw, distressed looking face, expression of fright/panic
Legs	Normal position or relaxed; usual tone and motion to limbs	Uneasy, restless, tense, occasional tremors	Kicking, or legs drawn up, marked increase in spasticity, constant tremors, jerking
Activity	Lying quietly, normal position, moves easily, regular, rhythmic respirations	Squirming, shifting back and forth, tense movements, mildly agitated, shallow/splinting respirations, intermittent sighs	Arched, rigid, or jerking, severe agitation, head banging, shivering, breath holding, gasping, severe splinting
Cry	No cry (awake or asleep)	Moans or whimpers, occasional complaints, occasional verbal outbursts, constant grunting	Crying steadily, screams or sobsl, frequent complaints, repeated outbursts, constant grunting
Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to: distractible	Difficult to console or comfort, pushing caregiver away, resisting care or comfort measures

- Wong – Baker faces pain rating scale [figure 1] – is based on the assessment of face expression; the rating scale ranges from a happy face at 0, or "no hurt", to a crying face at 10, or "hurts worst" (9).

Figure 1. Wong-Baker pain rating scale



Whichever scale is chosen, pain assessment must be done at regular intervals, and the results must be recorded.

Other methods of pain assessment

Very promising are the results of researches regarding pain assessment with the use of instrumental methods. Pain monitors have been used that measure the heart rate variability and the skin conductance variations. The former work without any contact with the patients, and take the data from a simple heart rate monitor, the latter require the use of special skin electrodes. The usefulness of such devices needs further analysis, but they may be helpful with pain assessment in patients provided with palliative care in hospitals, or they may complement the behavioral and physiological methods, or substitute them, if the patient's condition does not allow their use. They are also helpful in teaching parents how to assess their child's pain (10, 11).

Concerning neonates, methods based on the measurement of pain biomarkers, such as the concentration of cortisol, catecholamines, growth hormone, glucagon, insulin, or β-endorphins in blood, the concentration of cortisone in hair, the measurement of the pH of saliva and skin, the measurement of the skin conductance, or the bispectral EEG index monitoring, have still been in the stage of scientific research.

General principles of pain management in perinatal palliative care

In order to eliminate or to limit the suffering of patients provided with palliative care, different measures may be taken that aim at easing unpleasant sensations, in particular, pain. They consist, on one hand, in eliminating or considerably limiting iatrogenic causes of suffering, resulting from unnecessary blood tests or other unjustified diagnostic or curative procedures, and on the other hand, in using analgesic treatment, if the patient needs it. The optimal pain management for children requires a holistic approach combining the administration of different analgesics with non-pharmacological treatment. Non-pharmacological treatment is used for the management of mild or moderate pain, combined with the administration of non-opioid medications. In the management of severe pain, additionaly opioids are used (12).

Management of iatrogenic pain

The crucial point is to minimize painful diagnostic and curative procedures that relate to the patients disorder, patient's condition, and the scope of the treatment. In the case of terminally ill patients, the right approach is to give up any laboratory analysis, especially those related to the painful blood sampling. Patients who are candidates for palliative care, may be temporarily provided with a treatment that requires some tests. An example may be children with incurable diseases and a relatively long life expectancy, who are to be operated in order to improve their comfort (e.g. tracheotomy, gastrostomy). In such situations, intensive care methods are temporarily used, such as mechanical ventilation, and some tests are necessary. In neonates provided with perinatal palliative care, as well as in any patient provided with intensive care, the following rules have to be observed:

- Painful diagnostic procedures should be avoided or limited to absolutely necessary ones.
- Arterial or central venous lines should be used for blood sampling in patients undergoing intensive care.

- If possible, invasive procedures should be replaced by non-invasive ones (e.g. transcutaneous blood gas monitoring instead of arterial-blood gas test, or non-invasive bilirubin measurement instead of blood tests).
- Medical tests should be accumulated in order to decrease the frequency of painful procedures.

For neonates under palliative care, it is essential to formulate clear and precise rules and procedures to be implemented in the case of cardiac or respiratory arrests, in order to avoid futile medical care and the suffering of the patient (13).

Non-pharmacological methods of pain management

The efficacy and safety of non-pharmacological methods of analgesia described hereafter have been analyzed, mainly referring to the procedural pain. Nonetheless, these methods may also be used for the management of other kinds of pain in the neonates. They are usually sufficient to manage mild pain. They should also be taken into consideration if non-opioid and opioid analgesics are used.

