

Palliative nursing care of children and young people across Europe

Summary of key findings

The Paediatric Nursing Associations of Europe Network (PNAE) conducted a survey throughout 2016 to identify the current situation in respect of palliative and end of life care for children and young people across Europe, and to identify good practice. The “IMPACT: standards for paediatric palliative care in Europe”¹ acted as the basis for the survey.

The aim is to establish good practice recommendations to underpin the palliative nursing care of children and young people in all health care settings.

We believe that every child and young person has the right to expect good palliative care to be provided whether it is in a hospital setting or in a home environment. All children and young people with life-limiting and terminal illness should receive the care they need.

This document is a summary of the findings.

Armenia

Information not provided

Austria

Organisation of services

In Austria there are no national guidelines concerning paediatric palliative care. There is an 'Expert-concept "Hospice- and palliative care' for children and young people in Austria. The WHO definition of paediatric palliative care as adopted by IMPACT¹ is used.

There are no written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT)¹.

Austria follows the core standards in the provision of paediatric palliative care as outlined in IMPACT¹. The elements of care implemented in Austria include:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

There are paediatric palliative care teams in Austria as described in IMPACT¹:

- The care team recognises the individuality of each child and family and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm.
- The palliative care team has sufficient expertise to address the physical, psychological, emotional, spiritual and social needs of the family.

¹ IMPACT: standards for paediatric palliative care in Europe. European Journal of Palliative care 2007; 14(3): 109-114
(also available from <http://www.eapcnet.eu/LinkClick.aspx?fileticket=ShMQyZuTfqU%3D>, last searched for 26th April 2016)

- The skills and services provided include a physician, nurse, social worker, child therapist or psychologist and a spiritual adviser.
- Professional resources from the child's own community are utilised if appropriate.
- The care team ensures continuity of care at home, in the hospital and in a hospice through planning, sharing strategies and objectives.
- The direct caretakers provide psychosocial support and supervision.

One professional from the paediatric palliative care team is identified as the family's care coordinator or key worker. Nurses that provide paediatric palliative care for ill children are paediatric nurses. The nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) do not have specialised qualifications.

Paediatric palliative care management

IMPACT¹ describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. In Austria:

- there are written guidelines on pain and symptom management as described in IMPACT¹
- the symptoms of every child are recognised and assessed as described in IMPACT¹
- there are protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort

Ethical and legal rights of children in paediatric palliative care

Every child in Austria has equal access to paediatric palliative care. The Government does not fund paediatric palliative care services including all care and equipment needs. In some provinces of Austria the service is funded by Gesundheitsfonds (=province fund paediatric palliative care service) but it is not the same in every province of Austria. A lot of money is funded by charitable donation. Paediatric palliative care is not evaluated to see if the care is in the best interest of the child. For example in Styria there is no structured evaluation of the service itself, only case- based internal evaluation of the team members itself and consultation with ethics-committee if necessary.

IMPACT¹ also describes standards for communication and decision making. In Austria there is no structured written standard for communication and decision making. For example in Styria all basic principles described in IMPACT are followed but there is no written process described and no structured evaluation of communication and decision making. There are no written standards. Evaluation is case based and follows internal rules.

There is no structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPACT¹ All basic principles described in IMPACT are followed but there is no written process or structured programme.

Paediatric palliative care in Austria does not meet all the written standards of IMPACT¹

Belgium

Organisation of services

In Belgium there are no national guidelines concerning paediatric palliative care (PPC). Since 2015 a new group was established – Belgian Paediatric Palliative Care group (BPPC group). The members of this group are working on 5 national guidelines concerning Paediatric Palliative Care. These will hopefully be completed by the end of 2017.

The WHO definition of paediatric palliative care—as adopted by IMPaCCT¹ is used. The definitions used in the IMPaCCT study will also be included in the guidelines.

There are written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT)¹.

Belgium follows the core standards in the provision of paediatric palliative care as outlined in IMPaCCT¹. The elements of care implemented in Belgium include:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship
- A full range of clinical and educational resources are available for the child and family, in a format that is appropriate to age, cognitive and educational ability and within a suitable cultural context.
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

There are paediatric palliative care teams in Belgium as described in IMPaCCT¹:

- The care team recognises the individuality of each child and family and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm
- The palliative care team has sufficient expertise to address the physical, psychological, emotional, spiritual and social needs of the family.
- The skills and services provided include a physician, nurse, social worker, child therapist or psychologist (*all in the Team apart from a spiritual adviser*)
- Professional resources from the child's own community are utilised if appropriate.
- Expert paediatric palliative care support and advice are available to the child and family 24 hours a day, 365 days a year.
- The care team ensures continuity of care at home, in the hospital and in a hospice through planning, sharing strategies and objectives.
- The direct caretakers provide psychosocial support and supervision.

There are five Palliative Care liaison teams: the team includes a physician, nurses, social worker and psychologist. There is no spiritual adviser foreseen, but if necessary such expertise is sought. The teams are connected with a University Hospital. They rely on and work together with the referring multidisciplinary team within the hospital.

