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Improving the Mental Well-Being of Children Hospitalized with Chronic Illness

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Abstract

The psychological well-being of children hospitalized with chronic illness is of vital importance (Eccleston et al., 2015). In the first part of this project, I documented factors that influence their well-being and identified potential pathways for enhancing psychological health. In the second part, I did qualitative research in the form of interviews with four healthcare professionals who work closely with hospitalized children. I offer recommendations based on their observations, including a new type of staff position and closer collaboration among hospital staff.

Keywords: Hospitalization, Chronic Illness, Pediatric Illness, Pain, Support Systems, Peer Relationships, Child Life Services, Psychological Care

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The following paper is sectioned into two distinct chapters. The first chapter is a review of the literature regarding the experiences of hospitalized children with chronic illness. I focus on the positive and negative influences impacting hospitalized children with chronic illnesses before proposing a solution to improving their well-being. The second chapter is an interview-based qualitative research study that centers on the experiences of current healthcare professionals working with the identified population. The purpose of the research study was to deepen understanding of what care looks like for hospitalized children in order to provide more refined recommendations for improving the well-being of hospitalized children with chronic illnesses.

Chapter 1:

The Psychological Well-being of Hospitalized Children: Literature Review

Over the past few decades, the mortality rate of children has significantly decreased due to advances in the medical field resulting in more children living with chronic illness (Boyd & Hunsberger, 1998; Judson, 2004). Furthermore, the number of children diagnosed with chronic illness is expected to continue to increase in the coming years (Eccleston et al., 2015). Exact statistics regarding children diagnosed with chronic illness, specifically, are not tracked well, but it is estimated that 50,000 children each year gain a permanent disability as a result of injury or illness (Judson, 2004). Children with chronic illness are a particularly vulnerable population who must find ways to cope with the stress of hospitalization and long-term management of their disease (Boyd & Hunsberger, 1998). How can improvements be made in supporting the mental health and well-being of children hospitalized for chronic illness? To answer this question, I will first dive into some background on pediatric illness, specifically discussing chronic illness. Next, I will discuss the experience of hospitalization for children with chronic illnesses. After that, I look at how pain relates to chronic illness and impacts a child's well-being. Then, I will talk about the important role of support systems in a child's experience during hospitalization. Lastly, I will explore how psychological care currently exists within a hospital setting before digging into specific interventions currently used to help children. From these varying angles, I will then draw conclusions about the current interventions for children

hospitalized with chronic illness and propose a new staffing position within hospitals to address the well-being of hospitalized children.

Importance of Research

Childhood and adolescence are important periods to intervene in experiences that may later result in the development of psychological problems. Early treatment of psychopathologies can help prevent children from suffering long-term mental disorders. Children who experience problems with psychopathology are at an increased risk for developing comorbidity, suicidality, and lower educational success (Roest et al., 2023). In particular, the mental health and well-being of the identified population are at high risk due to the unique stress and challenges they face as a result of living with and being hospitalized for chronic illness. With the growing number of children who are living with chronic illnesses, the need for proper interventions targeting their well-being is also growing exponentially (Boyd & Hunsberger, 1998). In addition to improving well-being, supporting patients psychologically will translate to better physical health outcomes overall due to better adherence to treatments and a better understanding of how their illness fits into their lives going forward (Rohan & Verma, 2020).

The well-being of children and the factors that influence it are heavily discussed throughout this paper. The definition of well-being has varied across disciplines, but the definition used for this paper is “feeling and functioning well across a number of domains” (Lancaster et al., 2022). For example, the well-being discussed in this paper incorporates physical, mental, emotional, and social

well-being into one broad term. By using “well-being” as a holistic term, I investigate all of the aspects of chronic illness and hospitalization that impact a child.

Pediatric Illness

Pediatric illness–illness during childhood or adolescence– affects a significant portion of the younger population. Children suffering from illness can be put into three major categories: acute, chronic, and terminal. Acute medical conditions are sudden in onset and can be severe (*Acute Vs. Chronic Conditions*, n.d.). In contrast, chronic medical conditions are defined as diseases that develop over time and occur for at least 3 months (*Acute Vs. Chronic Conditions*, n.d.; Eccleston et al., 2015). Terminal illnesses are diseases that are life-limiting and result in irreversible decline (Hui et al., 2014). Chronic medical conditions impact about 27% of children and adolescents and are the primary scope of this paper (Eccleston et al., 2015). Different types of chronic illnesses in the United States include but are not limited to sickle cell anemia, bronchopulmonary dysplasia, cystic fibrosis, epilepsy, chronic renal failure, congenital heart disease, and diabetes mellitus. The most common chronic illness among children in the United States is asthma, impacting about 6 million children nationwide (Judson, 2004). While the causes of chronic illness are not straightforward, there are a few overlapping factors that can be pinpointed as increasing risk for chronic illness. The greatest risk factor for chronic illness diagnosis has been noted to be poverty due to inequities in access to and usage of resources (Judson, 2004).

Chronic illness impacts many aspects of children's lives and results in children facing one or more of the following consequences: (1) the limiting of typical functions for their age, (2) disfigurement, (3) dependence on medical technology, (4) dependence on medication, (5) need for extra medical care than what is typical for a child of that age, and/or (6) special treatment at home or in school (Judson, 2004). Whether hospitalized or not, the ability to participate in activities, school attendance, friendships, emotional functioning, and the families of the children are all affected (Eccleston et al., 2015). The psychological impact on diagnosed children can lead to increased levels of anxiety and depression, a decrease in physical activity, increased levels of tiredness, and an overall lower quality of life (Rohan & Verma, 2020; Szulczewski et al., 2017).

One factor that is significantly linked to the overall well-being of children diagnosed with chronic illness is pediatric illness uncertainty. As defined by Szulczewski et al. (2017), pediatric illness uncertainty is how a child or caregiver interprets an event relating to the child's illness as it is related to the child's well-being. The unpredictability of health outcomes coupled with a lack of understanding of the illness, treatment protocol, or the expected side effects or medications significantly impacts the psychological functioning of both caregivers and patients. The relationship between illness uncertainty, psychological functioning, and the ability to cope for patients may be a key area to work on improving the overall quality of life of pediatric illness patients.

Hospitalization

Children with chronic illness are more likely to acquire acute illness and to need frequent hospitalizations for both acute illness and aggravation of their chronic condition (Balling & McCubbin, 2001). Being in a hospital setting brings a lot of unfamiliarities for children such as new faces, sounds, sights, smells, and vocabulary which can be a source of anxiety and stress (Norton-Westwood, 2012; Jepsen et al., 2019). Similarly, being hospitalized may elicit feelings of fear surrounding a lack of knowledge about their treatment and how their illness will interfere with daily life. Children surveyed about their concerns during hospitalization were shown to worry about having to be separated from friends, family, and their usual routines (Ekra & Gjengedal, 2012). Another study conducted by Boyd & Hunsberger in 1998 found that the perceived stressors of hospitalized children were IVs, invasive procedures (particularly those involving needles), surgery, fear of death, lack of independence, the hospital environment, a loss of control, isolation from peers, and a lack of activities.

Coping with Hospitalization

Since children and adolescents experience a variety of emotions during hospitalization, having good coping skills is a necessity for them (Jepsen et al., 2019). Children's abilities to cope vary based on many internal factors including age, gender, personality type, perceived locus of control, self-esteem, and problem-solving abilities. However, outside influences such as social support and involvement in personal relationships also affect each child's ability to cope with their experiences (Boyd & Hunsberger, 1998). Similarly, a child's developmental

level affects their understanding of their illness which influences their coping behaviors tying back to the patient's level of uncertainty surrounding their illness (Jepsen et al., 2019; Szulczewski et al., 2017). Older children tend to be more aware of their surroundings, as well as more likely to have prior experiences with health care which may equip them with more coping strategies and less uncertainty about their condition (Jepsen et al., 2019). However, this is not always the case, and each child's experience is unique and is influenced by many factors.

Research has shown that children use a variety of coping strategies during their time in the hospital. For example, some of the most cited strategies included behavioral distraction, cognitive distraction, and seeking social support (Boyd & Hunsberger, 1998; Jepsen et al., 2019). Behavioral distraction is a tool that helps deflect attention from the stressor. Examples include activities such as deep breathing, watching television, listening to music, going for a walk, or playing games. Cognitive distraction entails thinking about something other than what is going on to distract attention from the situation. For example, patients may try to think about what they are going to do next, their family, or positive affirmations. Seeking social support involves reaching out and spending time with family or peers. To manage the unfamiliarity of their environment, one study found that children tended to utilize their social support such as spending time with parents and engaging with the healthcare staff (Jepsen et al., 2019).

Avoidance, as well as submission and cooperation, were also cited as highly used coping strategies for pediatric patients (Boyd & Hunsberger, 1998; Jepsen et al., 2019). Avoidance is when the child explicitly doesn't think about

what is happening to them or refuses care. For example, if a child refuses treatment or tries to sleep through exams, then they are utilizing avoidant coping strategies. On the other hand, submission and cooperation are when the child lets medical staff do what they need to do without refusal (Boyd & Hunsberger, 1998). Ekra & Gjengedal (2012) also found that allowing children to take an active role in their treatment helped them to adapt to their new situation. For example, allowing children to have input on various aspects of their treatment allows them to feel a sense of control. One way to encourage active participation from patients is by having them choose what position they want to be in during procedures or exams when possible.

Hospitals and medical care staff also have ways that they work to reduce the impact of hospitalization on children. Since the environment surrounding a person can impact both mental and physical health, considering the structure and design of the hospital can significantly change the experience of anyone who walks through the door (Norton-Westwood, 2012). Research shows that children tend to prefer a color scheme of blue and green with a sea or water theme (Norton-Westwood, 2012; Ekra & Gjengedal, 2012). Similarly, natural light, windows with a view, and the availability of outdoor spaces have been shown to promote positive emotions in pediatric patients (Norton-Westwood, 2012). Children have also reported that having areas to be able to connect with other children in the hospital to play reduces fear of the environment (Kleye et al., 2021). While pediatric hospitals and hospitals with designated pediatric wings

may give attention to the environmental factors that impact patients, the psychosocial effects of hospitalization are still very challenging.

Post-Hospital Syndrome

Both the physical and mental stress patients face during hospitalization can impact their recovery (Carabello et al., 2019). Sleep deprivation, loss of privacy and autonomy, limited mobility, as well as psychological stressors contribute to a phenomenon known as post-hospital syndrome. Post-hospital syndrome is the period following hospitalization when the risk for rehospitalization is high. Because being in the hospital can be extremely stressful for children, the biological mechanisms that control their 'fight or flight' response are constantly stimulated. The autonomic nervous system interprets the novelty and uncertainty of the environment to be threats disrupting patients' ability to adequately adapt to the hospital environment. This overstimulation of the nervous system coupled with the stressors discussed above causes an increased risk of rehospitalization for patients. Addressing the sources of stress for patients during their time in the hospital is key to decreasing post-hospital syndrome and increasing the overall well-being of patients (Carabello et al., 2019).

Chronic Illness and Pain

Along with hospitalization, pain is another factor that greatly impacts the well-being of children dealing with pediatric illness. Children and adolescents often experience pain in conjunction with medical interventions and their underlying illnesses. One study found that children view pain as one of the worst parts of having a long-term illness (Kleye et al., 2021). Approximately 49% of

children and adolescents with chronic illnesses experience average to extreme pain as a result of procedures and treatments (Matziou et al., 2016). Experiencing chronic pain can significantly impact the quality of life of a child as it increases depressive symptoms, decreases school attendance, restricts their social lives, and creates fear surrounding clinical care (Matziou et al., 2016; Kleye et al., 2021). There is a cyclic nature within the relationship between fear and pain. Increased fear about procedures can increase emotional distress and increase the pain experienced by the patient thus resulting in more fear during future procedures. The perception of pain is heightened when a patient is under increased psychological anguish thus targeting fear and pain for interventions could be beneficial in reducing psychological stress for children (Kleye et al., 2021).

Coping with Pain

Similar to the coping strategies children use for the overall experience of hospitalization, children also have coping strategies they utilize when feelings of fear and/or pain emerge. The ways children cope are a mix of strategies learned through interactions with medical staff as well as strategies the children have subconsciously learned through previous experiences. One way children have been shown to deal with pain during procedures is to try and control their thoughts. For example, avoiding thinking about the procedure and the pain while simultaneously thinking positively has been shown to help children reduce both fear and pain (Kleye et al., 2021).

