

ISSUE BRIEF

Telemedicine and Pediatric Home-based Palliative Care: Next Steps for Policy and Practice in California

Authors: Debra Lotstein, MD, MPH, FAAP, FAAHPM, Josseline Herrera Eguizabal, MS, Jessica Lira, MAOL, PMP, CCRP, and Jennifer Baird, PhD, MPH, MSW, RN, CPN

I. Background

Though children with medical complexity (CMC) make up less than 1% of all children in the U.S., they are a growing population with an outsized impact on the health care system, accounting for one-third of all pediatric health care spending (Cohen et al., 2012). While expanding the family-centered medical home model has appropriately been a primary focus for improving medical care for this population, pediatric palliative care (PPC) is an under appreciated resource that can provide an additional valuable layer of support for CMC and their families.

Often misunderstood as focused on end-of-life care, the goal of PPC is improving quality of life for children with serious illness, including those considered to be medically complex, at all stages of illness. PPC clinicians achieve this goal by focusing on aggressive symptom management, guidance with communication and medical decision-making, and psychosocial support for the entire family. Clinicians providing PPC consider the child within the context of their family and community, and help parents identify and focus on what matters most to the well-being of their child.

There are, however, relatively few physicians, nurses, and social workers with subspecialty training in PPC. Other important members of the interdisciplinary PPC team are also in short supply, including chaplains, child life specialists, and expressive therapists. Further, most PPC teams are based in children's hospitals or in hospice agencies, limiting access to PPC to CMC who are hospitalized or those who meet hospice criteria (i.e. a predicted six-month life expectancy). This limited access means that children and families are often without the support PPC can provide at home outside of end-of-life care.

Children with medical complexity deserve to maximize their time at home with family by limiting interruptions from medical appointments and hospitalizations. Providing care for these children and ensuring their comfort in the home can, however, place a burden on family caregivers. Families often struggle with providing medications and treatments, managing technology, and coordinating care across multiple fragmented service sectors. Providing pediatric palliative care services in the home has the potential to provide an extra layer of support for families to keep their child at home as much as possible.

In an effort to expand home-based PPC support for CMC in California, advocates successfully helped the state develop a home-based palliative care (HBPC) Medicaid waiver program (PPC Waiver), enacted in 2009 and available as a pilot program to children served by California Children's Services (CCS) in 10 counties. The program, known as "Partners for Children," was provided by community-based hospice and home care agencies, and the services covered are listed in Table 1 (CCCC, 2019). Unlike with hospice care, children were not required to have a short life expectancy to be eligible. A single state-wide evaluation of the PPC waiver program showed positive outcomes, including fewer inpatient days and high family satisfaction with the services (Gans et al., 2012; Gans et al., 2015).

On January 1, 2019, California changed how HBPC is provided for CMC, aligning the delivery model with the adult HBPC model for Medicaid beneficiaries, enacted in 2018 under California Senate Bill (SB) 1004. This shift in policy ended the PPC waiver program but expanded eligibility for HBPC services to all children with full scope Medi-Cal. It also removed the requirement that children should have a CCS-eligible condition. Anecdotally, uptake of the revamped program has been limited, with few community-based providers

offering services, and there is a lack of clarity on how care provided by HBPC providers might be integrated with the acute care services that CMC receive. Better ways of incorporating HBPC into existing care delivery models and increasing access to quality PPC services are needed.

Table 1. Current status of services previously covered by the PPC waiver, now under Medi-Cal (adapted from CCCC, 2019)

PPC Waiver-covered services	Yes, service still covered	yes, service still covered, but care defined/delivered differently	No longer covered
Pain and symptom management	X		
Personal care services	X		
Family counseling		X	
Care coordination		X	
Family training		X	
Respite care in and out of home			X
Expressive therapies (art, music, and massage)			X
24/7 palliative care phone consultation access			X

One potential way to improve access to hospital and community-based PPC is through telemedicine (TM), i.e. the use of real time videoconferencing between patients and clinicians. TM has been used successfully to increase access for CMC to other pediatric subspecialists and to provide PPC services, including blended models of virtual and in-person care (Miller et al., 2020). While uptake of TM had historically been slow due to billing challenges and lack of familiarity with TM technology, the feasibility and acceptability of using TM has rapidly increased in response to the COVID-19 pandemic, further bolstering its promise for PPC delivery.

