

Beads for Breath: A Psychosocial, Educational Intervention for Pediatric Patients with Primary Ciliary Dyskinesia at Children’s Minnesota

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Background

- Hospital bead programs have been developed at pediatric institutions worldwide to enrich the experiences of children with cancer, chronic illness, or those hospitalized on cardiac and neonatal units and have been shown to have a positive impact.¹⁻⁴
- Few specialized psychosocial interventions exist for the primary ciliary dyskinesia (PCD) population.
- The aim of the PCD Beads for Breath program is to support children and families in coping with and understanding of PCD.

Methods

- Our PCD center created a PCD-specific, arts-based psychosocial and educational intervention: the PCD Beads for Breath program.
- Patients with PCD six years and older were invited to join the PCD Beads for Breath program at their multidisciplinary team visit starting in the spring of 2025.
- Patients received unique and colorful beads for each PCD procedure, treatment milestone and visit with multidisciplinary team members (**Figure 1**).
- Surveys were administered to the participants in the PCD Beads for Breath program to gather feedback on the child and parental experience.
- Feedback was also gathered by the medical team to understand staff experience and feasibility.

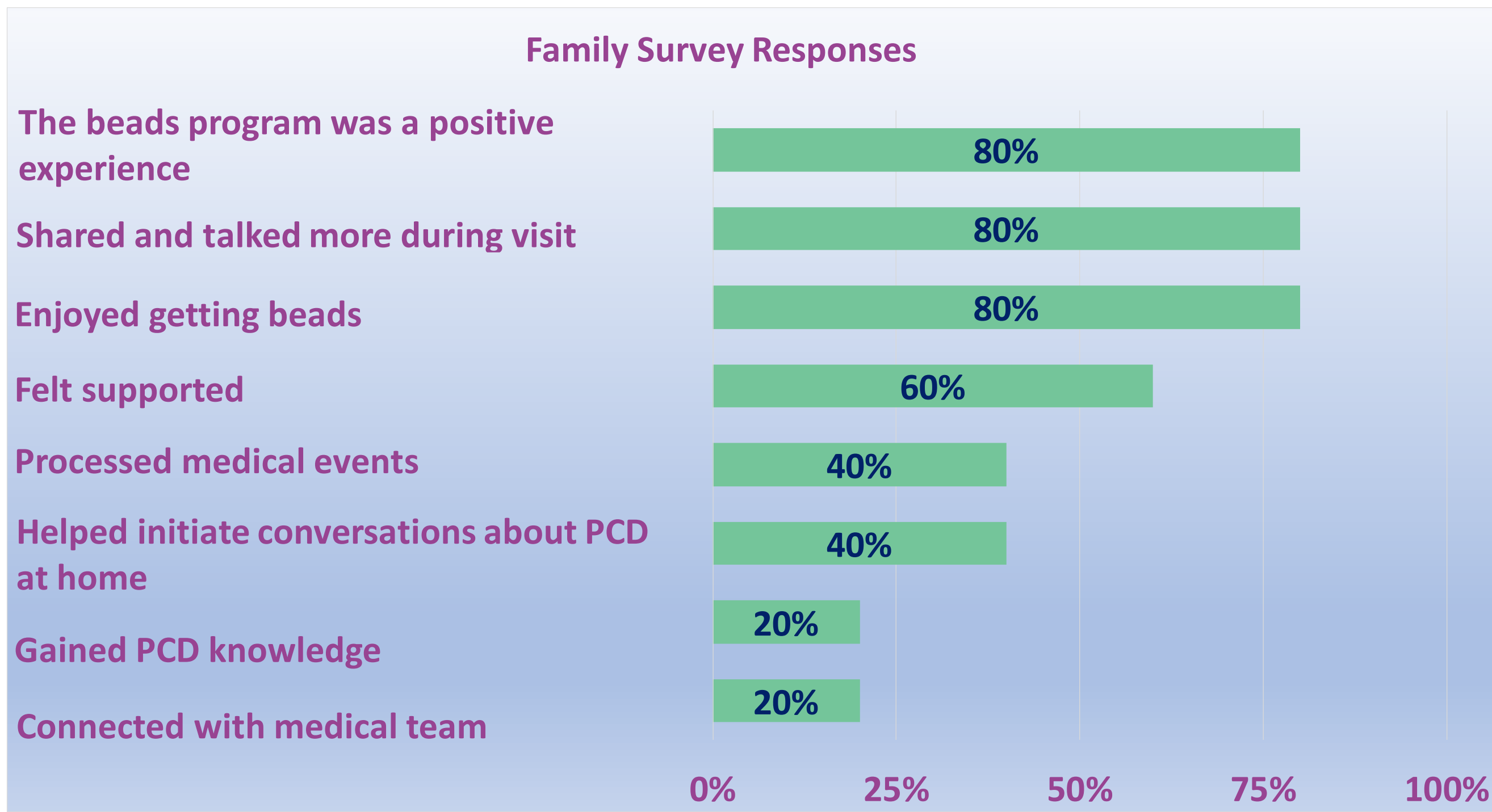
Figure 1.

