
Clinical protocols for pediatric palliative care
- a step towards quality and professionalism

Author: PhD. Psych. Mihaela Dumitrache

Presedinte Asociatia Lumina Bacau

Motto:

„When healing is no longer possible it is our duty to take care of them.“

dame Cicely Saunders

The current knowledge in this field:

-
- ❑ In Romania there are no concrete data on the number and the needs of children diagnosed with incurable/life-limiting diseases.
 - ❑ In the few studies that addressed the issue of palliative care in Romania, the population aged between 0-18 years is almost non-existent and is considered the “Cinderella of health system”
 - ❑ 6 pediatric palliative care services in Romania:
 - Iasi County – Sf. Maria Hospital
 - Bacău County – through Asociația Lumina – Bed unit - “Hospice” type , Day Center, Palliative care service at home for children
 - Bihor County – through Hospice Emanuel – Palliative care service at home for children and hospital team for the pediatric hemato-oncology section
 - Brașov and București Counties – Hospice Casa Speranței – Bed unit – X beds, Day Center, Palliative care service at home for children , ambulatory, mobile hospital team
 - București – Oncology Institute
 - Timis County - “Louis Țurcanu” Emergency Clinical Hospital for Children , Pediatric Clinic III, Timișoara

The current knowledge in this field, moreover:

- ❑ Order of M.H. 253/2018 – Regulation on the organization and functioning of palliative care services in Romania
- ❑ Epidemiological data, according WHO at global level;
- ❑ Epidemiological data in Romania;

The current knowledge in this field, moreover:



Epidemiological data according WHO :

source: Global Atlas of Palliative Care at the End of Life. (2014:98)

WHO Regiuni	Total	HIV/SIDA	Cancer	Progressive non-malignant	Băieți	Fete
La nivel mondial	1170011	119726	66625	983658	604393	565618
Europa	36135	252	4590	31292	20320	15814

Tabel1: Number of children who need palliative care by region, diseases and gender category

WHO Regiuni	Total	HIV/SIDA	Cancer	Progressive non-malignant	Băieți	Fete
la nivel mondial	63,4	46,5	3,6	53,3	63,3	63,5
în Europa	23,0	0,2	2,9	19,9	25,2	20,7

Tabel 2: The share of children who need palliative care (% per 100,000) by region, disease and gender category.

The current knowledge in this field, moreover:

□ Epidemiological data in Romania:

- *Method: Secondary data analysis – GDSACP database (processing by author) – 6 counties from N-E Romania (2015)*

- *Total children diagnosed with life-threatening diseases = **1728***

County	Country side		Urban	
	No. people	%	No. people	%
Bacău	201	56.5	132	37.3
Botoșani	273	64.5	149	35.2
Iași	237	58.7	167	41,3
Neamț	114	54.0	77	36.5
Suceava	70	45,2	71	45,8
Vaslui	90	53.6	77	45.8

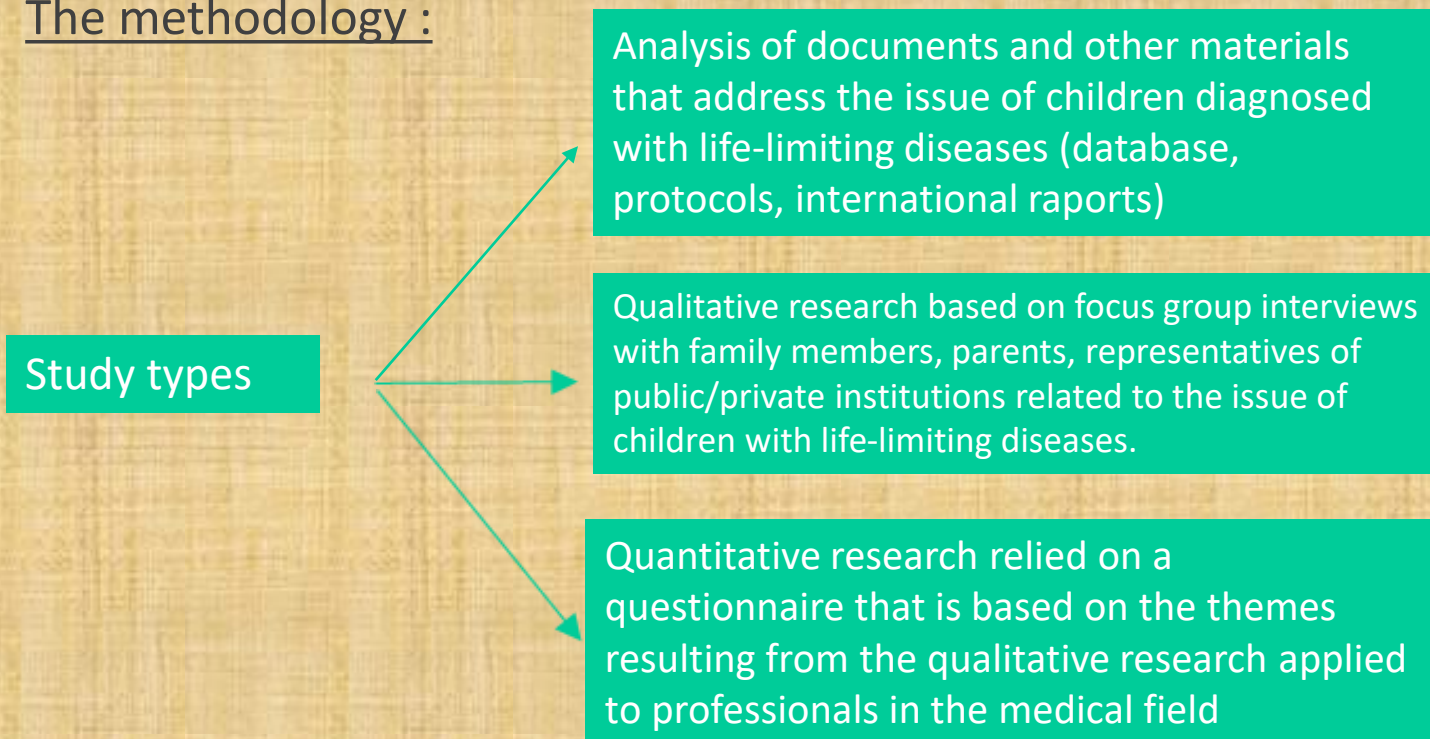
Tabel 3. Distribution of population (0-18 years) by residence

