

Pediatric Palliative Care Needs in the Canton of Bern, Switzerland

A Cross-Sectional Study

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Challenges

- In Switzerland, 450 – 500 children die each year
- The needs of children in Paediatric Palliative Care (PPC) are different compared to the needs of adult patients with palliative care:
 - ✓ The time PPC is required varies from less than one month up to several years
 - ✓ Early inclusion of PPC in the disease trajectory, i.e., concurrent to curative treatment, is strongly recommended
 - ✓ Support of the child's family is an essential part of PPC
 - ✓ Adjusted support is necessary for promoting physiological child development
- Today, no comprehensive care network for PPC exists in the Canton of Bern
- Prevalence data on the number of children needing PPC does not exist

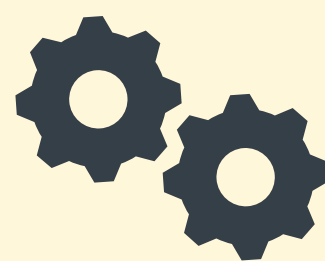


Aims

- To determine the number of children with life-limiting conditions living in the Canton of Bern who are cared for by Home Healthcare Organisations and who meet the criteria for PPC according to the START-IMPACT screening tool (version 1.8.)
- To describe the characteristics of the affected children and their families



Methods



Design:

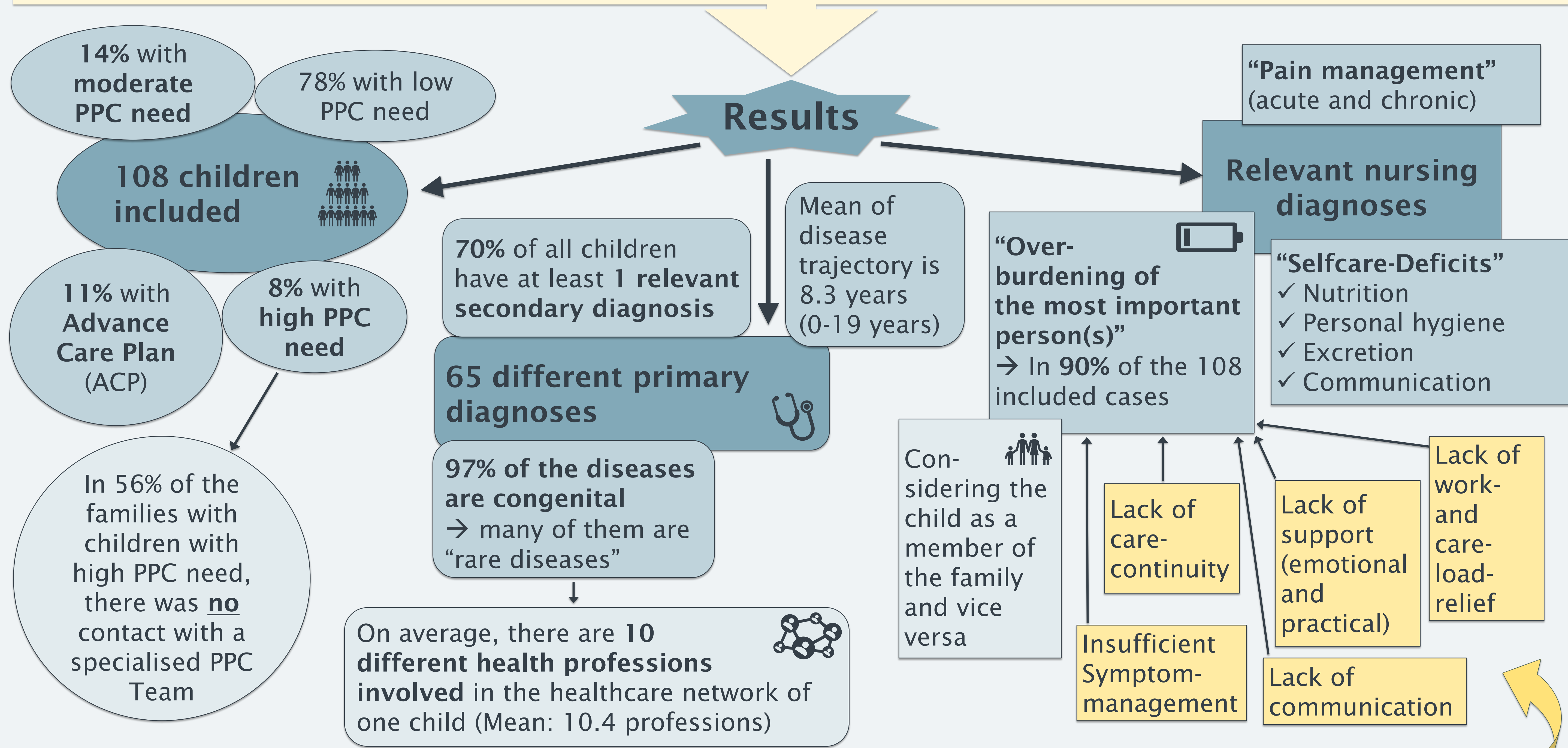
Cross-sectional study, patient dossier analysis