Allowing the child to choose their body position during potentially painful procedures has also been shown to give children a sense of control over their

treatment and has lessened fear and pain sensations. Giving children opportunities to distract themselves from the hospital environment also helps children to decrease their thoughts about fear and pain surrounding their illness. For example, having child-friendly decor such as fun things to look at while children are undergoing procedures can be supportive in reducing experiences of fear and pain (Kleye et al., 2021). Studies have shown that swaddling, breathing techniques, distraction, and visualization can aid in improving emotional distress during painful treatments in children (Committee on Hospital Care, 2014).

One common theme throughout all of the coping strategies used by hospitalized children was that they required adults to listen to what they needed. Allowing the children to communicate their wants and needs, dictate parts of their experience, and feel both heard and seen throughout their time in the hospital increases bodily autonomy and alleviates emotional distress (Kleye et al., 2021).

Support Systems

Because of the numerous stressors that accompany pediatric illness and hospitalization, support systems are pivotal for children. Managing a chronic condition requires the support of many different groups such as parents/caregivers, siblings, hospital staff, and peers, and can enhance the coping strategies used by children diagnosed with a pediatric illness (Boyd & Hunsberger, 1998). Promoting resilience for children who are hospitalized with chronic illness can help to mitigate the effects of the stress they may feel as a result of chronic illness, hospitalization, and the combination of the two. Resilience is defined as the ability of an individual to convert toxic stress into

endurable stress (Ashton et al., 2021). In other words, resilience is the trait that helps to negate the negative effects of adversity–the potentially toxic stress– for an individual and rather make the adversity tolerable. In the context of children hospitalized with chronic illness, various support systems and resources act as a barrier between the children and the potential negative psychological impacts discussed thus far (Ashton et al., 2021).

Caregiver/Familial Support

One critical support system for all children is caregiver and family support. Research has shown that engagement in a healthy parent-child relationship is the strongest influence in building resiliency in a child (Ashton et al., 2021). For children in the hospital, the presence and active engagement of a caregiver support the child physically and emotionally (Eccleston et al., 2015). Adolescence is usually a period developmentally where distance occurs between adults and teens, but a study conducted by Hall-Lande et al. (2017) found that a connection to adults, specifically family members, is important for protecting against social isolation among hospitalized teens.

Due to their prominent role in the day-to-day life of the child, the caregivers often become a spokesperson for the child during their hospitalization. The caregivers of children with chronic illness also have to become increasingly knowledgeable about their child's illness and treatment plan to assume the caregiving role once the child leaves the hospital (Balling & McCubbin, 2001). Familial participation is an essential component during treatment for a child with

illness because it contributes to patient- and family-centered care as well as the child's ability to adapt to their medical care (Committee on Hospital Care, 2014).

While pediatric hospitalization and chronic illness have an obvious impact on the child, it also has a great impact on the parents. Along with advocating for their sick child and the typical parental duties, they also have to balance work and possibly caring for other children (Eccleston et al., 2015). The emotional strain that parents feel watching their children go through repeated medical treatments and hospitalizations has a direct impact on their quality of life (Matziou et al., 2016; Kahhan & Junger, 2021). The emotional functioning of parents must be taken into account since research has shown a bi-directional relationship between parent functioning and child functioning which can then impact the child's adjustment to their diagnosis (Eccleston et al., 2015; Szulczewski et al., 2017; Kahhan & Junger, 2021).

However, even though the presence of parents/caregivers is of great importance for hospitalized children, parents are not always able to be physically present at the hospital. For example, logistical concerns such as having to care for other children, distance to the hospital, work, and transportation expenses may limit parental involvement (Dobbins et al., 1994). Limitations for parental presence also increase as the duration of hospitalization for the child increases. The longer the child is in the hospital, the likelihood increases that the factors listed above become a hindrance to parents. Interventions targeting parental coping, the parent-child relationship, and/or the ability of parents to be physically

in the hospital can help to improve the overall well-being of the child by increasing support for the child and increasing resilience.

Peer Relationships

While parental support is very important for hospitalized children, peer relationships also affect the well-being of a child. Peer relationships offer both emotional and psychological support for children (Carter et al., 2015). Children with well-established peer relationships are more likely to have higher levels of self-worth, be more active, excel more in school, and be more socially competent. For children and adolescents with chronic illness, it can be hard to develop and maintain peer relationships due to time away from school and other social activities as a result of managing symptoms, treatments for illness, appointments, and hospitalization (Carter et al., 2015).

Since separation from peers is one of the consequences of hospitalization, social isolation is more prevalent in the pediatric hospitalization population. Higher social isolation is linked to higher rates of depressive symptoms, higher risk for suicide attempts, and lower levels of self-esteem in adolescents (Hall-Lande et al., 2007). However, one way to combat social isolation during time in the hospital is to promote relationship-building between patients. Hospitals often have play areas for the patients and their siblings which offer a space for the children to interact with peers who are going through similar adversities. Playing with other children also acts as a distraction and has been shown to reduce feelings of fear and increase feelings of calmness and belonging (Kleye et al., 2021).

While time in the hospital deprives children of interactions with peers in typical social settings, having a chronic illness impacts the development of peer relationships outside of the hospital as well. Children may experience many negative emotions surrounding the management of their illness which can inadvertently strain peer relationships. Specifically, children with chronic illness may try to hide their illness and act similarly to their peers–e.g. not adhering to treatment protocols– in fear of being seen as different (Carter et al., 2015; Rohan & Winter, 2021). Feelings of embarrassment about symptoms can also cause a child to withdraw from peers (Carter et al., 2015). Because of the potential for social rejection, a hospitalized child may feel fear about returning to school post-hospitalization. Ensuring patients have the proper understanding of their illness to educate their peers on their experiences can increase confidence in leaving the hospital and decrease fear during hospitalization about the future impacts on peer relationships (Carter et al., 2015).

Child Life Services

Another critical support system hospitalized children have is Child Life Services. Child Life is a hospital-based program that looks to promote the positive psychological well-being and healthy development of children by minimizing the stress and anxieties that come with hospitalization (Committee on Hospital Care, 2014; Burns-Nader & Hernandez-Reif, 2016; Magrab & Bronheim, 1976). Child Life staff focus on helping to normalize the hospital experience for children and increase overall well-being by using strategies such as play, special events, facilitating family activities, encouraging routines, and educating patients and

families about diagnoses. For example, Child Life Services provides preparation for procedures to help decrease patient anxiety before undergoing medical exams and procedures. Child Life also utilizes therapeutic play to promote healthy development and growth for patients (*The Case for Child Life, n.d.*). Interactions with Child Life Services tend to show decreased anxiety, enhanced mood, and increased coping abilities in patients and family members. Parents are also supported by Child Life Services as the specialist assists parents in learning coping skills, informs parents about their child's condition, and may refer parents to support groups (Burns-Nader & Hernandez-Reif, 2016).

Within Child Life Services, there are two levels of support for children and their families. Certified Child Life Specialists provide clinical and therapeutic services for children and their families such as the therapeutic play that was mentioned above, as well as support during medical procedures and surgeries (*The Case for Child Life, n.d*; *Child Family Life Services*, n.d.). Child Life Specialists hold graduate or undergraduate degrees in child life and have professional certifications through the Association of Child Life Professionals (*Child Family Life Services*, n.d.). The lower-level Child Life staff are Child Life Associates who provide patients and families with bedside support to support growth. Child Life Associates usually hold two or four-year degrees in child development or related fields and are not allowed to be present during major medical procedures (*Child Family Life Services*, n.d.). The two levels of Child Life work together to provide the best possible care for hospitalized children.

Psychological Care For Hospitalized Children

Currently, there is a multitude of ways hospitals aim to support children psychologically. For example, there are a few different models of integrated psychological care–psychological services that are embedded within a medical setting– a hospital may use. A review conducted by Marshall and colleagues (2022) detailing 3 different integrated psychological care models in pediatric hospitals, found all models produced measurable improvements in physical, psychological, or behavioral aspects of patients within three to six months. The three models of psychological care discussed in the review included psychological services embedded within a specialty medical setting, psychosocial screening with an accompanying referral pathway, and an integrated neuropsychology service.

Some common characteristics of each model included having a multidisciplinary team, clinical care policies, treatment protocols, referral pathways, and staff education and training (Marshall et al., 2022). Having multidisciplinary teams (MDTs) – a group of staff from multiple departments within the hospital– is a key component of all of the models (Marshall et al., 2022; Magrab & Bronheim, 1976). Ensuring collaboration across hospital departments (e.g. psychology, psychiatry, nursing, etc.) provides the most holistic care for patients (Marshall et al., 2022; Rohan & Verma, 2020).

Referral pathways, used in all of the psychological care models, are tools that aid staff in identifying patients and families in need of specific services. Typically, the pathways have psychosocial screenings as a starting point to determine the degree of need, risk, or concern for the patient. Mental health

professionals or physicians may conduct the screenings and may rely on patient reports (direct child assessment) or parent reports (Marshall et al., 2022).

The treatment protocols, another commonality between all psychological models, often vary from hospital to hospital, but there are some similarities. Providing behavioral management techniques, improving treatment adherence, and helping patients and families develop coping skills to improve the health outcomes of patients exemplifies the basic goal of psychological care within hospitals (Marshall et al., 2022; Rohan & Verma, 2020). Lastly, all models included some form of staff education and training. Informing physicians and nurses about the services available to their patients and their benefits helps to increase the utilization of those services (Marshall et al., 2022). Overall, all models of psychological care within hospitals look to promote the well-being of patients and families.

Specific Interventions

Mental health professionals within hospitals provide an assortment of therapies and interventions for pediatric patients depending on the needs of the child and their family. By using screenings, child and parent reports, and referral pathways, interventions for the patients can be aimed at improving coping skills, increasing adherence to treatment plans, reducing pain and fear, and overall increasing well-being (Fisher et al., 2018; Eccleston et al., 2015; Rohan & Verma, 2020). Specific therapies such as cognitive behavioral therapy (CBT), medical coping, and motivational interviewing are common practices. Cognitive behavioral therapy is a treatment that focuses on reframing an individual’s

thoughts and actions which can be beneficial for hospitalized children. For example, CBT can be used to improve pain and distress as a result of illness and treatments (Fisher et al., 2018).

Medical coping for patients is the increased ability to function in stressful situations surrounding their condition (Rohan & Verma, 2020). Medical coping looks to reduce the trauma a patient faces during medical interventions. Identifying a patient's triggers around their medical trauma and desensitizing the patient while also providing them with problem-solving skills is the central focus of medical coping (Rohan & Verma, 2020). Motivational interviewing is a method of encouraging a change in patients' motivations and encouraging behavior change by exploring and resolving mixed feelings (Rohan & Verma, 2020; Enö et al., 2016). For hospitalized children, this means identifying what factors influence a patient's motivations about their health behaviors and positively shaping their motivations to fit beneficial behaviors (Rohan & Verma, 2020).

Support for Parents

Mental health professionals also screen, identify, and support the parents of hospitalized children. Parents and caregivers of chronically ill children are also sensitive to emotional difficulties such as increased symptoms of anxiety, depression, and traumatic stress (Marshall et al., 2022). Interventions such as parent training and problem-solving therapy can be used to improve parental symptoms of distress and the parent-child relationship, as well as positively shape the ways parents can support their children (Rohan & Verma, 2020; Eccleston et al., 2015). Being the parent of a hospitalized child comes with a wide range of

stressors such as financial burdens, stress of work, balancing time with other children and family, and fear about the future of the hospitalized child. Ensuring that parental distress is also addressed can improve the well-being of the child since there is a bi-directional relationship between parent distress and child well-being (Eccleston et al., 2015).

While there are many different ways mental health professionals can support hospitalized children, the overall goal is to identify areas of need and barriers to obtaining optimal health (Rohan & Verma, 2020). Studies have shown that a combination of strategies has the best long-term effects for children and their families (Eccleston et al., 2015; Fisher et al., 2018). Whether it's through direct interventions with the child or through supporting their parents to optimize family functioning, mental health professionals look to improve the overall well-being of the hospitalized child to promote the best health outcomes.

Play Therapy

One therapy, in particular, that is often utilized by mental health professionals with children is play therapy. Play is essential to human development and can act as a medium for children to express themselves (Haiat et al., 2003; Alvarez & Phillips, 1998). Play supports the learning and cognitive development of a child by allowing them to explore their social world and gain confidence. By giving children the opportunity to choose what and how to play, they develop a sense of agency (Alvarez & Phillips, 1998). Therapeutic play, in particular, has been shown to reduce signs of distress such as excessive

movement, sweaty palms, high blood pressure, and quickened pulse in children (Committee on Hospital Care, 2014).