One professional from the paediatric palliative care team is identified as the family's care co-ordinator or key worker, although not foreseen in every team at this point.

Not all nurses that provide paediatric palliative care for ill children are paediatric nurses². : It is a mix of paediatric nurses and other nurses with other specialisations (oncology) but mostly with experience in paediatric nursing. In Belgium there is no specialised course for PPC but (adapted) education on national and international level.

Paediatric palliative care management

IMPaCCT¹ describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. In Belgium:

- the symptoms of every child are recognised and assessed as described in IMPaCCT¹

There are no written guidelines on pain and symptom management as described in IMPaCCT¹ or protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of

² http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

comfort – work is in progress in BPPC group. In the meantime international and local guidelines are used.

Ethical and legal rights of children in paediatric palliative care

Every child in Belgium has equal access to paediatric palliative care. In Belgium the government does not fund paediatric palliative care services including all care and equipment needs. The PPC team have been working for 20 years on fundraising. Since 2010 2/3rds of the operating costs are funded by the government and 1/3rd from fundraising.

Paediatric palliative care is evaluated to see if the care is in the best interest of the child through local initiatives such as a satisfaction survey.

IMPACT¹ also describes standards for communication and decision making. In Austria there is a structured written standard for communication and decision making which includes:

- An honest and open approach is the basis of all communication and is sensitive and appropriate to the child's age and understanding.
- Parents are acknowledged as the primary caretakers and are centrally involved in the care and decisions involving their own child. Information is provided for the parents, for the child and for the siblings according to age and understanding. The needs of other relatives are also addressed. Every child is given the opportunity to participate in decisions effecting his or her care, according to age and understanding.
- Situations posing a high risk of conflict are anticipated and procedures for early communication, therapeutic interventions or ethics consultation are established.
- Every family is given the opportunity of consultation with a paediatric specialist who has particular knowledge of the child's condition, including the treatment and care options available.

There is no structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPACT.

Paediatric palliative care in Belgium does not meet all the written standards of IMPACT¹

Paediatric palliative care (PPC), and in particular transmural homecare, has been organised since 1990 in Flanders, later on in Brussels and Wallonia. Since the recognition of PPC by the government in 2010, a lot of work has been in progress to professionalise the care, to visualise and make recognisable the care, to reach as much children. With the establishment of the BPPC group it is our goal to come to written guidelines, to spread standards of care, to educate and to inform widespread on each level of care.

Croatia

There are no national guidelines in Croatia or declarations related to IMPACT minimum standards. The IMPACT minimum standards highlights that there is a need for development of palliative care for children in The Republic of Croatia. Collaboration is necessary between the Ministry of Health, Ministry of Social Policy and Youth, the Croatian Institute for Health Insurance, the community of local government, city government, churches and associations to ensure consistency of standards across Croatia.

It is necessary to ensure that the principles of palliative care engage in any hospital / pediatric medical institution (liberalization child visits from family and friends, fewer and less invasiveness of diagnostic and therapeutic procedures, oral therapy, pain control). The development of palliative care for children should go through the development of day hospitals in the place of residence of a sick child, and the provision of palliative care in the home of a child using multidisciplinary mobile teams.

It takes an organized network of providers of palliative care specially trained to work with children, and training volunteers in children's palliative care and its legal definition. The adoption of the Zagreb Declaration on palliative care for children will facilitate its implementation across the entire Croatia. Since the end of the year ends the Strategic Plan for the development of palliative care in Croatia 2014-2016 and implementation of palliative care in the health system (Zagreb Declaration on palliative care for children. – listopad 2016 g).

The needs of children and families who are living with the deadly and potentially deadly diseases are similar throughout Europe. Meeting these needs requires a comprehensive integrative approach to professional multidisciplinary team. We hope that in a very short time after the declaration is made the whole process of the realization of pediatric palliative care in Croatia is to be implemented. The Pediatric Society Croatian Nurses Association would be happy to include in the implementation if we are invited and recognized as important actors.

Cyprus

Information not provided

Czech Republic

Organisation of services

There are no national guidelines concerning paediatric palliative care in the Czech Republic. The WHO definition of paediatric palliative care-as adopted by IMPaCCT¹ is not used.

There are no written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT)¹.

The Czech Republic does not follow the core standards in the provision of paediatric palliative care as outlined in IMPaCCT¹.

There are paediatric palliative care teams in the Czech Republic as described in IMPaCCT¹ (although there are only 2 teams):

- The care team recognises the individuality of each child and family and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm
- The palliative care team has sufficient expertise to address the physical, psychological, emotional, spiritual and social needs of the family
- The skills and services provided include a physician, nurse, social worker, child therapist or psychologist and a spiritual adviser
- Professional resources from the child's own community are utilised if appropriate
- Expert paediatric palliative care support and advice are available to the child and family 24 hours a day, 365 days a year

One professional from the paediatric palliative care team is identified as the family's care co-ordinator or key worker.

Nurses that provide paediatric palliative care for ill children are *paediatric nurses*³. Nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) have specialised qualifications (no detail of specialised qualifications provided).

