

“What I Would Do to Take Away Your Pain”: A Photovoice Project Conducted by Mothers of Children With Medical Complexity

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Abstract

Research identifies that families of children with medical complexities in the United States have diverse and complex needs. Despite research emphasizing that families demonstrate higher needs that are not being met, limited research focuses solely on mothers of children with medical complexities. Specifically, how mothers understand and identify themselves, understand and define their role in coordinating care, and how they view their own mental and physical health. As such, this study provides a better understanding of how mothers in San Diego, CA, navigate the day-to-day psychological, social, and physical realities of having a child with medical complexities. Through the use of the participatory action research method photovoice, mothers conducted a critical analysis of their daily lives. Findings identify mothers' main concerns about the conditions of their lives as well as the strengths they employ to care for themselves and their children successfully. Implications provide recommendations for hospitals working with mothers of children with medical complexities.

Keywords

families of children with medical complexities, participatory action research, photovoice research

Families of children with medical complexity have diverse and complex needs that have the potential to lead to familial stress and burnout (Edelstein et al., 2016). Children with medical complexity have at least one severe chronic condition, limited functionality, high healthcare usage, and high health service needs (Cohen et al., 2011; Donnelly et al., 2020). These service needs involve reliance on medical equipment such as gastrostomy tubes, ventilators, tracheostomy tubes (trach), and the like. Families of children with medical complexities also require ongoing access to acute and community-based health services, home health care, and involvement from multiple specialists (Edelstein et al., 2016; Kuo et al., 2011).

Meeting the needs of children with medical complexities, who are estimated to constitute approximately .4% of all children in the United States (U.S.) (Berry et al., 2014), often requires families to take on more roles and

responsibilities compared to parents with “typically developing” children (Woodgate et al., 2015). Parents act as the primary care coordinators for their children (Golden & Nageswaran, 2012) and, with an increase in advancement in medical technology, provide round-the-clock specialized home care (Edelstein et al., 2016), which can lead to considerable stress.

Due to sociocultural norms, mothers in heterosexual families typically take on the role of the primary caregiver for their children with medical complexities

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(Currie & Szabo, 2019; Hartley et al., 2021). However, limited research focuses on how mothers of children with medical complexities understand and identify themselves within their role in coordinating care and how this role ultimately impacts their mental and physical health. Many care professionals only encounter mothers of children with medical complexities in the clinical setting, ultimately limiting their insight into the social context of mothers' lives. In response, this study examines how mothers in the U.S. navigate the day-to-day psychological, social, and physical realities of having a child with medical complexity (ages 0–6). Through the use of the Participatory Action Research (PAR) method of photovoice, the current study addresses the following aims:

Aim 1: Record and reflect mothers' identified main concerns and strengths within their lives by taking pictures.

Aim 2: Engage mothers in creating and sharing their own knowledge about the conditions of their lives through group discussion and analysis of pictures.

Aim 3: Identify and create policy and practice recommendations for hospitals and social care systems working with children with medical complexity.

The experiences of mothers of children with medical complexities are largely omitted from research, resulting in a lack of power to influence policies that positively alter the complex medical system in the U.S. Results inform actionable and programmatic strategies to help mothers overcome difficulties associated with the realities of caring for their child with medical complexity while recognizing and highlighting their strengths and social assets.

Background

Parents of children with medical complexities face challenges as they interact with varying and complex systems within the U.S.

Healthcare Systems in the United States

Fragmented healthcare systems in the U.S. result in disparities in access to integrated care, inadequate health insurance coverage, and deficits in the delivery of medical care (Allshouse et al., 2018). U.S. based medical specialists are limited in number, not equally distributed geographically, and practice primarily at children's hospitals; thus, where a child lives significantly impacts options for sufficient medical care (Allshouse et al., 2018). Integrated care across subspecialties is limited, creating challenges for families

that spend an average of at least 2 hours a week on care coordination (Kuo et al., 2011). Moreover, almost 50% of families of children with medical complexities report at least one unmet medical need, which includes specialty, preventative, and dental care (Kuo et al., 2011) with 33.1% indicating difficulty accessing nonmedical services such as childcare, early intervention services, rehabilitation, and community programs.

Further, expenditures tied to the child's medical needs are not generally reimbursed for families who incur out-of-pocket costs, such as adapted clothing, specialized food preparation, home modifications, and accessible transportation, among others (Allshouse et al., 2018). In one study, 56.8% reported financial difficulties, and 54.1% of families reported that a family member stopped working to care for their child's health (Kuo et al., 2011).

Time Spent on Caring

Along with financial challenges, families of children with medical complexities in the U.S. spend around 11–20 hours on direct homecare (Kuo et al., 2011). Families are constantly adapting to their children's medically complex and evolving needs, such as seizure control, management of home ventilators, and feeding pumps (Hall, 2011). The care that families provide their children at home has been described as "outpatient, intensive care" as it highlights the level of complexity and attention to detail necessary for families (Hall, 2011). In addition, parents' advanced expertise and knowledge in managing their children's symptoms and care needs are sometimes overlooked by healthcare providers during pediatric intensive care unit (PICU) hospitalizations (Hall, 2011; Rennick et al., 2019).

Impact on Mental and Physical Health

Although the home tends to be the preferred site for care and has positive benefits for the child and caregivers, this round-the-clock care for their children can impact parents' mental and physical health. Longitudinal studies in the U.S. indicate that the two most common reductions in physical and psychological health were pain and sleep disturbances (Hartley et al., 2021), derived from the nature of the care parents provide to their children. A study with parents of children with medical complexities in Australia found that parents' sleep is impacted, particularly when their children require overnight supervision (McCann et al., 2014). Parents reported higher fatigue and poorer daytime functioning than the general population,

leading to difficulties meeting and coping with their child's needs, altering their family relationships, and causing marital strain (McCann et al., 2014).

Available Supports

In a review of international interventions, the majority of which were in the U.S., it was found that most interventions emphasize the importance of streamlining medical services and minimizing the direct burden of care on families (Bradshaw et al., 2019; Edelstein et al., 2016). In particular, interventions targeted toward parents of children with medical complexities include mental health supports, hospital admission and discharge, and peer support groups (Bayer et al., 2021; Edelstein et al., 2016). Furthermore, providing various supports results in positive outcomes for caregivers and their children when the supports target specific issues, such as a lack of breaks from day-to-day demands and job loss (Bradshaw et al., 2019; Edelstein et al., 2016). Of note, interventions are not equally available with limited research highlighting what supports and interventions parents deem necessary for their families (Bradshaw et al., 2019). It is therefore essential to better understand the lives of families of children with medical complexities.

