Digital tool for better communication in Children’s Palliative Care

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Facts and figures Netherlands

- Annually app. 5000-7000 children and their family are in need of palliative care.

- App. 23% oncological diseases, 77% neonatology, neurological en metabolic diseases, etc.

- Annualy between 1200-1400 children (0-20 jaar) die from the consequences of a disease.
Facts and figures – particulars for children in the palliative care

Despite the particulars for children in the palliative care ……..

… the entire policy and regulations have been built on principles of adult care.

Since 2007 Foundation PAL, children's palliative expertise, worked together with parents, professionals, researchers for the specific attention and needs for Children’s palliative care.
2007 – until now: Foundation PAL -> Built up from scratch (1)

Aim: To create a nationwide structure for integrated children’s palliative care with substantive quality, coordination, and continuity to achieve the highest possible quality of life for families with a child with a life threatening of life limiting illness.

2007 – 2011

▪ Listen to parents
▪ Learning from good-practices abroad
▪ Building awareness through communication and lobbying
▪ Building expertise through education and networking
2007 – until now: Foundation PAL -> Built up from scratch (2)

2012 CPC team - Children’s Comfort Team

- Start pilot Emma Home Team, the first CPC team, Emma Children’s hospital, Amsterdam

- Results in 2 theses (1 en 2)

2014 CPC network – Network Integrated Child Care

- Pilot Regional network integrated CPC, region Leiden.

- Based on development model for integrated care (3)

1. L. Verberne ea, 2017
2. C. Jagt ea, 2017
A Nation wide structure for integrated Children’s Palliative Care

- 7 Regions
- 7 Regional Networks Integrated Care for family’s with a seriously ill child
- 7 Children’s Comfort Teams
- 1 Guideline ‘Palliative care for Children’(4)
- 1 Individualized pediatric palliative care plan (5)
- 1 central link: Center of Expertise Children’s Palliative Care

4. Dutch Association for Pediatrics, 2013
5. E.A.H. Loeffen ea, 2017
Sustainability

- CPC is now recognized as a specialized field of care and funded by the government.
- Increased specific CPC expertise of professionals
- Coordinated care in close collaboration with parents
- September 26, 2018: Foundation PAL became Centre of Expertise for Children’s Palliative care

The centre of expertise will provide a basis to preserve the CPC-structure with expertise, information, training and development.
But.....
Further exploration of the problem

- How to improve CPC from perspective of parents ->
  - Mirror meeting with 11 parents of 6 children
  - Working session about the 5 most important topics.
  - For more topics digital solutions mentioned as a solution direction

- Expectations of the digital tool:
  - Transparant communication
  - Sharing information
  - Supportive to transfer, connection hospital and general practitioner
  - Parents in charge who is allowed to join
Next step – digital community

- Development of a secured digital community around families:
  - Communication module (texting and video calling)
  - Information module (documents and videos)
  - Links

- Aim: For better communication between the family and all professionals involved in order to improve CPC and support the families. -> MyChildrensComfortNet
Welkom bij KinderComfortNet

MijnKinderComfortNet staat voor beveiligd online contact en verbindingen en samenwerking tussen gezin en mensen die betrokken zijn bij de kinderzorg en ondersteuning van een ernstig ziek kind.


Als u op deze pagina bent omdat u een uitnodiging hebt ontvangen voor mijnKinderComfortNet, kunt u hieronder inloggen.
<table>
<thead>
<tr>
<th>Naam</th>
<th>Rol</th>
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<tbody>
<tr>
<td>Testpatient</td>
<td>Manage</td>
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1 tot 3 van 3 resultaten 10 resultaten weergeven
Testpatient

Gegevens

Voornaam
Piet

Tussenvoegsel
Tussenvoegsel

Achternaam
Patient

Weergegeven naam
Testpatient

Geboortedatum
Voer de geboortedatum...

Toegang

Dossier verwijderen

Gegevens bijwerken
Testpatient

Zorgplan DK

27-08-2021
First experiences

- Start with the Children’s Comfort Team in Amalia Children’s hospital Radboud University Nijmegen. 1 parent involved from the beginning
- Children’s Comfort Team: Win-win about clearness, transparency and time

“Important for me to stay in control, this helps me”

“I can easily add photo’s to show something, it makes the conversation more clear”

“It would be great if the information is put in digital environment by the pediatrician and that I don’t have to argue with the gp and home care.

“In the communication app it is so nice that I can easily choose who should receive the message and I can organize the messages under a specific topic”
Sustainability

- After the process of design, testing, and redesign, myChildrensComfortnet will be available for all CPC teams and networks.

- The Dutch Centre of Expertise for CPC will provide a basis for ongoing improvements and updates to myChildrensComfortnet.
Take home message

▪ Success factors:
  ▫ Involvement of parents in the whole process.
  ▫ Parents in control over their own community
  ▫ Embedding in an existing environment. In our case the nationwide CPC structure and the Centre of Expertise as linking pin

▪ Learning lessons:
  ▫ Keep it simple
  ▫ Clear view of the requirements of the system and then look for an experience designer, who meets your requirements.
  ▫ Take time for testing
Questions??

Kenniscentrum kinderpalliatieve zorg