³ http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

Paediatric palliative care management

There are no written guidelines on pain and symptom management as described in IMPaCCT. Symptoms of every child are recognised and assessed as described in IMPaCCT. There are no protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort.

Ethical and legal rights of children in paediatric palliative care

Every child in the Czech Republic does not have equal access to paediatric palliative care. Currently, there are only two teams provide multidisciplinary specialised paediatric palliative care in the Czech Republic.

The government does not fund paediatric palliative care services including all care and equipment needs.

Paediatric palliative care is not evaluated to see if the care is in the best interest of the child.

IMPaCCT describes standards for communication and decision making. In the Czech Republic there is not a structured written standard for communication and decision making. There is not a formal required procedure for this used at national level, so it depends on the organizational culture in particular services.

In the Czech Republic there is no structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPaCCT.

Paediatric palliative care in the Czech Republic does not meet all the written standards of IMPaCCT

In 2016, a working group on pediatric palliative care was established as part of Czech Society for Palliative Medicine. This group is currently very active in developing the field in our country, organizing conferences and well-accepted meetings with different stakeholders and health service providers so I think we can expect a rapid improvements in some aspects (e.g. national guidelines). Of course, workforce and provision of care will remain an issue for some time.

Denmark

Organisation of services

In Denmark there are national guidelines concerning paediatric palliative care but only in paediatric oncology. The WHO definition of paediatric palliative care-as adopted by IMPaCCT¹ is used.

There are no written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT)¹.

Denmark does follow the core standards in the provision of paediatric palliative care as outlined in IMPaCCT¹. In spring 2016 a paediatric palliative care team in all 5 regions in Denmark was established and work commenced on core standards as recommended in IMPaCCT. The elements of care implemented in Denmark include:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship

- A full range of clinical and educational resources are available for the child and family, in a format that is appropriate to age, cognitive and educational ability and within a suitable cultural context.
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

There are paediatric palliative care teams in Denmark as described in IMPaCCT¹:

- The care team recognises the individuality of each child and family and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm.
- The palliative care team has sufficient expertise to address the physical, psychological, emotional, spiritual and social needs of the family.
- The skills and services provided include a physician, nurse, social worker, child therapist or psychologist and a spiritual adviser.
- Professional resources from the child's own community are utilised if appropriate.
- The care team ensures continuity of care at home, in the hospital and in a hospice through planning, sharing strategies and objectives.
- The direct caretakers provide psychosocial support and supervision.

Every paediatric palliative care team provide this in different ways. There isn't a masterplan for providing and implementing across Denmark. One professional from the paediatric palliative care team is not identified as the family's care co-ordinator or key worker.

Nurses that provide paediatric palliative care for ill children are *paediatric nurses*⁴. The nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) do not have specialised qualifications.

Paediatric palliative care management

IMPaCCT¹ describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. In Denmark:

- There are written guidelines on pain management as described in IMPaCCT but not symptom management.
- The symptoms of every child are recognised and assessed as described in IMPaCCT. The paediatric palliative care teams are quite newly-established, and are developing working with symptom management from general level to specialised level.

Ethical and legal rights of children in paediatric palliative care

Every child in Denmark has equal access to paediatric palliative care. The government funds paediatric palliative care services including all care and equipment needs. Paediatric palliative care is not evaluated to see if the care is in the best interest of the child. The government fund all the 5 new-established regional paediatric palliative care teams, but they have not made plans for evaluation.

IMPaCCT also describes standards for communication and decision making. There is no structured written standard for communication and decision making in Denmark. There is no structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPaCCT. There is no masterplan for any programme or goals in paediatric palliative care. It's up to the regions themselves to do what they think is best.

Paediatric palliative care in Denmark does not meet all the written standards of IMPaCCT¹.

⁴ http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

The people working in the paediatric palliative care teams in the 5 regions are using the written standards of IMPaCCT as a goal for the development of paediatric palliative care in Denmark

Estonia

Information not provided

Finland

In Finland there are no guidelines concerning pediatric palliative care. In Helsinki University Hospital a palliative care group -doctors, nurses, social worker, etc. has been established and a guide book written for children's palliative care. The plan is to educate all hospital workers. Many hospitals in Finland have similar a situation and their own guidelines.

There are some kind of guidelines concerning palliative care in Finland but not separately for children.

France

Information not provided

Germany

Organisation of services

There are national guidelines concerning paediatric palliative care. The IMPaCCT recommendations are widely accepted. Further legislative / regulative documents are

- Law on Palliative Care in Germany (December 2015) for people of all ages (*Hospiz- und Palliativgesetz*)
- Recommendations for specialized ambulatory palliative care of CYP (2013) by Central Organisation of Health Insurances (*Empfehlungen zur Ausgestaltung der Versorgungskonzeption der Spezialisierten ambulanten Palliativversorgung (SAPV) von Kindern und Jugendlichen*)
- Directive of the Federal Joint Committee on specialized ambulatory palliative care (2010) for people of all ages (*Richtlinie des Gemeinsamen Bundesausschusses zur Verordnung von spezialisierter ambulanter Palliativversorgung SAPV-RL*)
- Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (AWMF) Guideline: Psychosocial Care in Paediatric Oncology and Hämatology (2013)

The WHO definition of paediatric palliative care-as adopted by IMPaCCT is used.