Methods

Photovoice is a qualitative research method rooted in PAR that incorporates photography, analysis, group discussions, and action (D'Amico et al., 2016; Delgado, 2015). As an approach to knowledge production and civic action centered on the active participation of individuals impacted by the identified issue, PAR allows for the documentation of the experiences of mothers of children with medical complexities. The photovoice method has three main components, each corresponding with one of the aims of this study: taking pictures, analyzing the pictures and group discussions, and determining action to be taken (Wang & Burris, 1997).

Collective

We use the term collective in place of sample as the group consisted of a collective of mothers (labeled participants in non-participatory research) and university researchers. Two mothers, Darlene and Jesse, planned the project with the guidance of the first author who took on the role of methodological expert. The first author described how the weekly sessions typically run, facilitated the discussions around weekly topics, and provided insight into identifying sampling criteria. This initial collaboration resulted in identifying the weekly session topics, the focus of

recruitment, and recruitment methods. For more details on this process, see Sonsteng-Person & Van Leeuwen, 2020.

The sampling frame for this study was a group of 6–8 mothers of children ages 0–6 that live in San Diego, CA, and have children with medical complexity, defined as children that interact with any of the following systems: inpatient, outpatient, homecare, government programs, or medical equipment companies. Due to the participatory nature of this study, the creators decided they wanted to keep the sample limited to mothers in San Diego, CA, to build their supportive community. The study utilized snowball sampling (Rubin & Babbie, 2014), and, following ethical approval from the institutional review board (IRB), mothers were recruited via social media from October 2019 to January 2020; for more details about recruitment, see Sonsteng-Person & Van Leeuwen, 2020. Once the remaining four mothers were recruited, they took ownership for the direction of the study, decided on the goals for the study, identified the audience they would like to reach, created the virtual photo exhibit, and wrote their “calls to passion” or the policy and programmatic changes they wanted to see. This ensured that the expectations of the mothers were centered in project creation and outcomes (Golden, 2020). The final collective consisted of six mothers and the first author (see supplementary materials for the university researchers' reflexivity statements). Of note, the mothers chose to use their real names throughout this project.

Taking a step beyond Wang & Redwood-Jones' (2001) three aspects of consent in photovoice projects, the first author ensured that the consent for this project was ongoing and obtained each week and that mothers understood they could withdraw consent at any time (Creighton et al., 2017). The privacy of the mothers and their families was discussed in detail, particularly leading up to the exhibit and the writing and submission of this paper. Within the planning for the exhibition were ongoing discussions around the representation of the mothers and their families and the potential interpretation that audience members would have of each photograph (Wang & Redwood-Jones, 2001). The first author and the project's co-creators led a conversation around “indelible images” (Creighton et al., 2017) and what it meant for other people to access the pictures and stories of their family's experiences. With this awareness, the mothers had critical discussions about what they wanted to share and how they wanted to share it in the exhibit. These same standards were then brought to the writing of this manuscript. For a more detailed description of this process, see Sonsteng-Person & Van Leeuwen, 2020.

The mothers chose to use their real names in this manuscript. First is Darlene A., a 40-year-old Hispanic female whose child was born prematurely and has a chronic lung disease. Next is Rachel M., a 34-year-old

white female whose child was diagnosed with pyriform aperture stenosis, solitary median maxillary central incisor syndrome (SMMCI), and genetic mutation-nacc1. Next, Sara T. is 43 and identifies as Mexican and White and has a child with a diagnosis of Cerebral Palsy and Epilepsy. Jesse V., the project's co-creator with Darlene A., is 31 and white. Her child was diagnosed with Aicardi Syndrome. Next is Brittany J., a White, 30-year-old mother. At the time of the project her child was diagnosed with VACTERL association (vertebral defects, anal atresia, cardiac defects, tracheoesophageal fistula, renal anomalies, and limb abnormalities). Finally is Riahannon V., Hispanic and White and whose child has diagnoses of Apert syndrome, Tetralogy of Fallot, Congenital Hydrocephalus, Chronic Lung Disease, and Epilepsy.

Along with the collective group of six mothers there were four university researchers. The first author organized and supported the project and three additional university researchers were brought on to assist in the analysis and writing of the paper based on their expertise in the analytic methods used. See the supplementary materials for university researchers' positionality reflected on to narrow the "researcher-participant dichotomy" (Sitter, 2017, pg. 41).

Data Collection

The data collection and initial analysis took place across 5 months via the virtual platform Zoom. Prior to COVID-19, it was decided that Zoom would be used as a way to host each meeting in an accessible format for mothers who needed to be near their children. The group met weekly for 90 minutes from February 2020 to June 2020; for a more detailed explanation of the content of the six weeks, please see [Sonsteng-Person & Van Leeuwen, 2020](#). Of note, five of the six weeks spent collecting data occurred before the COVID-19 pandemic lockdown. The entire exhibit was planned and executed during the lockdown. Data collection used for analysis occurred throughout each of the following three aims.

Aim 1: *Record and reflect mothers' identified main concerns and strengths within their lives by taking pictures.* This aim allowed mothers to assume the role of researcher and storyteller and capture events and lived experiences that have gone unacknowledged and unaddressed ([Delgado, 2015](#)). Mothers took pictures across five weeks to record and reflect on what they identified as the most significant concerns and assets within their lives ([Wang & Burris, 1997](#)). Each week the six mothers presented and discussed the photographs they took to encompass that week's topic. The five topics were Identity, Advocacy, Health, Voice, and Day in the Life. Darlene and Jesse decided upon the

first four topics, and the six mothers voted on the Day in the Life topic.

Aim 2: *Engage mothers in creating and sharing their own knowledge about the conditions of their lives through group discussion and analysis of pictures.* The goal of this aim was to promote critical dialogue and knowledge through group discussions of photographs ([Wang & Burris, 1997](#)). After each mother shared their photos, the group discussed the photographs where mothers could exchange and reflect on their experiences ([Gabrielsson et al., 2022](#)). During these conversations, the first author took on the role of moderator and asked the mothers to talk about what they saw in the picture, how it related to their lives, why the situation existed, and what might be done about it ([Wang & Redwood-Jones, 2001](#)). These conversations were audio recorded and transcribed.

