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Joint PhD VUB & UGent
2022-2023

INVITATION to the Public defence of

Veerle PIETTE

To obtain the academic degree of

'DOCTOR OF MEDICAL SCIENCES' (VUB)
'DOCTOR OF HEALTH SCIENCES' (UGENT)

Appropriateness of end-of-life care in children with serious illness: The development and measurement of pediatric-specific population-level quality indicators for big data

The defence will take place on

Tuesday, 22nd November 2022 at 5 p.m.

In Auditorium Piet Brouwer

Faculty of Medicine and Pharmacy, Laarbeeklaan 103, 1090 Brussel

and can be followed online, accessible through the following link:

https://gf.vub.ac.be/redirects/PhD_defense_Veerle_Piette.php

Summary of the dissertation

Despite advancing treatment, up to one fourth of first-world deaths in children still occurs due to serious illness, such as cancer, neurological conditions, and genetic and congenital conditions. This group of children can suffer from burdensome symptoms at the end of life, such as pain and anxiety. A broad evaluation of the quality of end-of-life care for children with serious illness is therefore advised, and quality indicators tailored specifically to the child at the end of life have been requested nationally as well as internationally for this purpose. This dissertation developed such pediatric-specific indicators for potentially appropriate and potentially inappropriate end-of-life care, and measured them within Belgian population-level administrative healthcare data. Quality indicators were developed using the RAND/UCLA methodology, and measured using population-level decedent cohort designs. Three sets of pediatric-specific quality indicators were finalized, for the disease groups of cancer, neurological conditions, and genetic/congenital conditions. Potential comfort medication and treatment, such as specialized medication and palliative care, were reimbursed to upwards one third of children. Potentially aggressive treatment, such as surgeries, was reimbursed for nearly no children for all illness categories, but blood drawings and ICU admissions for up to half of the children at the end of life. Continuous reimbursed care provision by specialist physicians was present for circa three quarters of children, yet multidisciplinary care in less than one fifth of children. Administrative measures were provided to less than one fifth of children. Further research into pain and symptom interventions alongside patient input is recommended, as well as the incorporation of learning and improvement strategies using indicators as flexible benchmarks.

Curriculum Vitae

Veerle Piette (°1992) holds a Master's degree in Language Psychology and Pathology as well as a Bachelor's in Biological Psychology from the Vrije Universiteit Brussel. During her studies, she has worked as a care teacher and care coordinator in kindergarten and middle school, and has done clinical internship for pediatric neuropsychological practice. After her studies, Veerle joined the End-of-Life Care Research Group as a PhD researcher in 2017, working on an FWO-funded project for the development of quality indicators for children with serious illness at the end of life, and various other research projects centering on the improvement of children's care. Veerle was supervised by Prof. Dr. Luc Deliens, Prof. Dr. Joachim Cohen, and Prof. Dr. Kim Beernaert. The findings reported and discussed in her dissertation were published in international high-impact pediatric journals, and were presented at various national and international conferences.