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Peters, Vincent J. T.; Winter, J. Peter de

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EDITORIAL

Navigating the path home: pioneering hospital-to-home transitions for children with medical complexity

Vincent J. T. Peters[1,2] · **J. Peter de Winter**[3,4,5]

In recent decades, there has been a significant increase in the number of Children with Medical Complexity (CMC). This can be attributed to a number of factors including improved outcomes after critical illness, medical and technological developments, better treatment options, and the adaptation of medical devices for home use, which have improved the life expectancy of children with previously considered untreatable conditions. These children make extensive use of complex medical care through the involvement of multiple healthcare professionals. In addition, they use complex home care since they require nursing care, medical equipment, and frequent inpatient contact with different healthcare professionals, among others. The transition from hospital-to-home care for CMC presents numerous challenges for their families, who suddenly find themselves responsible for providing complex care and coordinating various aspects of their child's care needs. Emotional support is also crucial during this fragile and delicate process. Guiding this transition carefully is important because living at home has shown positive psychological, emotional, and social benefits for both CMC and their families.

The works by de Lange and coworkers [1] and the work by Haspels and coworkers [2] should be commended for their efforts in summarizing and categorizing the outcomes of interventions conducted to improve the hospital-to-home transition for CMC [1] and the development of an evidence-informed Core Outcome Set (COS) that healthcare professionals and parents consider as essential outcomes for future intervention research [2].

By conducting a thorough systematic review on evaluating the effectiveness of hospital-to-home transitional care interventions for CMC, de Lange and coworkers [1] identified 25 unique outcomes assigned to six outcome domains. Interestingly, the delivery of care was identified as one of the unique outcomes, but the delivery of care was not further specified. Previous studies have suggested various approaches to care delivery during hospital-to-home transitions, including transitional care units, telemedicine, post-discharge nurse home visits, and standardization of procedures and checklists, among others [3]. As highlighted by de Lange and coworkers, the lack of a standardized approach to hospital-to-home care transition for CMC families is a significant gap in current care practices [1]. Developing a tailored yet standardized approach that improves the home-to-hospital transition for CMC, their families, and healthcare professionals is crucial. Haspels and coworkers [2] emphasized the importance of involving the families to identify their needs and barriers during the hospital-to-home transition. Patient navigators are a promising intervention designed to facilitate the transfer from hospital-to-home care [4]. The utilization of patient navigators has shown promising results for developing a tailored transition in which the needs of patients and their families form the starting point of care delivery.

One strength of the work by Haspels and coworkers [2] is their development of the 'COS transitional care for CMC', which involved the active participation of CMC parents in the research team and empirical data collection. While patient and parent involvement in research is considered essential, it is not yet common practice in hospital-to-home transitions. The World Health Organization (WHO) also recommends involving patients and families in designing their transitional care [5]. The work by Peters and

✉ Vincent J. T. Peters
v.j.t.peters@tilburguniversity.edu

1 Department of Management, Tilburg University, Tilburg, The Netherlands

2 Department of Tranzo, Tilburg University, Tilburg, The Netherlands

3 Department of Pediatrics, Spaarne Gasthuis, Haarlem and Hoofddorp, Hoofddorp, The Netherlands

4 Department of Development and Regeneration, KU Leuven, Leuven, Belgium

5 Leuven Child and Youth Institute, KU Leuven, Leuven, Belgium

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coworkers [6] in the context of children with complex care needs has shown that utilizing the perspective of children and their relatives can contribute to increased responsiveness and integration of healthcare services. Although this study focuses on a different patient population, it can illustrate how the perspectives of CMC and their families can be used to design care delivery. The involvement of the patients' opinions in the transfer of care could help bridge the gaps between different care levels and care professionals and increase patients' satisfaction and safety levels. The latter is especially importantent, given that the quality of hospital-to-home transition is of significant importance for patients' health and well-being [3].

Together, these two works [1, 2] provide valuable insights and directions for CMC's hospital-to-home transition field. The shortlist of 25 outcomes can assist researchers and program evaluators in appropriate outcome selection to improve the hospital-to-home transition process. Additionally, the identified COS can facilitate standard reporting in future research on hospital-to-home transition for CMC. Future studies should seek to provide regular updates on COS, delineate CMC and their family needs, and involve CMC and families in hospital-to-home transition to identify their needs and overcome their barriers. Only in doing so we can truly deliver the transitional care that CMC and their families need and deserve.

References

1. de Lange A, Alsem MW, Haspels HN et al (2023) Hospital-to-home transitions for children with medical complexity: Part 1, a systematic review of reported outcomes. Eur J Pediatr. https://doi.org/10.1007/s00431-023-05050-9
2. Haspels HN, de Lange AA, Alsem MW et al (2023) Hospital-to-home transitions for children with medical complexity: Part 2 - a core outcome set. Eur J Pediatr. https://doi.org/10.1007/s00431-023-05049-2
3. Oksholm T, Gissum KR, Hunskår I, Augestad MT, Kyte K, Stensletten K, Drageset S, Aarstad AKH, Ellingsen S (2023) The effect of transitions intervention to ensure patient safety and satisfaction when transferred from hospital to home health care—A systematic review. J Adv Nurs 79:2098–2118. https://doi.org/10.1111/jan.15579
4. Dimitropoulos G, Morgan-Maver E, Allemang B et al (2019) Health care stakeholder perspectives regarding the role of a patient navigator during transition to adult care. BMC Health Serv Res 19:390. https://doi.org/10.1186/s12913-019-4227-6
5. World Health Organization (WHO) (2016) Transitions of care. Accessed from https://apps.who.int/iris/bitstream/handle/10665/252272/9789241511599-eng.pdf
6. Peters VJT, Meijboom BR, Bunt JEH, Bok LA, van Steenbergen MW, de Winter JP, de Vries E (2020) Providing person-centered care for patients with complex healthcare needs: A qualitative study. PLoS ONE 15(11):e0242418. https://doi.org/10.1371/journal.pone.0242418