

Family Caregiver Partnerships in Palliative Care Research Design and Implementation

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Patient- and family-centered care “is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient’s life.”¹ Similarly, family partnerships in pediatric palliative care (PPC) research represent an innovative approach to the planning, delivery, and evaluation of research that is grounded in mutually beneficial relationships that recognize the importance of the family caregiver perspective. The goal of partnered research or study teams is to synthesize the unique perspectives of family caregivers, clinicians, regulatory representatives, and researchers to strengthen research design and implementation. This is accomplished by each unique stakeholder speaking from their own perspective, contributing what they know, and working together to integrate perspectives. The process of moving from just inviting family caregivers to be research subjects to actually engaging with family caregivers as partners with input into research design and development leads to feasible, acceptable, and effective research design and methods.

Bereaved family caregivers or those facing serious illness in a loved child often experience themselves being on

the outside of research or having research done to them rather than with them.^{2,3} Given the benefits of partnering as part of care delivery, it follows that the child’s family caregivers would also be partners in research aimed at expanding the knowledge base to guide clinical care. PPC aligns well with the tenets of patient- and family-centered research: trust, reciprocal relationships, honesty, transparency, respectful partnerships, cultural competency, and shared decision-making. In this article, we introduce family partnerships that include the role for family caregivers as coinvestigators through their inclusion in research design and implementation. Members of our geographically diverse study team have collaborated together through a PPC special interest group over the past decade to develop and implement proactively participatory-based PPC research. Each contributing author was provided with the writing prompt “What does family partnership in PPC research entail?” Collectively, the study team engaged in 10 collaborative conversations over the past 6 months to reflect their shared thoughts about the benefits, challenges, and opportunities for family partnership in PPC research. We provide the parent, clinician, research regulatory, and researcher perspectives, each of which



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encourages inclusion of family caregivers early and throughout the research process as valued members of the research team to advance the science of PPC while honoring the core values of the field.

The actual research partnership shows itself along a chronological programmatic continuum, from inviting parents to engage in research to inviting them to serve as participants, to give feedback, to declare what is missing from the science, and then to be cocreators of the science. The actual extent of partnership depends on provider and family caregiver comfort, opportunity, and maturation of research infrastructure. The format and timing of formal partnership development may vary by the culture of the institution and clinical area (hypothetical example: the NICU may host a fully integrated family advisory panel, whereas the PICU may have been slower). Research partnerships require an investment of time, trustworthiness, and mutual respect.

PARENT PERSPECTIVE, Dr MOON

As a parent of a child who died of neuromuscular disease, I welcome the opportunity to share my experience with the research team. Being approached for research partnership within the context of purposeful relationships feels like an opportunity to coengage in a shared mission to improve care quality and the mutual goal of enhanced PPC. For example, I can share the words and gestures of the nurses who made us feel safe. I can help you make the PICU less horrible (more soundproofing, please, and a space where parents can break down: it should never happen in a crowded hallway). Above all, I would implore health care providers to introduce PPC clinical and research partnerships early. Such engagement helped us to stop fixating on our

daughter's incurable disease so she could be a child again, and then we had 18 beautiful months.

The pain of losing a child is without comparison, so the needs of families like ours are urgent and complex. The only way to know what we are going through is to ask, and we want to talk about it. Failure to involve family caregivers in research because of perceived burden is like the well-meaning friend who doesn't talk about your child anymore for fear of upset. Yes, it can be hard to talk about our child's end of life, but it's worse not to be asked. If our input is valued, I, along with every family caregiver I know who has lost a child to serious illness, want those who provide care to seriously ill children to learn from our story. It brings meaning to our suffering and gives our child a voice. Research provides a means to altruistically contribute.

Although families are diverse in cultural, ethnic, educational, gender, and spiritual backgrounds, family caregivers emphasize the benefits and nonharms of participation in PPC research.^{2,4-6} Research is best informed by learning from us about the ways that our backgrounds may influence our readiness for research or even our trust in the research process. Just as the research team has insight into methodology and study design, we do have a complementary perspective on when and how our experiences should be shared. For example, as an evidence-based project for a palliative program, I am currently creating videos that help to make PPC education more accessible to clinicians based on my family's experience and my perspective on the PPC research. I am making this available as a potential education intervention that could have informative measurable outcomes for PPC education.