Since the hospital environment can be such a stressful experience for a child, utilizing play therapy can be very beneficial in increasing cooperation, decreasing anxiety, and improving recovery from procedures (Burns-Nader & Hernandez-Reif, 2016). Through play, a child can build relationships with their peers and with medical staff, while also being distracted from the hospital environment and painful experiences (Haiat & Shochat, 2003). Specifically, healthcare play– play that directly relates to one’s condition or experiences with medical scenarios– can help reduce emotional distress and help children cope with their hospitalization (Committee on Hospital Care, 2014).

Therapeutic play is commonly employed by Child Life specialists as it is easily adaptable and has many benefits for young patients. For example, depending on the developmental level of the child, roleplay, exploratory play, sensory play, and art activities are all different types of therapeutic play that can be used (Committee on Hospital Care, 2014). Using play as a preparation for procedures and treatments can help reduce anxiety and create a positive experience for the patient. Parents and other family members can also be incorporated into the play to relieve some feelings of helplessness experienced by parents that may build up during the child’s hospitalization (Committee on Hospital Care, 2014). Overall, play therapy is a great strategy for improving the well-being of hospitalized children.

Barriers to Care

There are likely to be barriers to care for patients and families no matter what model of psychological care is used, what clinical policies there are, or what treatment protocols the hospital has. Among the most commonly identified barriers for both patients and families were wariness to interact with new medical staff, stigma around accepting support, cost of services, time commitment, and travel time if parents are not staying at the hospital with their child (Marshall et al., 2022). While an integrated model of care helps address some barriers such as cost, time, and possibly travel since psychological services are a part of the holistic care of a child in a hospital in an integrated model, a willingness to accept support can be a difficult hurdle to overcome. Ensuring parents and children feel comfortable with staff and understand the importance of receiving psychological services can help to make certain that children and families are receiving the support they need.

Future Action

Many factors play into the child's well-being, some controllable and some not. To best improve the mental health and well-being of hospitalized children with chronic conditions, the whole experience of the child needs to be taken into account. Hospitalization brings a lot of unknowns for a child which can cause emotional distress (Norton-Westwood, D, 2012; Jepsen et al., 2019; Ekra & Gjengedal, 2012; Boyd & Hunsberger, 1998; Carabello et al., 2019; Szulczewski et al., 2017). Because of the distress that both illness and hospitalization cause, having support systems–parents/caregivers, siblings, medical staff, and peers– is critical for this population of children (Boyd & Hunsberger, 1998). Of the support

systems, the presence and active role of parents/caregivers have been shown to have a large impact on the psychological well-being of patients (Eccleston et al., 2015). However, logistical concerns for parents may keep them from being present consistently (Dobbins et al., 1994).

Child Advocate

To best support children as a whole, and hospitalized children in particular, it is important to ensure that positive influences on the child's well-being outweigh the negative. In the context of children hospitalized with chronic illness, various support systems and resources are protective factors for children against the potential negative psychological impacts discussed thus far (Ashton et al., 2021). However, when these support systems are not present or are weak, the well-being of a hospitalized child is hindered. As can be seen in the figure below, finding a way to interrupt the negative effects of aspects of a hospitalized child's experience can greatly improve their well-being. Establishing a new role within hospitals– Child Advocates– could help improve the well-being of hospitalized children.

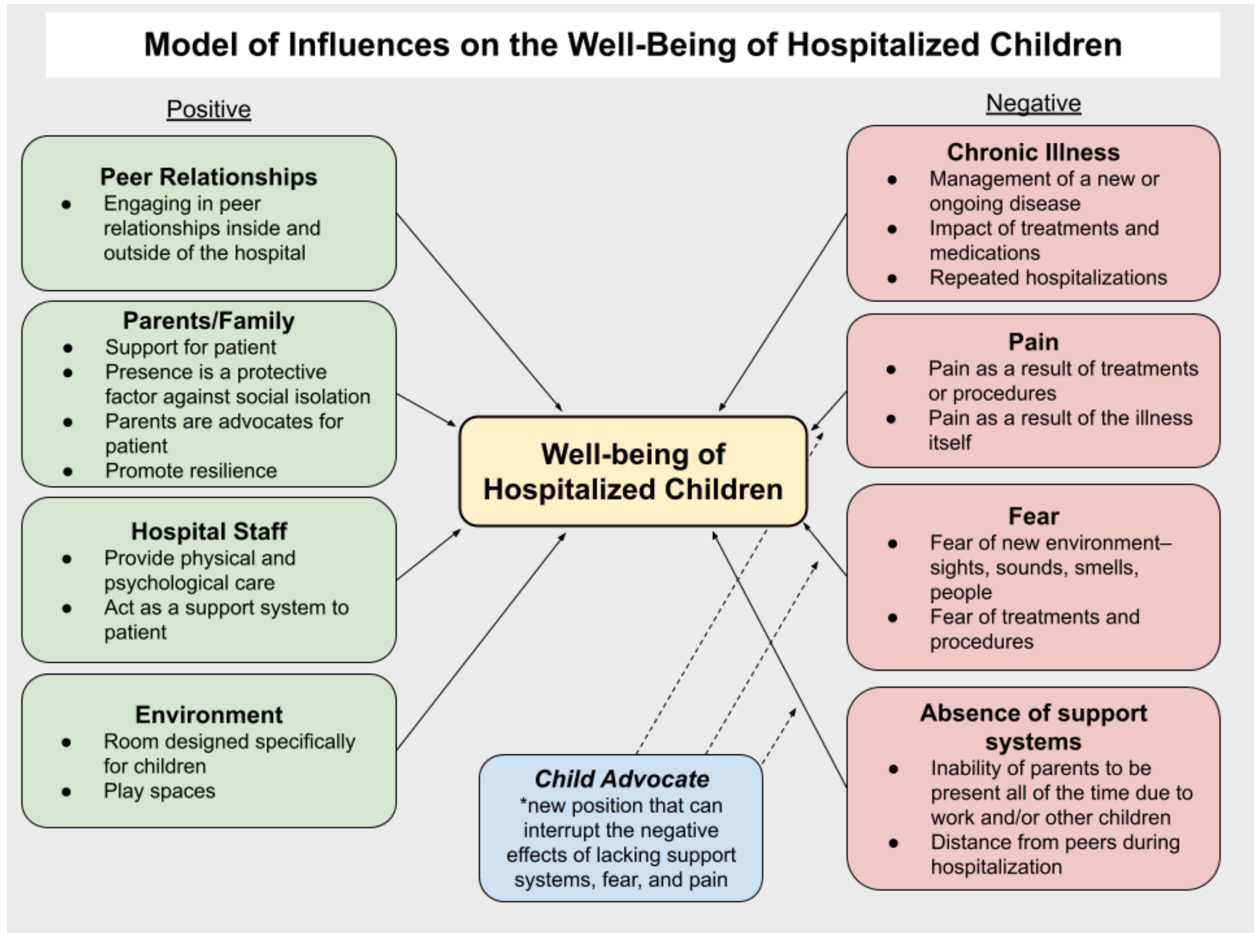

Figure 1. *Model of the influences on the well-being of hospitalized children with a proposal for a new position.*

Child Advocate Responsibilities

As proposed in the model above, a new role within Child Life Services would look to interrupt the negative effects that have been outlined thus far. The role of a Child Advocate would be a third level of Child Life that could provide more support for the Child Life team, patients, and their families. Since Child Life Services already provides an abundance of support for patients and families, an added role would fit best under their department. The new position would be an entry-level position requiring only a high school diploma and prior experience

with children with any relevant training being provided by the hospital. A Child Advocate would not provide any therapeutic services for patients or families; however, they can still provide support that addresses the lack of support systems, as well as experiences of fear and pain during hospitalization.

The differentiation between Child Life Associates and Child Advocates would be in the level of training required before employment, the services provided by each, and where the staff members are stationed within the hospitals. Currently, Child Life Services has its own separate spaces from in-patient hospital wings and there are no Child Life team members permanently stationed in in-patient sections of hospitals. For example, in some hospitals, Child Life Services has the Child Life Zone where patients, siblings, and family members can go to play games, do arts and crafts, and do other activities (*The Child Life Zone | Children's Minnesota*, n.d.). In hospitals that have them, the Child Life Zone is the center for Child Life staff members. In hospitals that do not have Child Life Zones, the Sibling Play Area– which may be titled something slightly different in different hospitals– is staffed by Child Life staff. To provide direct services for patients such as preparation for procedures, one-on-one education about one's condition and treatments, or to deliver therapeutic interventions, Child Life Specialists and Associates schedule time to see patients in their respective rooms.

To support the work of both Child Life Specialists and Child Life Associates, Child Advocates would be positioned in each inpatient wing of hospitals, working out of an office in their unit. For example, the NICU–

Newborn Intensive Care Unit, the PICU– Pediatric Intensive Care Unit, and all other pediatric units would have a Child Advocate assigned to work in them. The baseline for hospitals would be one Child Advocate per unit, but the number of CAs could be increased and adjusted if the caseload calls for it. The Child Advocate for each unit would work closely with nurses and doctors and would only be responsible for the children in their unit. This consistency would allow the Child Advocate to intimately know all of the children, their families, and their unique circumstances. The Child Advocate would then be able to relay information to the Child Life Specialists and Associates to improve the care they are providing for the children. Furthermore, having the Child Advocate present in their hospital unit at all times would help to integrate Child Life Services with other departments more deeply to ensure the best care for patients and their families.

The Child Advocate's daily responsibilities would include a variety of tasks ranging from patient interactions, writing notes for other Child Life staff, and ensuring patients have what they need to feel supported. For example, a Child Advocate would be in charge of knowing the preferences of each of their patients by gathering this information from patients themselves, nurses, and caregivers. The Child Advocate would be in charge of sharing preferences with the rotating staff taking care of the patients to ensure each patient receives the best care tailored to them. Each patient has a different liking for lighting, music, TV shows, food, etc, and having a staff member that guarantees these preferences are fulfilled can increase satisfaction with care for patients and their families. While

this task is usually provided by the caregiver, a patient's family may not always be able to be at the hospital. Nurses also often take care of such preferences for their patients, but with the rotating shifts of nurses, having a staff member who is always with the same patients ensures that all needs will be met.

Another job of the Child Advocate is to consistently check on their patients throughout the day. While Child Life Specialists and Associates may see patients at scheduled times, the Child Advocate is available to all of their patients whenever a child may need company or any other support a caregiver may otherwise provide them. The Child Advocates will stock patient rooms with developmentally appropriate toys, games, and books and engage patients in play. When able, Child Advocates will also allow patients to engage in play with peers.

The role of the Child Advocates is similar to that of volunteer services in that both provide emotional support for patients and families. However, as has been outlined already, the responsibilities of Child Advocates are much more extensive than what is expected of a volunteer. Volunteers typically act as a momentary distraction for patients by engaging in activities such as coloring, playing a game, or watching a movie. In contrast, Child Advocates check in on their patients throughout the day, ensure they have what they need, and are a bridge between patients and other services such as the volunteers.

Another difference between CAs and volunteers is the scheduling and consistency of time spent with patients. Child Advocates are full-time, paid employees, while volunteers are scheduled for 3-hour shifts. Volunteers are usually at the hospital during the day, however, who the volunteer is rotates based

on scheduling. Since volunteers only come once a week for a few hours, they don't provide the same consistency and intimate connection that Child Advocates provide. Volunteers can act as a momentary distraction for patients, but Child Advocates take it a step further by providing more extensive support for patients and families.

Overall, the Child Advocate is under the supervision of both Child Life Specialists and Child Life Associates. Since they would be positioned in each unit of the hospital, CAs would act as the eyes and ears for the higher-level Child Life staff. They would provide more day-to-day support for patients and their families rather than the scheduled support Child Life staff members tend to engage in currently.

Absence of Support Systems

The first area of support that a Child Advocate would provide is in the absence of parents/caregivers. Parental support is a key component of ensuring the positive well-being of a child, but too often parents have to leave their child at the hospital to attend to other areas of their lives such as work, siblings of the hospitalized child, etc, leaving the patient alone. With the absence of a caregiver, hospitalized children lose not only emotional and physical support but also a person/people who speak up for them and provide for them (Balling & McCubbin, 2001).

One of the roles of a Child Advocate would be to help negate some of the loss of support a patient may feel when their parents/caregivers are unable to be at the hospital. As stated above, Child Advocates can gather information from

parents and nurses about the child's preferences to help advocate for what the child wants and needs when the caregiver cannot do that. Similarly, when parental support is missing, patients may feel a sense of loneliness and isolation (Hall-Lande et al., 2007). The Child Advocates can serve as persons for patients to interact with, and they can also be point persons to contact other services in the hospital to distract a child from parental absence. For example, many hospitals employ volunteer services that have trained volunteers to play with patients. The Child Advocate would also provide a sense of consistency that may be lacking for the child if the parents are gone and the medical staff caring for the child's physical health are constantly rotating.

