

“There When We Need Them”: Assessing Patient and Family Satisfaction with a Growing Pediatric Palliative Care Program

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Background

- While palliative care has been established as an important medical subspecialty, it remains a novel concept to many patients and families experiencing serious illness.
- The assessment of patient and family satisfaction with pediatric palliative care (PPC) services is crucial to ensuring that the needs of our patients and families are met.
- We strived to develop a survey tool with minimal participant burden in addition to a sustainable and efficient standardized operating procedure to assess patient and family satisfaction with our hospital’s current PPC services.

Methods

- An anonymous 20-question online survey was created using core and program building questions from the Pediatric Palliative Improvement Network (PPIN)’s patient/ family satisfaction survey in addition to several program-specific questions.
- Eligible potential respondents were approached in person, or via telephone and/or email communication.

Eligibility Criteria

•Patient is followed by the PPC team.

•Participants had at least one PPC interaction in the past 6 mo., speak English or Spanish and are not in emotional distress.

•Patient participants are at least 13yo and capable of completing the survey.

Figure 1. Eligibility criteria.

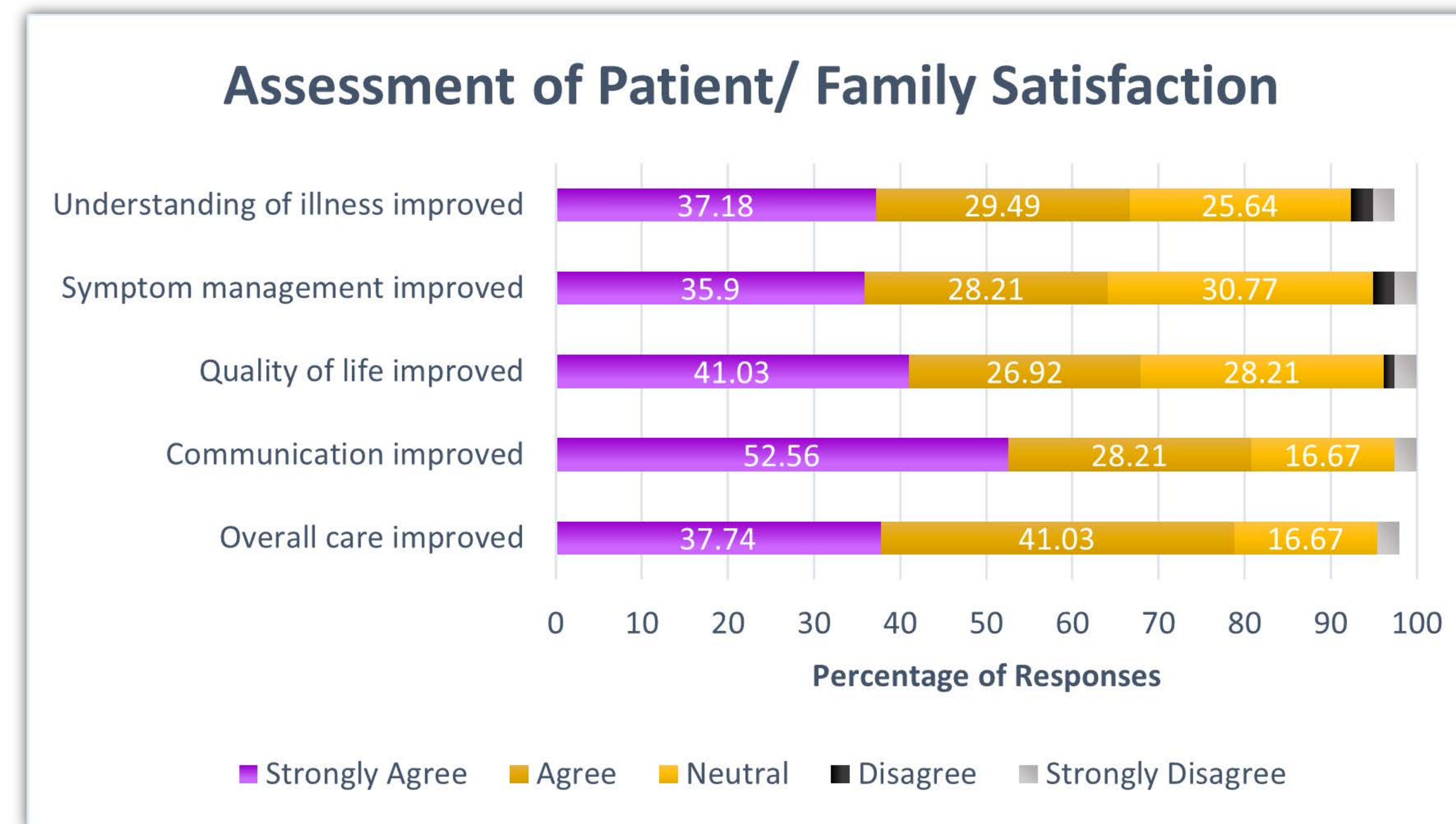


Figure 1. Patient and family satisfaction with the PPC team.