No national written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT) have been published so far.

Germany follows the core standards in the provision of paediatric palliative care as outlined in IMPaCCT, although the standards may not (yet) be available in every region of the country. The elements of care implemented in Germany include:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship

- A full range of clinical and educational resources are available for the child and family, in a format that is appropriate to age, cognitive and educational ability and within a suitable cultural context.
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

There are paediatric palliative care teams in Germany as described in IMPaCCT¹:

- The care team recognises the individuality of each child and family and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm.
- The palliative care team has sufficient expertise to address the physical, psychological, emotional, spiritual and social needs of the family.
- The skills and services provided include a physician, nurse, social worker, child therapist or psychologist and a spiritual adviser.
- Professional resources from the child's own community are utilised if appropriate.
- Expert paediatric palliative care support and advice are available to the child and family 24 hours a day, 365 days a year.
- The care team ensures continuity of care at home, in the hospital and in a hospice through planning, sharing strategies and objectives.
- The direct caretakers provide psychosocial support and supervision.

Some teams may lack the inclusion of a social worker or a spiritual adviser and then contact these resources externally.

One professional from the paediatric palliative care team is identified as the family's care coordinator or key worker. Nurses that provide paediatric palliative care for ill children are *paediatric nurses*⁵. Nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) are required to have specialised qualifications in order to be accepted for work in specialised paediatric care at home..

Paediatric palliative care management

IMPaCCT describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. There are written guidelines on pain and symptom management as described in IMPaCCT. The symptoms of every child is recognised and assessed as described in IMPaCCT. There are protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort. There is an overall national expert standard on pain management for people of all ages (*Expertenstandard Schmerzmanagement*). There is a textbook on paediatric palliative care and paediatric pain management that is widely accepted as a guideline. When the child has – due to regional lack of structures - no access to specialised care, the IMPaCCT recommendations may not be followed.

Ethical and legal rights of children in paediatric palliative care

Every child in Germany has equal access to paediatric palliative care. The health insurances cover the requirements for paediatric palliative care services including all care and equipment needs.

Paediatric palliative care is evaluated to see if the care is in the best interest of the child. External evaluation is rarely established. Every team is required to evaluate these items internally. There is an evaluation of the implementation of the Directive of the Federal Joint

⁵ http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

Committee on specialized ambulatory palliative care. The focus is mostly on structural aspects and how the directive can and must be improved.

IMPACT also describes standards for communication and decision making. There is a structured written standard for communication and decision making as part of the AWMF Guideline on Psychosocial Care in Paediatric Oncology and Hämatology in Germany. The standard includes

- An honest and open approach is the basis of all communication and is sensitive and appropriate to the child's age and understanding.
- Parents are acknowledged as the primary caretakers and are centrally involved in the care and decisions involving their own child.
- Information is provided for the parents, for the child and for the siblings according to age and understanding. The needs of other relatives are also addressed.

There is no structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPACT. Every child with a life-threatening condition and the need for palliative care has by law the right to receive this specialized care. But due to lack of special structures, counselling and skilled personnel it may be the case, that in individual cases not all goals can be reached.

Paediatric palliative care in Germany does not meet all the written standards of IMPACT. Although there exist regional networks and also in the German Association for Palliative Medicine in future a better networking is preferable for all participants in paediatric palliative care.

Greece

Organisation of services

In Greece there are no national guidelines concerning paediatric palliative care. Every hospital (or medical ward) e.g. pediatric oncology ward, has its own strategy concerning palliative care for children and teens according to the "golden standard" that the young patient should not suffer from pain. However, there is a non-profit organization, called "Merimna" that was founded in 1995 by nine professionals comprised of university professors, pediatric hospital directors, mental health professionals and a clergyman who wanted to create something effective and well organized in Greece for children whose lives have been overturned by a life threatening illness or the death of a loved one (<http://www.merimna.org.gr/en>). Merimna's mission statement includes:

- To provide quality care services, without charge, that will meet the needs of children and families who either live with a life threatening illness or are grieving the loss of a loved one.
- To cultivate a supportive community through the sensitization of the general public as well as to offer specialized education and training to professionals in existing services that work with children and their families. Thus, every referral to the paediatric palliative care means the services provided by "Merimna".

The WHO definition of paediatric palliative care-as adopted by IMPACT¹ is used. In paediatric hospitals the assessment of pain is usually done empirically by the physicians, without the use of a pain scale. Pain relief is performed by the physicians according to WHO analgesic ladder. Nurses always perform doctors' instructions for pain relief and palliative care as well.

There are no written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT)¹.