To also address a lack of peer support, Child Advocates can promote peer play. Child Advocates can bring authorized children to communal playrooms, for example, the Child Life Zone if the hospital has one, to interact with other patients and siblings. If a patient's caregivers are unable to be at the hospital, a child may have to spend the majority of their time in their designated room with little contact with peers. This is because nurses are often assigned to multiple patients and cannot leave the area with one patient. However, having a Child Advocate on each floor could create opportunities for more peer-to-peer interactions and interrupt the negative influence of the absence of support systems.

Fear and Pain

While Child Life Specialists and Associates do the bulk of the work to interrupt the pain and fear children face during hospitalization and as a result of

their illness, adding the role of Child Advocates could help support patients as well. As discussed above, Child Life staff use procedure prep and education about treatments and procedures to familiarize patients and families with the situations the child will face to help decrease fear and perceived pain. Since Child Advocates would not be required to have any certifications or training before hiring, they would not be able to therapeutically support patients. However, Child Advocates could act as emotional support for children and promote the use of coping strategies the child has already been taught. As a, hopefully, trusted adult figure during the child's hospital stay, just being present for the child emotionally during minor exams and procedures could positively influence the child's well-being. Many other medical staff constantly in and out of a patient's room are primarily concerned with the child's physical health, so having a staff member who is solely thinking about the child's holistic experience would benefit the child.

Overall, the goal of adding a Child Advocate position would be to support the child's needs as a result of having less parental involvement. The sole focus of this role would be the psychosocial well-being of the child and providing the stability of care the patient may be lacking while in the hospital. As a secondary effect of Child Advocates supplementing the support systems for patients, they could also support Child Life staff in reducing fear and pain.

Limitations and Future Direction

While the Child Advocate role looks to improve the overall mental health and well-being of hospitalized children, there are a few limitations to note. First

of all, the implementation of this new position would require a high level of supervision from both Child Life Specialists and Child Life Associates. Adding a new role within Child Life adds more responsibility for the higher staff positions. For example, Child Life Specialists would have the added responsibility of having check-ins with Child Advocates to ensure their work is being done properly which could take time and energy away from patients. However, with the added benefits that Child Advocates provide– more emotional support for patients and families– the benefits would outweigh the consequences.

One other key limitation of this proposal is that Child Life Services are not offered in all hospitals. Most Child Life programs are in hospitals with large pediatric patient populations such as in Children's Hospitals across the country (*The Case for Child Life, n.d*). Implementing a new role within Child Life Services would impact a large number of pediatric patients within hospitals, but it would still leave a large proportion of pediatric patients unaffected. While the Child Advocate role wouldn't be reaching all populations of hospitalized children, starting this role in hospitals that do have Child Life Services could lead to expansion in the future. If the position makes a noticeable difference in hospitals with large pediatric populations, other hospitals could look to implement a similar position.

One last limitation to note is the financial cost of implementation. Hospitals wanting to add a new position would need to adjust their budget to accommodate paying more salaries and to pay for the necessary training for the new staff. Since this position requires a high school diploma and no certifications,

hospitals would have to train Child Advocates to respond to any situations they may encounter– Child Advocates would come into contact with a wide variety of patients who have many unique needs. For example, Child Advocates would need to be properly trained on how to interact with patients with language/communication impairments, families who speak another language, and any other situations CAs may come across. Overall, there are some limitations of the Child Advocate role; however, with the right implementation, limitations would be minimal.

Outside of the Child Advocate role, there are many different directions that future research could take. While research suggests the value of parental support for hospitalized children because it brings emotional support, increases resilience, and protects against social isolation, more research needs to be done looking at the causes and consequences of not having parental support for hospitalized children (Ashton et al., 2021; Eccleston et al., 2015; Hall-Lande et al., 2017; Committee on Hospital Care, 2014). Once a fuller assessment of the causes has been made, the next step would be to find systemic ways to make parental support during hospitalization more feasible. Looking at the experience of hospitalization through the eyes of the child would also add to our understanding (Jespen et al., 2019). Specifically, future research looking at the child's point of view regarding the management of fear and pain during hospitalization could direct care towards using a more child-directed approach (Kleye et al., 2021).

Conclusion

As has been discussed throughout this paper, the mental health and well-being of hospitalized children are of growing importance due to the increasing rates at which children are hospitalized for chronic illness (Judson, 2004). Chronically ill children are a vulnerable population who require new and improved ways to be supported. Analysis of the many factors that influence a hospitalized child's well-being can lead to the development of ways to improve the child's hospital experience. One way to interrupt the negative influences that impact a hospitalized child's well-being is through a new hospital position within the Child Life department. A Child Advocate would supplement support systems that may be lacking for patients, promote peer-to-peer relationships, and aid Child Life staff in reducing feelings of fear and pain for children. Overall, the psychological health of the child is of the utmost importance and should be treated as such.

Chapter 2: Primary Research

Throughout the literature review that I did as the first part of my research, both positive and negative factors were identified as influencing the well-being of a hospitalized child. Interview-based research was a common theme of many of the articles I reviewed with the perspectives of both parents and children being well-represented (e.g. Ekra & Gjengedal, 2012; Balling & McCubbin, 2001). For example, Boyd and Hunsberger (1998) interviewed children directly asking about their experience being hospitalized and their perceived coping strategies. Similarly, Rohan and Verma (2020) analyzed four case studies of chronically ill pediatric patients to assess different interventions used with the patients and the effects of those interventions.

Other studies also highlighted different interventions for hospitalized children to improve the experience. For example, Burns-Nader & Hernandex-Reif (2016) looked at the ways that Child Life Services promotes the healthy development of hospitalized children while the Committee on Hospital Care and Child Life Council (2014) wrote about Child Life Services engaging in therapeutic play to help reduce patient and caregiver anxieties surrounding illness and treatments. While both of these sources discuss important aspects of Child Life, both rely on information that is dated. Since Child Life plays such an integral role in promoting positive well-being within hospitalized children, acquiring the perspectives of individuals in this department would aid in making improvements to the care provided for children's well-being while they are in the hospital.

The primary research question driving this study was: how can the mental well-being of hospitalized children be improved? Since the dominant perspective in the literature I previously reviewed was the patients and their families, I was interested in the experiences of healthcare professionals and their goal to provide optimal care for hospitalized children. Healthcare professionals, in particular, were my target population for this research because they play a critical role in the support patients and families receive during the hospitalization process. They also have first-hand experiences that hold answers about how to improve the well-being of hospitalized children. In the first part of this paper, I proposed a new staffing position within the Child Life department aimed at providing more support for hospitalized children. To provide more nuanced recommendations for improving the overall well-being of hospitalized children, I intended to explore the first-hand experiences of healthcare professionals to identify additional gaps in care and areas that can be refined.

Method

Participants

All participants in this study are current medical professionals working with hospitalized children and their families. All participants were at least 18 years of age and were fluent in English. Participants were recruited through my connections with the volunteer services at Children's Minnesota in Minneapolis. In total, I interviewed 4 participants with varying positions at the hospital to gain a variety of perspectives.

Participant 1 currently works in the Volunteers Services Office of Children's Minnesota. She also has extensive experience working as a Child Life Specialist and splits some of her work time at Gillette Children's Hospital. She is both female and white-presenting; however, participants were not directly asked about their social identities. Participant 2 was also female-presenting, but other social identities were masked since the interview was over the phone. Her current job is as a social worker at Children's Minnesota, primarily serving in departments such as the Emergency Department and the in-patient units of the hospital such as the PICU. Participant 3 is a current Child Life Specialist at Children's Minnesota. She is white and female-presenting. Participant 4 is a current Child Life Associate at Children's Minnesota. She is also female-presenting; however, similar to Participant 2, all other social identities were masked due to the interview being over the phone.

After completing the interview process, I realized that more questions regarding the background of the participants would have been helpful. Primarily, knowing how many years of experience participants had in their current position as well as what other positions they have worked in would have been beneficial. However, all participants displayed knowledge of working with hospitalized children.

Interview

Interview Process

This study used interview-based qualitative research to identify a range of improvements that could be made in caring for hospitalized children. Participants

took part in 20-30-minute audio-recorded interviews either in-person, virtually, or over the phone. Participants responded to a semi-structured interview guide (see Appendix A) that they had access to in advance. At times, I asked follow-up questions regarding a participant's answer that were not in the interview guide. The interview guide was developed following recommendations provided by Magnusson and Marecek (2015). In particular, I utilized Chapter 5, entitled "Designing the Interview Guide," to generate my open-ended questions. Before the interview, participants were sent the consent form to read at their leisure (see Appendix B). At the beginning of the interview, participants were reminded that participation was voluntary, there was minimal risk involved with their participation, that the interview would be audio-recorded, and that their identities would be kept confidential. Participants were compensated $15 for their time.

Interview Questions

There were 7 main questions in the interview guide. The questions covered factors that influence a child's well-being, shortcomings professionals see in their day-to-day work with hospitalized children and their families, and ideas for improving the overall well-being of hospitalized children. For example, the first main question asked of the participants was "What kinds of mental health needs have you witnessed while working with this population of children?". This question was then followed up with, "Do you have examples of what has helped children work through or relieve their mental health concerns?" These two questions aimed to identify what struggles hospitalized children face and to set the stage for the following questions regarding the gaps and challenges the healthcare

professionals have seen or experienced while attending to a child's mental health needs. The final two questions in the interview guide centered on how to improve the care being provided by the hospital. For example, the last question directly asked participants, "Do you have any ideas for additional services to support this population's mental well-being?" All questions were open-ended to invite the fullest possible responses from the participants.

Data Analysis

To analyze the data, I first transcribed the audio recordings using Otter.ai. The transcriptions can be found in appendices C through F. Once the interviews were transcribed and manually read through for transcription errors, I began working on the thematic analysis. I followed the steps outlined by Braun and Clarke (2012) by deciding that I would use a deductive approach during analysis. This meant that I first developed a list of ideas or themes to code the data from the literature review in Chapter 1. There were five distinct themes: (1) mental health struggles facing hospitalized children, (2) hospital-based support for hospitalized children, (3) other support for hospitalized children, (4) gaps and challenges to optimal care, and (5) barriers to improving care. Once I developed these themes, I shared them with a second person who also coded the transcripts. The second coder was also a student at Macalester who had experience coding qualitative data. The other individual and I both used guidance from Braun and Clarke (2012) to code the interviews. My goal was to ensure that my own coding was not idiosyncratic or biased. The individual and I coded the data separately and then discussed any discrepancies to reach a consensus agreement (Mod•U: Powerful

Concepts in Social Science, 2019). There were minimal inconsistencies in the coding, but one example of a discrepancy occurred in coding interview 4. I had noted that pain and discomfort (22:58) are a part of the struggles faced by hospitalized children while the other coder did not note them. To resolve this, we discussed why we had or had not noted it as important to the themes and agreed that it fell under the theme "Mental Health Struggles Faced by Hospitalized Children." Once the transcripts were coded and discrepancies were resolved, quotes from each participant were aligned with their corresponding theme (See Tables 1-4).

Results

The following sections will highlight the core themes prevalent in the interviews. Responses from interviewees were similar on the main themes outlined below which could have been a result of wanting to show the best parts of Children's Minnesota rather than discuss the less positive details of issues within the hospital.

Mental health struggles facing hospitalized children

The first theme concerned the typical mental health struggles faced by hospitalized children. This theme was critical because understanding the needs of hospitalized children leads healthcare professionals to be able to meet those needs proficiently. Some of the struggles outlined by interviewees were anxiety, depression, isolation, and lack of autonomy. They also noted that hospitalized children face individual circumstances that impact their well-being that must be considered.