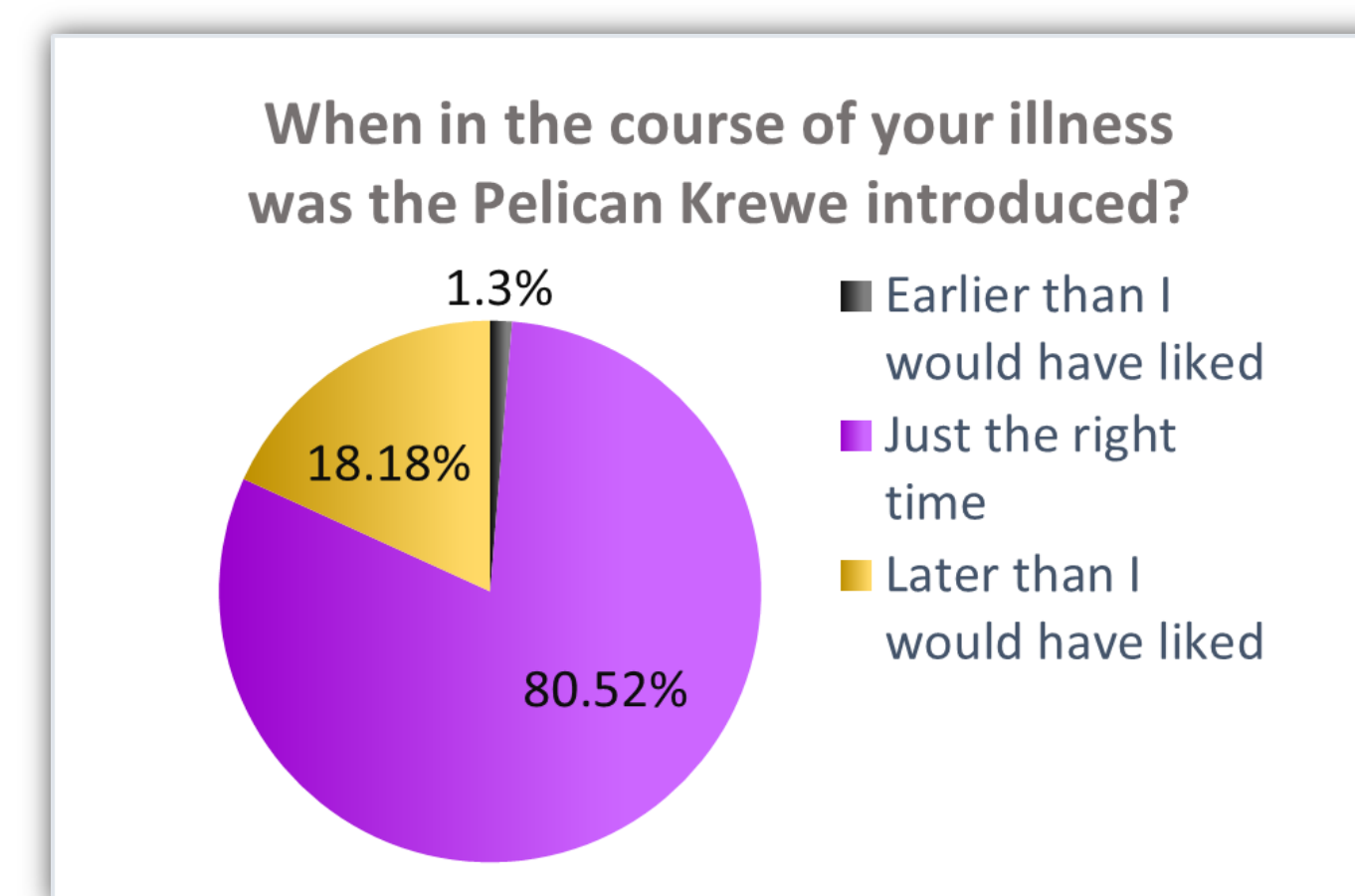


Figure 2. Introduction of care by the PPC team.

