

Making the invisible more visible: A retrospective study identifying children and adolescents with complex chronic conditions and their access to specialised palliative care teams

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BACKGROUND

In Belgium, **paediatric liaison teams (PLTs)** ensure continuity of care across all care settings for children with complex chronic conditions (CCC). Data on access to those **PLTs** is lacking.

AIM

To evaluate the access to **PLTs** for children and adolescents (0-19 years) diagnosed with a CCC (classification of Feudtner et al, 2001).

To estimate service provision needed.

METHODS

Comparing data collected between 2010 and 2014 in all hospitals in Brussels (n=8)



With data collected in all **PLTs** in Brussels (n=2)

Analysis: National registration number pseudonymised by Trusted Third Party (eHealth), data analysed through descriptive statistics and results interpreted through 3 meetings with steering committee and external consultations

Ethical approvals: by Data Protection Authority, Sectoral Committee for Social Security and Health (n°CSSSS/16/193) and all Ethics Committee of the participating hospitals

RESULTS

22533 children/adolescents diagnosed with a CCC were identified through the database of the 8 hospitals. From these, a minority (1,7% , n=384) were referred to a PLT.

DISEASES	Hospital % (n)	PLTs % (n)
Cancer	14% (3011)	17% (98)
Digestive disease	4% (848)	4% (24)
Cardiovascular disease	28% (6310)	10% (60)
Hematol/immunol disease	6% (1391)	5% (29)
Neurological disease	18% (4125)	21% (121)
Respiratory disease	3% (752)	5% (26)
Urinary disease	7% (1553)	2% (11)
Congenital/genetic disease	8% (1810)	5% (28)
Metabolic disease	4% (972)	5% (27)
Unknown	8% (1761)	26% (148)
Total	100% (22533)	100% (572)

AGE CATEGORIES	Hospitals % (n)	PLTs % (n)
0<1	30% (6692)	31% (177)
1-4	28% (6243)	31% (176)
5-9	18% (3978)	16% (94)
10-14	16% (3715)	17% (97)
15-19	8% (1905)	5% (28)
Total	100% (22533)	100% (572)

CONCLUSION

Referrals to **PLTs** who ensure continuity of care for children and adolescents living with CCC in Belgium might be insufficient. Further research is requested to document the type and degree of care needed for this population.

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