Administration of oral sweet solutions

Many publications have pointed out the efficacy of oral administration of sweet solutions to neonates in order to alleviate pain. Orally administered sucrose or glucose have been proven to be an effective means to decrease pain in premature neonates and full-term neonates. The analgesic effects of sugar solutions may be based on the activation of mechanisms of pain suppression by influencing the structures located in the area of the periaqueductal gray and the raphe nuclei (14).

The dosage of sucrose is relatively flexible, but the most popular dose is 0.5 ml of a 24% solution administered orally (on the tongue or under it) two minutes before the painful procedure.

The oral administration of sweet solutions has become a routine procedure in hospital units taking care of the neonates. The lack of significant side effects has been emphasized, but some matters, such as the optimal dose, the route of administration, the possibility of repetitive doses, the interval between the dose and the painful procedure, the efficacy in extremely premature neonates, and the remote effects, still need to be addressed.

The oral administration of 0.5 ml of a 30% (or 20%) solution of glucose is also used.

The oral administration of sweet solutions is a simple method that can also be used by parents, which makes it recommendable for perinatal palliative care.

Other non-pharmacological methods of pain management

Apart from the administration of sweet solutions, there are other non-pharmacological methods of pain management, whose efficacy has been more or less proved. They are commonly used in hospital units and by parents at home, as a part of broadly understood care. They include breastfeeding and the oral administration of mother's milk, non-nutritive sucking (the use of pacifiers), skin-to-skin contact, mother's voice, hugging, wrapping, rocking,

music therapy, massage, mechanical vibration, or hydrotherapy. Parents should be included in these actions, which is beneficial for the neonate and for the mental state of the neonate's guardians who actively contribute to the child's comfort.

Pharmacological analgesia

The analgesia, or the pain management, mustn't be replaced by sedation or the reduction of agitation. These treatments have synergistic effect – effective pain management usually has a calming effect, and the sedation of the patient often supports the analgesic treatment and decreases analgesic demand. The level of analgesia depends on the degree of pain intensity. Perinatal palliative care takes into consideration the WHO guidelines on the pharmacological treatment of persisting pain in children (4):

- using a two-step strategy of the analgesic treatment (step-ladder treatment); the first step consists in using non-opioid analgesics, and the second step means the administration of opioids;
- dosing at regular intervals is advisable when administering analgesics because it is more effective than dosing on demand;
- using an appropriate route of administration and appropriate doses – it is recommended to choose the easiest, most effective and the least painful way of administration – oral administration is recommended, and if it is impossible, other routes are acceptable; intramuscular injections are to be avoided;
- treatment should be adjusted individually, depending on the patient's reaction, especially regarding the choice and the dosing of opioids.

Routes of administration

Route administration of analgesics has to be based on an analysis of individual situation of the patient, taking into consideration his or her location (hospital vs. home), the intensity of pain, and other health problems. On one hand, invasive methods of treatment, such as intravenous or subcutaneous administration of medications, are to be avoided, on the other hand, if other route of administration is impossible or ineffective, the use of those routes may be justified.

Oral and intragastric route

Oral administration of analgesics is optimal and preferable in the treatment of chronic pain in children because of its non-invasive character. It is usually effective and easy, it poses a relatively minor risk of complications, and it may be used at home. If swallowing difficulty occurs, the medications may be administered via an intragastric tube or gastrostomy. Nonetheless, it is important to note that in some situations (such as anomalies of the gastrointestinal tract) the absorption of medications from the gastrointestinal tract may be significantly disturbed. That also concerns patients in terminal condition, especially if big doses of opioids are administered.

Rectal route is a good alternative for the oral route both for non-opioid analgesics and for morphine. However, it is important to take into consideration the constraints resulting from a variable bioavailability of the medications administered in this way in children.

Subcutaneous route may be used to administer morphine, especially if the enteral administration is impossible or ineffective.

Intravenous route of administration in palliative care is dedicated to patients staying in hospital, and it is used exceptionally, if another way of providing an effective analgesia is impossible.

Intranasal route
As for opioids, the intranasal route of administration may be an alternative to the intragastric route. Such a method may be used in the labor room, for extremely premature neonates or neonates with a lethal anomaly, if the do-not-resuscitate decision has been taken and palliative care is to be implemented.

Intramuscular route should not be used in perinatal palliative care because of the pain accompanying the administration of the medication.

Oral mucosal route happens to be used to administer opioids if the intragastric administration is impossible or ineffective. However, it is not recommendable due to the limited absorption of the medication, and a good alternative, which is the intranasal route.