In order to realize the full potential of California’s pediatric HBPC program, researchers from Children’s Hospital Los Angeles and University of Southern California’s Keck School of Medicine engaged a diverse group of stakeholders to better understand their perspectives on the current use of hospital and community-based PPC and how the transition in state policy has impacted them. Further, insights from these interviews were used to identify recommendations to improve implementation of the SB1004 policy for children and to develop new models of care integrating TM to increase access to high quality PPC.

II. Methods

Forty-two stakeholder semi-structured interviews were conducted between November 2019 and June 2020. Stakeholders included young adults with CMC, parents (interviews conducted in English (n=11) and Spanish (n=5)), payors, and pediatric medical care clinicians, including non-palliative care clinicians and hospital and community-based palliative care providers. To represent a wide range of backgrounds, families recruited varied in age of child, disease stability, child’s neurodevelopmental status, and primary language. Focus was primarily on stakeholders from Los Angeles County, as the project team is planning on piloting a TM HBPC model in the greater Los Angeles area. Individuals from other parts of California were included in the sample to understand how barriers and facilitators may differ across the state, and subject matter experts from outside of California were included to provide examples of successful models of HBPC for CMC in other states. Participants were identified by the study team using purposive and snowball sampling.

All stakeholders were asked about their understanding of PPC and about their experiences with and perspectives about TM (for palliative care or otherwise). Interviews with families and youth focused on the extent to which current or previous PPC and HBPC services met their/their child's direct care and care coordination needs, the components of the service that they found most/least beneficial, and the challenges they encountered in accessing providers, services, and equipment or supplies. Interviews with hospital and home-based palliative care providers focused on understanding the ways in which HBPC is currently accessed and delivered, and challenges they face in getting patients appropriately connected to services. Other stakeholders were asked questions targeted to their expertise in their care of CMC.

A qualitative thematic analysis was carried out on written transcripts of these interviews to synthesize key learnings. Additional feedback was solicited on the themes at a virtual design meeting held with 25 previously interviewed stakeholders on September 1, 2020. This feedback supported the study team's interpretations and provided additional context and examples for each theme.

This issue brief summarizes findings especially relevant to PPC policy and program development in California.

III. Key Findings

A. Families value pediatric palliative care, although awareness of the services included and how palliative care differs from hospice care is low

Families interviewed who have received PPC endorse its value, citing symptom management, psychosocial support, and assistance with goals of care decision-making as key benefits. Parents also shared the value of connection to PC providers. They expressed a sense of being seen, understood, and affirmed in a way that they do not typically experience from other providers. Other parents shared how PPC providers were able to help advocate for the family to have their needs met, whether around logistical challenges or material support (e.g. with receipt of needed supplies).

Many families shared that prior to receiving PPC, they had been unaware of the availability of these services, or had thought PPC was only for end of life care (like hospice care). Yet families were not alone in this perception, as there was confusion among multiple non-palliative care professionals about the differentiation between hospice and palliative care, lack of awareness of the availability and core services of HBPC, and of the benefits of this type of care.

Further complicating the distinction between hospice and HBPC was the observation from both families and providers that children commonly shift eligibility between hospice and HBPC, depending on the stability of a child at any moment. PPC providers confirmed the challenge of determining a six-month prognosis for children, noting that this adds to the complexity of knowing which program to refer a child to, and when and how to change programs/services when the child's status changes.

B. Telemedicine is a feasible way to increase access to PPC in the home

Receiving PPC from within the patient's home, whether delivered in-person or via TM, has benefits for both families and providers. Families described how care at home reduces the burdens associated with going to visit an office or clinic, including disrupting a child's complex routine, and the challenges of transporting a medically fragile child. They additionally described the significant financial costs to transportation and time off work that might be needed to bring the child to an office. Parents also described how they appreciated the ability to show clinicians how their child functions in the home setting.

