Department of Paediatrics
Tampere University Hospital
Tampere, Finland

References

1. Blencowe H, Krasevec J, de Onis M, Black RE, An X, Stevens GA, et al. National, regional, and worldwide estimates of low birthweight in 2015, with trends from 2000: a systematic analysis. Lancet Glob Health 2019;7:e849-60.
2. Lee AC, Kozuki N, Cousens S, Stevens GA, Blencowe H, Silveira MF, et al. Estimates of burden and consequences of infants born small for gestational age in low and middle income countries with INTERGROWTH-21st standard: analysis of CHERG datasets. BMJ 2017;358:j3677.
3. Christian P, Lee SE, Donahue Angel M, Adair LS, Arifeen SE, Ashorn P, et al. Risk of childhood undernutrition related to small-for-gestational age and preterm birth in low- and middle-income countries. Int J Epidemiol 2013;42:1340-55.
4. Katz J, Lee AC, Kozuki N, Lawn JE, Cousens S, Blencowe H, et al. Mortality risk in preterm and small-for-gestational-age infants in low-income and middle-income countries: a pooled country analysis. Lancet 2013;382:417-25.
5. Bourassa MW, Osendarp SJM, Adu-Afarwuah S, Ahmed S, Ajello C, Bergeron G, et al. Review of the evidence regarding the use of antenatal multiple micronutrient supplementation in low- and middle-income countries. Ann N Y Acad Sci 2019;1444:6-21.
6. Kramer MS, Kakuma R. Energy and protein intake in pregnancy. Cochrane Database Syst Rev 2003;4:CD000032.
7. Das JK, Hoodbhoy Z, Salam RA, Bhutta AZ, Valenzuela-Rubio NG, Weise Prinzo Z, et al. Lipid-based nutrient supplements for maternal, birth, and infant developmental outcomes. Cochrane Database Syst Rev 2018;8:CD012610.
8. Hambidge KM, Westcott JE, Garcés A, Figueroa L, Goudar SS, Dhaded SM, et al. A multicountry randomized controlled trial of comprehensive maternal nutrition supplementation initiated before conception: the Women First trial. Am J Clin Nutr 2019;109:457-69.
9. Krebs NF, Hambidge KM, Westcott JL, Garcés AL, Figueroa L, Tsefu AK, et al. Growth from birth through six months for infants of mothers in the "Women First" preconception maternal nutrition trial. J Pediatr 2021;229:199-206.e4.
10. Lanou H, Huybregts L, Roberfroid D, Nikiema L, Kouanda S, Van Camp J, et al. Prenatal nutrient supplementation and postnatal growth in a developing nation: an RCT. Pediatrics 2014;133:e1001-8.
11. Kusin JA, Kardjati S, Houtkooper JM, Renqvist UH. Energy supplementation during pregnancy and postnatal growth. Lancet 1992;340:623-6.
12. Khan AI, Kabir I, Ekström E-C, Åsling-Monemi K, Alam DS, Frongillo EA, et al. Effects of prenatal food and micronutrient supplementation on child growth from birth to 54 months of age: a randomized trial in Bangladesh. Nutr J 2011;10:134.
13. Taneja S, Chowdhury R, Dhabhai N, Mazumder S, Upadhyay RP, Sharma S, et al. Impact of an integrated nutrition, health, water sanitation and hygiene, psychosocial care and support intervention package delivered during the pre- and peri-conception period and/or during pregnancy and early childhood on linear growth of infants in the first two years of life, birth outcomes and nutritional status of mothers: study protocol of a factorial, individually randomized controlled trial in India. Trials 2020;21:127.
14. Merchant KM, Villar J, Kestler E. Maternal height and newborn size relative to risk of intrapartum ceasarean delivery and perinatal distress. BJOG 2001;108:689-96.
15. Moore SE, Fulford AJ, Darboe MK, Jobarteh LM, Jarjou LM, Prentice AM. A randomized trial to investigate the effects of pre-natal and infant nutritional supplementation on infant immune development in rural Gambia: the ENID trial: Early Nutrition and Immune Development. BMC Pregnancy Childbirth 2012;12:107.