Interviewees discussed anxiety as a common occurrence among hospitalized children due to in-hospital experiences and due to missing normal life outside of the hospital. In particular, many children experience medical anxiety as a result of the novelty of medical equipment, staff, treatments, and procedures. Similarly, children may experience anxiety surrounding constant medical care such as dressing changes and blood draws because of the pain associated with these events. In relation to the medical anxiety experienced by this population, children may also experience medical trauma or PTSD as a result of their fear surrounding the medical environment, the perceived pain they experience, and the lack of autonomy they have. Participant 3 noted:

> *As a Child Life Specialist, you can literally tell in a procedure, like let's say it's an IV start in the Emergency Department or something, but you can kind of tell the moment that this is becoming traumatic and the kid just feels like they have no control. You know, they're being pinned down, they're yelling "Stop, please get off me," but we keep doing that, you know, you just feel it and that is heavy.* (13:42)

Another common struggle experienced by hospitalized children involves symptoms of depression. Interviewees noted that presenting symptoms of depression can be caused by several factors for the children such as pain and discomfort, isolation, loneliness, and boredom from the monotony of the day-to-day. Participant 3 stated:

> *[Child Life] often gets referred from like nursing staff or doctors like, "Oh they're like down, they're in a funk. Maybe showing some signs of*

> *depression. But from our perspective, as a Child Life Specialist, it's like, 'But is it developmentally appropriate?' Like if you were 13, and you'd been in the hospital for two months, you might have a bad day or, you know, maybe you start snapping at your parents or the nurse or whatever, like to us that is completely developmentally appropriate.* (3:53)

There are a limited number of activities that children can do while they are in the hospital and that number can be dictated by the illness that put them in the hospital in the first place. For example, hospitals have precautions to keep patients safe, but that means certain patients may not be able to leave their room while other patients require a nurse to accompany them when leaving their room. Both of these scenarios can be difficult for patients because both force children to be confined to their room for most of, if not the full, day. Furthermore, one interviewee noted that nurses often have more than one patient to attend to which makes it extremely difficult for them to find time to take their patients out of their room during busy hours of their shifts.

Also related to the isolation and depression hospitalized children experience is loneliness. While in the hospital, children are separated from normal parts of growth and development such as their friends and school. While there are opportunities for peer support in the hospital, which will be discussed a bit more in-depth later, patients are still missing out on normal experiences with their friends. Similarly, a hospitalized child may also be separated from their family. Many families might live far away from the hospital, parents may have to work, or the patient has siblings at home that the parents must also take care of.

Some other factors noted by the interviewees that are not direct mental health struggles faced by the identified population but that impact their experience are the age of the patient and the feelings of the caregiver(s). The patient's age can greatly affect how they experience the medical environment because the child's level of understanding about what is happening to them may vary depending on their age. For example, a baby may experience the pain going along with medical treatments and procedures, but they may not realize their family is not with them the entire time and not experience the same levels of isolation and loneliness that a school-aged child may experience. Similarly, the feelings of the caregiver(s) can also impact the child's experience because the child can pick up on the stress levels of the caregiver(s) which could exacerbate the child's mental health struggles.

Hospital-based support for hospitalized children

As has been outlined, there are a lot of factors impacting the experience of a hospitalized child that can cause mental health struggles. Each child faces their own challenges and will have their own reactions to the medical environment. However, many departments and services are in place to help support hospitalized children and their families. The individuals who participated in the interviews represented perspectives from departments such as Volunteer Services, Child Life, and Social Work. Along with these three departments, others that were mentioned in support of the patients were Psychology, Psychiatry, the Family Resource Center, Spiritual Life, Nursing, as well as all of the departments concerned with the physical health of the child (e.g. Neurology, Hematology, Oncology, etc).

Participant 4 commented: "I think we have a lot of really, really wonderful staff who go above and beyond for a lot of the children here" (26:23).

Child Life

The Child Life Department plays a direct and critical role in promoting positive well-being for hospitalized children and their families. One of the services that Child Life provides for patients and their families is education about treatments and diagnoses. As was mentioned by Participants 1, 3, and 4, teaching children about a procedure or treatment beforehand can help to reduce anxiety for both patients and their caregivers by lowering the unknowns that go along with new medical experiences.

Similarly, Child Life staff typically also provide education about new diagnoses for patients and their families to help translate the medical information into more understandable language. Participant 1 offered this description:

> *A lot of times it's that education of like, 'well what part of the body is not doing its job? Why does that happen?' Even if it's an answer that like, 'Well, we don't know why it happens to some kids and not to other kids yet' or 'We don't know why that part of the body just stops working.' That is an answer.* (3:12)

Child Life staff ensure that parents are able to explain to the child what is happening to them so that once they leave the hospital, the parents can answer the child's questions in a developmentally appropriate manner without over or under-explaining. Furthermore, having these conversations with patients and their

families provides a gateway to promote coping skills to deal with the stress of a new diagnosis.

Another key part of Child Life is building rapport with the patients and their families to become a trusted part of the patient's care team. Participant 3 highlighted this:

> *I would say a big thing is having rapport built because especially my mind goes to the older kids, like have a new face coming in and being like "Let's talk about your depression" really doesn't make as much of an impact as if you have like a really good relationship.* (3:53)

Building strong relationships with patients helps Child Life staff ensure that the activities they do with the patients positively influence them. For example, some other aspects of Child Life are providing distracting activities for patients, fostering normalization, and providing novelty. Staff do these things through normative play, art activities, and music therapy which all look to create a less daunting experience within the hospital for patients. The sibling play area is also a big part of support for the families as it is a place where both the siblings and the hospitalized child can go and play together with different toys in a novel space away from their hospital room. While the patient is the main concern for Child Life staff, offering support for siblings is also a part of the job.

Outside of one-on-one support, Child Life also looks to promote peer-to-peer support through support groups for patients. Fostering an environment where patients can connect with peers in the hospital who may be going through similar circumstances is a big support for hospitalized children.

The chance to meet peers in the hospital helps to reduce some of the isolation and loneliness hospitalized children experience, especially when they are hospitalized for an extended time. Similarly, group time is another opportunity for patients to get out of their rooms and have novel experiences to help mitigate boredom.

Child Life staff interact with patients many times throughout the week and end up often having a strong connection with patients and families. The support that Child Life staff provide to patients and families is unmatched and is key in promoting a positive hospital experience for patients, siblings, and caregivers.

Social Work

While Child Life staff primarily focus on the well-being of the patient, Social Workers play a critical role in managing the case of a hospitalized child. Social workers often engage with parents of hospitalized children to identify ways to help the family cope with illness and hospitalization as well as to help make referrals to other departments and services that would help the family. Participant 2 discussed how her position collaborates with other departments to connect families with needed resources within and outside the hospital:

> *On more of a non-acute side, so like, if they're here for a medical issue, but they have other mental health concerns or a history of mental health, we do screenings around that, like when they get admitted, the nurses are asking, you know, 'do you have any concerns about safety? Do you have any mental health concerns?' So they usually catch a lot of those, like if a parent or a patient speaks up and says, 'Yeah, I'm concerned about this, then they'll get social work involved, and then social work kind of directs*

it to the appropriate people, whether that's psychology or psychiatry. (17:54)

Similarly, social workers often make referrals for long-term patients to receive tutoring while in the hospital as well as ensuring that the adults in the patient's life are taken care of. For example, social work helps parents and caregivers take care of parking, work notes, etc so that the adults can show up in the best way for their child.

Other Hospital Supports

While other departments were not discussed as heavily in the interviews, the participants mentioned the support hospitalized children also receive from departments such as Volunteer Services, Spiritual Care, the Family Resource Center, the Ronald McDonald Houses, Nursing, Psychology, and Psychiatry. There are many different spaces in the hospital where families can take a break, find answers to questions, and connect with support. Participant 1 also highlighted the impact volunteers have by stating "You know, there's research on volunteers making a positive impact on the patient, family, hospital stays. Just increasing that normal experience having playtime" (8:53). Volunteers often step in when family isn't able to be present and spend time with patients who may be feeling lonely or need a distraction from their normal routine. Volunteers also provide breaks to family members who may need to step away from the hospital room for a while but don't want their child to be alone.

A lot is going on in the hospital environment and it can be overwhelming for both patients and their families. However, with the efforts of many different

departments, the hospital environment is made less stressful and easier to manage. Whether that's due to the 'warm and welcoming' atmosphere created by the welcome desk staff, a result of the connections made with Child Life staff, or the support received from the many other services, the well-being of children and their families is the primary focus during hospitalization.

Other sources of support for hospitalized children

While hospitalized children have a lot of support provided to them by the hospital staff, they often receive support from other sources as well. Although it was not commonly discussed by the participants, support from non-staff members is also important to mention. Participants 3 and 4 brought up the support children have from their families as being an important factor in children's well-being. Participant 3 noted:

> *Family members can be very helpful if they're like, supportive in like, 'No, we're gonna pick something fun to do today.' Or, like, I know this girl who has been here for a month and has kind of been low and mom is like, 'Nope, today we are getting out of the room like you can pick where we go.' You know, just like they are encouraging to break out of those kind of like slumps that kids sometimes get in.* (17:54)

Participant 3 also noted that siblings can bring a sense of normalcy to patients when they visit and part of her job as a Child Life Specialist is to help facilitate family time by encouraging activities such as board games.

One other support briefly brought up was the connections made between patients during and outside of facilitated group time. As was discussed earlier,

there are support groups for patients that can help build relationships between patients and give them a feeling that they aren't alone in their experiences at the hospital. These support groups can be music therapy-based or may be led by Child Life Staff. Unfacilitated peer interactions may take place in the playrooms, the sibling play area, the gym used for physical therapy, or in other shared spaces. Patients and family members often use the playrooms and the sibling play area as a fun diversion from the routines of long-term hospitalization and are a great space for patients to connect. Whether patients interact in communal spaces in the hospital or meet during a facilitated support group, they can offer each other comfort in the feelings of shared experiences.

Gaps and challenges to optimal care

With all of the support hospitalized children receive, there are still areas that can be improved to provide more optimal care for the children and their families. One of the big challenges named by multiple interviewees was the lack of staffing. Participant 1 stated:

> *So we just only have so many staff here. So we are only able to cover so many patients in a day. So maybe it's like, you know, one kiddo could use some extra TLC, but meanwhile, we have four different procedures going on down the hallway. That is what makes it a challenge too. There's one of us on the units, and we can't be in four places at one time.* (6:56)

Participants explained that not having enough staff to provide all patients with what they need leads them to have to 'triage' or prioritize which patients get seen when. Because of the prioritization, patients who could use some extra

attention from services like Social Work and Child Life end up not getting optimal support if they aren't deemed to be the most in need that day. Participant 4 put it best by saying a lack of staffing "incentivizes putting out fires, like, unless a patient is actively in an acute crisis, like you're gonna be pushed to the back burner and a lot of these mental health issues are gonna go unaddressed" (17:53). Inadequate staffing also extends outside of the social services within the hospital. Participant 4 discussed how nurses may be assigned to multiple patients limiting them to the amount of time a nurse can spend with a patient. As was brought up earlier, some patients aren't able to leave their rooms unless accompanied by a nurse, so these patients are left to sit in their rooms most of the day because of their nurse's other responsibilities.

Similarly, Participant 3 noted that there is a lack of mental health resources for patients who are not in the mental health unit and that patients who are referred to psychology may have to wait weeks for their consult. Rapport - an important factor in the relationships formed with Child Life staff - is challenging to build when a psychologist only visits a patient once a week.

Another gap that was highlighted by the interviewees was the difficulty in transitioning patients from hospitalization to community resources. Participant 3 talked about how rural areas lack resources such as psychological services once patients leave the hospital which can lead to patients stopping their medications or discontinuing treatments they have been receiving from hospital psychologists and psychiatrists. Paradoxically there are also resources that children, particularly

children hospitalized with chronic illnesses, can't access while they are in the hospital either. Participant 2 stated:

> *If we meet them, and we think that they would benefit from like a PCA, or you know, respite, or any kind of waiver services to help them, they, the county, says that they have to be out of the hospital before they'll do that assessment. And so the families can't really get those extra supports…. And you, same with neuro-psych testing. Like, there's, just, we don't have anybody that does neuro-psych testing on the in-patient side.* (12:18)

Furthermore, once children leave the hospital, it can be difficult to ensure they receive needed resources. Paperwork, referrals, and assessments may get overlooked when cases are transferred between social workers.

One of the other gaps discussed by participants was the environmental aspects of the hospital. Having more social spaces dedicated to adolescents would potentially improve peer-to-peer interactions and create more support for the patients. Since the playrooms tend to be geared more towards toddlers with the toys and books that are offered, more spaces with natural light or more greenery spaces could be created with older patients in mind.

Lastly, I noted an apparent lack of collaboration between departments. While this topic was not directly spoken about by any of the interviewees, I learned that neither the participant working in the Volunteer Services office (Participant 1) nor the Child Life Specialist had connections with any individuals in the Psychology department at Children's MN in Minneapolis. I had asked both participants if they could help me set up an interview with an individual in the

Psychology department, but neither participant had a working relationship with the current staff there. The lack of collaboration between Child Life and the Psychology department was highlighted when Participant 3 said:

> *"I've never met anyone from Psychology here. I've just seen, like for example, the patient I've been referencing did get a Psychology referral. I think they've seen her three or four times in like a month. I've never seen them. I have no idea if that's something that's like been brought up. Yeah, the impression to me is just like, they require a legit consult and they'll come when they can and it might be next week or whatever."* (12:48)

A partnership between departments such as Child Life and Psychology seemed like an obvious thing to me since the focuses of the two departments– well-being and mental health– are so closely related. However, participants did not explicitly note that lack of collaboration is an issue to be addressed.

