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Abstract

Paediatric settings use shared decision-making, which is also known as the pinnacle of patient-centred care. Nevertheless, implementing shared decision-making is relatively challenging as it involves the triad constellation interaction (communication between parents, children and healthcare professionals). This article provided an overview of previous studies related to children's involvement levels in health care decisions and the perception of children, healthcare professionals, and parents of children's participation in shared decision-making. It was concluded that children were engaged minimally in decision-making and most children were involved in minor decisions instead of major decisions. Furthermore, there was a diverse participation pattern, which varied in the same child based on the circumstances. © 2023 UPM Press. All rights reserved.

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Children; Decision-making; Healthcare; Participation

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References

Barsky, EE, Berbert, LM, Dahlberg, SE, Truog, RD.
 Attitudes towards involving children in decision-making surrounding lung transplantation

(2021) Pediatric Pulmonology, 56 (6), pp. 1534-1542.

• Park, ES, Cho, IY.

Shared decision-making in the paediatric field: a literature review and concept analysis

(2017) Scandinavian Journal of Caring Sciences, 32 (2), pp. 478-489.

- Charles, C, Gafni, A, Whelan, T.
 Shared decision-making in the medical encounter: What does it mean? (Or it takes, at least two to tango)

 (1997) Social Science and Medicine, 44 (5), pp. 681-692.
- Wijngaarde, RO, Hein, I, Daams, J, Van Goudoever, JB, Ubbink, DT.
 Chronically ill children's participation and health outcomes in shared decisionmaking: a scoping review
 (2021) European Journal of Pediatrics, 180 (8), pp. 2345-2357.
- Minneci, PC, Cooper, JN, Leonhart, K, Nacion, K, Sulkowski, J, Porter, K, Wei, L, Deans, KJ.

Effects of a Patient Activation Tool on Decision Making Between Surgery and

Nonoperative Management for Pediatric Appendicitis: A Randomized Clinical Trial (2019) *JAMA Network Open*, 2 (6), p. e195009.

- Beck, CE, Boydell, KM, Stasiulis, E, Blanchette, VS, Llewellyn-Thomas, H, Birken, CS, Breakey, VR, Parkin, PC.
 Shared decision making in the management of children with newly diagnosed immune thrombocytopenia

 (2014) Journal of Pediatric Hematology/Oncology, 36 (7), pp. 559-565.
- Coyne, I, O'Mathúna, DP, Gibson, F, Shields, L, Leclercq, E, Sheaf, G.
 Interventions for promoting participation in shared decision-making for children with cancer
 (2016) Cochrane Database of Systematic Reviews, 11, p. CD008970.
- Rost, M, Wangmo, T, Niggli, F, Hartmann, K, Hengartner, H, Ansari, M, Brazzola, P, Elger, BS.
 Parents' and Physicians' Perceptions of Children's Participation in Decision-making in Paediatric Oncology: A Quantitative Study
 (2017) Journal of Bioethical Inquiry, 14 (4), pp. 555-565.
- MacDonald, AI, Chorney, J, Bezuhly, M, Hong, P.
 Shared decision-making in older children and parents considering elective adenotonsillectomy

 (2020) Clinical Otolaryngology, 45 (1), pp. 32-39.
- Carlsson, IM, Nygren, JM, Svedberg, P.
 Patient participation, a prerequisite for care: A grounded theory study of healthcare professionals' perceptions of what participation means in a paediatric care context (2017) *Nursing Open*, 5 (1), pp. 45-52.
- Coyne, I, Amory, A, Kiernan, G, Gibson, F.
 Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences
 (2014) European Journal of Oncology Nursing, 18 (3), pp. 273-280.
- Quaye, AA, Coyne, I, Söderbäck, M, Hallström, IK.
 Children's active participation in decision-making processes during hospitalisation: An observational study (2019) *Journal of Clinical Nursing*, 28 (23–24), pp. 4525-4537.
- Ruhe, KM, Katharina, M, Badarau, DO, Brazzola, P, Hengartner, H, Elger, BS, Wangmo, T.
 Participation in pediatric oncology: views of child and adolescent patients (2015) *Psycho-Oncology*, 25 (9), pp. 1036-1042.
 Sep
- Ruhe, KM, Maria, Katharina, Wangmo, T, Clercq, ED, Badarau, DO, Ansari, M, Kühne, T, Niggli, F.
 Putting patient participation into practice in pediatrics results from a qualitative study in pediatric oncology

 (2016) European Journal of Pediatrics, 175 (9), pp. 1147-1155.
- Schalkers, I, Parsons, CS, Bunders, JFG, Deddin, C.
 Health professionals' perspectives on children's and young people's participation in health care: a qualitative multihospital study (2016) *Journal of Clinical Nursing*, 25 (7-8), pp. 1035-1044.
- Sjöberg, C, Amhliden, H, Nygren, JM, Arvidsson, S, Svedberg, P.
 The perspective of children on factors influencing their participation in perioperative care

 (2015) Journal of Clinical Nursing, 24 (19–20), pp. 2945-2953.