During the exhibit planning, the six mothers collaboratively wrote a shared description for each of the five topics and decided on the top pictures and captions to be used for the exhibit. They reflected on their storytelling throughout the project and created a shared meaning for their experiences ([Gabrielsson et al., 2022](#)). The photographs, along with their corresponding titles and narratives, were displayed at a virtual art gallery. During this virtual art gallery, the mothers presented each description and its corresponding pictures to the 147 attendees.

Aim 3: *Identify and create policy and practice recommendations for hospitals and social care systems working with children with medical complexity.* The final phase in the process included coding or identifying the issues, themes, and theories generated from discussions ([Wang & Burris, 1997](#)). This was done in two ways. First, the six mothers identified what they termed "calls to passion." These were presented in the exhibit to inform interventions and policies and reach policy makers ([Wang & Burris, 1997](#)). Second, the mothers expressed a desire to have their project analyzed by the first author to be used as credible evidence to influence policy and practice ([Golden, 2020](#)). Although the first author identified her desire to write an academic manuscript, the mothers decided on and led the remaining action-oriented outcomes of the study ([Catalani & Minkler, 2010](#)). The role of the first author was to support these efforts when the mothers desired. For example, one of the mothers' goals for the project was to present their findings during their local children's hospital's yearly conference. To help accomplish this goal, the first author wrote an abstract for them and, upon acceptance, created a poster that they presented to hospital staff to further influence support of policy and programmatic changes at the hospital level.

Analysis

The first author and three additional university researchers undertook a qualitative analysis process for this manuscript. To ensure the mothers' voices continued to be centered, the first author asked the mothers if they wanted to continue meeting weekly to participate in data analysis and writing (Evans-Agnew & Rosemberg, 2016). After already spending five months on the project, the mothers decided that, due to time constraints, they wanted the first author to conduct the formal qualitative analysis while utilizing Synthesized Member Checking, which ensures the co-creation of knowledge by giving the mothers the opportunity to engage with and add to findings (Birt et al., 2016).

The four university researchers analyzed the six transcribed weekly discussions, the recorded and transcribed virtual exhibit, and the photos and accompanying descriptions. As the main descriptions identified from the mothers' analysis were presented in the exhibit, they were coded as part of the overall project analysis. The university researchers conducted reflexive thematic analysis to formulate meaning connected to mothers' experiences through collaborative coding and the production of themes (Braun & Clarke, 2022). This analytic process was chosen as it situates the researcher's subjectivity as a tool for knowledge production (Braun & Clarke, 2022). Collaborative coding was used and combined descriptive, In Vivo, and emotion coding (Braun & Clarke, 2022; Saldaña, 2016). Initial themes were generated by discussing the commonalities, differences, and shared meanings between the codes in each of the five topic sessions (Braun & Clarke, 2022). This led to reviewing, naming, and defining the four initial themes by the first author (Braun & Clarke, 2006). Findings were then written and sent to the six mothers to participate in Synthesized Member Checking with the goal of extending the co-construction of knowledge (Birt et al., 2016). The six mothers were emailed the results and asked to respond to the following questions: "Does this match your experience?" "Do you want to change anything?" "Do you want to add anything?" (Birt et al., 2016). Mothers had the option to respond via email, text, or phone call. Five of the six mothers returned these documents with comments. Mothers were pleased with the results and stated they accurately reflected their experience, with two mothers indicating that the results made them "feel seen." After the manuscript was written in its entirety, it was again sent over to the mothers to provide edits, feedback, and consent. Most suggested revisions ensured the use of person first language.

Findings

Four themes were created to describe the meaning mothers give to their experiences: *The Repetitive Nature of Trauma*, *Finding and Creating Space*, *Light in the Darkness*, and *Mother versus Caregiver*. In the theme *The Repetitive Nature of Trauma*, mothers describe how uncertainty, repetition, and continual moments of trauma pervade their experiences with their children and impact their physical and emotional well-being. *Finding and Creating Space* highlights how mothers work to create physical and social spaces of normalcy for themselves and their children. Next, the theme *Light in the Darkness* embodies the mothers' emphasis on maintaining hope on their journey of medical motherhood through personal coping, social support, and medical support. The last theme, *Mother versus Caregiver*, highlights the complexity of the mothers' identities as they take on the varying roles of mother, caregiver, and expert.

The Repetitive Nature of Trauma

Amid the pictures and descriptions presented by the mothers was the impression of a rollercoaster that not only goes up and down but may stop or break at any moment. The theme, *The Repetitive Nature of Trauma*, subsumes the uncertainty, repetition, and continual moments of trauma that the mothers describe experiencing while caring for their children with medical complexities.

The drastically, very rapidly, and continuously changing life with a child that has medical complexities reverberated throughout each story. Emotions were dynamic, the highs and the lows were enveloped in a daunting uncertainty. As described by Jesse,

I guess in some ways, uncertainty and wait and see, feel like old friends of mine. My family and I live our day-to-day life with the uncertainty around Nora's chronic health conditions, daily seizures, sudden and lengthy illness, and a weak immune system.

Although caring for a child with medical complexities, a unique experience of 'wait and see' loomed over each of the mothers. The trauma from this uncertainty and the fear of medical complications and even death is exemplified in Rachel's story of her son during the *day in the Life* Session (Figure 1). Rachel recounts,

I remember Jacob had the best day of his life December 15th and then December 16th, we were in the hospital and that was the worst hospitalization where he came closest to passing away. And it is just like, "How is this our life?"