Sample:

Complete survey of all registered children due to the heterogeneity of the study-population and the estimated low number of children with life-limiting conditions in the study area

Recruitment:

Children cared for by Home Healthcare, age 0 –20 years, with a START-IMPACT Score ≥ 4



Discussion



- The burden of illness and care of the affected children and their families is enormous
- Access to specialized PPC Services is inadequate
 - ✓ Early inclusion of PPC in the disease trajectory is strongly recommended
- Care and treatment gaps in various areas exist
 - ✓ High care and treatment burden of the families
 - ✓ Elevated risk for depression, sleeping problems, social isolation and financial problems → mothers are more often affected
- Establishment of an adequate comprehensive care network for PPC in Bern needed
 - ✓ ACP and the continuous care by an interprofessional, specialized PPC team (in- and outpatient) is recommended

References: Palliative Care des Bundesamtes für Gesundheit. <https://www.plattform-palliativecare.ch/arbeiten/zugang-zu-palliative-care-fuer-vulnerable-gruppen-verbessern>; Bundesamt für Statistik (2019). Anzahl Menschen mit Behinderungen; Bundesamt für Statistik. (2021). Todesfälle; Bogatz, J. F., Revette, A., Rosenberg, A. R., & DeCoursey, D. (2020). "I Could Never Prepare for Something Like the Death of My Own Child": Parental Perspectives on Preparedness at End of Life for Children With Complex Chronic Conditions; Constantinou, G., Garcia, R., Cook, E., & Randhawa, G. (2019). Children's unmet palliative care needs: a scoping review of parents' perspectives; Craig, F., Abu-Saad Huijjer, H., Benini, F., Kuttner, L., Wood, C., Ferris, P. C., & Zernikow, B. (2008). IMPaCT: standards of paediatric palliative care; Detrekoy, C., Steiner, E., & Zürcher, T. (2016). Behindertengpolitik im Kanton Bern 2016; Fraser, L. K., Bluebond-Langner, M., & Ling, J. (2020). Advances and Challenges in European Paediatric Palliative Care; Gray, J. R., & Grove, S. K. (2021). Burns and Grove's The Practice of Nursing Research - Appraisal, Synthesis, and Generation of Evidence; Inselspital Bern. (2021). Pädiatrische Palliative Care; Koch, K. D., & Jones, B. L. (2018). Supporting Parent Caregivers of Children with Life-Limiting Illness; Melin-Johansson, C., Axelsson, I., Jonsson Grundberg, M., & Hallqvist, F. (2014). When a child dies: parents' experiences of palliative care-an integrative literature review; Obsan, (2020). Gesundheit in der Schweiz - Kinder, Jugendliche und junge Erwachsene: Nationaler Gesundheitsbericht 2020; Streuli, J. (2021). St. Galler Triage Assessment und Reevaluations Tool (START) für ein interprofessionelles mobiles pädiatrisches Advanced Care Team (IMPACT); Streuli, J., Bergsträsser, E., M., F., & Sattler, A. (2018). Kinder-Palliativmedizin Essentials; Van den Broeck, J., Argeseanu Cunningham, S., Eckels, R., & Herbst, K. (2005). Data Cleaning: Detecting, Diagnosing, and Editing Data Abnormalities; Verbeke, L. M., Kars, M. C., Schouten-van Meeteren, A. Y. N., van den Bergh, E. M. M., Bosman, D. K., Colenbrander, D. A., Grootenhuys, M. A., & van Delden, J. J. M. (2019). Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: a qualitative study; Weltgesundheitsorganisation [WHO]. (2018). Integrating palliative care and symptom relief into paediatrics: a WHO guide for health care planners implementers and managers; Winger, A., Kvarme, L. G., Løvland, B., Kristiansen, C., Helseth, S., & Ravn, I. H. (2020). Family experiences with palliative care for children at home: a systematic literature review; Wright, L. M., Leahey, M., Shajani, Z., & Snell, D. (2021). Familienzentrierte Pflege. Lehrbuch für Familien-Assessment und Interventionen; Zahnd, P. G. (2020). Bedürfnisse und Versorgungsbedarf von Familien, die ihr Kind mit einer schwerwiegenden chronischen Erkrankung zu Hause betreuen; Zernikow, B. (2015). Schmerztherapie bei Kindern, Jugendlichen und jungen Erwachsenen; Zernikow, B. (2021). Pädiatrische Palliativversorgung - Grundlagen; Zernikow, B., Gertz, B., & Hasan, C. (2017). Pädiatrische Palliativversorgung - herausfordernd anders: Aufgaben, Ziele und Besonderheiten.



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