Greece follows the core standards in the provision of paediatric palliative care as outlined in IMPaCCT¹. The elements of care implemented in Greece include:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

There are paediatric palliative care teams in Greece as described in IMPaCCT¹:

- The care team recognises the individuality of each child and family and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm.
- The palliative care team has sufficient expertise to address the physical, psychological, emotional, spiritual and social needs of the family.
- The skills and services provided include a physician, nurse, social worker, child therapist or psychologist and a spiritual adviser.
- Expert paediatric palliative care support and advice are available to the child and family 24 hours a day, 365 days a year.
- The care team ensures continuity of care at home, in the hospital and in a hospice through planning, sharing strategies and objectives.
- The direct caretakers provide psychosocial support and supervision.

One professional from the paediatric palliative care team is identified as the family's care co-ordinator or key worker. Nurses that provide paediatric palliative care for ill children are not *paediatric nurses*⁶. The nurses of "Merimna" that provide paediatric palliative care have been awarded MSc in paediatric nursing. The nurses of the paediatric hospitals are all paediatric nurses. Nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) do not have specialised qualifications.

Paediatric palliative care management

IMPaCCT describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. In Greece there are no written guidelines on pain and symptom management as described in IMPaCCT. The symptoms of every child are recognised and assessed as described in IMPaCCT. There are protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort.

Ethical and legal rights of children in paediatric palliative care

Every child in Greece has equal access to paediatric palliative care. The government funds paediatric palliative care services including all care and equipment needs. The funding of "Merimna" is done by donations or by sponsors. Moreover, everyone who wants to be a volunteer can join "Merimna's" services. Paediatric palliative care is not evaluated to see if the care is in the best interest of the child.

IMPaCCT describes standards for communication and decision making. There is no structured written standard for communication and decision making. Doctors on paediatric wards evaluate communication and decision-making.

There is a structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPaCCT.

⁶ http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

Paediatric palliative care in Greece does not meet all the written standards of IMPaCCT¹

Hungary

Information not provided

Iceland

Information not provided

Ireland

Information not provided

Italy

Information not provided

Lithuania

Information not provided

Luxemburg

Information not provided

Malta

Information not provided

Netherlands

Organisation of services

There are national guidelines concerning paediatric palliative care which were set up and authorised in 2013. The WHO definition of paediatric palliative care - as adopted by IMPaCCT is used - both definitions of WHO are used. One is the WHO definition on Palliative care from 2002 and the second one is the WHO definition on Palliative care for children in 1998.

There are written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT) contained within the national guideline.

The Netherlands follows the core standards in the provision of paediatric palliative care as outlined in IMPaCCT¹. The elements of care implemented in Netherlands include:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship

- A full range of clinical and educational resources are available for the child and family, in a format that is appropriate to age, cognitive and educational ability and within a suitable cultural context.
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

There are paediatric palliative care teams as described in IMPaCCT:

- The care team recognises the individuality of each child and family and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm.
- The palliative care team has sufficient expertise to address the physical, psychological, emotional, spiritual and social needs of the family.
- The skills and services provided include a physician, nurse, social worker, child therapist or psychologist and a spiritual adviser.
- Professional resources from the child's own community are utilised if appropriate.
- Expert paediatric palliative care support and advice are available to the child and family 24 hours a day, 365 days a year.
- The care team ensures continuity of care at home, in the hospital and in a hospice through planning, sharing strategies and objectives.
- The direct caretakers provide psychosocial support and supervision.

One professional from the paediatric palliative care team is identified as the family's care co-ordinator or key worker. Nurses that provide paediatric palliative care for ill children are *paediatric nurses*⁷. Nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) have specialised qualifications.

Paediatric palliative care management

IMPaCCT describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. There are written guidelines on pain and symptom management as described in IMPaCCT. The symptoms of every child is recognised and assessed as described in IMPaCCT. There are protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort.

Ethical and legal rights of children in paediatric palliative care

Every child in the Netherlands has equal access to paediatric palliative care. The government funds paediatric palliative care services including all care and equipment needs. Paediatric palliative care is evaluated to see if the care is in the best interest of the child. While the evaluation criteria are written in the national guideline it is unclear if everyone follows the guidelines to the max. The palliative care team together with the patient and the parents evaluate the care.

IMPaCCT describes standards for communication and decision making. There is a structured written standard for communication and decision making:

- An honest and open approach is the basis of all communication and is sensitive and appropriate to the child's age and understanding.
- Parents are acknowledged as the primary caretakers and are centrally involved in the care and decisions involving their own child.
- Information is provided for the parents, for the child and for the siblings according to age and understanding. The needs of other relatives are also addressed.

⁷ http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

- Every child is given the opportunity to participate in decisions effecting his or her care, according to age and understanding.
- Situations posing a high risk of conflict are anticipated and procedures for early communication, therapeutic interventions or ethics consultation are established.
- Every family is given the opportunity of consultation with a paediatric specialist who has particular knowledge of the child's condition, including the treatment and care options available.

There is a structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPaCCT.

The paediatric palliative care in the Netherlands meets all the written standards of IMPaCCT.