The mothers learned to adapt to the extreme and traumatic uncertainty surrounding the unpredictable

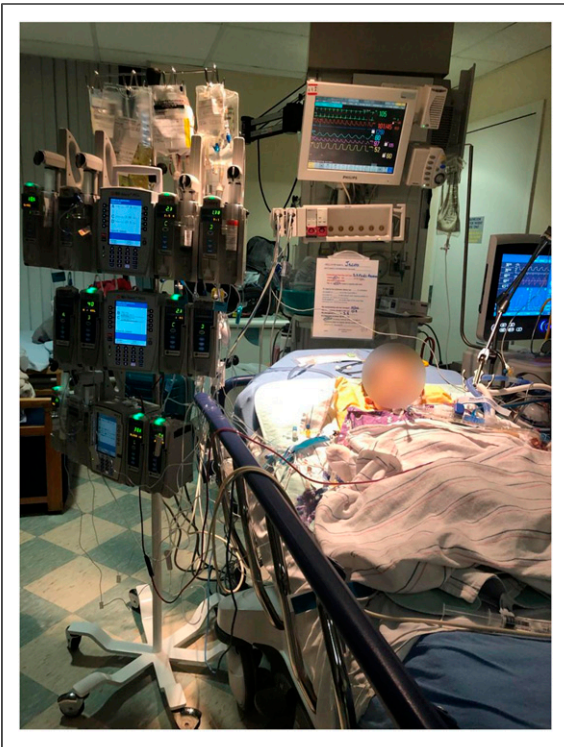


Figure 1. “Meds on Meds on Meds.”

transformation in their children’s health from one day to the next. As Jesse states, “there are days Nora has woken up smiling, happy and healthy only to be admitted to the hospital by bedtime. As a family, we understand how quickly life can, and does, change.” The uncertainty that the mothers faced necessitated them to be constantly alert, leading to a type of hyperarousal permeating throughout their stories each week.

Along with uncertainty, an instinctive repetition was salient throughout each week. Hospital stays, medical procedures, and providing constant care seemed to play on repeat in the lives of the mothers and their children. Although describing her daughter’s medical care, Brittany describes an almost robotic response to meet her daughter’s needs. She paints the picture when she states,

Anytime she gets a fever, it’s a UTI and we have to go to the hospital for four days and wait for cultures to grow. It’s this whole thing, and each time we would have to go to the O.R. for her to get the PICC line, so that we could do the medication at home for a period of time. Then she would get the PICC taken out and then she would get a UTI five days later after getting her PICC taken out...

And the story goes on as Brittany repeats this cycle of illness and care with her daughter. With uncertainty and repetition permeating throughout their stories, the mothers

constantly re-experience the most traumatizing moments of their lives as they pray for their child’s well-being. The possibility of death looms.

Mothers bring the life and death stress of the hospital home with them as they continue to provide constant care for their children’s medical needs, resulting in continual moments of trauma. To cope with this, mothers learned medical skills that became part of their daily care routines. These include dressing changes, trach care, and the like. Rachel states,

This is daily life of the trach child just doing his trach care. I still remember, like, being in the hospital and learning how to do it and just thinking, you’re literally holding your child’s airway into his throat. It’s just crazy to me to think of holding something that his life depends on as he wiggles around.

Mothers reported feeling stressed while performing these procedures for fear of something going wrong, as an error on their part has the potential to lead to dangerous outcomes for their child. This fear is present in Ria-hannon’s reminiscence of the first time she had to change her son’s trach by herself (Figure 2) “... I had to change his trach. And so I was like, ‘There’s no way I can wait for my husband to get home in like seven hours’. So I had to just do it. I was terrified.” Mothers knew they had to release this fear to perform these medical procedures daily. As they became accustomed to the stress, mothers started to describe the medical care as a daily routine, much like “brushing their teeth.” When discussing this movement from the initial fear to these automated moments of care (Figure 3), Darlene jokes, “I was like, ‘No, I’m terrified. No thanks.’ But now it’s like, this is no big deal.” Although the mothers describe a continuous trauma they cannot escape, they have learned to perform routine medical procedures on their children at home to successfully navigate the stress of caring for their medically complex children.

Throughout each meeting, the uncertainty, repetition, and continual moments in which mothers feared the passing of their child embodied the theme of *The Repetitive Nature of Trauma*. As expressed by Darlene, we are left with the question, “how can a person endure this much pain and trauma with their child?” Through a lack of targeted care for the mothers within hospitals, doctors, and insurance companies, mothers were not offered the necessary relief to regulate themselves following traumatic events. And yet, the mothers worked tirelessly to create a space for themselves and their children, an imperative aspect of the mother’s survival.

Finding and Creating Space

The theme *Finding and Creating Space* characterizes mothers’ endeavor to create normalcy by creating



Figure 2. “My EVERY day.”

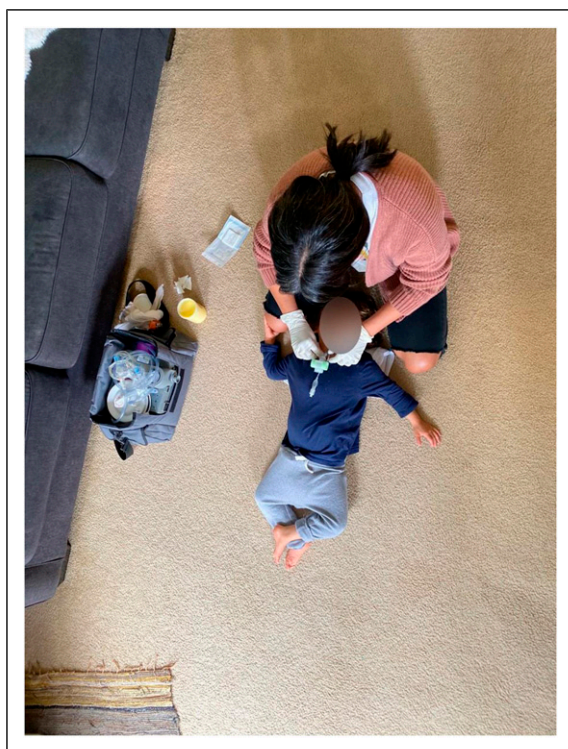


Figure 3. “Trach Care.”

physical and social spaces for themselves and their children. In an often hostile environment, mothers have had to overcome what Jesse terms a “societal silence” as they actively advocate for these spaces of comfort.

A significant mechanism through which mothers can create space for themselves and their children is advocacy.

Mothers described not knowing what it meant to advocate for their children in a complex medical system and how they initially struggled to embrace their roles as experts of their children’s needs. Sara highlights the challenge of stepping into this role when she states, “I think it’s so easy to think that moms turn into advocates overnight for their own families. I think that that’s the idea that I had and I still struggle with that.” Reinforcing this challenge is the fact that mothers are not always heard. Jesse describes how the medical system tried to silence her as she reflects on having to file multiple safety and incident reports. She states, “I ultimately blame myself. This is reinforced when these instances go unacknowledged or unprocessed by those involved.” Without being able to process these experiences with her daughter’s medical team, Jesse is left questioning her role as an advocate and, ultimately, her space within the medical setting.

