

Normalize-Ask-Pause-Connect: A Clinical Approach to Address the Emotional Health of Pediatric Patients with Chronic Conditions and Their Families

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Over the past 50 years, the prevalence of childhood chronic health conditions has increased.¹ Pediatric chronic illness is a major threat to the emotional health and wellness of children and their families.² Children with chronic health conditions are at substantially elevated risk for mental health problems, including anxiety, mood, and behavioral disorders.³ Mental health concerns in this growing population pose a high burden to individuals, families, communities, and society.²⁻⁴

Diagnosis of a pediatric illness can also be a stressful and traumatic experience for parents and family members. Caring for a child with a chronic health condition imposes long-term stressors for the family.⁴ Parents of children with chronic health conditions frequently experience mental health difficulties including anxiety, depression, and traumatic stress.⁵ Parental mental health exerts a powerful influence on child developmental and behavioral trajectories and is often a stronger predictor of child outcomes than disease- or treatment-related factors.^{6,7}

It is important for pediatric health care professionals to proactively address both the physical *and* emotional difficulties inherent within childhood chronic illness.^{2,8-10} Initiating discussion about patient and family emotional health early and often, beginning at the time of diagnosis, can prevent the emergence or worsening of mental health symptoms by helping patients and family members understand that their feelings are common and expected, identifying early signs of distress, and connecting families with available supports.⁴ This discussion can also affect how patients and families perceive mental health support and whether they view this as a standard component of health care that can be accessed when needed.¹¹ This must be prioritized within the pediatric health care setting, particularly given the current epidemic of mental health problems in children and diminished access to specialized mental health care.¹²

Unfortunately, routine discussion about patient and family emotional health seems to occur infrequently in practice.^{4,11} Barriers to discussion about emotional health include insufficient training of health care professionals to promote emotional health and wellness, discomfort with initiating conversations about emotional health, time constraints, and limited referral resources.^{4,8-10} Health care professionals are trained to “fix” or treat issues and may

avoid asking about social or emotional difficulties that they perceive they cannot fix or treat. However, this practice gap inadvertently communicates to patients and families that the pediatric health care setting is not an appropriate or safe space to disclose emotional difficulties or that the health care professional is too busy to discuss these topics.¹¹ We propose a straightforward approach for pediatric health care professionals to address emotional health and wellness with patients and their families, acknowledging the barriers within standard clinical practice.

Normalize-Ask-Pause-Connect

Normalize-Ask-Pause-Connect (N-A-P-C) is a novel clinical approach designed to proactively address patient and family emotional health and wellness within pediatric health care (**Figure**). *N-A-P-C* was developed by the authors in response to calls for health care professionals to address the emotional health of children with chronic conditions and their families. The *N-A-P-C* approach has been included within the American Board of Pediatrics Roadmap Project as a resource for health care professionals to build capability in supporting the emotional health of patients and families.^{4,13} Although *N-A-P-C* is new within the context of pediatric health care, it is based on well-established, fundamental therapeutic communication skills: normalization of emotional responses, open-ended questions, active listening, reflection of feelings, compassionate silence, and identification of strengths and supports.¹⁴ The *N-A-P-C* approach is also aligned with existing tools to facilitate discussion of difficult issues in health care.^{15,16} Although existing tools have focused on medical decision making and advance care planning rather than emotional health specifically, they provide evidence that open

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N-A-P-C *Normalize-Ask-Pause-Connect*