Norway

Organisation of services

In Norway there are national paediatric palliative care guidelines. The guidelines were finalised in March 2016. There is a lot of work to be undertaken to ensure the guidelines are implemented in practice. No money was identified to support implementation.

The WHO definition of paediatric palliative care—as adopted by IMPaCCT underpinned the guidelines in Norway. There is however no guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT). The process has just started, ensuring that palliation is understood. Future work is to develop practical instructions for practitioners.

Norway does not follow core standards in the provision of paediatric palliative care. The elements of care implemented in Norway include:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship
- A full range of clinical and educational resources are available for the child and family, in a format that is appropriate to age, cognitive and educational ability and within a suitable cultural context.
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

There is a lot of good work the concept of palliative care and structure is not in place yet.

There are no paediatric palliative care teams as described in IMPaCCT. According to Norwegian law a patient with long-term need for health care has the right to have a care team consisting of professionals needed. The leader of this team can be a physiotherapist, nurse, psychologist or a doctor depending on the patient's needs. It is also called "Individual plan". Nurses that provide paediatric palliative care for ill children are mostly *paediatric nurses*⁸. Sometimes in the municipalities the Public Health Nurses are the providers. Nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) do not have specialised qualifications. There are only a few that have specialised qualifications in palliative care throughout the country.

Paediatric palliative care management

IMPaCCT describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. There are written

⁸ http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

guidelines on pain and symptom management as described in IMPaCCT. The symptoms of every child are not recognised and assessed as described in IMPaCCT. It is not a systematic approach. In Norway there are no protocols for pain or symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort. There are new guidelines from “The National Competence Network on Drugs for Children

<https://www.legemidlertilbarn.no/helsepersonell/Sider/Smertebehandling.aspx>

Ethical and legal rights of children in paediatric palliative care

Every child in Norway has equal access to paediatric palliative care. Different practice exists throughout the country, according to level of competence. The government funds paediatric palliative care services including all care and equipment needs. Paediatric palliative care is evaluated to see if the care is in the best interest of the child but not systematically. The person that evaluates the best interest of the child depends on the health care level the child needs. In the municipalities often the Public Health nurse together with the local physician. In hospital – the paediatric nurse and the paediatrician.

IMPaCCT describes standards for communication and decision making. There is no structured written standard for communication and decision making. The description of the written standards in IMPaCCT are in line with the practice, but there are no written standards for communication and decision making in palliative care.

There is no structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPaCCT. The work has started. The work ahead is to implement the guidelines, make practical routines.

Paediatric palliative care in Norway does not meet all the written standards of IMPaCCT¹

Poland

Information not provided

Portugal

Organisation of services

In Portugal there are no national guidelines concerning paediatric palliative care. The WHO definition of paediatric palliative care-as adopted by IMPaCCT is not used. There are no written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT)¹.

Portugal does not follow core standards in the provision of paediatric palliative care.

There are no paediatric palliative care teams as described in IMPaCCT. In Portugal the professionals that are involved in the palliative care are physician, nurse and social worker. One professional from the paediatric palliative care team is not identified as the family's care co-ordinator or key worker.

Nurses that provide paediatric palliative care for ill children are not *paediatric nurses*⁹. Nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) do not have specialised qualifications.

Paediatric palliative care management

IMPACT describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. In Norway there are no written guidelines on pain and symptom management as described in IMPACT. In Portugal each institution has its guidelines for pain control. The symptoms of every child are recognised and assessed as described in IMPACT. There are protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort.

Ethical and legal rights of children in paediatric palliative care

Every Child in Portugal does not have equal access to paediatric palliative care. There is no paediatric palliative care system. The government does not fund paediatric palliative care services including all care and equipment needs. Paediatric palliative care is now beginning in Portugal with government help. Paediatric palliative care is evaluated to see if care is in the best interest of the child. Parents, health professionals and ethics committees evaluate the best interest of the child.

IMPACT describes standards for communication and decision making. In Portugal there is a structured written standard for communication and decision making which includes:

- An honest and open approach is the basis of all communication and is sensitive and appropriate to the child's age and understanding.
- Parents are acknowledged as the primary caretakers and are centrally involved in the care and decisions involving their own child.
- Information is provided for the parents, for the child and for the siblings according to age and understanding. The needs of other relatives are also addressed.
- Every child is given the opportunity to participate in decisions effecting his or her care, according to age and understanding.
- Situations posing a high risk of conflict are anticipated and procedures for early communication, therapeutic interventions or ethics consultation are established.
- Every family is given the opportunity of consultation with a paediatric specialist who has particular knowledge of the child's condition, including the treatment and care options available.

There is no structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPACT. Portugal have started to have an organized structure in order to bring more benefits to child/family but it is still not enough.

Paediatric palliative care in Portugal does not meet all the written standards of IMPACT.

Romania

Information not provided

Republic Serbia

Information not provided

⁹ http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

Slovakia

Information not provided

Slovenia

Information not provided

Spain

Information not provided

Sweden

Organisation of services

In Sweden there are national guidelines concerning paediatric palliative care. The WHO definition of paediatric palliative care—as adopted by IMPaCCT is used. There are written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT). There are no special hospitals, but there are palliative care units, everywhere in Sweden. In Stockholm, there is a hospital, "Little Ersta" which only deals with palliative care to children and adolescents.