- Harder, M, Söderbäck, M, Ranheim, A.
 Health care professionals' perspective on children's participation in health care situations: encounters in mutuality and alienation

 (2018) International Journal of Qualitative Studies on Health and Well-Being, 13 (1), p. 155542.
- Vigilante, VA, Hossain, J, Wysocki, T, Sharif, I.
 Correlates of type and quantity of child communication during pediatric subspecialty encounters

 (2015) Patient Education and Counseling, 98 (11), pp. 1352-1359.
- Wiering, BM, Noordman, J, Tates, K, Zwaanswijk, M, Elwyn, G, De Bont, ESJM, Beishuizen, A, Van Dulmen, S.
 Sharing decisions during diagnostic consultations; an observational study in pediatric oncology (2016) Patient Education and Counseling, 99 (1), pp. 61-67.
- Feragen, KB, Myhre, A, Stock, NM.
 "Exposed and Vulnerable": Parent Reports of Their Child's Experience of Multidisciplinary Craniofacial Consultations (2019) Cleft Palate-Craniofacial Journal, 56 (9), pp. 1230-1238.
- Gilljam, BM, Arvidsson, S, Nygren, JM, Svedberg, P.
 Promoting participation in healthcare situations for children with JIA: a grounded theory study
 (2016) Int J Qual Stud Health Well-being, 11, p. 30518.
- Bennett, KG, Patterson, AK, Schafer, K, Haase, M, Ranganathan, K, Carlozzi, N, Vercler, CJ, Waljee, JF.
 Decision-Making in Cleft-Related Surgery: A Qualitative Analysis of Patients and Caregivers

 (2020) Cleft Palate-Craniofacial Journal, 57 (2), pp. 161-168.
- Fay, M, Guadarrama, J, Colmenares-Roa, T, Moreno-Licona, I, Cruz-Martin, AG, Peláez-Ballestas, I.
 The relationship between proxy agency and the medical decisions concerning pediatric patients in palliative care: a qualitative study (2021) *BMC Palliative Care*, 20 (1), pp. 1-11.
- Gutman, T, Hanson, CS, Bernays, S
 Child and parental perspectives on communication and decision-making in pediatric chronic kidney disease: a focus group study (2018) American Journal of Kidney Diseases, 38, pp. 81-95.
- O'Connor, D, Lynch, H, Boyle, B.
 A qualitative study of child participation in approaches in pediatric occupational therapy

 (2021) *PLoS ONE*, pp. 1-21.
- Kelly, KP, Mowbray, C, Pyke-Grimm, K, Hinds, PS.
 Identifying a conceptual shift in child and adolescent-reported treatment decision making: "Having a say, as I need at this time."
 (2017) Pediatric Blood and Cancer, 64 (4), pp. 1-8.
- Kerklaan, J, Hanson, CS, Carter, S, Tong, A, Sinha, A, Dart, A, Eddy, AA, Craig, JC.
 Perspectives of Clinicians on Shared Decision Making in Pediatric CKD: A Qualitative Study
 (2022) American Journal of Kidney Diseases, 80 (2), pp. 241-250.
- Koller, D. **'Kids need to talk too': inclusive practices for children's healthcare education and**

participation

(2017) J Clin Nurs, 26 (17-18), pp. 2657-2668.

- Lundberg, V, Eriksson, C, Lind, T, Coyne, I, Fjellman-Wiklund, A. **How children with juvenile idiopathic arthritis view participation and communication in healthcare encounters: a qualitative study** (2021) *Pediatric Rheumatology*, 19 (1), pp. 1-12.
- Melong, J, Meier, J, Hong, P.
 Shared decision making during surgical consultations: An observational study in pediatric otolaryngology
 (2019) European Annals of Otorhinolaryngology, Head and Neck
 Diseases, 136 (3), pp. S15-S19.
- Sahlberg, S, Karlsson, K, Darcy, L.
 Children's rights as law in Sweden–every health-care encounter needs to meet the child's needs
 (2020) Health Expectations, 23 (4), pp. 860-869.
- Teleman, B, Vinblad, E, Svedberg, P, Nygren, JM, Larsson, I.
 Exploring barriers to participation in pediatric rehabilitation: Voices of children and young people with disabilities, parents, and professionals (2021) International Journal of Environmental Research and Public Health, 18 (19), p. 10119.
- Vinblad, E, Larsson, I, Lönn, M, Olsson, E, Nygren, JM, Svedberg, P.
 Development of a digital decision support tool to aid participation of children with disabilities in pediatric rehabilitation services: Explorative qualitative study (2019) *JMIR Formative Research*, 3 (4).
- Jeremic, V, Sénécal, K, Borry, P, Chokoshvili, D, Vears, DF.
 Participation of Children in Medical Decision-Making: Challenges and Potential Solutions

 (2016) Journal of Bioethical Inquiry, 13 (4), pp. 525-534.
- Lee, SP, Haycock-Sturat, E, Tisdall, K. Participation in communication and decisions with regards to nursing care: The role of children

(2019) Enfermería Clínica, 29 (2), pp. 715-719.

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