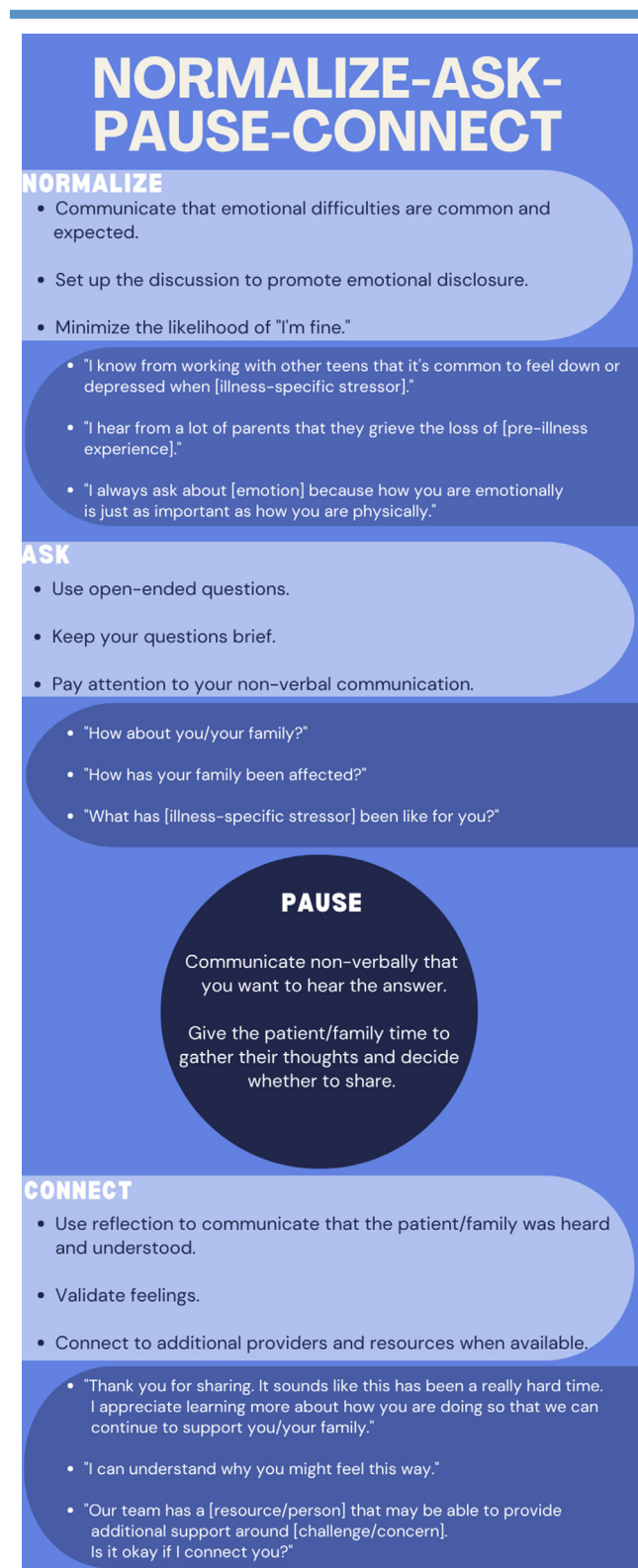


Figure. *Normalize-Ask-Pause-Connect* clinical approach.

communication about difficult or sensitive issues within the health care setting can reduce patient anxiety^{16,17} and increase feelings of closeness to the provider.¹⁸

The *N-A-P-C* clinical approach is designed for use by any health care professional, including those without specialized training in mental health. It can be used for both patients and family members, beginning at the time of diagnosis (including prenatal diagnosis with expectant parents) and continuing through long-term follow-up care. In some cases, such as an adolescent who is unlikely to disclose emotional difficulties in front of parents, or a parent of an older child who may be distressed by listening to the conversation, this approach is most appropriate for individual discussion with the patient or family member. Although it is common practice to document in the electronic health record during a patient encounter, health care professionals should refrain from charting during a *N-A-P-C* discussion given the central role of the patient-provider relationship for this clinical approach.

The first step, *Normalize*, communicates to patients and families that emotional difficulties are common and expected in response to chronic health conditions (eg, "I hear from a lot of parents that they feel really anxious when [illness-specific stressor]."). The intent of this step is to proactively reduce stigma and set up the discussion in a manner that promotes emotional disclosure. Patients and families who understand that their experiences are normal tend to feel more comfortable and safe in sharing their experiences. Health care professionals should avoid discussing "strength" or labeling patients or family members as "strong," as this inadvertently communicates that emotional difficulties are unexpected or signify weakness.

The second step, *Ask*, communicates through open-ended questions that there is more than one "right way" to experience or react to a clinical stressor/situation and that the health care professional is interested in their thoughts, feelings, and experiences. The questions in this step should be brief to allow patients and families to do most of the talking (eg, "How about you?" "How have you been affected?"). Nonverbal communication, such as facing the patient, sitting down, and maintaining eye contact, to demonstrate engagement in the conversation is paramount.