Important steps towards quality and professionalism

A. The mapping of the need:

- children diagnosed with life-threatening diseases and their families;
- professionals from the healthcare system;

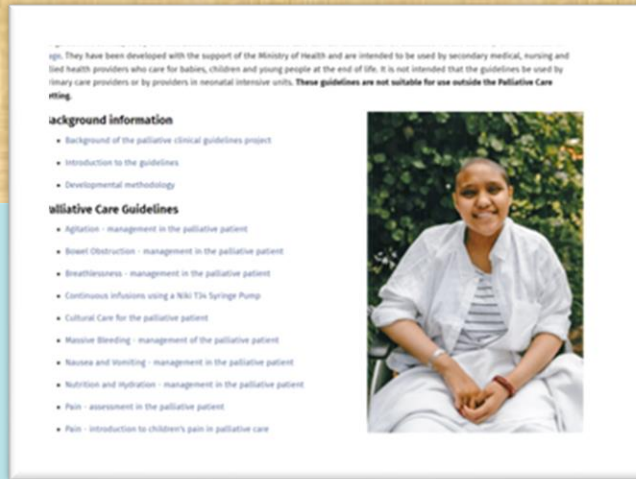
The methodology :



Important steps towards quality and professionalism, moreover:

B. Clinical protocols for pediatric palliative care

- Creation of a working group – experts working in PPC
- Studying international models;
- The conduct of 10 clinical protocols



PALLIATIVE CARE FOR CHILDREN WITH LIFE-LIMITING CONDITIONS IN IRELAND
- A National Policy

A Palliative Care Needs
Assessment for Children

A practical guide to
PALLIATIVE CARE
in paediatrics

Clinical protocols for professionals



Useful and necessary due to the fact that they :

- ❑ support all professionals that work or have in evidence children with life-threatening diseases
- ❑ support authorities to allow medication insurance adapted for children and access for intervention needed for children with life-threatening diseases
- ❑ support authorities to calculate the real costs for palliative care interventions