IMPaCCT recommends minimum core standards for Europe in the provision of paediatric palliative care. Sweden follow core standards in the provision of paediatric palliative care:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship
- A full range of clinical and educational resources are available for the child and family, in a format that is appropriate to age, cognitive and educational ability and within a suitable cultural context.
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

There are paediatric palliative care teams as described in IMPaCCT:

- The care team recognises the individuality of each child and family and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm.
- The skills and services provided include a physician, nurse, social worker, child therapist or psychologist and a spiritual adviser.
- Professional resources from the child's own community are utilised if appropriate.
- Expert paediatric palliative care support and advice are available to the child and family 24 hours a day, 365 days a year.
- The care team ensures continuity of care at home, in the hospital and in a hospice through planning, sharing strategies and objectives.
- The direct caretakers provide psychosocial support and supervision.

These teams include a nurse, doctor, social worker, dietitian, psychologist, physiotherapist and hospital chaplain. One professional from the paediatric palliative care team is identified as the family's care co-ordinator or key worker.

Nurses that provide paediatric palliative care for ill children are *paediatric nurses*¹⁰. Only specialist nurses, pediatric nurses. Nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) have specialised qualifications. One year specialist nurse education from the university, master level.

Paediatric palliative care management

IMPACT describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. In Sweden there are written guidelines on pain and symptom management as described in IMPACT. The symptoms of every child are recognised and assessed as described in IMPACT. There are protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort.

Ethical and legal rights of children in paediatric palliative care

Every child in Sweden has equal access to paediatric palliative care. The government funds paediatric palliative care services including all care and equipment needs. Paediatric palliative care is evaluated to see if the care is in the best interest of the child.

IMPACT describes standards for communication and decision making. There is a structured written standard for communication and decision making:

- An honest and open approach is the basis of all communication and is sensitive and appropriate to the child's age and understanding.
- Parents are acknowledged as the primary caretakers and are centrally involved in the care and decisions involving their own child.
- Information is provided for the parents, for the child and for the siblings according to age and understanding. The needs of other relatives are also addressed.
- Every child is given the opportunity to participate in decisions effecting his or her care, according to age and understanding.
- Situations posing a high risk of conflict are anticipated and procedures for early communication, therapeutic interventions or ethics consultation are established.
- Every family is given the opportunity of consultation with a paediatric specialist who has particular knowledge of the child's condition, including the treatment and care options available.

There is a structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPACT.

The paediatric palliative care in Sweden does not meet all the written standards of IMPACT. There is a need to evaluate paediatric palliative care.

Switzerland

Information not provided

Turkey

¹⁰ http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

Organisation of services

In the Turkey there are no national guidelines concerning paediatric palliative care. The WHO definition of paediatric palliative care-as adopted by IMPaCCT is used. There are no written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT).

IMPaCCT recommends minimum core standards for Europe in the provision of paediatric palliative care. Turkey follow cores standards in the provision of paediatric palliative care:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

Information is given to the family but if the family wants, the information is given to the child. The family usually doesn't want to give information to the children to protect them. There is not enough clinical and educational resources are available for the child and family. There are no special palliative care units for children yet in Turkey or special paediatric palliative care teams. The paediatric oncologist and nurses take care of the patients in oncology units for palliative care.

One professional is identified as the family's care co-ordinator or key worker. Nurses that provide palliative care for ill children are *paediatric nurses*¹¹. The nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) do not have specialised qualifications. Some have however undertaken specific palliative care courses and seminars.

Paediatric palliative care management

IMPaCCT describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. In Turkey there are no written guidelines on pain and symptom management for children in our country, but Most of doctors and nurses follow up international guidelines for care and treatment. The symptoms of every child are recognised and assessed as described in IMPaCCT. In Turkey there are protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort.

Ethical and legal rights of children in paediatric palliative care

Every child in Turkey does not have equal access to paediatric palliative care. There are not enough palliative care units, but the children who need palliative care can access to the paediatric clinics for symptom control. The government does not fund paediatric palliative care services including all care and equipment needs. Paediatric palliative care is not evaluated to see if the care is in the best interest of the child

IMPaCCT also describes standards for communication and decision making. In Turkey there is no structured written standard for communication and decision making but the doctor explains to the family about the diagnosis and treatment.

There is no structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPaCCT.

¹¹ http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

Paediatric palliative care in your country meets all the written standards of IMPaCCT?