Within the theme of *Finding and Creating Space* is mothers’ ability to create a physical space for themselves to enjoy normalcy within medical settings. This was done, in part, during the daily medical care of their children. When discussing a picture of Darlene changing Owen’s trach (Figure 3), Rachel describes how a loving space is created,

I think it looks so cute how he’s smiling and looking at you straight in your eyes... It looks like bonding time, he has his hand on your knee, and it’s just special time and it’s your routine together that he enjoys.

Along with medical care in the home, mothers described how they create comfortable spaces in hospitals to make “these clinical environments less scary and really humanizing...” Jesse describes this process as she reflects on Brittany’s picture of her son reaching for her daughter in the NICU (Figure 4),

It’s all a reflection of a physical, tangible space you’ve created and you’re capturing it with your photo and I think what this says to me is like, ‘It’s not so scary.’ This is the context for normalcy and it can be the context for normalcy and beauty and tenderness and those important things I think we cling to in these settings sometimes.

During conversations about *Health*, mothers explored how normalcy was important in their coping processes while in the hospital. Brittany presents a picture of her and her husband eating dinner in their favorite space in the hospital during one of her daughter’s NICU stays (Figure 5). In response to Brittany’s picture, the mothers commented on their attempts to find similar spaces within the medical world for themselves and their families to enjoy. For Jesse, this included skating. She states, “I first wore, stood up, and learned how to stop on roller skates at my daughter’s hospital bedside... Since then, roller

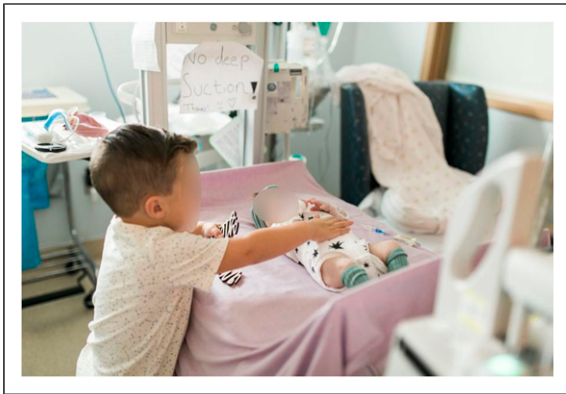


Figure 4. “My Camera is my Voice.”

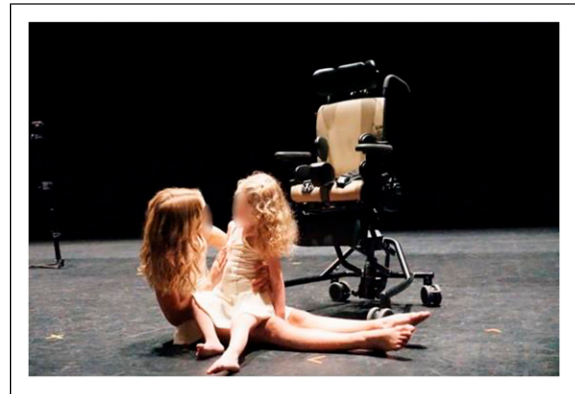


Figure 6. “Advocacy Demands Strong Partnerships and Friendships.”



Figure 5. “Our Happy Place.”

skating has become a major source of stress reduction, freedom, confidence, and just straight up fun.” Knowing that she needed a space to be, Jesse turns a hospital room or parking lot into a space for her to skate.

Outside of the medical setting, mothers advocated to create social spaces for their children to enjoy normalcy. Brittany shares a picture of her daughter at the beach in Hawaii with her G tube and Picc line as she describes the steps she had to take to ensure that her daughter could participate in the activities that her family loves. She states she had to fight “for her [daughter] to be able to have normal experiences, even though she’s got all this stuff going on...” Mothers repeated this idea of “even though” throughout their stories. Jesse, with encouragement from a family friend, has created a social space for her daughter to enjoy a dance class (Figure 6),

Nora has this amazing connection with her class. She’s been with the same class now since she was three. She’ll be six this

month. I drop Nora off at dance and they all climb on Nora’s chair ... I learned so much about advocating for things for Nora that I never would have envisioned for Nora, I guess, from other people.

Through this dance class, both Jesse and Nora can find space for themselves to participate in childhood activities. Jesse excitedly talks about Nora’s confidence as she engages with her friends in her classroom. “You have a place here. And she does. They’ve done everything to make a place just for her, and it’s amazing.” Mothers sought to make a social space for their children and their families as they navigate a society that tried to silence them through inaccessibility.

Light in the Darkness

Light in the Darkness embodies the mothers’ journey towards hope in the midst of the darkness they often experience. Within their descriptions of each picture, lightness in the mother’s voices can be heard, but then, suddenly, there comes a darkness in their tone. Their emotions go from high to low and back up again as they jump from joy, to sadness, to anxiety and avoidance. But through it all there is a sense of movement. Just like their children’s diagnoses, the mothers’ lives are constantly moving and changing. This can be heard when Brittany concludes that their pictures show “our life as beautiful as it is, even when it’s ugly sometimes.” Mothers find *Light in the Darkness* through personal coping, social support, and medical support.

In order to find light in the darkness, mothers utilized various mechanisms to cope with the repetitive nature of trauma in their lives. Mothers explored what it meant to find light when the world expects them not to be ok. Riahannon states

...us seasoned parents get a little looked down upon. 'How are you seeing the light at the end of the tunnel? Your kid is going through something and you just look so happy.' But it's like if we internalized everything our kids went through and every admission and every surgery, we wouldn't be here. We just wouldn't.

Riahannon's comment brings up a significant aspect of finding light in the darkness; the stark reality that light is needed to survive. However, while the mothers might feel, as described by Jesse, "physical, mental, emotional, and spiritual fatigue," they know that there will be good days and bad days. Their ability to find light in the darkness hinged on accepting this, and taking days as they come.

With time and lots of work, mothers learned various ways to cope and find relief, even if just for a moment.