Barriers to improving care

There are a lot of ways that support for hospitalized children could be improved; however, there are also barriers making it difficult to implement new ideas. The most referenced barrier to improving care and resources at the hospital was finances. The hospital's budget can only go so far and finding extra funding isn't always possible. Related to this, Participant 4 talked about how money is allocated in the hospital's budget by stating:

> *Most social service departments really have to fight to like, prove their place in a hospital and like hospitals aren't super willing to hire more staff and pay more staff… Theoretically, a hospital could function without*

> *somebody in my job, like, I'm not a surgeon, I'm not a nurse, I'm not a physical therapist, but you would see all of these mental health, like the well-being of children and the patients and the families would suffer at the expense of that, but I think it's hard to convince the healthcare field of the necessity of psychosocial departments.* (19:55)

While not directly said, Participant 4 alluded to the way that psychosocial departments are perceived. Services such as Child Life and Social Work are deemed less important in hospital settings than departments like Nursing because they don't work directly with the physical health of patients. Because of this, social services departments may have to find creative ways to use the budget they do have. Child Life and Social Work were also mentioned to be not billable services like occupational or physical therapy which could be impacting how they are perceived and budgeted. To take it one step further, the Children's Hospital where all of the interviewees work has more financial support to work with than many smaller or more rural hospitals have; it may be even more difficult for patients to access social services in those places. Participant 3 put it best by saying:

> *I think there are good services set up. It's just that like, as with most healthcare areas, like everyone's stretched so thin, and like not anytime soon that we're going to have a ton of extra money lying around. So that's just kind of the main things like whenever coming up with like great ideas for new services. Typically, the barrier is going to be money.* (19:42)

Discussion

The purpose of this research was to gain insight into the first-hand experiences of healthcare professionals working with hospitalized children with chronic illnesses to identify the support children are receiving and how it can be improved to better support their well-being. The first of the themes concerned the mental health struggles faced by hospitalized children. As was discussed in Chapter 1, hospitalization comes with a lot of new experiences that elicit feelings of fear and anxiety (Norton-Westwood, 2012; Jepsen et al., 2019). Participants shared experiences of working with children who suffer from anxiety due to the hospital environment being very stressful for them. Similarly, participants also noted pain from treatments and illness greatly affects the patients and can potentially result in medical anxiety; this aligns with previous research done by Kleye and colleagues (2021) and Matziou et al. (2016).

Prior research also emphasized the social isolation that hospitalized children face (Carter et al., 2015; Hall-Lande et al., 2007). Interviewees talked about how isolation and loneliness may lead to depressive symptoms experienced by the children while they are in the hospital as a result of missing out on typical child/adolescent experiences. Relatedly, as found in past research, participants discussed how parents may not always be able to be present at the hospital which can impact the psychological well-being of a hospitalized child (Ashton et al., 2021; Eccleston et al., 2015; Hall-Lande et al., 2017). However, interviewees noted that parental presence is not always positive. They talk about how a parent or caregiver’s anxieties and feelings can negatively impact a hospitalized child.

These findings echoed previous research showing children pick up on and are influenced by parental emotions (Eccleston et al., 2015; Szulczewski et al., 2017; Kahhan & Junger, 2021).

One circumstance that was mentioned in the interviews, but not much in previous research was the impact that age has on the experience of a hospitalized child. Interviewees noted how they often prioritize a child's needs based on their age. If a child is young enough to most likely not remember what is going on, Child Life and Social Work will prioritize a school-age child who will remember the stress that hospitalization causes them. One study by Boyd & Hunsberger (1998) mentioned age as a factor in a child's ability to cope, however, the study did not center age as a main influence which differs from how current healthcare professionals use age as a determinant for who may need the most support.

Another aspect of hospitalization that impacts a child's experience that was not discussed in the literature is hospital precautions. The purpose of hospital precautions is to keep the child and staff safe and are set based on the type of infection a patient has. For example, contact precautions are designated for rooms where neither direct nor indirect contact with a patient's environment should occur because they have an infection that can be transmitted through contact (Douedi & Douedi, 2023). Interviewees noted how precautions can force a patient to stay in their room which can be difficult when hospitalized for an extended period.

Participants also talked about all of the staff at the hospital who are willing to support children and their families in many ways. The interviewees who

discussed the Child Life department's role in promoting positive well-being outlined many of the same ways of engaging with patients and families that have been discussed in prior research such as facilitating family activities, encouraging routines, and educating patients and families on diagnoses and treatments (Committee on Hospital Care, 2014; Burns-Nader & Hernandez-Reif, 2016; Magrab & Bronheim, 1976). The role of the social worker, however, was a new perspective discussed in the interviews that was not mentioned in the review of the literature. Participant 2 expressed how her role works with the whole family of the patients and ensures that the caregivers have what they need to best feel supported. Previous research mainly focused on the role of Child Life and Psychology in supporting hospitalized children, but social workers also have a part in supporting the whole family which directly impacts the patient.

Other sources of support highlighted in the interviews with participants were that of peers and family members. Prior research also called attention to the familial role in promoting resilience in a child and helping a child adapt to their medical treatments (Ashton et al., 2021; Committee on Hospital Care, 2014). Similarly, previous research has shown that building peer relationships in the hospital helps to reduce feelings of fear and increase feelings of belonging in hospitalized children (Kleye et al., 2021). Participants reflected these findings by discussing how the spaces that allow patients to connect– playrooms, sibling play areas, common rooms, facilitated support groups, etc.– are essential for promoting peer-to-peer relationships.

While interviewees talked about the support that hospitalized children have from family and peers within the hospital, there was no mention of the impact that hospitalization has on peer relationships outside of the hospital. Previous research outlined how hospitalization can negatively impact relationships outside of the hospital as a child with a chronic illness may miss out on normal activities due to hospitalization like school that help to develop stronger peer connections (Carter et al., 2015; Rohan & Winter, 2021). Also, a child may withdraw from peers to hide symptoms and for fear of potential rejection (Carter et al., 2015).

Recommendations

The information gathered from my review of the research literature done in Chapter 1 and the first-hand experiences of healthcare professionals aligned nearly perfectly and support several recommendations for changing the care available to hospitalized children. Participants highlighted various gaps and challenges that they have experienced such as lacking resources for non-mental health patients and not having enough staff for all patients. Adding more staff to departments such as Child Life, Psychology, and Social Work would allow staff to limit the prioritizing they have to do and better support all patients and families.

Although not directly discussed by participants, another gap that was noted during the interview process was the lack of collaboration between departments. Specifically, there is a lack of collaboration between the Psychology department and the Child Life department. With participants stating that they don’t have any working relationships with individuals in the Psychology

department, I recommend that action be taken to bring the two departments together. As was discussed in previous research, collaboration between departments is critical for the holistic care of patients and their families (Marshall et al., 2022; Rohan & Verma, 2020). Since both departments have similar focuses on the child's mental health and well-being, weekly meetings should be added to discuss patients and their circumstances. These weekly meetings would serve as contact points for highlighting which patients may need more attention and what course of action should be taken.

In Chapter 1, I proposed a new staff position within the Child Life department to better support hospitalized children by ensuring that there are more staff available to build meaningful relationships with them. In particular, the proposed position would look to directly improve the well-being of children whose families are unable to be at the hospital with them full-time. However, the position would also be providing support for all patients. The position that I proposed goes along with the challenges that interviewees noted of not having enough staff to fully support all patients. Participants also mentioned that Child Life is one department that could use more staff. Participant 3 specifically stated that the Child Life staff-to-patient ratio is higher than what is recommended in Child Life Association guidelines. Having more staff in the Child Life department would also potentially reduce the workload and stress of other staff members resulting in better support for patients.

Overall, I recommend hiring more staff in roles that will promote positive well-being for hospitalized children with chronic illnesses such as in the Child

Life department or the Psychology department. I also recommend adding weekly meetings between Child Life and Psychology staff to discuss patients and their needs. By doing this, more space is created to consider the mental health needs of children who are hospitalized for non-mental health-related concerns, but who still need support for their mental well-being. While money was noted as a barrier for hospitals to hire more staff, adjustments could be made to the budget allowing for new hires. Similarly, if a new position such as the Child Life Advocate were to be created, hospitals would not need to pay as high of a salary as they would have to for a position such as a new psychologist.

Limitations

One limitation of the current research is that all of the interviewees were from the same hospital in Minneapolis, Minnesota. Because I had connections to Children's MN from my volunteering there, I was easily able to set up interviews with individuals currently working there. While I did try to reach out to healthcare professionals working at other hospitals and in other spheres of the psychology field with children, I was unsuccessful in setting up other interviews. Since all participants spoke from their experiences at the same hospital, the diversity in experiences was limited. Having perspectives from individuals in varying environments might have revealed additional gaps and challenges professionals experience in providing optimal care and promoting positive well-being for patients. Furthermore, only having input from professionals at one hospital makes the results non-generalizable to other hospitals that may vary in size, staffing, budget, patient population, and location.

Another limitation to note is the limited departmental viewpoints represented in the interviews. Three of the participants spoke primarily about the services provided by the Child Life department. The perspectives of Child Life staff are critical, but having input from other departments that also work with hospitalized children with chronic illnesses would have provided a more well-rounded framework of the support currently in place. For example, the social worker I interviewed helped me to understand how they and their colleagues support the parents of hospitalized children which ultimately impacts the child. Having the viewpoints of departments such as Nursing and Psychology would have given a better understanding of how departments work together for the health of the child and how the child's well-being factors into their care.

Future Directions

First of all, a future study should seek out interviewees from a variety of hospitals to nuance the results and allow for the generalizability of the findings. For example, having different sizes of hospitals with different types of staffing and in different parts of a state (e.g. rural, suburban, etc) could yield new insight. As discussed in Chapter 1 of this paper, not all hospitals have Child Life departments or have the resources to support hospitalized children the way Children's MN in Minneapolis does. Therefore, research in more diverse settings is necessary.

Another direction that further research could take is to specifically explore collaboration between departments. Future research should look more into how much departments work together for the optimal care of hospitalized children and

how much collaboration impacts the well-being of patients. Similarly, looking at why collaboration is difficult now and ways to promote easier points of contact could be of use for improving collaboration between departments.

Lastly, future studies might focus on how social service departments are perceived in the hospital ecosystem. As discussed by Participant 4, some departments in the hospital have to prove their place and have to fight to not be discontinued. Future research could look at how social services departments are viewed by the other departments in the hospital and how that impacts the care provided by these departments like Child Life. For example, does the budget that hospitals employ reflect how valued a department is perceived to be? Understanding how other departments feel about services like Child Life may also be relevant to how utilized they are and how many resources they are allotted.

Conclusion

Overall, there are a lot of ways that positive well-being is promoted for hospitalized children with chronic illnesses. However, some areas of improvement are adding more staff and encouraging more collaboration between departments like Child Life and Psychology. To do this, I recommend creating a Child Advocate position and employing more staff at a low salary to be mindful of the hospital budget. Based on the experiences of participants I also recommend adding weekly meetings to discuss the status of patients and for staff in these departments to get to know each other. Between the review of literature done in Chapter 1 and the first-hand experiences of healthcare professionals, I believe these are the best courses of action with the present circumstances.

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Appendix A

Interview Questions

Below are the questions that participants will be asked by the researcher.

Opening Prose:

All of the following questions will focus on the psychological and social well-being of children experiencing hospitalization because of chronic illness.

Questions for Providers:

1. How would you describe your role, specifically relating to the identified population?
2. What kinds of mental health needs have you witnessed while working with this population of children?
3. Do you have examples of what has helped children work through or relieve their mental health concerns?
4. What gaps or challenges have you seen or heard about that you believe should be addressed?
5. What gaps or challenges have you personally experienced while meeting a hospitalized child's mental health needs?
6. In an ideal scenario, what would happen to fully address the mental health needs you've observed?
7. Do you have any ideas for additional services to support this population's mental well-being?
    a. In what department(s) would additional support services be housed?
    b. Do you foresee any logistical challenges to implementing additional support services?

Additional Questions, Time Permitting:

1. In your professional experience, what factors do you believe contribute to the origin of mental health needs in this child population?
2. In your experience, what kinds of support do children typically have during hospitalization?

