

Family empowerment beyond the perioperative period: Optimization of pain experience for children undergoing pectus and spine surgeries

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INTRODUCTION

Spine fusion for scoliosis and Nuss procedure for pectus are among the most painful surgeries healthy, opioid naïve adolescents undergo. Pain can extend beyond the perioperative period, and pain experience depends on family interactions and preexisting psychosocial factors.^{1,2} Thus, in order to optimize pain experience, focusing on perioperative pain protocols is not sufficient. We conducted a quality project in conjunction with the Livewell Collaborative (LWC) to design an optimal pain management system extending from the early preoperative stage through post-surgical recovery at home, and to create a solution system that empowers both patient and parent at all stages of this perioperative journey. The LWC applies innovative design-thinking based on collective learnings from previous projects, benchmarking and input from all stakeholders.

Goal: create a solution system that empowers both patient and parent in the recovery process at all stages of the perioperative journey.

METHODS

All phases of this project have been conducted over 24 weeks:

- the research phase, during which 7 semi-structured interviews were conducted across stakeholders (families/children who had previously undergone spine and pectus surgeries at our institution, and healthcare providers), benchmarking and LWC learnings to map perioperative journeys and identify factors that provide positive and negative pain experiences for patients;
- the ideation phase, during which interactions with stakeholders to create a system of tools that will help educate and inform patients and caregivers.
- the refinement phase, during which tools were envisioned and proposed for implementation

RESULTS

In the first phase, a common journey map with major milestones for patients undergoing both surgeries was created, starting from referral, and ending with first follow up evaluation by surgeon after home discharge. Anxiety levels from the patient's/parent's perspectives were mapped out as a visual tool to help understand key periods of enhanced anxiety, which were identified as timings for future interventions (Fig 1). Key positive and negative influencers of pain experiences, and potential improvement opportunities in 5 areas were identified (Fig 2).

Fig 1: Periods of high anxiety in the perioperative period for parent/child based on focus group interviews - key intervention periods

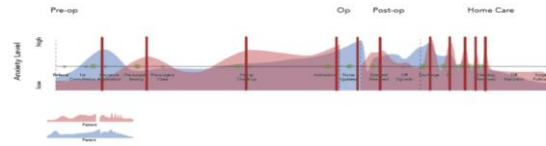


Fig 2: Potential improvement opportunities identified

Areas of Opportunity

The following areas of opportunity were translated from of the research phase's insights:

| Patient Engagement | Right Info Right Time | Resource Options | Connectedness | Defined Role of Parent |
|---|---|--|---|--|
| The better engaged a patient is with the process (from pre-op to home care) the more empowered they will feel and the smoother recovery they will have. The solution should engage and empower the patient. | Relevant information should be delivered or repeated at appropriate times, in a manner that is digestible for all stakeholders. | Additional resources, outside ones currently supplied, act as essential supplemental assistance and emotional support. | There are many relationships involved in the process, such as the parent/patient or patient/medical staff. As each stage of the process, these relationships need to remain strong for a successful recovery. | The parent performs a critical role in every stage of the process. They act as a figure of comfort, a coach, and a caregiver for the patient, often acting in multiple roles at once. Helping to give the parent(s) a clearer defined role will in turn help give confidence to the patient and aid in recovery. |

CONCLUSIONS

Our findings are driving the implementation of identified innovations at key periods of increased anxiety. They will be further refined and tested, with a goal of decreasing stress at these periods. Holistic, non-opioid strategies targeting the patient-family unit, with family empowerment through support, information, are being emphasized through this project as a means of optimizing the perioperative pain experience.

RESULTS

The ideation phase used a non-weighting matrix within these 5 areas to evaluate current tools. New enhanced tools targeted to 4 parent-child engagement dynamic spectrums were identified, with three system themes – empowering, road map and communications.

| Criteria | Current Tools | | | | | Child of Color/Minority | Healthcare Inequality | Healthcare Access |
|--------------------------------|---------------|-------|-----|-------|--------------------------------|-------------------------|-----------------------|-------------------|
| | Web | Print | App | Video | Former Patient/Parent Dialogue | | | |
| Empowering | 1 | 1 | 1 | 1 | 1 | N/A | 1 | 1 |
| Road Map | N/A | N/A | 0 | .5 | 1 | 1 | 0 | 0 |
| Communication | N/A | N/A | N/A | N/A | N/A | 1 | 0 | 0 |
| Website | 1 | 0 | .5 | 1 | 0 | 1 | 0 | 1 |
| App | 0 | -1 | -1 | 1 | 0 | 1 | -1 | 1 |
| Video | 1 | -1 | 0 | 0 | 1 | 0 | 0 | 0 |
| Former Patient/Parent Dialogue | 0 | 0 | 0 | 1 | 1 | 1 | 1 | 1 |
| Healthcare Inequality | 1 | -1 | 1 | 1 | 0 | -1 | -1 | 1 |
| Healthcare Access | .5 | -1 | 0 | .5 | 1 | 0 | -1 | 1 |
| Healthcare Cost | 0 | 0 | -1 | 1 | 0 | 0 | -1 | 1 |

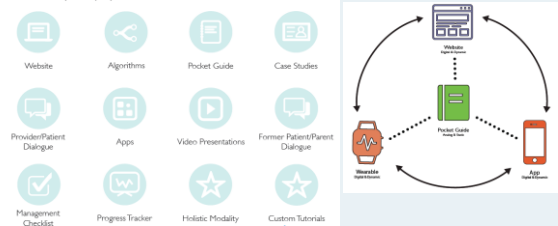
The Refinement phase identified and ranked necessity of holistic health, consistent messaging, Process expectations and goals for patients and parents, Emphasis on parent roles, expectations, and empowerment

Solution System

These themes emerged from the insights from the co-creation sessions conducted in the ideation phase. These themes will be applied to the final system, helping to ensure a strong solution. The tools selected by the majority of stakeholders were combined and refined into a final conceptual solution system.

System Themes

- Empowering**
An aspect of the tools should provide patients the means to find answers and ways to reach personal goals on their own, giving them the ability to take control of their own recovery.
- Road Map/Overview Guide**
The idea of a road map or an overview guide would give parents, patients and even clinicians an idea of next steps, their progress, and what is left to achieve.
- Communication/Information**
The tools should all have some face of communication and facilitates information.



REFERENCES

- Rabbits JA, et.al. Pain 2015; 156(11): 2383-9.
- Chidambaran V, et. al. European journal of pain 2017. Aug;21(7):1252-1265