The third step, *Pause*, communicates to patients and families that the health care professional is genuinely interested in their response and that emotional health is sufficiently important to dedicate time within the clinic visit or hospital encounter. This step gives patients and families the time to gather their thoughts and decide whether to disclose any difficulties. This may be the first time a patient has ever been asked about emotional health within the health care setting and the patient may not have come prepared to discuss these topics. It is important to remember that compassionate silence is a fundamental therapeutic communication skill.¹⁴ Health care professionals should refrain from filling the silence with their opinions on the subject or additional prompts due to their own discomfort with silent pauses.

The final step, *Connect*, focuses on validating feelings and identifying available supports. In this step, the health care professional first uses reflection and supportive statements to communicate that the patient or family member was heard

and understood (eg, “It sounds like this has been a really hard time,” “I can understand why you might feel this way”). The use of supportive statements is important, as launching into problem-solving without first reflecting and validating experiences could be perceived as oversimplifying the depth of their struggles. Health care professionals should also refrain from trying to cheer-up the patient or family member, as these responses can feel invalidating. Next, it is important to understand the supports that patients and families already have available to them within their social network and community and to encourage use of these supports, including peer-to-peer support. When available, patients and families should also receive connections with a social worker or case manager within the health system for additional resources. These resources may include referrals to mental health care within the community. It is important to consider the accessibility and feasibility of recommended services and to have a direct conversation with the family about how barriers to care could be addressed. Although some families may not be ready to access these services when first recommended, knowing they are available can still be helpful, allowing for follow-up when the family is ready.

These 4 steps can be repeated at every clinic visit or hospital encounter, even when families choose not to disclose difficulties initially. These steps could also be used to initiate discussion about social factors, given the importance of reducing stigma, understanding lived experiences, and identifying available supports for families experiencing adverse social determinants of physical and emotional health. Continued use of the *N-A-P-C* clinical approach provides ongoing opportunities for discussion of emotional health and provision of support, thereby demonstrating that emotional health and wellness are integral components of the patient’s and family’s health and well-being.

Case Vignettes

Case 1: Child with Type 1 Diabetes

A 12-year-old girl with type 1 diabetes presented to endocrinology clinic with her mother. She was diagnosed with type 1 diabetes 2 years prior and was clinically well. She and her family collaborated with the school nurse and endocrinology team after receiving the diagnosis. She quickly returned to her usual activities, and her blood sugar levels were well controlled. However, at this clinic visit, her mother reported concern about high blood sugars and an increase in conflict around the medical maintenance of diabetes at home. Her reminders for her daughter to take insulin or check her blood sugar often resulted in an argument.

The provider began by normalizing these difficulties along with the general challenges of managing a chronic illness (“Many patients have shared with me how challenging diabetes care can be. You are asked to do so much every day.”). The provider described different emotions that often arise for patients managing a chronic illness and asked her which emotions she had experienced. She disclosed feeling angry and frustrated that she was different from her peers

and burnt out due to the emotional burden of managing her diabetes. The provider listened attentively and then validated her feelings and reflected on the ways in which emotions may be impacting illness management and family communication (“I can understand why you feel this way. It sounds like these feelings are starting to affect areas of your life that are important to you, like taking care of your health and your relationships with family.”). With this further insight, the provider identified additional resources to support the family. The provider, parent, and child agreed upon meeting with a psychologist at the hospital who could collaborate with the medical team, while further supporting the child’s emotional functioning and family communication. The family left this appointment feeling heard by their provider and hopeful about the plan they created together.

Case 2: Young Adult with Heart Failure

A 20-year-old man was admitted to the pediatric cardiac intensive care unit with decompensated heart failure. He was diagnosed as an infant with a metabolic disorder and associated cardiomyopathy, for which he was followed his entire life by several specialists. Over the past 10 years, he was hospitalized repeatedly for heart failure exacerbations, often requiring intensive care. Despite his diagnosis, he was pursuing his education while working full time.

During this admission, he appeared upbeat and hopeful about returning to his everyday life, as he had with prior hospitalizations. His family was frequently at his bedside, keeping him company but mostly avoiding the topic of his illness. He was well-versed in his diagnosis and understood the poor prognosis but did not seem to recognize how close he was to ultimately succumbing to his disease. During routine medical care by his cardiac intensivist, he never complained of symptoms, despite being obviously symptomatic on examination.