Mirroring the movement in their children's lives, the mothers' journeys are constantly moving as they fight for their family's survival. In the session on *Health*, Riahannon (Figure 7) describes the realization that her ability to care for herself needed to be prioritized. Recounting the story of her own body failing and admittance to the hospital, Riahannon reflects, "if I'm not happy or if I'm not in a good place, I can't be there for anybody." For Darlene (Figure 8), coping meant being able to practice yoga while her son plays. She states that she does yoga poses when my mind, body, or emotions are sending me warning signs. Here, I'm doing child's pose to stretch my



Figure 7. "The Longest Year Ever."

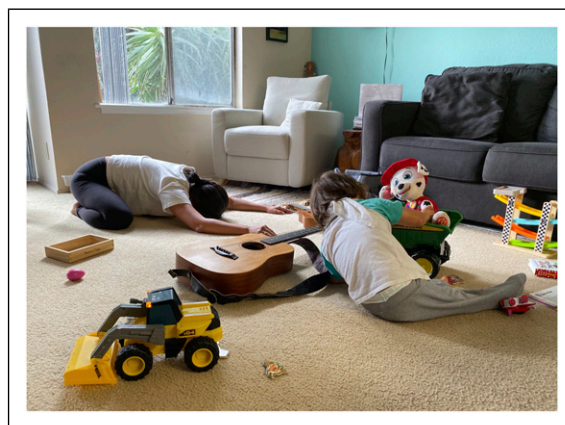


Figure 8. "Finding Balance Anywhere."



Figure 9. "The Most Badass Mother of Them All."

stiff back from the trauma it holds and to take deep breaths to balance my nervous system of all the stress I encounter daily.

Although the mothers understood the weight of caring for themselves, they also questioned their ability to cope successfully. When describing the picture of her serenity prayer card (Figure 9), Jesse recalls that her “doctor told me—who like, doesn’t really know me that well— that I need stronger coping skills.” Yet she listed the various methods she uses to constantly cope. This fact was pointed out by Brittany, who reminded Jesse that the serenity prayer card was clearly clutched over and over again proving that Jesse, like the other mothers, is constantly coping, constantly praying, constantly holding on. Although never labeled as a burden, the mothers describe the steps they must take for themselves to be well so they can ensure that their children and their families can move beyond just survival. However, mothers note that sometimes all they can do for themselves is survive and get through one day at a time. Although the mothers have worked hard to find ways to care for themselves to find light in the darkness, the mothers agree with Darlene when she states that she is “still looking for healthier ways to cope with something I cannot remove from my life.” As mothers made the decision that “as they keep fighting, I’ll keep fighting” and therefore did everything in their power to ensure that their children felt cared for and loved. Although they did not always feel like they were doing a good job, they fought to find strength within themselves, strength within their community, and strength within their children.

As the mothers highlighted the lifesaving need to keep themselves healthy to care for their children, they describe the social support that brings light into their lives. Rachel talks about the unparalleled support that she receives from her friends. She states, “I just feel the whole weight of the world comes off my shoulders when I’m around them.” Rachel goes on to explain, “they’re just family to me. And they’re just so amazing. ...People, just sign up to come over to hold Jacob so I could get stuff done around the house. They’ve just been such a rock to me.” As Rachel describes her friendships, we see Sara’s face light up, revealing the significance of friendships in her own life. In the same week, Sara’s picture and description (Figure 10) lift up her friendships:

K-Y-T-S pronounced kites is the initial of our names. And although it started as a fun way to name our group, it later came to represent so much more to us. These women have encouraged me to take flight and sail into things that have felt utterly scary, stupid, or impossible.

Sara describes her friends as the ones that lift her up and provide her with the social support she needs to get



Figure 10. “KYTS.”

through the repetitive nature of trauma that she experiences. Their children’s medical complexities require the mothers to need a little more support, a task their communities are happy to take on.

Beyond their friendships, mothers describe the importance of medical support in ensuring that both themselves and their children are well cared for. Many of the relationships that were salient to providing care for themselves and their children were medical personnel, other medical parents, and support groups through social media platforms. Mothers discussed how having medical support was helpful when they did not know what to ask for or what to expect when they felt “new to this kind of life,” as described by Rachel. In this regard, a community of “good” medical personnel is crucial. The mothers listed the traits of good medical personnel as exuding optimism for their child, being relatable, advocating for their child, taking time to teach the mothers, and most importantly, being willing to learn from the mothers. Although the mothers recounted some negative experiences with medical personnel, they emphasized that having medical support in the hospital significantly impacted their quality of care. Building mutual trusting relationships and expanding their supportive community was essential to navigating this space and finding light in the darkness.

Mother vs Caregiver

The theme of *Mother vs Caregiver* portrays mothers' descriptions of being forced into a role between a mother and a caregiver. As mothers of children with medical complexities, the mothers were expected, and as such expected themselves, to simultaneously identify as a mother, caregiver, and expert. The mothers did their best to hold space for their multiple identities as they identified missing parts of motherhood, taking on the caretaker role and becoming advocates and experts on their children's medical complexities.

Not promised tomorrow, mothers were forced to live in the present and focus on the "here and now." From this came a sense of missed time and yearning for some "typical" experiences of motherhood. When describing her first experiences in the NICU with her son, Riahannon states, "You miss that time with them, holding them, cuddling with them... I'm barely just now getting that all with him to be able to hold him." She grapples with this missed time as she further explains that "it's something that you don't think about as a parent, like, 'Oh, I'm not going to be able to hold my kid'. Until you don't get to hold your kid." When processing her early experiences with her daughter, Sara notes that she "didn't realize how much I missed." Missing these initial opportunities to take on the role of mother was further emphasized by Darlene when she describes "things that were stolen from me as a mom because he was born early." Although each of the mothers could identify these "stolen" opportunities, they began redefining motherhood for themselves. This was evidenced in Darlene's story as she presented a picture with her son (Figure 11), "I still get to be a mom. I still get to hold him. I still get to be his mother and have mother type experiences."

The mothers explored the distinction between their roles as mothers and their caretaker duties. Often, they were unsure of where one role began and another role ended. Describing her picture (Figure 11) Darlene grapples with this tension, "I want to comfort him as a mother. But as his caretaker, for lack of a better word, there's also things that need to be done in order to help him get to a place where he's better." Darlene emphasizes the idea that certain aspects of motherhood have to be relinquished to care for their children's medical complexities. Jesse states there is a fine line between "caring for them and physically caring for them." The mothers articulate the difference between caring as a mother and ensuring the survival of their child as a caretaker. Sara was confronted with this role divergence during her daughter's first hospitalization. Sara describes a picture of her holding multiple bags of her breastmilk (Figure 12). Wanting to continue her typical role of mother to her daughter Sara "pumped, and pumped for this baby that wasn't awake... for months..."