When we, as family caregivers, are invited to participate in the research process, we are essentially being invited to collaborate in sharing how we perceive our child's experience or our family's experience so that it would be best explored and understood. Such inclusion may provide family caregivers with a tangible sense that their child's story mattered and that their insight into their family's experience is worth exploring together.⁷

PHYSICIAN PERSPECTIVE, Dr WEAVER

Colleagues approach me every few weeks with PPC studies that my patient population would qualify for based on inclusion criteria. As I respect the importance of research as an academic approach to all fields of medicine, I keenly consider the stresses and struggles that the ill children and their family caregivers are facing concurrently. The idea of risk/benefit ratio in obtaining additional blood for a laboratory study from an already-placed intravenous line feels less intrusive than asking a family caregiver to engage in a survey or a long research interview when their child is critically ill. Although PPC research is important for raising awareness and adding insight, we need to also consider whether the research is ideal for the family caregiver in terms of timing and format. Family caregivers, through presence on research advisory committees, would bring this unique insight.

I would trust the research methods and approach more if I knew that family caregivers had been part of the research design and development and if I received deidentified summation of the overall results for further dialogue after study completion. The idea of having family caregivers on the institutional review board (IRB) and

scientific review committee would offer an additional layer of inclusion. Importantly, when the perspectives of patients, family caregivers, and providers are included in the same study, significant similarities and differences can be quickly discerned and then used to inform care. For example, several studies on end-of-life decision-making in pediatrics have concluded that some children, adolescents, and parents identify faith and religious practices as influencing their end-of-life decision-making, but providers did not identify this factor. In addition, perceived influencing factors reported by providers, such as financial costs, were not identified by parents.⁸ Such differences relevant to decision-making convey the importance of patient- and family-centered research in PPC and offer insightful clinical guidance.

Examples of when family partnership in research impacted research efficacy include when a multistep consent process for a PPC care study was approved by the IRB despite objections from the study team about the process likely being burdensome for eligible bereaved family caregivers. Enrollments rates were concerningly low (two-thirds lower than similar types of studies previously conducted at the same setting). The IRB agreed to alter its approved multistep process when an eligible father explained that the many steps were preventing him from being in the study: "Since my son died, I can't find my checkbook—never mind some study consent form that you mailed me. I just want to be in the study." This led to a change in the consent process from 9 steps to 3 steps. Enrollment increased from 12% to 36%. That narrative is one of benefit for family engagement and research processes. In a separate setting, when working closely with a family caregiver advisory committee about

a planned study, family caregiver feedback altered the timing of the planned initial approach to the eligible family caregivers by 3 days and naming of the study variable also resulted. As a result of the name change, the findings were valuable but could not be compared with previous studies in which a different variable name was used.

Partnering in PPC research is evident when family caregivers and providers jointly identify research priorities for this specialty, as was modeled through a Delphi study including family caregiver perspectives on PPC research priorities.⁹ Family caregiver partnerships can help prioritize research topics to ensure focused resource distributions and stronger future family-centered clinical care.

REGULATORY AFFAIRS PERSPECTIVE, Dr GORDON

Effective PPC depends on evidence on which to base clinical decisions; however, much of PPC is based on anecdotal experience rather than research codesigned and informed by family partnerships. Part of the difficulty with family partnerships in PPC research arises from the perception by IRBs that research partnerships with the terminally ill and their family caregivers differs fundamentally from other types of research partnerships. Family-centered care implies that research partnerships may involve multiple parties at multiple levels, not exclusively the patient. Out of an abundance of caution and concern, IRBs may view children and their family caregivers as particularly vulnerable or warranting extra protections in what may actually be mutually beneficial and collaborative relationships.