Pulmonary		Respiratory Therapy		Courage		Cilia Biopsy		Surgery	
Cardiology		Hearing & Audiology		Birthday		Nasal Nitric Oxide		Hospitalization	
ENT		Research		PCD Awareness		Sputum/Throat Culture		Genetics	
Social Work		Multidisciplinary PCD Team		Airway Clearance		Know Your Situs		Daily Treatment	
Radiology		Exercise		Sinus Rinse		Bronchoscopy		Pill Swallowing	

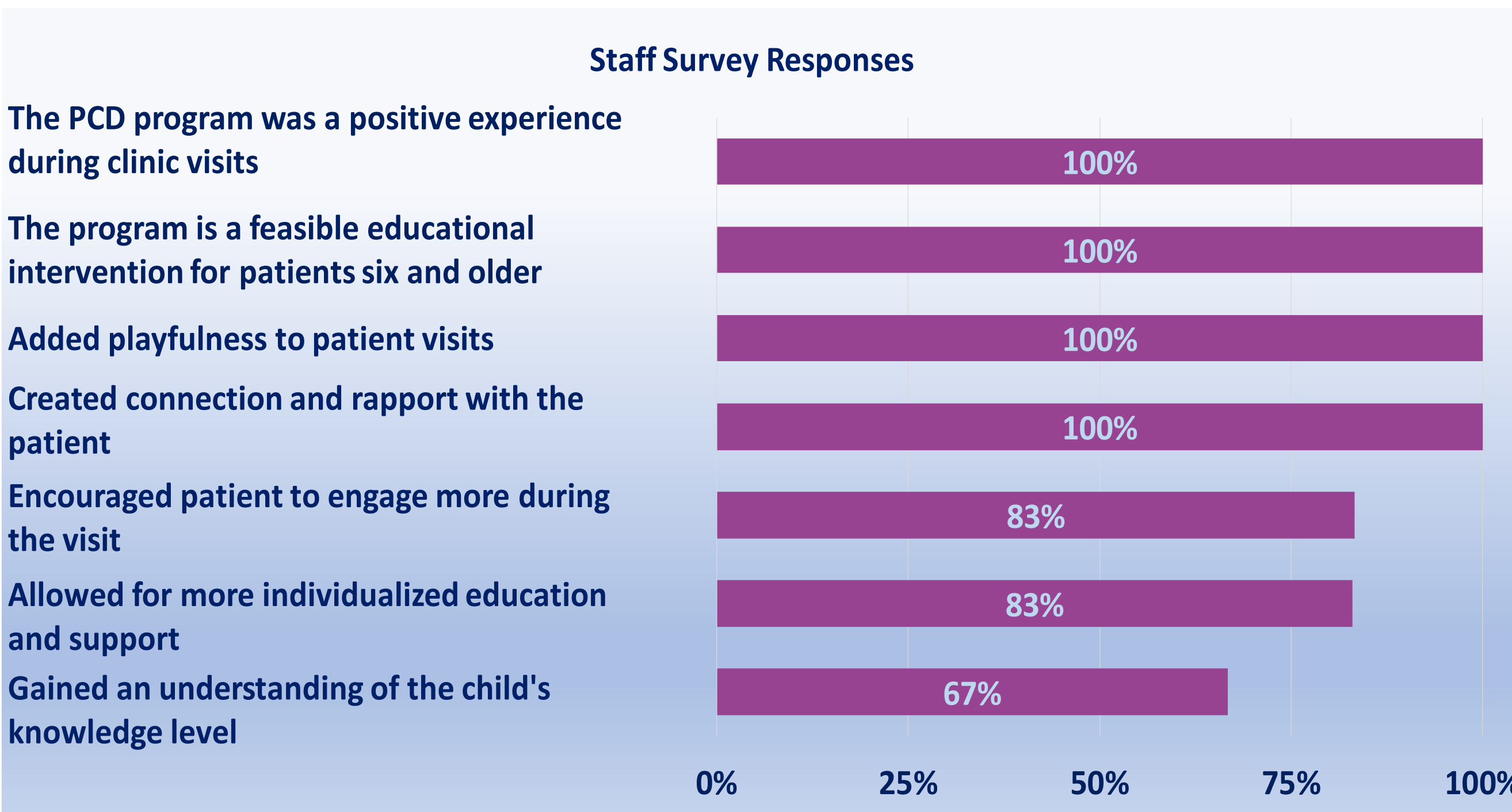
Results

- Sample size: n=11 (Ages 6-17, 5 F, 6 M).
- Family survey responses received: n=7 (**Graph 1**).
- Staff survey responses (n=6). Included a pulmonologist, nurse practitioner, respiratory therapist, social worker, and genetic counselor (**Graph 2**).

Graph 1.



Graph 2.



Conclusions

- Overall, the PCD Beads for Breath program was found to be a positive experience for the majority of patients and families as well as the medical team.
- The beads help create a therapeutic narrative for the child and family regarding the medical treatment they endure while also gaining knowledge of PCD care management.
- The program also allows the medical team to understand the patient and family’s experience, learn ways to best support them, and create positive connections with patients during clinic visits.

Future Directions

- Based on these preliminary survey results, we will continue the PCD Beads for Breath program and survey families for feedback as new patients enroll.
- Other PCD centers could consider implementing a similar arts-based intervention Beads for Breath program to enhance patient engagement and education.
- The PCD Foundation may consider supporting these efforts to enrich the psychosocial care provided to patients and families.

References

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