Improving Advance Care Planning for Seriously Ill Children: Engaging a Diverse Research Population Early and Often

See related article, p 247

In this volume of *The Journal* DeCourcey et al describe the development of a new pediatric serious illness communication program to support providers in advance care planning conversations with their patients and families.[1] Despite advanced care planning long being considered the standard of care for patients with life-limiting or life-threatening conditions,[2] there is increasing awareness that pediatric providers still have room to improve.[3] To address this meaningful gap, the authors used a step-wise, rigorous approach to adapt an adult communication guide for children. Study participants found the work to have the potential to "augment current practice and reduce variation" in advance care planning for children with serious illness. This patient group, identified in the study by Feudtner et al, complex chronic conditions,[4] may be familiar to many readers as overlapping with if not synonymous with children with medical complexity.

In addition to describing the development of the toolkit itself, the authors identified barriers to current advance care planning. These challenges will ring familiar to those providing time-intensive, conversation-focused medical care such as care coordination or mental and behavioral health, to include: barriers to incorporate care into current workflows, limited provider time, a need for usable documentation of the conversation in the electronic health record, and a gap in training impacting provider comfort with the care task itself. In particular, the authors highlighted that although interviewed providers expressed fears that initiating advanced care planning many cause anxiety or stress in their

C.F. supported under 1K23HL149829-01A1 for research related to care of children with medical complexity. E.P. supported under 1K23HD098289-01A1 for research related to engaging seriously ill children/families at risk for health disparities in research. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.
The authors declare no conflicts of interest.

0022-3476/$ - see front matter.
https://doi.org/10.1016/j.jpeds.2020.10.058

patients and families, the family caregivers and patients themselves did not share this concern. As quoted in the article by one parent, "there is little we have not already considered and worried about."

Thus, the authors' work meaningfully addresses the tendency of many pediatric providers to put off advanced care planning. The adapted forms for patients and their families include guided prompts to consider goals and other key elements to share with the provider, in a worksheet-style format. The accompanying conversation guides for providers, family caregivers, and patients help with normalizing and initiating advance care planning and could be used by providers at any point in their career, trainee or veteran.

In an explicit attempt to make the toolkit generalizable, the project engaged stakeholders from 2 large urban academic centers across a variety of disease types. The project included family and adolescents/young adult patients as stakeholders early in the process—an approach that should be applauded. Unfortunately, all family participants and the overwhelming majority of patients were of white race. Non-English-speaking participants were excluded. Acknowledging the authors' stated next steps of further adapting the guide to more diverse populations, this limitation highlights a widespread struggle to include nonurban, racial/ethnic minority, limited English proficient, and low-literacy patients and families in our research endeavors.

The reality is we must all do better to include diverse patients and families earlier in our research and quality improvement work.[5] Adaptation of materials designed by one population is not the same as concurrent involvement of other populations. It is not self-evident that this worksheet format and guide are the right set of tools for a more diverse set of patients and families. Advanced care planning can be understood as a chief example of shared-decision making, and research in this area has demonstrated that there are cultural differences in how patients and families choose to receive information as well as what type of information they prioritize in making decisions.[6,7] There may also be significant differences in how groups who have different communication preferences would choose to express these. Communication challenges have been shown to lead to increased team-family conflict in the pediatric intensive care unit, with higher rates of conflict in the Medicaid population, suggesting possible differential communication needs or styles for different populations.[8] To optimize communication strategies across a diverse set of populations might then require a menu of different options of tools rather than a single applicable of tools.

Institutional challenges with engaging minority populations in our research endeavors early and often are real and deserve our targeted eradication efforts. This research team likely faced common barriers to effective engagement of diverse groups in their study, although many of these are addressable. The cost of transcription and translation of materials into minority languages can be prohibitive during pilot stages especially; academic centers and sponsor organizations should consider how to support proposed research budgets to include these costs. Hiring of research staff should include the recruitment and professional development of staff with expanded language skills sets, so that participants with limited-English proficiency and low-literacy can be included in key-informant interviews, focus groups, and other stakeholder tasks. Processes for reviewing internal review board submissions also must support the inclusion of non-English materials by facilitating their rapid review, rather than the often-real experience of their review leading to a delay in study start. For example, allowing for bilingual internal study staff to be certified in translation may allow for quicker turnaround in language adaptation within a study.