“ At first I was very hesitant (about the palliative care referral)... To this point, I refused to sign all the paperwork because I keep on saying, once he's in palliative, he's one step closer to hospice. And I don't feel like we're anywhere near that. But they're following him for pain, so that's how we've started (with palliative care). ”

— (Parent)

Respondents felt that the use of TM could increase access to subspecialty PC for families who live far from hospital centers with more robust PPC teams. PPC providers shared that the counseling/discussion-based nature of care is conducive to a TM visit. Stakeholders suggested that another way TM might increase PPC access is by lowering the burden of coming to a palliative care clinic. As a result, this could lower the threshold to follow through with a PPC appointment, especially for newly referred patients who may be unsure of the reasons for a PPC consultation due to confusion over what PPC is and how it can be helpful. The ease of a TM visit also can help families who appreciate the benefits of PPC but may choose to skip in-person PPC visits in weighing the risks vs. benefits of having many frequent clinical visits for their child.

Providers shared that another benefit of providing care while the patient is in their home is the ability to assess the child's environment, providing insights on behavioral patterns, family coping, and potential challenges to adhering to treatment plans. Most of these benefits to care in the home can be translated to TM-based home visits, although physically helping to rearrange either medications or equipment might be more challenging over TM.

Prior to the COVID-19 pandemic, feasibility of TM was a significant concern for stakeholders. Some providers worried about the technology resources and know-how of families to hold a visit. Yet even in the interviews conducted prior to March 2020, families and providers with TM experience were generally satisfied with them. Stakeholders reported that with minimal assistance of support staff before the scheduled TM visit, families were able to successfully log-in and speak with their provider. During the September 2020 stakeholder meeting, participants shared how their perspectives on what can be done over TM had expanded, although there were still concerns on how to maximize the value of TM visits in terms of ease and quality. WiFi access and bandwidth remains a concern for some stakeholders, which can affect the quality of the transmission of the visit.

C. Transitioning from the “PPC waiver” to the new SB1004 policy for pediatric HBPC created confusion around eligibility, authorization, and payment for HBPC

Despite 10 years with the PPC waiver program in Los Angeles and other counties in California, two years since the passage of SB1004 for palliative care for adults, and ongoing educational efforts to differentiate palliative care from hospice services, there remains confusion across all stakeholders interviewed about the core services of palliative care, and the differences between palliative care and hospice. The transition from the PPC waiver to the new SB1004 policy exacerbated the confusion that already existed about the difference between the PPC waiver and hospice. Furthermore, many providers interviewed (all pediatric focused) were unaware of the availability of an HBPC benefit for children with serious illness.

Some payors and providers were uncertain which children are (or should be) eligible for HBPC. Some respondents felt that having a list of specific eligible diagnoses would be helpful, although others felt that might restrict eligibility too much. Respondents also shared that some Medi-Cal managed care organizations (MCOs) require that children have a limited life expectancy of one year (which may be derived from the adult guidelines) while other MCOs do not. Variation in eligibility requirements could lead to disparities, with some children not being eligible for services they otherwise might benefit from, simply because of which MCO they are in.

Shifting administrative and financial responsibility for HBPC services from CCS to MCOs raised concerns among stakeholders, as coordination and payment for medical services for many CMC historically has been led by CCS. Stakeholders noted that staff unfamiliar with the needs of CMC generally and PPC specifically are now overseeing eligibility decisions, which might limit access to services. Further, MCOs may lack motivation to pay for palliative care services due to a misalignment of the potential program benefits. The limited existing evidence suggests that cost savings associated with high-quality palliative care comes from fewer hospital days. However, for many CMC, the cost of hospitalization is paid by CCS, while HBPC is paid for by the MCOs. Thus, CCS realizes the cost savings while the MCO assumes an additional expense.

“[The telemedicine visit] saved me from having to do the whole trip to [the hospital], packing all ten bags to go out the door and make sure everything, the meds are drawn, everything is ready to go, and then fight traffic all the way there, fight traffic all the way home. It's so much easier. I'm not very good electronically, so it always takes me a few minutes to get connected properly. But other than that, it's very easy.” — (Parent)

While the now obsolete PPC waiver program was authorized and paid for by CCS, with SB1004 the state signaled the intent for MCOs to cover these services as they do for adults. However, as the guidance was released, per the study’s stakeholders, there was confusion over who would authorize referrals to HBPC. The state guidance from the California Department of Health Care Services (DHCS) said that in some cases MCOs would pay for the services and in other situations CCS would continue to be fiscally responsible. While this was clarified in a later numbered letter indicating that if a CCS special care center made the referral then CCS would be responsible, stakeholders continue to feel this guidance is overly complex when put into practice.