Appendix B

Consent Form

Improving the Mental Well-being of Hospitalized Children

You are being asked to participate in a research project that seeks to understand the perspective of medical professionals on the mental well-being of children who are hospitalized with chronic illness.

Emily Pedersen, a senior undergraduate researcher, is conducting this research project under the guidance of Professor Jaine Strauss.

Procedures:
If you agree to be in this study, you will be asked to participate in an interview regarding your work with children experiencing hospitalization as a result of chronic illness. I will record the audio of this interview for later processing. Your name will not be associated with the recording. We anticipate that interviews will take approximately 20-30 minutes but, with your permission, could extend longer.

Voluntary Nature of the Study:
Participation in this study is voluntary. Your decision to participate will not affect your current or future relations with Macalester College. If you decide to participate, you are free to not answer any question or withdraw at any time without consequence.

Risks of Participation:
The risk of participating in this study is minimal, although it may involve recalling work with children experiencing hospitalization that could have been secondarily traumatic. Your participation will be a valuable contribution to the psychology community.

Privacy:
The records of this study will be kept private. I will not include any information that will make it possible to identify a participant in any paper or presentation I make based on this research. Research records will be stored securely and only the investigator, her advisor, and one additional researcher will have access to the records. The audio recordings will only be accessed by the three previously stated individuals. The recordings will be deleted after the conclusion of the project, along with any identifying information.

Privacy:
You may ask any questions you have now. If you have questions later, you are encouraged to contact the investigator Emily Pedersen (epederse@macalester.edu) or Professor Jaine Strauss (strauss@macalester.edu, 651-696-6114) at any time. If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, you are

encouraged to contact the Macalester College Institutional Review Board at 1600 Grand Avenue, St. Paul, MN 55105, by email at irb@macalester.edu or by phone at 651-696-6872.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

____
____
Signature of Participant Date

____
____
Signature of Investigator Date

Appendix C

Participant 1 Transcript

Emily Pedersen 0:00
Okay, we're good.

Participant 1 0:01
So part of our role as child life specialists is just helping kids cope while they're in the hospital setting. So that can mean a variety of things of different ways to help demonstrate coping tools during procedures, teaching, and learning, you know, new, like medical equipment or procedures that are about to happen or have happened in the past and helping reiterate, medical play emotional expression activities, those all kind of go into the overall package of helping kids cope while they're here in the hospital. But specifically relating to population. So we see a variety of kids, whether they're here for a lifetime visit or for here for you know, getting diagnosed with a chronic illness or managing their chronic illnesses. So we see, you know, a variety of levels of just psychological and social well-being, you know, in the hospital setting, and just different ways of coping.

Emily Pedersen 1:05
Yeah. And what kinds of mental health needs Have you witnessed while working with this population of children?

Participant 1 1:11
Yes. So one thing I noted that I was thinking of when I was looking at this question, is medical anxiety. So we see a lot of children with like needle phobia or, you know, really catastrophizing. You know, ideas of what the actual procedure could be or IV confusing that what does that sound like. I mean, what is that? So medical anxiety actually could be one of those, like, maybe it's not, it doesn't have a specific diagnosis to it. But yeah, we see it all the time. But it definitely affects children's mental health. There are also patients here for suicidal ideation. You know, we, I, when I first was a child life specialist, one of my main roles was with the eating disorder program. So you know, you go into more diagnosis-specific realms of, you know, and those can be considered chronic illnesses as well with eating disorder population. So we see a variety, variety, I think there's, there's, you know, and there's no one size fits all with, when it comes to like, the children's like mental health, right. So it could be they're experiencing anxiety over, you know, medical procedures, while my next patient might be experiencing, maybe none of that they kind of have their routine drill down. They know, they know why they're here, but kind of the just depression of the isolation of being in the hospital setting, and then time and time again, if we're talking

about chronic patients, depending on you know, what if they have to be admitted time and time again, okay, what does that look like? And, you know, falling into bouts of isolation, symptoms of depression, you know, and managing, trying to manage the anxiety levels, the hospital too?

Emily Pedersen 3:05
Yeah, um, do you have any examples of what has helped children work through or relieve like, these mental health concerns?

Participant 1 3:12
And so more, so just like kind of trying to stay on task with examples, I will give some of the medical anxiety. A lot of that, you know, that is promoting child life. So are we, you know, do we have enough time to go in ahead of time and teach about the procedure that's about to happen or teach a lot of diagnosis teaching. So especially for those chronic illnesses? I think of diabetes, that's a population I have worked with for a long time and still continue to work with. And a lot of times, it's that education, of like, well, what part of the body is not doing its job? Why does that happen? Even if it's an answer that like, well, we don't know why it happens to some kids and not to other kids yet, or we don't know why that part of the body just stops working? That is an answer. So providing that education is huge for decreasing medical anxiety, there is research on that in child life textbooks. So there's, that gets to my like further thoughts later on of research needing to be more prevalent in this field. Another thing that has helped children is that I've noticed over time and this is strictly like observation, I haven't done any research on my side, but we have scheduled group time. So helping kids you know, feel more connected to their peers, increasing normal growth and development through providing accessible activities for all. So that could look like a therapeutic play group time in the playroom and getting kids to come down and be a part of that and get to know one another interact with volunteers and Have some of that peer-to-peer support have some of that socialization, that all helps encourage during normal growth and development, and meanwhile, is also helping them forget that they're in the hospital for a little while. And therefore I'm, you know, helping with decreasing their feelings of isolation and loneliness, or you know, missing their class in normal, normal classroom activity time. They get to instead come to this group time that can be really supportive for them. Yeah.

Emily Pedersen 5:31
Is that an option for all patients? Are there certain patients that aren't able to do the group time?

Participant 1 5:36
That's a great question. Yeah, due to precautions in the hospital, really only those on standard precautions, which is like our most basic precautions in the hospital, meaning they don't have anything contagious, that they can come down to that group time, but unfortunately, those that are on specific precautions, they are not able to join for that group activity time.

Emily Pedersen 5:58
Yeah. Um, and then what gaps or challenges have you seen or heard about that you believe should be addressed?

Participant 1 6:04
Yeah. So one thing I jotted down was research, like a lack there of I think there can be a lot more research out there there is some a lot of our Child Life, particular ones are very, very dated. But I do think there could there could be benefits to, you know, increasing education and research, or at least different topics of, you know, what helps a child's well being while they are in the hospital with, you know, diagnosis, whether it's a new diagnosis or, you know, a diagnosis of years ago, and they're, you know, they're in for various reasons pertaining to their chronic illnesses. Yeah.

Emily Pedersen 6:47
And then what gaps are challenges have you personally experienced while trying to meet a hospitalized child's mental health needs?

Participant 1 6:56
So sometimes its resources, sometimes it comes down to like, what resources do we have? And what can we utilize, depending on what the goal is, right? So I know in, like, smaller hospital experience, budget looks very different. Whereas, you know, here at this large Children's Hospital, we're so fortunate enough to have so many donations, and maybe you have a larger budget than maybe some of our smaller programs have. But just kind of Yeah, noticing, like a gap in resources, and I will be interested, you know, I refer a lot of patients to social work to, or collaborate heavily with social work, because they have a lot of resources that I'm not aware of. But in terms of like, yeah, meeting those child, or children's mental health needs that I see. It could be also a time management issue. So we just only have so many staff here. So we are only able to cover so many patients in a day. So maybe it's like, you know, one kiddo could use an extra TLC, but meanwhile, we have four different procedures going on down the hallway. That is what makes it a challenge too. there's one of us on the units, and we can't be in four places at

one time. So yeah, an increase for resource and increase for staff. Yeah. And increase of awareness of what the job does. Yeah,

Emily Pedersen 8:31
um, I guess that's kind of leading into the seven questions if we could skip to number seven, and we'll come back to six. But do you have ideas for additional services? Like mentioned more staffing, that would support like, the mental well being? And what department do you think like more staff would be welcomed or other services?

Participant 1 8:53
Yeah, so we have, all of us are under the Family Services umbrella, I think as a whole, increasing the staffing in those areas. So that goes for Child Life, social work, psychology, volunteer services, you know, there's research on volunteers making a positive impact on patient, family hospital stays just increasing that normal experience having playtime. Yeah, encouraging that normal growth and development. That's all there. So that all follow that falls under the Family Services, umbrella, Star studio, that in-house programming that we have, I mean, welcome desk staff making families feel invited and creating, you know, a warm and welcoming environment when they first initially check in so it all falls under that Family Services umbrella that I think an increase in staffing in that department as a whole be beneficial for these children.

Emily Pedersen 9:50
Yeah. And then you talked a little bit about the budget, but would you foresee any other logistical challenges to implementing additional support services?

Participant 1 9:58
I think, um, You know, all for the like, you know, social work, child life all of these ones that I'm thinking of we're not billable services. And that's where that's where that there's that difference between like services like occupational therapy or physical therapy, we are not a billable service. And I think that's where that financial barrier sets in. And that's where I, you know, I would imagine there's limitations to like staffing that we could have. But in terms of challenges, I think it does, again, come down to that also impacts timing, like, so if we have less staff, we're just not going to be able to see every single patient in one day. I know, I worked full house here on Saturdays for a while. Yeah, and, you know, a full house for one person, you just have to prioritize, okay, where, you know, is there a death dying or bereavement going on today? What procedures are going on today? Who's going to surgery so I can provide that preparation? Whether it's, you

know, and then assessing to Okay, we have all these things going on today? Has this child had surgery before? Where am I most needed? So having more staff to, on top of the financial need to be able to support that. What will be needed.

Emily Pedersen 11:26
Yeah. And then, in an ideal scenario, what would happen to fully address the mental health needs you've observed?

Participant 1 11:34
I did get like stumped on this question because I found repeating kind of stuff. Yeah. Question number five. And question number seven. But, I, one thing that comes to mind in terms of when I'm jumping back to that diabetes, population divert heavily with, there's a huge barrier and costs for insulin. And so there's, there's that, from the family experience, you that can cause stress on parent caregivers, and then therefore, the child's can pick up on those stressful emotions from the parents. And therefore to so just finding free or inexpensive resources would be super helpful for any of these families, you know, that have to experience the hospital life, especially if they're here for a long time, you know, they might have jobs at home, they might have, you know, children, the patients have siblings at home. How are you able to balance and manage both? So all of these things to consider when it comes to children in the hospital setting.

Emily Pedersen 12:37
Yeah. And then those are my the main questions from the interview. But, um, if you would like to answer the other two, I don't know, if you had a minute to look at them.

Participant 1 12:47
I didn't get to those. That's okay. I can totally try to wing it.

Emily Pedersen 12:52
In your professional experience, what factors do you believe contribute to the origin of mental health needs in this child population?

Participant 1 12:59
Yeah. I'm sorry, can you let go into detail a little bit more about like, the mental health needs? Like basically like, to clarify that a little bit?

Emily Pedersen 13:10

Yeah. So you talked a little bit about, um, like, the medical anxiety and things like that. Like, are there other factors like, like you said, the children need, like, do they need like more support, like family support? Like you talked about peer support? If any of these things are like lacking? Would that be like an issue that would cause like, more mental health needs?

Participant 1 13:33
Yeah, yeah. No, that's I think let me know if I'm not thinking on the right track. But one thing, especially for like, group time, okay, is that child alone, like families and caregivers, like I said, they might live far away, they might have kids at home, other kids at home, like have jobs during the day. So I look for those kids. Okay, are they alone? Do they need that peer-to-peer support, that might be one factor. That may affect you know, more of the mental health at its age, we look at prioritizing age too. So okay, like there is research on, like, Who's more likely to have effects from medical experiences. So based on prioritizing if I have two IVs, weighing on at the same time, if there's a team going on with an IV or a school-aged child if we are going to go to that school-aged child first. And so that could be you know, an age could be a factor two, and just prioritization. Ideally, of course, you'd want to be in all the situations and be everywhere at one time. So that could be a factor too. So age. Yeah, are there siblings involved too, so are siblings present? There we also a part of our work focuses on sibling support. So not just that child, but also you know, the sibling and their mental health needs and well-being as well and to try to continue those normal, normal routines for them. So yeah, I got that one. Yeah.

