

Logic Model

Outcomes

- 13 parents shared their experience and offered guidance to families who are embarking on a similar journey – 11 via focus groups and 2 via questionnaires
- Education guide will be created to help families navigate end-of-life care with their child

Outputs

- Creation of recruitment materials
- 2-3 people attending a 2-hour focus group (total of 5 focus groups)
- Conduct 60-minute Zoom interviews with COA personnel
- Identifiable themes

Activities

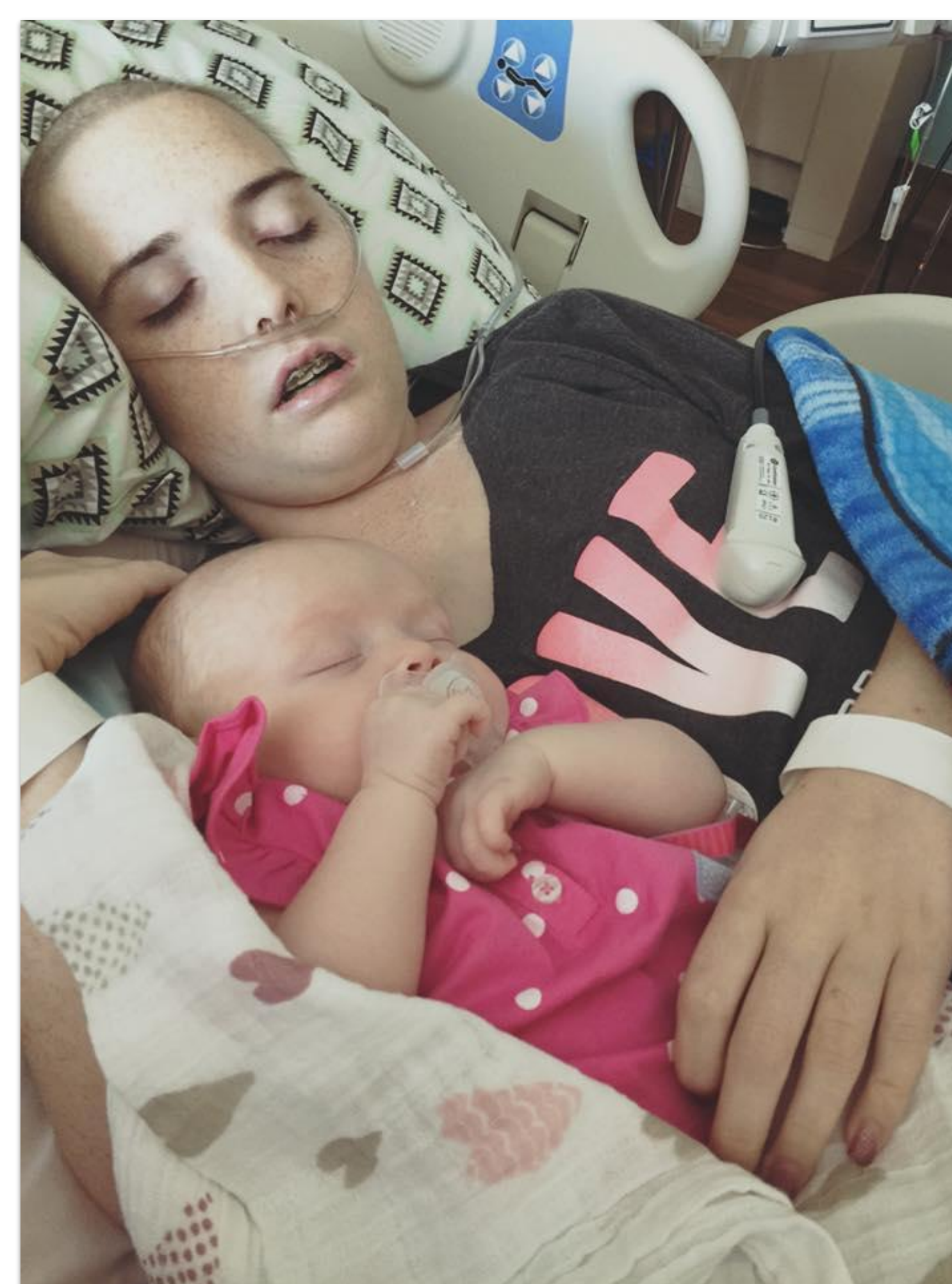
- Design recruitment materials
- Focus groups with parents who have lost a child to cancer
- Individual interviews with Children's of Alabama medical personnel
- Individual written questionnaires