In attempting to engage more diverse populations in future research, research teams will also need to contemplate interpersonal barriers to engagement and consider strategies to address them. In one study examining enrollment of seriously ill children in research in the pediatric intensive care unit, only 74% of parents reported they felt respected during a research approach and 63% believed that they had adequate time to decide about participation, suggesting both of these as targets for research teams to consider when attempting to enroll patients into research studies.[9] In addition, for stakeholder driven studies such as this, study teams may bring to bear principles of community engaged research to research conducted within the institution. Respecting that distinct ethical issues may arise with engaging children and parents in community-based research approaches, strategies that embody stakeholder involvement at all stages of the research process will ideally incorporate the viewpoints of diverse groups.[10] For example, considering partnership with a local community group engaged in advanced care planning activities in a community of diverse participants may be one way to expand the pool of eligible stakeholders. Adapting community-based engagement strategies for research in institutional settings in this way could improve participation of minority groups in subsequent efforts to modify this important intervention.

Other innovative approaches to improving engagement should also be considered. With the expanded use of telemedicine for clinical care, tools such as secure videoconferencing can be used to engage patients in focus groups, interviews, and other stakeholder-engaged research. Often institutions' legal and regulatory systems can create barriers to adoption of these tools due to privacy and other regulatory concerns. Instead, institutions should work to support these tools as a means of including participants from more rural areas or with other transportation barriers, which may distinctly impact those of lower socioeconomic status. With the rise of remote health platforms, there may even be more opportunities to engage patients previously perceived as out of reach in clinical data collection (eg, physiologic monitoring).

The ultimate goal of these efforts is to design and build our healthcare interventions with a diverse population as the starting point. This key limitation in development of the current intervention aside, the development of the pediatric serious illness communication program is an important step-forward in the expanded use of advance care planning in pediatrics. Subsequent iterations may benefit from the strategies discussed here to expand its generalizability and impact. ■

Carolyn C. Foster, MD, MSHS
Division of Academic General Pediatrics
Department of Pediatrics
Northwestern University Feinberg School of Medicine
Chicago, Illinois

Mary Ann and J. Milburn Smith Child Health Outcomes, Research, and Evaluation Center
Ann and Robert H. Lurie Children's Hospital of Chicago
Chicago, Illinois

Erin T. Paquette, MD, JD, MBe
Division of Pediatric Critical Care
Department of Pediatrics
Northwestern University Feinberg School of Medicine
Chicago, Illinois

Center for Bioethics and Medical Humanities
Northwestern University Feinberg School of Medicine
Chicago, Illinois

Northwestern University Pritzker School of Law (by courtesy)
Chicago, Illinois

References

1. DeCourcey DD, Partin L, Revette A, Bernacki R, Wolfe J. Development of a stakeholder driven serious illness communication program for advance care planning in children, adolescents and young adults with serious illness. J Pediatr 2021;229:247-58.e8.
2. American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children. Pediatrics 2000;106:351-7.
3. Orkin J, Beaune L, Moore C, Weiser N, Arje D, Rapopor A, et al. Toward an understanding of advance care planning in children with medical complexity. Pediatrics 2020:145.
4. Feudtner C, Feinstein JA, Zhong W, Hall M, Dai DS. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. BMC Pediatr 2014;14:199.
5. Coleman C, Abraham M, Johnson B. Strengthening diversity in research partnerships: knowledge to action guide. institute for patient- and family-centered care. 2019. https://www.ipfcc.org/bestpractices/strengthening-diversity/index.html. Accessed October 2, 2020.
6. Derrington SF, Paquette E, Johnson KA. Cross-cultural interactions and shared decision-making. Pediatrics 2018;142(Suppl 3):S187-92.
7. Tulsky JA, Beach MC, Butow PN, Hickman SE, Mack JW, Morrison RS, et al. A Research agenda for communication between health care professionals and patients living with serious illness. JAMA Intern Med 2017;177:1361-6.
8. Studdert DM, Burns JP, Mello MM, Puopolo AL, Truog RD, Brennan TA. Nature of conflict in the care of pediatric intensive care patients with prolonged stay. Pediatrics 2003;112:553-8.
9. Paquette E, Shukla A, Davidson J, Rychlik K, Davis M. Burden or opportunity? Parent experiences when approached for research in a pediatric intensive care unit. Ethics Hum Res 2019;41:2-12.
10. Anderson EE, Solomon S, Heitman E, DuBois JM, Fisher CB, Kost RG, et al. Research ethics education for community-engaged research: a review and research agenda. J Empir Res Hum Res Ethics 2012;7:3-19.