Child – adult transition

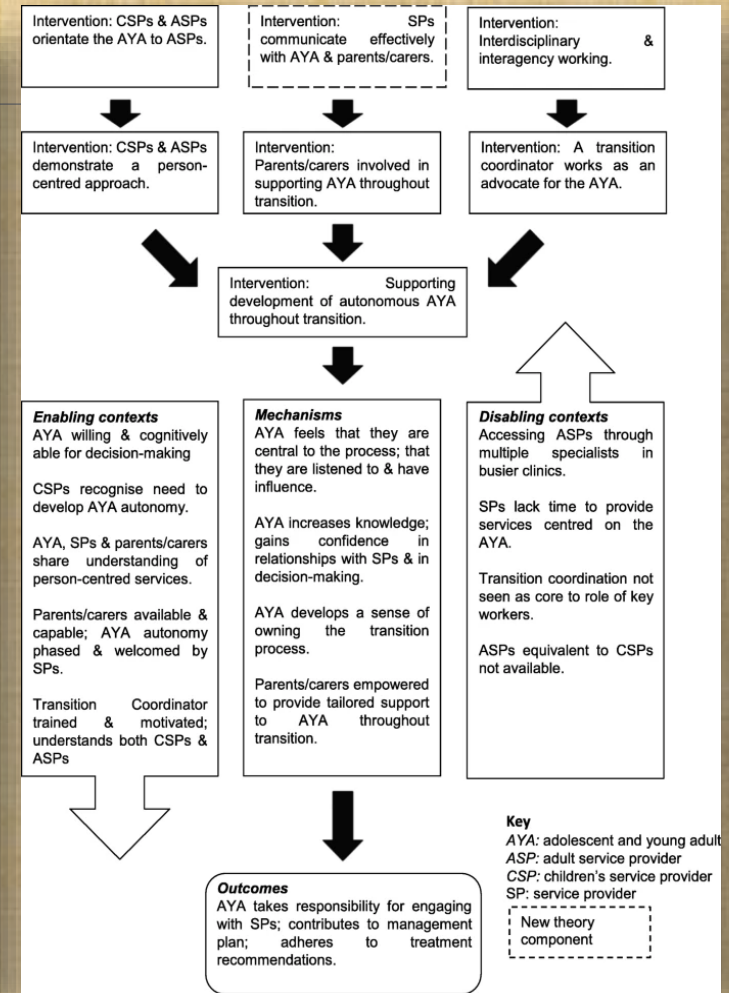
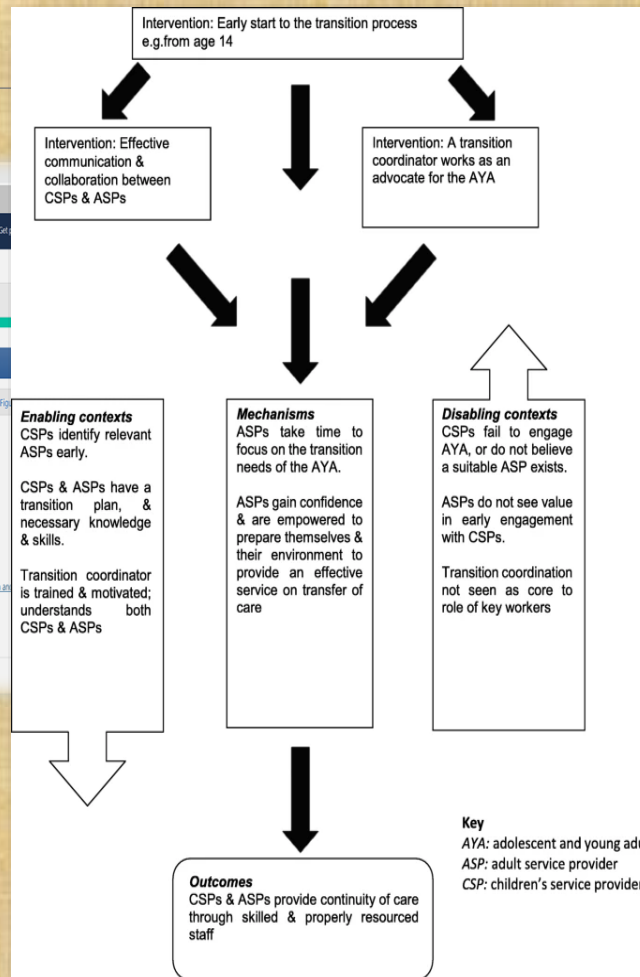
- Another step towards quality and professionalism

□ an important step for children's palliative care professionals because:

- The services will be exempt from the costs related to the care of adults (not settled by the health insurance company in a children service)
- Lack of equipment adapted to adults in children's services
- Young people autonomy



Child - adult transition — other countries experiences

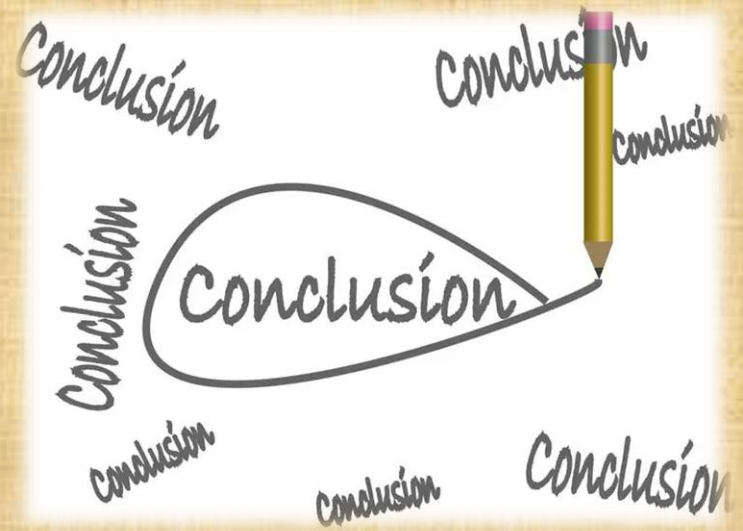


Key priorities for an easy transition:

1. Effective communication, cooperation and commitment to work together – services for children and adults
2. Hiring a transition coordinator
3. Interdisciplinary and inter-services working together
4. Person-centred care approach to be demonstrated by services providers
5. Family/ carers involvement
6. Early start of the transition process and their orientation to adult services
7. Autonomy development of young adults during the transition process

Conclusions

The more informations a specialist or an institute which offers palliative care services has about the population that they are addressing , the more efficiently they can organise the work and support the population way better.



THANK YOU!