Inputs

- Physical space or virtual platform for focus groups
- Graphic design experience
- InDesign (or other design program)
- Mentor expertise
- Communication skills/interviewing skills
- Transcription software

Introduction

- In 2022, an estimated 1,600 children aged birth to 19 years will die from the disease in the U.S (Siegel et al., 2022). The families left behind are not only dealing with the death of their child, but also experiencing the emotional turmoil that comes with the disease and treatment phase leading to the death (Hoffmann et al., 2018).
- Socioeconomic status and parents' education level has a significant impact on whether bereaved parents seek support or even have access to grief support services and/or resources. Cacciatore et al. (2016) found that bereaved parents living in poverty are “less likely to seek support” and have fewer grief support resources available to them.
- Grief is defined in many ways but at the core it is a response to loss, which can be physical, mental, or emotional. Many years after the introduction of the stages of death, Dr. Elisabeth Kübler-Ross, a medical doctor and psychiatrist, and David Kessler, a death and grieving expert and author, looked at how those same stages presented differently in grief, and they presented an additional 6th stage (finding meaning) in the 2005 book “On Grief and Grieving.” A child's death throws off the natural order of life events, and by assigning meaning to that tragedy, families are attempting to restore their belief that the world is just, and life is worthwhile. (Meert, K. L., Egely, S., Kavanaugh, K., Berg, R. A., Wessel, D. L., Newth, C. J., Shanley, T. P., Harrison, R., Dalton, H., Dean, J. M., Doctor, A., Jenkins, T., & Park, C. L. (2015). Meaning making during parent-physician bereavement meetings after a child's death. Health psychology : official journal of the Division of Health Psychology, American Psychological Association, 34(4), 453-461.)



A little girl grows up without her big sister because of cancer.

Impact

This project addressed the meaning-making stage (of the stages of grief) by allowing bereaved families an opportunity to share their experience with others. The impact was verified through qualitative data generated by focus groups/questionnaires.

“During our journey with Alex, I realized that not everyone is going to have a cancer story. The pain and hardship that they are going through is their own ‘cancer.’ It's an overwhelming and stressful time for them, as well. I have always wanted to be the one that others knew they could turn to without judgement or measuring our pain because pain is pain. Knowing I could be that one others can lean on is what helps me through my grieving process.” ~ Tracy, mother of 18-year-old Alex who died from Ewing's sarcoma on 1/3/21

“Sharing our story helps with my grief because it's something I CAN do. That's the thing about losing a child to cancer – so much is out of your control. I think sharing her story helps keep her memory alive and all grieving parents have the fear that everyone will forget their child. It's hard to relive the hardest time in your life, but it's also healthy and healing to talk about it and, in a way, be proud that you are still surviving and one day maybe even start living again.” ~ Zoshia, mother of 5-year-old Natalie who died from Acute Lymphoblastic Leukemia (ALL) on 10/19/17

The project will continue through the creation of additional educational guides for various populations impacted by pediatric cancer. A proposal of ideas is also being created to present to COA personnel to address challenges faced by bereaved families. This is a direct result of information gathered by parents during the focus groups.

Critical Assessment

Time was the biggest challenge. I did not realize how much time it would take to recruit families, conduct focus groups, analyze the data, and complete a finished product. I had to re-evaluate multiple times and make numerous changes. In the end, I chose to not rush through the end design and take the extra time so the finished product would be approved for dissemination. These challenges faced have been a valuable learning experience. The research I am doing for my doctoral degree will involve qualitative data so understanding the time it takes to complete this process now will help me succeed with my dissertation research.



This is the reality of pediatric cancer – a mother sitting by her daughter's side in the hours leading to her death.

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