Off-label use
Pain management is the priority in perinatal palliative care. Therefore, it is acceptable to overlook registered medical indications and to administer analgesics in an off-label manner if needed. That means the administration of a drug registered for patients from other age groups, the use of another route of administration, or the administration of a dose that may be higher than the one recommended in the description of the medical product. An example may be the administration of opioids which have no limitations in dosage, or the use of a so-called palliative sedation.

Non-opioid analgesics
The medicines of this group are used to manage pain of mild or moderate intensity, and they are combined with non-pharmacological methods. The WHO recommends to use paracetamol in children below 3 months old, older children should receive paracetamol or ibuprofen.

Acetaminophen (paracetamol) is a non-opioid analgesic of choice in children below 3 months old however, some aspects of its administration to neonates and infants require further research (4, 15). Paracetamol has a central analgesic effect, and consists in the inhibition of prostaglandin synthesis or through influencing cannabinoid receptors. The route of administration may be oral or intragastric (tablets, syrup), rectal, and intravenous. The medicine is well absorbed from the gastrointestinal tract. The time between the administration and the maximum plasma concentration depends on the form of the drug, the stomach contents, and the type of pathology. In neonates and infants that time is longer than in adults, and it amounts to 1.5 – 2 hours, if the medicine is administered orally, and to 1-2 hours if it is administered via gastric tube. The medicine absorption is slower in premature neonates. For rectal administration the absorption is slower and variable. The plasma half-life depends on patient's maturity – in premature neonates it amounts to 5-11 hours, and in full-term neonates and infants – less than 2 hours (16).

Paracetamol has relatively few side effects. The most important one is hepatotoxicity related mainly to overdose or long-term administration of high doses. Different dosage protocols are possible. The dosage that the authors of this paper find recommendable is the one presented in the table 4.

Table 4. Dosing of acetaminophen (paracetamol) in neonates and and infants depending on their maturity

Postconceptional age	Administration route	Introductory dose (mg/kg bw)	Maintenance dose (mg/kg bw)	Administration interval (hours)
28–32 weeks	Oral	20	10–15	8–12
	Rectal	20	15	12
	Intravenous	–	–	–
32–52 weeks	Oral	20	10–15	6–8
	Rectal	30	20	8
	Intravenous	7.5	7.5	8
> 3 months	Oral	20	15	4
	Rectal	40	20	6
	Intravenous	10	10	6

Non-steroidal anti-inflammatory drugs

Among the non-steroidal anti-inflammatory, antipyretic and analgesic medicines the one used in children over 3 months old is ibuprofen. Its dosage is shown in the table 5.

In some centers, metamizole is administered (3 x 10-15 mg per kg bw), in children, in off-label manner. Since ibuprofen and metamizole do not prevail over paracetamol as for analgesic effectiveness, and they entail risk of significant adverse reactions, their usefulness in perinatal palliative care is limited.

Table 5. Dosing of ibuprofen in infants and toddlers

Administration route	Child's age/weight/dose		
Oral	3–6 months (5–7.6 kg)	6–12 months (7.7–9 kg)	1–3 years (10–15 kg)
	3 x 50 mg	3–4 x 50 mg	3 x 100 mg
Rectal	3–9 months (6–8 kg)		9–24 months (8–12 kg)
	3 x 60 mg		4 x 60 mg

Opioids

Opioids are used for severe pain management, usually combined with non-opioid analgesics and non-pharmacological methods. The medicine recommended for all age groups is morphine. Another medicine used may be fentanyl. Methadone has gained more and more recognition. The use of other opioids in perinatal palliative care is not justified.

The administration of opioids entails numerous **adverse reactions**. Most notably:

- respiratory depression – in small doses, opioids decrease the respiratory rate, in large doses, they also decrease respiratory volume; a quick administration of a loading dose causes muscle stiffness and chest wall rigidity;

- circulatory depression – bradycardia and decrease of blood pressure caused by the decrease in sympathetic nervous system activity;
- inhibition of intestinal motility, higher pressure in pyloric sphincter, sphincter of Oddi and ileocecal valve, nausea, and vomiting;
- urinary retention;
- itchy skin;
- pupil constriction (miosis) and other adverse reactions with a minor significance.

The presence of side effects in the administration of opioids is directly proportional to dosing. It is also individually variable.

Opioid administration eventually leads to analgesic **tolerance**, as well as a tolerance to side effects is developed. It does not uniquely concern miosis or effects on the digestive tract. That means that in a long-term opioid administration an effective analgesia requires permanent increasing of the dose, and the notion of maximum dose is not applicable. With increased doses of opioids the risk of respiratory or circulatory complications does not increase considerably. In contrast, from the clinical point of view, an important factor is the digestive tract disfunction, especially persistent and refractory constipation, which may make oral administration of analgesics challenging.