Stakeholders reported that billing codes and other information needed to provide and pay for PPC were not created in the state policy guidance from DHCS. According to some stakeholders, there is no payment mechanism for HBPC for children who are not in an MCO, i.e. children with fee-for-service Medi-Cal. Providers also reported that only hospice agencies can bill for some of the codes provided for reimbursement, so that home nursing agencies providing HBPC cannot be reimbursed for these services. In addition, specific guidance around billing codes for CCS were not designated.

Furthermore, stakeholders described how providing HBPC may not be financially sustainable for some providers. Many providers and some payors shared that it was difficult to have a fiscally viable program with fee-for-service billing and that case rates were more feasible, allowing providers to personalize services towards patient needs.

D. Stakeholders report variation in the services offered in HBPC, and lack of certainty over which services should be covered

There is variation in the services currently being offered as part of the current HBPC model and concern that some important services are no longer explicit parts of the HBPC benefit (see Table 1 for the list of services). More specifically is a sense among those with experience with the PPC waiver program that two services, respite care and expressive therapies, are no longer included under the HBPC benefit, and yet they accounted for a large part of what was valuable to families about the PPC waiver.

Some HBPC providers who were also providers under the PPC waiver have continued to offer expressive therapies (including art, music and massage), a popular part of the PPC waiver program. Their ability to offer these services depends on how they are reimbursed for their care – some can pay for these under capitated contracts, allowing them more flexibility in services offered. Other providers may be using philanthropy to provide the services. Some payors reported being reluctant to pay for “non-medical” services (e.g. expressive therapies or respite care) without evidence for their impact on quality of life or utilization outcomes.

Another area of uncertainty is that services from a physician or nurse practitioner are now included in the pediatric HBPC program, as they are in the adult model in SB1004. As this was not required under the PPC waiver, the role of the medical provider in pediatric HBPC is not well defined. Further, the paucity of trained PPC physicians and nurse practitioners means that some children may not have access to HBPC services at all if these agencies are unable to negotiate contracts with payors. In addition, hospital-based PPC clinicians noted that if medical care is being provided from the HBPC agency, additional coordination is needed to avoid overlapping services.

Stakeholders also shared that some variation in services offered by HBPC can be useful, as the roles HBPC play may vary depending on which part of the continuum of care is missing for a given family in a particular setting. For example, in areas where comprehensive pediatric medical homes are lacking, the HBPC agency might be able to provide the medical care coordination that other families in robust medical home models already have.

“...in the transition to SB1004, expressive therapies were essentially eliminated — they are not required by DHCS. And some payers are, essentially, paying for them or allowing them in a per member per month rate type situation. But for the most part, payers are not including expressive therapies, and that’s been a piece that has needed advocacy.”

— (Community-based palliative care advocate)

IV. Policy Recommendations and Next Steps

In these interviews, families and providers described how, when delivered in a robust manner, palliative care can decrease burdens and reduce suffering for patients and families. Yet it was notable how many study participants were unable to differentiate between hospice and palliative care or to clearly articulate the “essentials” of palliative care (symptom management, medical decision-making, psychosocial support). Few outside of hospital-based PPC providers appeared to have a clear conceptualization of the core composition of the PPC team as providers with a unique skill set and approach to symptom management and to building trust with families in order to align the family’s goals and values with the care the child receives.

This lack of understanding of PPC may be both a cause and a result of the current varied models of both hospital and home-based PPC, which have been shaped by the systems for PC created for adults or specific to the model of care provided in the now-obsolete PPC waiver program. This confusion is compounded by a lack of guidance from California DHCS on how to implement pediatric HBPC services. Payors and service providers appear to be unsure of the next best steps for providing the HBPC they are now required by law to provide to all eligible children in California.

Further, the confusion around PPC eligibility and services appears to underlie multiple other concerns heard in the interviews: the fear about enrollment in PPC services from families who worry they are being referred for end-of-life care, the paucity of referrals made to PPC from non-PC providers, inconsistencies in services offered by (community-based) PPC providers, and reluctance and variations in contracting between MCOs and agencies delivering HBPC.