On several occasions, the cardiac intensivist sat down with him and normalized the struggles of a chronic illness (“It can be really hard to have a chronic illness and to spend so much time in the hospital. A lot of patients tell me they worry about their future or how the illness will affect their family.”). She asked about his life outside of the hospital, his family, and his feelings around this hospitalization and his illness. She sat quietly as he began to reflect on his illness. He started with his typical refrain of “things will get better” and “I’ll be back to work soon.” However, over time, he revealed that he had a hard time admitting to himself and others the severity of his diagnosis. His family was in denial, and he felt he had to maintain an optimistic outlook for them. Although he had contemplated his wishes around his end of life, he never had a conversation with family for fear that it would cause them distress. He shared his anxieties and fears around dying, mostly around leaving his family behind to grieve, and how he would want to spend his last days. He engaged in discussion around resources and strategies that would help support him and his family. With support from his medical providers, he articulated his end-of-life wishes to his family. By giving him the space and time to process his own grief and express his

wishes, he ultimately passed away as he wished, surrounded by people he loved.

Case 3: Mother of Infant with Congenital Heart Disease

A 6-month-old infant presented to clinic with his mother for routine developmental follow-up due to his history of newborn cardiac surgery. A diagnosis of congenital heart disease had been made prenatally and he spent the first 4 weeks after birth in the hospital. He required an urgent procedure immediately following birth and experienced complications after cardiac surgery that prolonged his hospital stay. These experiences placed immense stress on the family.

The mother struggled emotionally since returning home with her baby. She had been in “survival mode” since receiving the prenatal diagnosis and it was not until her baby was medically stable at home that she realized the extent of her distress and intrusive thoughts. The mother did not know if what she was feeling was normal and worried what others would think if she were to disclose these difficulties. She thought it might be inappropriate to bring up a concern related to her own well-being at a clinic visit for her baby. She attended frequent outpatient clinic visits with her baby following hospital discharge, but these visits seemed entirely focused on the baby’s medical status.

At this visit, however, the provider normalized parental emotional struggles following discharge from the hospital and asked how she and her husband were doing emotionally (“Many parents struggle with difficult feelings after their baby is discharged from the hospital. How have you and your husband been doing?”). The mother decided to share her experiences. The provider validated her feelings and reassured her that these emotional reactions were common (“It sounds like this has been a really hard time. I want you to know that what you are feeling is very common.”). The mother felt relieved and engaged in a discussion about coping strategies and resources.

Recommendations for Health Care Professionals

Addressing emotional health and wellness within pediatric health care requires a practice change. Health care professionals may express discomfort asking questions about emotional health, concerns around a lack of knowledge or resources to address emotional health challenges, or worry about the time commitment for these discussions.⁸⁻¹⁰ Although ongoing practice with the *N-A-P-C* approach will result in increased comfort and confidence, we offer the following considerations and recommendations to health care professionals:

Trust Your Instincts

Do not overthink these conversations. Consider how you check-in with family and friends about their experiences and use this as a starting point. Start early in the provider-patient-family relationship (ie, time of diagnosis), so families

view this as a standard component of the health care visit. For longstanding relationships, describe this as a practice change based on what is now known about emotional health difficulties with chronic health conditions. Practice change in pediatrics based on new evidence is common and this is no different.

You Do Not Need to Have All the Answers

Patients and families do not expect their health care providers to be experts in emotional health.⁴ Use reflective statements and active listening. Ask the family what has helped them get through current or previous stressors and highlight coping strategies and family strengths. Familiarize yourself with resources available in your setting, including family and peer support resources, and guide the conversation toward options for support. Although these actions may not “fix” or cure mental health difficulties, addressing emotional health within pediatric health care can help to strengthen provider-patient/family relationships and support decision-making and treatment planning.^{4,18}

What Families Disclose is Likely the Tip of the Iceberg

Patients and families may not feel comfortable or ready to disclose all the emotional and social difficulties they are experiencing. With additional opportunities, they are likely to share more over time. If questions about emotional health result in lengthier discussions than can be accommodated within the clinic visit, thank the family for sharing, use reflective statements to communicate that what they have shared is important, and direct the conversation toward available supports (eg, “It sounds like things have been tough. What has been helpful in getting through this, if anything?”). Make a direct connection to a social worker, mental health professional, or peer mentor when available.