The Turkish Ministry of Health has started a “National cancer control program” with the World Health Organization called Pallia-Turk. There is no special paediatric palliative care teams in Turkey. There are some doctors who have received special education about palliative care in other countries. There are some nurses and doctors who have also received palliative education by seminars, congress, and so on. The lack of a coordinated referral system to access palliative care services is a potential barrier to the development of the discipline. The lack of coordination among palliative care providers may make it difficult to deliver an integrated health-care service

United Kingdom

Organisation of services

In the UK there are national guidelines concerning paediatric palliative care, including the Royal College of nursing competencies, Together for short lives documents; standard framework for children’s palliative care 2015; Extubation care pathway 2013; Difficult conversations for young adults 2012; Basic symptom control in paediatric palliative care ed. 9.5; Jointly commissioned palliative care CYP; Guide to end of life care 2012; Charter 2012; Medicines management toolkit ; Association of Paediatric palliative care medicine (formulary).

The WHO definition of paediatric palliative care-as adopted by IMPaCCT is used across the UK. There are written guidelines/ standards on the 3 levels of paediatric palliative care as described by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT).

IMPaCCT recommends minimum core standards for Europe in the provision of paediatric palliative care. The UK follow cores standards in the provision of paediatric palliative care:

- The unit of care is the child & family. Family is defined as those who provide physical, psychological, spiritual and social comfort to the child, regardless of genetic relationship
- A full range of clinical and educational resources are available for the child and family, in a format that is appropriate to age, cognitive and educational ability and within a suitable cultural context.
- The child and family are included in identifying the needs and priorities for care, once given as much information as desired regarding disease and treatment options.

In the UK there are paediatric palliative care teams as described in IMPaCCT:

- The care team recognises the individuality of each child and family and upholds their values, wishes, beliefs, unless this exposes the child or carers to avoidable harm.
 - The palliative care team has sufficient expertise to address the physical, psychological, emotional, spiritual and social needs of the family.
 - The skills and services provided include a physician, nurse, social worker, child therapist or psychologist and a spiritual adviser.
 - Professional resources from the child’s own community are utilised if appropriate.
 - The care team ensures continuity of care at home, in the hospital and in a hospice through planning, sharing strategies and objectives.
 - The direct caregivers are provided with psychosocial support and supervision
- 24 hour 365 support and advice is not even in its provision across the UK. In particular when children are cared for in the home setting, there is wide variation in support available.

One professional from the paediatric palliative care team identified as the family's care co-ordinator or key worker. Nurses that provide paediatric palliative care for ill children are *paediatric nurses*¹². Nurses that provide paediatric palliative care to children and young people in all settings (hospital, hospice, at home) do not have specialised qualifications. Palliative care is part of pre-registration training for paediatric nurses. There are courses available at degree, masters and doctorate levels although not all nurses within this field will have completed one of these. There is a wide range of training opportunities available for example; Foundation courses in paediatric palliative care and study days on specific issues and conditions. Surveys of nursing staff working in these fields indicate many years of experience organisations frequently utilise RCN competencies in designing job descriptions and requirements.

Paediatric palliative care management

IMPACT describes that every child should have access to professional, pharmacological, psychological and physical management of pain and other symptoms. In the UK there are written guidelines on pain and symptom management as described in IMPACT. The symptoms of every child are recognised and assessed as described in IMPACT Services work to the standards described however evidence on the effectiveness of this on individual children has not been fully studied. There are protocols for pain and symptom management within paediatric palliative care so that all children and young people can get appropriate treatment to achieve an acceptable level of comfort

Ethical and legal rights of children in paediatric palliative care

Every child in the UK does not have equal access to paediatric palliative care. 24/7 access to care in the home is not available in every location. In the UK the government funds paediatric palliative care services including all care and equipment needs. Government funding is supplemented by charity provision.

Paediatric palliative care is not evaluated to see if the care is in the best interest of the child. Some of these are able to be more effectively met than others in practices across the UK. There are challenges in relation to treatment burden and benefits and early planning for transition. Many health care organisations have an ethical framework to aid best interest decision making sometimes resulting in judicial hearings.

IMPACT describes standards for communication and decision making. There is structured written standard for communication and decision making:

- An honest and open approach is the basis of all communication and is sensitive and appropriate to the child's age and understanding.
- Parents are acknowledged as the primary caretakers and are centrally involved in the care and decisions involving their own child.
- Information is provided for the parents, for the child and for the siblings according to age and understanding. The needs of other relatives are also addressed.
- Every child is given the opportunity to participate in decisions affecting his or her care, according to age and understanding.
- Situations posing a high risk of conflict are anticipated and procedures for early communication, therapeutic interventions or ethics consultation are established.
- Every family is given the opportunity of consultation with a paediatric specialist who has particular knowledge of the child's condition, including the treatment and care options available.

¹² http://www2.rcn.org.uk/_data/assets/pdf_file/0009/634527/Definition-of-a-Paediatric-Nurse-2015.pdf

There is no structured programme within the paediatric palliative care provided to reach the goals of care management, respite care and family support as described in IMPaCCT. There are structured programmes to cover all of these issues but however provision is variable and we would draw attention to respite care provision and on-going bereavement provision.

The paediatric palliative care in the UK meets all the written standards of IMPaCCT. Financial planning (tariffs) for statutory services in relation to paediatric palliative care is being developed in England and Wales. On-going research is taking place through a number of collaboration between academic and clinical services.

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