Certainly, I recognize that patients receiving PPC (and to an extent, their families) represent a population who

may have difficulty providing voluntary informed consent or assent and may be at risk for exploitation, even in well-intended partnerships.¹⁰ Assessment of the risks and benefits of the research partnerships may be difficult and may change rapidly because patients' goals change substantially as they near death; the concept of "minimal risk" as the risks of daily life may be difficult to apply in these research partnerships particularly during bereavement because of the complex nature of grief. All of these issues may contribute to IRBs reviewing PPC research partnership as though it were fundamentally different from other types of research partnerships.¹¹

I consider that although these vulnerabilities are real and pose a threat to the autonomy and the rights of patients and families in engaging as co-collaborators in research design, they do not differ qualitatively from the vulnerabilities of other research populations who join together in research design and development.^{12,13} Creative models of partnership exist in pediatrics, such as family advisory panels for genetic research in pediatrics and even consent forms that offer family caregivers and pediatric patients the option of serving as traditional research participant or engaged partner in future interfamily research opportunities.¹⁴ And questions of risk and benefit puzzle IRBs over a wide range of partnership-based research activities, from phase I research guidelines developed with family caregivers of children with cancer¹⁵ to clinical effectiveness trials.¹⁶

When the IRB reviews PPC research that has a purpose of enhancing knowledge about the unique perspectives of clinicians, researchers, and family members, it must ensure that research methods proposed to solicit and synthesize the unique perspectives are appropriately

identified and adequately described in the research proposal and consent forms. Study team members (including family) must be adequately prepared for this role of partnering. The IRB should ask what process is in place to support study team members encountering the experience of PPC research. The IRB should also consider the risks and potential benefits for clinicians, researchers, and family members being given access to the study findings in a partnering sense. With each of the above possible partnering roles, the IRB may not be in a position of regulating partnership but instead of asking for a thoughtfully articulated process that addresses possible benefits/risks of proposed partnership. This level of engagement by an IRB is humanistic while still

upholding regulatory standards, and that is when the posing of questions to ensure safety of all partnering roles becomes an important inquiry.

The research is often highly personal. I believe that learning from family caregivers about the ways in which they prefer to partner in qualitative and quantitative studies may further define the field of PPC research.

RESEARCHER PERSPECTIVE, Drs WIENER AND KELLY

The design of our research studies, particularly those that are addressing issues pertaining to PPC, need to be mindful of the potential emotional burden associated with study partnership. Burden can extend beyond study participants

because the emotional content may have a significant impact on the clinicians and researchers conducting the research. To assure that the most impactful questions and outcomes are achieved, we invest careful attention to the family caregiver and child voice. We believe this can be achieved by family caregiver partnership in each stage of the research process, from designing the research design to dissemination of the findings. The Patient-Centered Outcomes Research Institute (PCORI) resources for training lay-person partners have been helpful to the research process in our setting.¹⁷

Our research teams benefit from having contributions and buy-in from the interdisciplinary team that provides care to the patients and/or family caregivers being studied. Referral of study participants to only those who clinicians feel would benefit (not find the study questions intrusive) and those they perceive would be least inconvenienced by asking, or not be burdened by the experience, can result in data bias. Gatekeeping at the clinician level represents a real risk to the reliability of research findings.¹⁸ However, working with family caregivers, and also the clinical team, about when best to approach family caregivers about research has helped reduce burden on families and fostered research acceptance among clinicians.

We have engaged family caregivers by developing research family advisory groups. In large clinical trials, organizations focused on the care of children and adolescents with cancer, family caregivers and adult survivors of childhood cancer are engaged as members of the cooperative group and serve as an advisory board to the group. These key stakeholders are assigned to disease and supportive care research steering committees, serve



Steps of Engagement	Exemplar Resource or Reference
1. Participate in research	Engaging Parents and Stakeholders in Patient-Centered Pediatric Research: A Guide^a
2. Provide feedback on research experience	Bereaved parents' experiences of research participation^b Engaging Parents of Children Who Died from Cancer in Research Early Grief Experience^c
3. Prioritize research topics	Patient-Centered Outcomes Research Initiative^d
4. Codesign research agenda	https://courageousparentsnetwork.org/pages/collaborations-and-co-authorship-in-research^e and https://courageousparentsnetwork.org/topics/clinical-trial^f
5. Influence research design and approach	Pediatric Research Consortium Parent Advisory Board Development^g
6. Impact research policy and practice	Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities^h