The lack of clarity prevents achievement of the goal that all CMC in California will have timely access to the services they need from providers skilled and experienced in PPC. The following recommendations and next steps could help remedy this situation to achieve that goal.

A. Increase referrals for HBPC by identifying children who may benefit at the agency level (MCO or CCS) based on diagnoses, medical technology dependence and high avoidable health care utilization

As referral rates to HBPC were low under the PPC waiver and have continued to be under the new policy, novel strategies to increase referrals are needed. Identifying eligible patients from administrative records had been a successful strategy for some PPC waiver counties wherein some CCS agencies proactively identified children who could benefit from the service. Some payors are also using this approach in identifying adults who might benefit from HBPC under SB1004. The payors (i.e. MCO or CCS) should make primary care providers aware of the referral via written communication and have a mechanism to discuss the appropriateness of the referral if there are questions.

B. Use telemedicine to expand the reach of specialty trained PPC providers to children throughout California

TM allows subspecialty PPC providers, primarily based in children’s hospitals, to be a resource for community-based HBPC agencies who lack pediatric specialization. The PPC providers can separately or jointly provide direct patient care and offer consultation and education for community-based staff. Involving hospital-based PPC teams can also help to integrate care plans of the child’s acute medical and community-based providers, which is especially important as most CMC receive ongoing care from multiple subspecialists. This integration is likely more important than it is for adults who have a smaller list of common conditions with more predictable disease trajectories, and who may be under less active disease management regimens.

Given the rapid expansion of the use of TM and video conferencing as society navigates the COVID-19 pandemic, TM is now a highly feasible method to deliver integrated, high-quality PPC care to the most children possible. Furthermore, COVID-19 and recent social unrest have laid bare the racial/ethnic and economic inequalities of the U.S. health care system, making it clear that clinicians need to be more proactive in assuring that supportive services are reaching medically underserved families. Additionally, historical mistrust of medicine among Black and Latinx communities might impact the uptake of TM, which should be studied and considered in program planning. (Eberly et al, 2020). While some families may require individualized adaptations, current TM service appears to be simple and ubiquitous enough to reach nearly all families, especially if technological support and instructional tools (e.g. Family Voices, 2021) are available when needed.

C. Clarify guidance on program eligibility and financial responsibility and create needed payment mechanisms for providers

Clarifying guidance from California DHCS on pediatric HBPC will minimize disparities in access to services and support adequate reimbursement for HBPC providers. Priorities for improvement include the need to:

- Clarify and simplify guidance on who is responsible for payment of HBPC: CCS vs MCO vs fee-for-service Medi-Cal
- Clarify that payment for hospital-based PPC is outside of this SB1004 benefit
- Assure that appropriate billing codes and payment mechanisms are available for all providers to be reimbursed by different payors
- Assure that life expectancy is not an eligibility criterion for HBPC. Prognosis-based criteria are likely to exclude many children who otherwise could benefit.

Over time, as more evidence is available to show which patients benefit most from which sets of services, the guidance should be more prescriptive about a guaranteed minimum set of services. In addition, the state should address the issue of misaligned incentives, i.e. if MCOs are paying for HBPC but not receiving the cost-savings that might accrue.

D. Increase the financial viability of providing HBPC for more children by creating a uniform tiered, capitated payment system for HBPC services

If CA DHCS set up a uniform tiered, capitated payment system, all children might start at a higher payment tier during the intensive enrollment process where urgent needs are identified and addressed, and connections are made in the care network. Cases could be reviewed every 6 months to assess if a child's and family's service needs have stabilized, with a lower-case rate given to cover less intensive ongoing services. This would foster access for more children, avoid overuse, and give providers the resources necessary to provide a higher level of services when needed for the child and family. Processes would need to be developed for appropriate tier reassessment, and mechanisms created to prevent discontinuation of helpful services that are preventing ER use and family burnout.

E. Encourage HBPC agencies to coordinate care with primary and hospital-based medical clinicians, including PPC providers where available

As CMC frequently have multiple medical teams and various people supporting care coordination, it is important that HBPC teams are part of these networks. This could be enacted via quarterly reports from HBPC agencies to acute care providers and payors. Access to the same medical records would also facilitate this coordination.