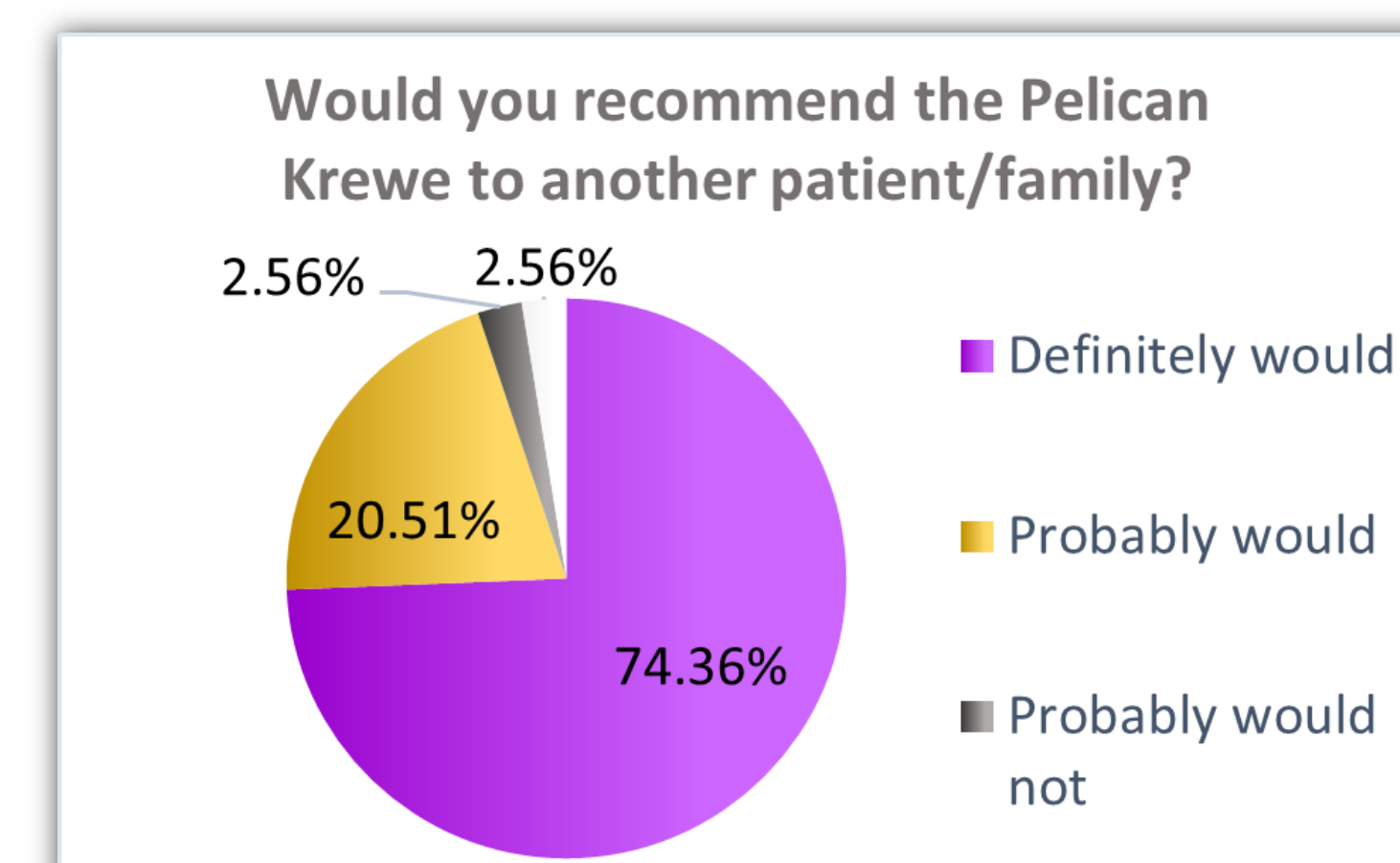


Figure 3. Likelihood of recommending the PPC team.