FIGURE 1

Family caregiver involvement and resource samples. ^a [https://medschool.cuanschutz.edu/accords/cores-and-programs/practice-based-research-network-\(pbrn\)-core/coconet/resources](https://medschool.cuanschutz.edu/accords/cores-and-programs/practice-based-research-network-(pbrn)-core/coconet/resources). ^b <https://bmc-palliat-care.biomedcentral.com/articles/10.1186/s12904-018-0375-4>. ^c <https://pubmed.ncbi.nlm.nih.gov/32949763/>. ^d <https://www.pcori.org/engagement/research-fundamentals>. ^e <https://courageousparentsnetwork.org/pages/collaborations-and-co-authorship-in-research>. ^f <https://courageousparentsnetwork.org/topics/clinical-trial>. ^g <https://www.pcori.org/engagement/research-fundamentals>. ^h <https://pediatrics.aappublications.org/content/142/5/e20180822>. ⁱ <https://pubmed.ncbi.nlm.nih.gov/30761699/>.

on study committees, and are also members of the clinical trials data safety monitoring boards. The addition of “expert family caregivers” to advise on the timing, approach, and content of research fosters a functional co-participatory role.¹⁹

Expert family caregivers can improve the convenience of research request timing, the time commitment of research methods, and the flexibility of enrollment to include recommending tele-based consent modalities. They have expanded colearning to ensure that family caregivers understand the research process and researchers understand family caregiver-centeredness. They have improved the transparency of our process for sharing results, including expanding return of research results to disease-specific support groups. This inclusion empowers family caregiver and patient voices to inform the research continuum. Assessment and transparent reporting of perceived benefit-burden in palliative care research allows us to further assess family caregiver experience as a way to guide future research.

Incorporating key research partnerships far outweigh the risks. By synthesizing the unique perspectives of family caregivers, we honor the shared caring and, in many instances, shared values so that best practice can be achieved. Methodologic practices that are sensitive to time, place, and context are then identified. Research partnerships provide an opportunity for the unique perspectives of each stakeholder to be recognized and shared values identified, which limit the risk of one voice becoming too dominant.

Recognizing and regarding roles in research partnerships is important. Out of an abundance of respect for the family caregiver role or out of high regard for the relationship with the family caregiver, research teams may yield a study question, surrender a scientific approach, or abandon what is known from data. This is a risk we must be mindful of in interactions. The goal is the clear understanding that study teams are not necessarily asking family caregivers for their research expertise but are instead asking for how the research would impact their experience.

We have come to appreciate that the actual partnership is one of mutual learning and benefit. The partnerships can shift the standard of research practice, as happened when family caregivers and childhood cancer survivors effectively advocated for data sharing in a way that changed the expectations and standards for returning research results to participants.²⁰ Our research team brings a care and science expertise, and our family caregiver partners bring a care and experiential expertise, which, when combined synergistically, results in better, more family informed, and culturally respectful science.

CONCLUSIONS

Children receiving palliative care, their family caregivers, and their providers have together documented the overwhelmingly positive impact of not only their participation but their actual partnership in PPC research.^{2,4-6} Family caregiver partnerships have brought underrecognized and underexplored topics (hospice transitions, support for bereaved siblings, and symptom management)

to the forefront of research and intervention priorities; have reviewed and refined data collection materials to foster understandability; have expanded research participation to underrepresented communities through established and trusted peer relationships; and have creatively disseminated research results to foster family access.

Best practices for PPC have resulted from these partnerships. PPC researchers benefit from establishing family caregiver partnerships to inform research agendas and influence research procedures (Fig 1). We strongly recommend scientific review committees consider engagement of expert family caregivers in review of research design and methods. Family caregivers’ intimate knowledge and input regarding the research questions to be studied, as well as potential risk and/or benefit to families, are critical to studies that will be of interest to and ultimately benefit families.

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ABBREVIATIONS

IRB: institutional review board
PPC: pediatric palliative care

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