Figure 11. "With Child."



Figure 12. "I Just Want to Give Her a Hug."

there was so much milk. I filled up friends' freezers, and our freezer, and my mother-in-law's freezer. And then there was not enough room anymore." During her daughter's hospitalization, Sara's breastmilk acted as the physical representation of her desire to maintain her previous role as mother to that of caretaker, advocating her daughter's survival. In their exhibit, the mothers explain,

Our primary role has become our primary identity, that of a medical mother. We are accustomed to feeling for our children, entering into their shoes, and perceiving the world through their eyes. As we take on their identity so frequently, their identities often become our own. We extend ourselves to our children and become one with them.

And found within this need to change their identity to become one with their children is Rachel's lingering plea as she holds her son while he screams, "what I would do to take away your pain." Overall, when the mothers spoke of motherhood, there was a sense of loss when they had to act as caregivers.

To ensure that their children received the best care, mothers had to take on the role of experts in their children's medical care. Riahannon describes her acceptance of the role as expert when she states, "everybody looks at me as the one with all of the answers. And I kind of feel like I expect that of myself." In fact, as mothers presented their pictures for the *Day in the Life* session, they described the specialized medical care that they provide to their children daily. This is heard when Brittany presents a picture of her daughter's nightly routine (Figure 13). Brittany names the medical supplies she has gained expertise in using,

In clockwise order there is: her g-tube pump, formula, and five different enteral medications, then antibiotic flushes that we injected directly into her bladder through her vesicostomy, then her nightly enema that we home make, then her IV medication that is injected through her broviac chest port.

Although the mothers joke that they could pass the NCLEX (the national licensure examination for nurses in the U.S.) with their collective knowledge, they also recount the difficult path towards becoming experts. Sara explained that in the beginning, advocacy was difficult as she always felt like she was in crisis. Even after she learned how to navigate the hospital, Sara often feared doing something wrong and that she had to trust doctors over herself. This was reiterated by Riahannon, who admitted to initially feeling embarrassed when the doctors wouldn't listen to her. However, she describes how she gained confidence in her role as expert,



Figure 13. "Nighttime Regimen."

I've just really learned that my gut is usually right. And most moms are like, you're usually right. If your gut is telling you "something's not right, this isn't okay" you're usually right. I've yet to meet a mom that wasn't.

The mothers reflect on how each hospitalization felt like a new learning experience which Brittany labeled "trial by fire." Throughout this process, mothers gained confidence in themselves and their abilities to care for their children in the medical system. Although mothers agree that finding your voice in the medical system takes practice, Sara highlights that "as they grow, you grow in your advocating." Within their expressed desire to experience the "traditional" role of motherhood, the mothers understood that their primary responsibility was to focus on the physical needs of their children as their caregivers.

Discussion

Throughout their time together, the mothers' pictures and stories highlighted the ever-present repetitive nature of trauma as they sought to find light in the darkness, find and create space for themselves and their children, and grapple with the tension between their role as mothers and as caregivers. Through the use of photovoice, findings from this study move beyond the current deficit conceptualizations of parenting children with medical complexities as it humanizes mothers and their children within a complex medical system. Although mothers affirmed the negative impact on their well-being, the mothers conveyed a message of hope. Because of their love for their children, the mothers worked hard to build the

advocacy skills, coping mechanisms, and systems of support they needed to keep going.

The Repetitive Nature of Trauma

Trauma is defined by the Substance Abuse and Mental Health Services Administration (SAMHSA) as “experiences that cause intense physical and psychological stress reactions.” This experience can be a single event, multiple events, or a set of circumstances that has lasting effects on the individual (SAMHSA, 2014). The theme *The Repetitive Nature of Trauma* highlights that mothers experience continuous trauma as they relive what they deem the scariest moments in their lives when their children are hospitalized. As heard in Rachel’s story of Jacob, this hospitalization happens suddenly and unexpectedly, leading to the increased hyperarousal associated with traumatic events (van der Kolk et al., 2005). This is particularly concerning as research on trauma indicates when trauma is unaddressed, individuals become stuck in the fight or flight response and cannot think logically and rationally, have difficulty regulating their emotions, and have an increase in vigilance (Thomason & Marusak, 2017). Although mothers unmask a message of hope currently missing from the literature, they also describe the mental and physical impact of constantly fighting for their children’s lives within the current health system. This reaffirms previous research that identifies mothers of children with medical complexities having lower mental health than mothers from the general population (Bayer et al., 2021).

Finding and Creating Space

A significant aspect of creating space for themselves and their families in the medical system was advocacy. Similar to previous research (Hall, 2011; Rennick et al., 2019), the mothers reflected on how challenging it was initially to have their voices heard in a system that does not consider them experts. Despite this “societal silence,” mothers worked hard to gain the confidence and skills necessary to make a space for their families. This finding is particularly significant, as the majority of current research centers on challenges medical parents face, and is largely missing mothers’ perseverance within the current environment.

Although mothers reinforced previous research that highlights the impact that round the clock care has on parent’s well-being (Hall, 2011; Kuo et al., 2011) and, in particular, on the physical and emotional well-being of mothers in heteronormative families (Lindahl Norberg, 2007), they described how they transformed these initially scary moments into bonding time with their children. Mothers’ pushback on research that frames caring for their children as a burden as mothers encounter these as special

moments that they have come to cherish. Throughout the theme, finding and creating spaces, mothers describe how they find the strength to enjoy moments that they have with their children as they create space just to be.

Light in the Darkness

The most salient finding from this study was that for mothers to care for their children, they must first care for themselves. Mothers reinforce research that highlights these experiences take a toll on their physical health (Hartley et al., 2021; McCann et al., 2014) as they describe the impact of their declining well-being on their ability to care for their children. Mothers responded to the lack of supports to address their well-being by building supports through friendships, peer mentorships with other mothers of children with medical complexities, and supportive medical personnel. Findings reiterate the significance of providing multiple and diverse supports to children as well as their families (Bayer et al., 2021; Bradshaw et al., 2019; Edelstein et al., 2016) but extends current intervention research by describing the need to have access to things such as mobile medical equipment and accessible children serving institutions. Furthermore, it highlights the significance of identifying supports offered by extended family and friends.