V. Conclusion

These findings suggest that HBPC, provided by professionals with training and experience in PPC, has the potential to support the quality of life of CMC and their families. However, existing care models of pediatric HBPC in California are not optimally meeting this potential. Current models are shaped by either the adult model of HBPC outlined in SB1004 or the older PPC waiver model of HBPC. The adult HBPC program is designed to support the needs of adults in Medi-Cal MCOs who have one of a small number of diseases with predictable courses (e.g. heart failure, dementia, cancer). The former PPC waiver model covered children in CCS; it largely focused on social/emotional support (e.g. expressive therapies) and lacked medical management of the child's care. Neither of these models provides the structure for a strong pediatric HBPC model that can accommodate children with rare and complex diseases, cared for in complex pediatric health systems. Further it can be difficult to predict life-expectancy in these children, and many will have ongoing needs for symptom management, support with medical decision-making, and psychosocial support for many years.

Ongoing advocacy is needed to ensure that changes are made to maximize the potential of quality HBPC services to reach as many CMC and their families as possible. State policymakers should partner with families, providers, and payors to address the recommendations listed above. In addition, there is an urgent need to develop and evaluate novel models of HBPC to support the expansion of PPC to CMC statewide. As suggested by these findings, these models could use TM to help address the shortage of experienced PPC

clinicians, as well as to better integrate providers across settings. These evaluation efforts could help with identifying which services are the most helpful for specific populations of CMC, and further define the impact of these services on child and family quality of life and health care utilization. Coordinated model development across locales could provide information needed on how to implement effective programs. Transparent data about utilization from the state and from individual MCOs would help hold policymakers and payers accountable for how well they are reaching the target population. With further experience and evidence, California DHCS could refine its guidance for pediatric HBPC, to best serve the most children

Clarity around HBPC policy and evidence for effective models of care will go a long way to help stakeholders understand what pediatric HBPC can offer, encouraging them to use and pay for the most supportive services for vulnerable children and their families.

References

- Cohen, E., Berry, J. G., Camacho, X., Anderson, G., Wodchis, W., & Guttmann, A. (2012). Patterns and costs of health care use of children with medical complexity. *Pediatrics*, *130*(6), e1463-e1470.
- Coalition for Compassionate Care of California. **Pediatric Palliative Care Waiver Transition Resource Guide**. <https://coalitionccc.org/pediatric-palliative-care-waiver-transition-resource-guide/> Published 2019. Accessed April 20, 2021.
- Eberly, E., Kallan, M., Julien, H. et al. (2020). Patient Characteristics Associated with Telemedicine Access for Primary and Specialty Ambulatory Care During the COVID-19 Pandemic. *JAMA Network Open*, *3* (12); e2031640. Family Voices. Nuts and Bolts of Telemedicine: Essentials for a Family-Centered Experience. <https://familyvoices.org/telehealth/curriculum/> Published 2021. Accessed April 22, 2021.
- Gans, D., Kominski, G. F., Roby, D. H., Diamant, A. L., Chen, X., Lin, W., & Hohe, N. (2012). Better outcomes, lower costs: palliative care program reduces stress, costs of care for children with life-threatening conditions.
- Gans, D., Hadler, M. W., Chen, X., Wu, S. H., Dimand, R., Abramson, J. M., ... & Kominski, G. F. (2015). Impact of a pediatric palliative care program on the caregiver experience. *Journal of Hospice & Palliative Nursing*, *17*(6), 559-565.
- Miller, K. A., Baird, J., Lira, J., Eguizabal, J. H., Fei, S., Kysh, L., & Lotstein, D. (2020). The use of telemedicine for home-based palliative care for children with serious illness: a scoping review. *Journal of pain and symptom management*.

The Lucile Packard Foundation for Children’s Health unlocks philanthropy to transform health for all children and families – in our community and our world. Support for this work was provided by the Foundation’s Program for Children with Special Health Care Needs. We invest in creating a more efficient system that ensures high-quality, coordinated, family-centered care to improve health outcomes for children and enhance quality of life for families. The views presented here are those of the authors and do not reflect those of the Foundation or its staff. Learn more at: lpfch.org/CSHCN