Morphine is the most commonly used opioid in palliative treatment [table 6]. It may be administered by different routes. In palliative care, oral or intragastric routes of administration are most commonly used; sometimes a subcutaneous route is used. However, in newborns, and premature neonates in particular, it may be necessary to use the intravenous route due to the immaturity of their digestive tract and intolerance of morphine administered by another route. A biochemical stability and a microbiological safety were proved successful for oral morphine solutions dedicated to parenteral administration (17). In subcutaneous administration, it is recommended to use very thin cannulas (such as PVC), and to change the injection site every 3 days.

Fentanyl. In palliative care, fentanyl does not prevail over morphine for analgesic effect or the number of side effects. It is considered slightly less safe. Its usefulness in perinatal palliative care results from the possibility of using intranasal administration route, which may be particularly important in patients in whom the oral or intragastric administration is impossible or ineffective. The products dedicated to being administered by intranasal route dose the medicine in portions appropriate to adults, but in neonates and infants, the fentanyl drops may be instilled on the nasal mucus. The drops are made by diluting an intravenous product in normal saline, and the concentration of the solution must be calibrated to the volume of the dose to be applied which cannot be more than 0.3 ml [table 6] (18).

Methadone is most commonly used for alleviating symptoms related to opioid withdrawal, and for the same reason it is applied to neonates. It is also more and more widely used in palliative care (19). It may have the form of syrup. In Poland, the intravenous form is not available [table 6].

Tramadol, due to its analgesic mechanism considered as "verging" opioid, may be taken into consideration in palliative care, which is also pointed out in the WHO guidelines (4).

In neonates, its analgesic effectiveness was proven to be close to fentanyl (20). It is available in different formulations, including drops [table 6].

Table 6. Dosing of opioids (suggested by the authors of the present section)

Opioid	Oral, intragastric, oral and intranasal mucosal routs	Rectal route	Intravenous route	
			Loading and fractionated dose	Continuous infusion
Morphine	0.15-0.3 mg/kg bw every 4 hours		0.05-0.1 mg/kg bw every 2-4 hours	0.01-0.04 mg/kg bw/h
Fentanyl	1-2 µg/kg bw intranasal		0.5-2 µg/kg bw every 1-2 hours	0.5-2 µg/kg bw/h
Methadone	0.2 mg/kg bw every 4-8 hours*		Unavailable in Poland	Unavailable in Poland
Tramadol	1-2 mg/kg bw every 4-6 hours**	1-3 mg/kgbw every 6 hours***	1-2 mg/kg bw every 6 hours**	0.2-0.3 mg/kg bw/h**

* in children – off-label administration

** < 12 months of age – off-label administration

*** no original form to be administered to neonates and infants

Palliative sedation

Palliative sedation consists of inducing a pharmacological state of decreased or absent consciousness until death, to a patient suffering unnecessarily. Like analgesia, it may also cause side effects or, in some cases, it may even hasten patient's death. Nonetheless, in certain circumstances, it is medically and ethically justified, especially in the youngest children, if their dying process is accompanied by unacceptable discomfort, pain or anxiety that cannot be managed by other methods. What matters is the physician's intention. His objective is to offer relief to the dying child, and not to hasten the child's death or to increase the comfort of the child's guardians or that of the medical personnel. An example of a justified palliative sedation in perinatal palliative care is gasping of a terminally ill neonate.

The ethical dimension of palliative sedation is appropriately demonstrated in the following definition of the principle of double effect. If doing something morally good has a morally bad side-effect, it is ethically acceptable to do it providing the bad side-effect was not intended. The ethical judgment does not change even then, the bad effect can be predicted. (21)

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The Minister of Health may by regulation set the standards of medical procedures in selected areas of medicine or regarding selected healthcare providers, in order to guarantee a proper quality of healthcare services (Article 22 par. 5 of the law from 15 April 2011 on healthcare activity; OJ, 19 January 2018, 160)

The present publication is dedicated to the Minister of Health. Our objective is to convince that "a proper quality of healthcare services" in perinatal and home hospices for children in Poland is necessary and must be provided.

Why?

Perinatal and pediatric palliative care are new areas of perinatology and pediatrics. They are still marginalized, and consequently devoid of a proper specialist supervision. Such supervision requires prior standardization and methodology of evaluation of the quality of services.

The present situation resulting from the current Regulation of the Minister of Health raises serious doubts whether perinatal and pediatric palliative care is not confused with paramedical activities.

The fact that the abovementioned areas are mainly specialty of NGOs should not hamper the introduction of regulations aiming at raising them to the rank of professional medicine.

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