Asking and Listening Can Serve as an Intervention

For some patients and families, understanding that their feelings are normal and safe to discuss with a trusted health care professional will promote emotional health and wellness. Although many patients and families could benefit from professional mental health care, factors including limited availability and affordability of mental health services, competing demands, and stigma serve as significant barriers to accessing these services.¹⁹ However, the vast majority will continue to follow-up with pediatric health care professionals and view their providers as an important source of support,⁴ representing ongoing opportunities to intervene and promote emotional health and wellness.

Considerations for Implementation

Implementing change in clinical practice is a slow process, often with unanticipated barriers.²⁰ Most pediatric chronic illness care is provided within health care systems that are highly complex due to the diversity of tasks involved in the delivery of patient care, variation in clinical environments

and policies, and large number of relationships between patients, family members, health care professionals, administrators, payers, and other stakeholders.²¹ The American Board of Pediatrics Roadmap Project has tested project resources and strategies, including *N-A-P-C*, in a pilot improvement Learning Collaborative with 11 teams from 9 children's hospitals.^{4,13} Testing the *N-A-P-C* framework with a Plan-Do-Study-Act process (starting with 1 patient/family at a time) has been a helpful way for clinicians to use and adapt this model to integrate into their practice setting. We propose the following suggestions for implementation, with the understanding that these and other implementation strategies will need to be tested in a range of settings with diverse chronic illness populations.

Identify *N-A-P-C* Champions

It may be helpful to identify 1 or 2 *N-A-P-C* champions who can take responsibility for promoting the integration of this clinical approach into team practice. A partnership between a psychosocial provider (eg, social worker) who is already comfortable with *N-A-P-C* skills and a medical provider who can champion the use of this approach by health care professionals could be optimal.

Conduct Training in *N-A-P-C*

Champions can facilitate training and role-playing sessions as well as ongoing support regarding the use of *N-A-P-C*. Training sessions could be incorporated into the onboarding of new providers and could also be recorded for asynchronous learning or continuing education. Students, residents, and fellows from multiple disciplines should be included in the learning experience. Importantly, training will need to be an ongoing process rather than a one-time event in order to sustain behavior change.

Incorporate *N-A-P-C* into Existing Clinic Processes

It may be helpful to include *N-A-P-C* within an existing clinic checklist or electronic health record template, as this could also serve as a reminder to use this clinical approach during the visit and to document its use. However, the approach itself cannot be administered as a checklist or while charting in the electronic health record. It may also be helpful to integrate use of *N-A-P-C* with existing clinic screening processes (eg, screening for adolescent depression, assessment of patient-reported outcomes). In this case, the health care professional can normalize common difficulties when introducing the rationale for the screening ("Many teenagers with chronic health conditions feel down or depressed at times. Would you mind filling out a questionnaire to let us know how you've been feeling?"). Then, the health care professional reviewing the screening results with the patient or family member can use open-ended questions, active listening, and reflection to further understand and validate their experiences before connecting them with needed supports.

Communicate with Team Members About Emotional Health

Communication about the emotional health and wellbeing of patients and families should be incorporated into team meetings and rounds, although consideration should be given to privacy and the type of information that should be shared in this setting. In the case of a multidisciplinary clinic, it may be important to identify the provider who will initiate discussion about emotional health with the patient and family during that clinic as it could feel overwhelming to be asked repeatedly about emotional health. Although this could at times be a social worker or mental health professional if embedded within the team, use of *N-A-P-C* should not always be delegated to individuals in these roles. It is crucial that patients and families hear from their treating physician that emotional health is a core aspect of overall health and that what they are feeling and experiencing is important.⁴

Conclusion

Patient and family emotional health and wellness must be proactively addressed within pediatric health care.^{2,8-10} As demonstrated by the case vignettes, normalizing emotional struggles, asking open-ended questions about feelings and experiences, and providing space for emotional disclosure can help patients and family members feel comfortable and safe in sharing emotional difficulties and obtaining support. These steps can help to prevent the escalation of mental health problems that threaten the health and wellness of so many children with chronic illness and their family members. The *N-A-P-C* clinical approach could complement ongoing national efforts to provide pediatric health care professionals with the tools and resources needed to initiate conversations about emotional health. In time, this will train the next generation of health care professionals to address emotional health and wellness alongside physical health as part of routine clinical care.⁸⁻¹⁰ ■

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