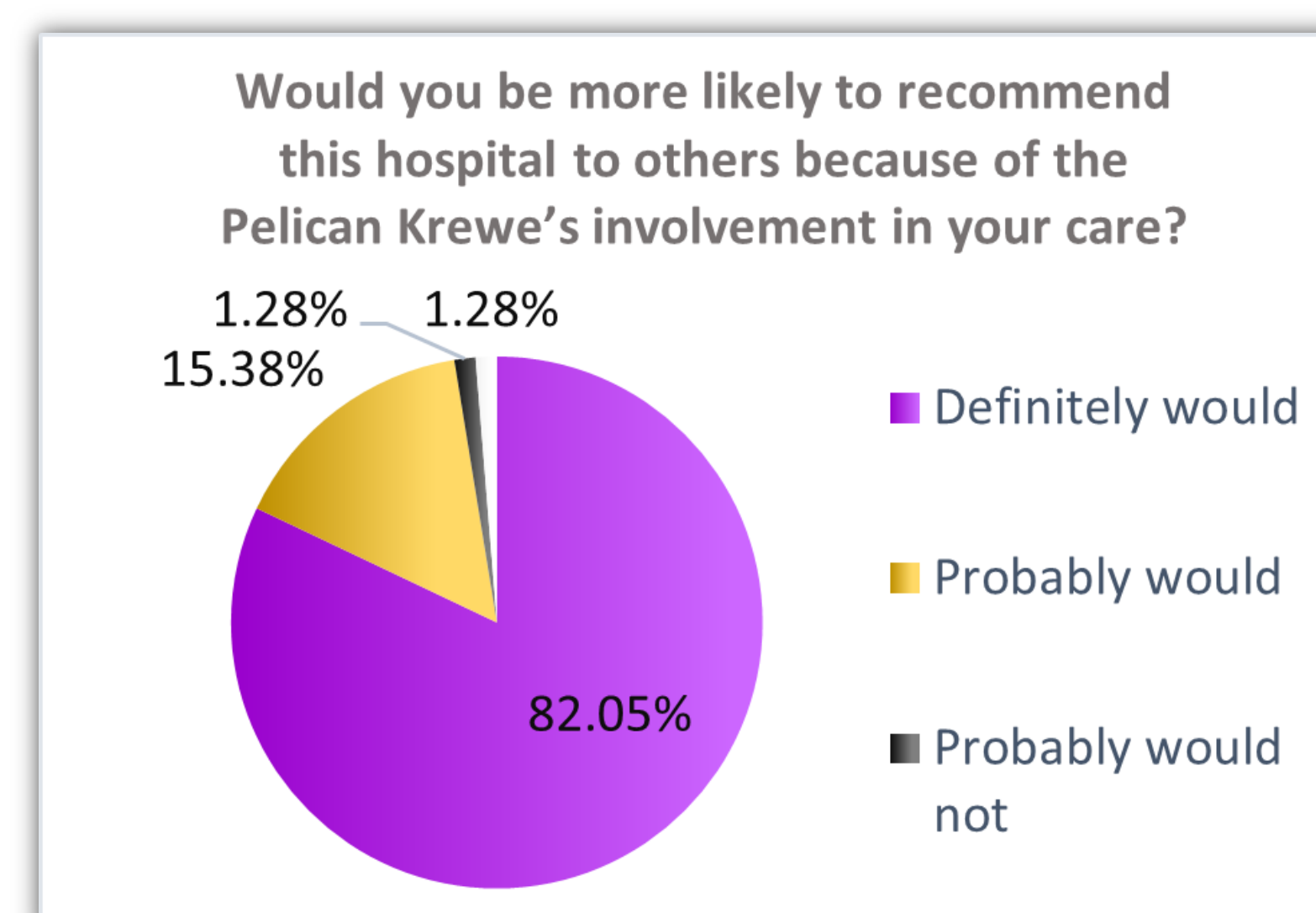


Figure 4. Likelihood of recommending hospital because of PPC team.

Results

- 78 of 176 eligible participants (51%) completed the survey.
- More than half of participants agreed or strongly agreed that the PPC team improved their child's overall care (80%), quality of life (68%), and symptom management (64%), their communication with the medical team (84%), and their understanding of their child's illness (67%); the vast majority of other responses were neutral (Figure 2).
- Only 1 participant felt that PPC was introduced too early (Figure 3).
- An overwhelming majority of participants stated that they definitely or probably would recommend the PPC team to another patient and/or family and would be more likely to recommend the hospital to others because of the PPC team’s involvement in their care (Figures 4 and 5).
- Additional praise and suggestions for improvement were shared as comments throughout the survey (Figure 6).

In response to how our team has been particularly helpful:

- “The Pelican Krewe was there from the very beginning of the whole process... They provided a fabulous **holistic approach to caring for our family.**”
- “Always **there when I need them most!**”

Brochure feedback:

- “Maybe add a few more specific **resource links**”
- “No. I loved that y’all had **pictures to go with the names** of the members.”
- “Put (patient’s name)’s face on it”

Welcome bag feedback:

- “Something to make you happy, Something to wipe your tears, Something to make you calm, **Something to snack on**, Something to hold on, Something relaxing”
- “Add a little thing of **Kleenex**... for days where its hard and tears are there”

Figure 6. Qualitative feedback.

Conclusions

- This data demonstrates that a new, growing PPC team is positively impacting the overall experience of their patients and families.
- Ongoing assessment of patient and family satisfaction is important as PPC programs continue to grow.

Authors have no financial relationships to disclose.