Findings highlight how mothers can cope with circumstances they cannot change to care for their children successfully. Outside of the hospital, mothers fought for their children to have a sense of normalcy in their lives. They describe how family and friends ensure that they are provided a space to be children and to be a family. Through these spaces, they create light in the darkness.

Mother vs Caregiver

Mothers, on average, spend more time with their children in direct physical and nonphysical care, such as engaging in specific activities (e.g., food preparation), caring for ill children, shopping for their children, and nurturing (Renk et al., 2003). In fact, researchers postulate societal norms better prepare women for motherhood than men for fatherhood (Yamoah, 2021). Interactions with their children remain integral to women’s identity as mothers are the primary parent in charge of children’s lives (Renk et al., 2003). This was heard throughout each week as mothers described what it means to be a mother of a child with medical complexities as they took on the role of mother, caretaker, and expert. With this holistic understanding of the identity of medical mothers, it becomes essential that each aspect of their lives are acknowledged, supported, and upheld as mothers attempt to balance their multiple identities in their care for their children.

Limitations and Future Research

This study provides a better understanding of mothers' individual experiences with children with medical complexities; however, a few limitations should be noted. The collective did not include a specific focus on demographic data during recruitment. As a result, the mothers do not represent all cultural or economic experiences. Next, it was important to the co-creators of this project to build a network of support with other mothers in San Diego. As such, the findings only represent the experience of mothers from one children's hospital. This study should be replicated in different counties to further elucidate mothers' experiences within various healthcare settings.

The mothers were all cis-gendered and in heteronormative families. This limits the understanding of how gender and sexual identity might impact the experiences of parents of children with medical complexities. Future research should target a more inclusive and diverse group of collaborators who might glean insight into the impact of the role of mothers in families with parents from opposite sexes. Furthermore, as the term "family" varies widely in academic literature and lay definitions, future research needs to ask who and what constitutes a family. Particularly as scholarly definitions focus on structure (e.g., biological or legal ties), function (e.g., caretaking or financial support), or transactions (e.g., creation of shared meaning through affective ties or symbolic communication such as stories and rituals). It is also imperative that future work looks into the experiences of fathers of children with medical complexities to understand their role in care. Although fatherhood is important to explore in relation to children with medical complexities, the collective wanted to understand the perspective and voices of mothers from mothers.

Finally, our methodological choices impact the results presented here. The first author maintains that participatory research should be entirely led by the community while ensuring that reaching the agreed upon goals does not overburden the community. In this particular study, learning and conducting qualitative analysis was determined by the mothers to be a burden. As such, the first author brought in three additional university outsiders to analyze the data. Having the data analysis led by university outsiders changes the lens through which the data were approached and understood. As this was understood by the university researchers, it was important to leverage a method of member checking that ensured that the mothers were able to engage with and add to the interpretation of the data (Birt et al., 2016). This required the mothers to read the paper in its different drafts and make or suggest any edits to the paper. Although all but one of

the mothers were able to engage with the paper in this way, future work that utilizes synthesized member checking should provide various mechanisms to do this such as group discussions. The last methodological consideration is the choice to turn the in-person exhibit to virtual as the study was wrapping up at the start of the COVID-19 pandemic. Although this allowed more people to attend the exhibit, it altered how mothers were able to engage with the audience. Future work should include audience responses to the exhibit within their analysis and findings.

Implications

True to participatory action research, the aims of photovoice are to record and reflect on mothers' own concerns and strengths to create and share their knowledge to inform community-driven policies and practices. In particular, the full participatory nature of this study led to the creation of implications at the policy, community, and individual levels (Catalani & Minkler, 2010). These were derived from what the mothers termed "Calls to Passion" which they collectively created following the analysis of their pictures and discussions for their virtual exhibit in June 2020. The calls to passion seek to engage outcomes at the policy, community, and individual levels of hospitals and social networks.

The study's call to passion included six recommendations for hospitals engaging with children with medical complexity to enhance the support for the mothers: (1) creation of a case manager collaboration, (2) accessible resources, (3) quarterly community forum, (4) mentorship support, (5) creative collaboration, and (6) further use of photovoice research.

Through their photovoice exhibit, conference presentation, and individual led advocacy (Catalani & Minkler, 2010) the mothers identify specific areas for action and advocacy. First, the mothers call for hospitals to create a position of case manager who will develop community resource guides for family-centered services. This will ease the burden of "trial by fire" as mothers learn to advocate for the resources that are available to them and their families. Next, mothers ask for accessible resources to better support theirs and their children's needs. This would include information regarding hospice, medical insurance, and the like. These resources must also include resources that are available in multiple languages and formats in order to ensure inclusivity.

Mothers emphasize the need to increase understanding of their lived experiences among service providers and community members. (Catalani & Minkler, 2010). Mothers call on hospitals to create quarterly community forums that include hospital staff and families of children with medical complexities in order to identify and fill the

unaddressed needs of families and their children. Although the photovoice project enhances the understanding of the assets and needs of mothers of children with medical complexities, it is imperative that hospitals serving children with medical complexity continue to address the needs of their particular communities. Along with this, mothers highlight the significance of creating a space with mothers of children with medical complexities to learn from each other. Therefore, they call on hospitals to create peer-mentoring programs that match seasoned medical parents with families that have obtained a recent diagnosis. For example, this project resulted in the mothers' advocacy to implement a peer support program which has been stalled at the hospital level due to funding issues.

Finally, mothers focus on empowering themselves and others to capture their lived experiences with their children. As the peer support programs are stalled at the programmatic level, mothers are now planning to create their own informal support networks. Furthermore, through this project mothers highlight the importance of recording intimate moments with their children, sometimes before their passing. They therefore ask hospitals to implement creative collaborations for families of children with medical complexities so that they can treasure these moments with their children. This can take on the form of future photovoice projects with parents which allows them to showcase their experiences with their children. Which, findings from this project highlight the importance of using the voices of mothers of children with medical complexities to inform policy and practice. As such, mothers call for the replication of this project through the use of photovoice with mothers of children with medical complexities who are affiliated with other hospitals. Although these six research implications move our understanding and support for mothers' forward, it is imperative that a community centered approach is used to guide the implementation of these recommendations.

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