Emily Pedersen 15:08
And then in your experience, what kinds of support do children typically have during hospitalization? And you touched on this a bit with the obviously with like, all the different departments and like siblings, family. But if there's anything else you'd like to add

Participant 1 15:25
volunteers, I like to point out to just because that's my other main job here. So having volunteers, that's where it's readily available is phenomenal. families, you know, we're fortunate, both of our campus hospitals, we have Ronald McDonald Houses, for families in, you know, intensive care units or, you know, referred to by social work, they can use those spaces to grab something to eat, or just take a break and unplug or the family resource center that can print things out or get things notorize, things that they need to like, get on their way if they need, like school documentation sent out their way. There's so many different facets that

once I've worked in the hospital, I just didn't realize there were all of these different things, there's music therapy, that is really, I mean, I've just been blown away by some of their sessions and what they can do that really, you know, they really impact to the mental well being of children in the hospital setting too, and they kind of all go hand in hand with that child's life, umbrella as well. Having group time, those were scheduled group time. So I think music therapy has good times here at Children's Hospital, you know, even referring to like my job at Gillette on Wednesday evenings, we have our group time. So that, you know, that makes a huge difference in the child's day. And then having, especially for kids with chronic illnesses, having the supports once they leave the hospital setting. So social work, you know, has a lot of great resources for those families too, or I think of with my patients with diabetes, okay, like, we would provide them with books that they can read to help with like adjustment, to taking insulin to getting finger pokes. We have support groups, for children. So whether there is an outlet for children with a loved one who has passed away, and then there is a facet for children with diabetes, they can come to our support group. And that's something that I facilitate and run their sibling support groups. So there are resources for setting them up for success beyond this. So and I think social work helps with a lot of, you know, if they need further resources beyond, you know, like, beyond medical, yeah, as well, they helped me those social needs as well outside of the hospital setting to make referrals. And there's so many different, you know, different individuals that help kind of support, whether it's during hospitalization or post hospitalization. So many different jobs out there. In terms of mental well being within the hospital, I think that's something that specifically you know, social work, child life, psychology goes and sees, you know, these patients as well. And they, I'd be curious to learn how they prioritize and, you know, there's so only, you know, there's so many patients and only so many of them, so, how do we meet those needs and determine who kind of gets seen first?

Emily Pedersen 18:48
Um, well, that's all my questions that I have

Appendix D

Participant 2 Transcript

Participant 2 0:01
Good. Yeah, I'm glad it's a sunny Friday, so I'm feeling good. Yeah, me too. Um, second, I just printed your questions. So I just want to grab them from the printer real quick, and then we can keep going. Would You Rather we do this like on teams or as a phone call?

Emily Pedersen 0:18
Phones, okay for me if that works for you? Yeah,

no, it's fine. As long as you can hear me, okay. I'm happy to invest. Okay. All right. Okay, so I read through the rest of what you sent, like the consents, and everything. And I read through these questions, and I think it looks really, really interesting. I'm curious to see if you could share it, like the outcome of this gathering of information?

Yeah, um, I. So I'm a senior at Macalester. And I am working on my honors project. And the original part of my honors project was, I created a literature review about the mental well-being of hospitalized children. And so now, for this honors part of it, I am just interviewing medical professionals to get their experiences to add on to my paper. So. Yeah, um, so before we start, I would like to, obviously obtain verbal consent, but also just reiterate that this is a voluntary study, and you're able to withdraw at any time or refrain from answering any questions. And then any identifying information that may come up during this interview will remain confidential. And then the recordings of this study will be kept private. Does that sound okay? Yep. Awesome. Okay. Um, and then, yeah, so basically, um, the entirety of the questions will be based on the psychological and social well-being of children that are hospitalized with chronic illness. So yeah, the first question to dive right in is, how would you describe your role specifically relating to the identified population?

Participant 2 2:19
Um, well, so I'm a social worker, and in an inpatient medical setting, so I work across a bunch of different areas. So one of those would be in the emergency room. And both campuses but primarily Minneapolis. So in that role, a social worker does a lot of things. they can get called for, you know, families that come in with a medical issue, but have other co-occurring needs, you know, like anxiety or housing concerns, or, you know, trauma histories, domestic violence, physical

assaults, that kind of stuff. But then the other big thing that we do in the emergency room would be crisis, mental health assessments, so kids coming in, either with suicidal ideation or some other kind of unsafe behaviors, whether they're like homicidal, or just, like, out of control, and people aren't able to keep them safe in their home environment. So assessing kind of like do they meet criteria for an inpatient level of care? Or can we come up with some sort of discharge plan with them. And then the other part of my job is working more with kids with more chronic medical conditions. So working on our inpatient units upstairs mostly med surg, and I work a lot with kids with type one diabetes. So anytime they're admitted, we'll do psycho socials and kind of follow them just because we know there's a lot of comorbidity between like depression and chronic health conditions. So that I would say, That's my role. And often, you know, it is working directly with kids, especially if they're older and sometimes it is working more with parents to try to help them identify like, how do they want to help their kids cope with this? What are the resources? What are the barriers and then just providing like support overall because it can be really challenging. A lot of things I'm hoping more specific things that cause mental health concerns.

Emily Pedersen 4:23
Yeah, that sounds really great. Um, and then I guess that leads us right into the next question of what kinds of mental health needs Have you witnessed while working with this population of children?

Participant 2 4:32
What's the second question what kind of mental health have I witnessed? Yes. Okay.

I can hear you better now awesome, perfect.

Gosh, I mean, we see pretty little kids with trauma responses, whether it's physical, environmental kind of community trauma, we see kids with mental health needs related to like persistent trauma, physical abuse, sexual abuse, that kind of stuff. And we see a lot of kids with anxiety and depression, a lot related to social media. And like bullying has been a bigger thing in the last couple of years. And then I would also say, not only mental health, but like the substance abuse, and comorbid presentation of that has been really challenging, too, because it's kind of hard to treat one, when the other one isn't really well treated. And a lot of our inpatient mental health treatment won't take kids who have issues too. I would say, that's kind of the gist of the mental health needs that we've seen. And I think, too, you know, I do see a lot of kids up on the floors that has specific like medical

trauma, and that impacts their ability to engage in cares, or like, they might get kind of burned out of doing some of the cares that that, that they need to, it's kind of a cycle of like, they're there has a medical condition, which causes them to feel, you know, lonely or anxiety or burnt out, and then they don't take care of it, which makes them feel worse.

Emily Pedersen 6:50
Yeah, um, and then diving more into like, how you were talking about, like the children up on the floors? Like, do you have any specific examples of what has like helped those children work through or relieve like, their mental health concerns? Like you said, a little bit about? Like anxiety? Yeah.

Participant 2 7:13
Yeah, I mean, it. Yeah, I have some ideas. So, I mean, it kind of depends. So some kids are here with us for a long time. Where like the mental health is the primary. So I don't know how much you know about it. But we have kids who will come in for like a mental health assessment or come in because they had a behavior and then like their, either their foster care or their home situation, like, isn't able to take them back, because they just aren't able to keep the space. But the kids also doesn't need to go to an inpatient psychiatric unit, like they don't need that criteria. So then they're just kind of stuck here. So for those kids, you know, I think what helps them is having really consistent support people, whether that's Child Life, or psychologist coming to see them and we do that often for kids is has psychology and psychiatry, like partner with social work. And in those in those settings, it's often like we kind of triage, like, I'll take parents, psychology will take the kid and psychiatry will address the medication piece. So that access to being able to get psychiatry or therapy in the hospital has been really helpful. It's just being able to start medications to help with, especially if it's like depression or anxiety, it's kind of that realm. I think having like routine is also helpful for kids to know what to expect, and consistent responses from us at the hospital is also helpful for them to kind of at least know that they're safe, and like feel like because a lot of kids, you know, if they're depressed or suicidal, like they don't, they don't feel safe and a lot of settings. And so I think that can kind of help and just reassuring them. But yeah, I think this kind of leads to your next question. But the problem is that we don't have enough services for everyone like, and then those kids that I talked about where they come in, and they're not facing the community, but they don't need inpatient psychiatric treatment, and they don't meet that criteria. Like those kids, the system doesn't really have a good level of support for them other than, like, we keep them safe and clothed and fed. Like that's how we're handling them. But that in all likelihood, I mean, that probably

makes some of their mental health concerns worse, especially if they've got some history of medical trauma or they're having, I don't know how much you know about our code green, but like those some of those kids have constant code green. And that's obviously not good for anyone's mental health either. Yeah, I think yeah, I think, you know, especially in like rural areas, but even in the metro, there's just super long wait time so it can be really hard to get into somebody to get treatment. Um, and then I think there's not enough people who are trained in like trauma-specific modalities to help kids address like, specifically trauma, but like EMDR, or some of those other ones. It's just Yeah, people, I hear people all the time that are from Greater Minnesota that are like we've been on waitlist for like six months, and just can't get in or there's not something that's like feasible for them to drive to. Yeah. But telehealth telehealth has helped a lot. I think with that, I think it's kind of like each, some kids, I don't know that that's the best option for them. You know, like if they've got social anxiety, or somehow that, like, avoidance of doing some of these things, but other cases, that is really a helpful opportunity.

Emily Pedersen 10:50
Yeah. Um, and then the fifth question is very similar to the fourth question, But what gaps or challenges have you personally experienced while meeting a hospitalized child's mental health needs?

Participant 2 11:08
Yeah, I mean, I think the same thing, I think, lack of available community resources. And in that sense, like, lack of ability for us to come up with a safe discharge plan is, is hard. And then there's certain things that like kids can't get while they're in the hospital, like we can't do psychological testing, like we can't bill for neuro-psych testing or get that done while they're in the hospital. We can't we also can't, the counties have told us that they can't do assessments. They call us MN choices, assessments, but that's how we determine how the county determines like if kids are eligible for waiver services, or different kinds of funds that they can get. We can't do that when kids are in the hospital. So like, there's lots of barriers. Just like from a billing perspective. Yeah. To getting people what they need.

Emily Pedersen 11:59
Um, is that true for children? So that's true for children that are in the hospital for like mental health concerns specifically. But is that also true for children that are, like maybe hospitalized for like a physical illness? And then may also be experiencing mental challenges as well?

Participant 2 12:18
Yep. Yep. If we meet them, and we think that they would benefit from like a PCA or, you know, respite, or any kind of waiver services to help them they, the county says that they have to be out of the hospital before they'll do that assessment. And so they families can't really get those extra support. So they do that. And yeah, same with neuro-psych. Testing. Like, there's just we don't have anybody that does neuro-psych testing on the inpatient side.

Emily Pedersen 12:46
Okay. And then, so in an ideal scenario, what would happen to fully address the mental health needs that you've observed? Yeah, so like, what would address those gaps or challenges?

Participant 2 13:02
Yeah, this was one of the ones I didn't have an answer for when I was looking at it. But I think first off, I think I think having more time and having more like staffing and time and like, financial support, because often we're just like, triaging, we're like jumping from one crisis to the next. And kind of prioritizing these based on things in the hospital as far as like being a social worker and trying to address those needs. So I think, you know, having more time dedicated to each family would help I think having more access to outpatient follow-up would be helpful. Like sometimes we can get kids to see psychology or psychiatry when they're here. But then they can't get established with anybody in their community. And so they just kind of stop their meds. And then I think another thing that would be helpful is to have more of like a wraparound kind of model, like, like, somebody who can follow them, from their admission to like, make sure that this church safety plan is followed and to make sure that there's continuity, so more like somebody who could follow them out into the community after they've been in an inpatient setting to kind of provide that like, crisis stabilization. I think that would be a really helpful model.

Emily Pedersen 14:26
And so you also brought up like, additional staffing, leading into the seventh question, like, Do you have any ideas for additional services to support like, mental well-being, like, in what department would more staffing be needed?

Participant 2 14:43
I think social work psychiatry and psychology, like all of those areas, would be helpful and they all seem under, like under-resourced. We're, um, you know, I say

that and like, we're fully staffed we have for what FTE Like our department has, but it doesn't let us do the level of care that probably everybody needs. Because we're, we're still running from thing to thing, if that makes sense. Yeah. So funding to those areas, I think having space in this setting, like there's not a lot of green space or outdoor safe space. And I feel like that's also a piece that contributes to a lot of adolescent mental health. And then some of those barriers I mentioned above, as far as like, the logistical challenges. Yeah, it's like, who's licensed the bill? What things can we get done when somebody else is billing? Like, the payment part of it, like the funding is a really big barrier to because there's all these different players? And that logistically, I mean, I think there's just, there's a group of kids in our community that we don't have appropriate care for, like, we don't have enough group homes, or we don't have enough places where, like, they can be safe. So they kind of get stuck. And those are the kids that like end up in the emergency room for weeks on end, or for a long time.

Emily Pedersen 16:20
Thank you. Um, those were all the general questions that I had. There's also two more additional questions, if you would like to answer them if you have time. The first one is, in your professional experience, what factors do you believe contribute to the origin of mental health needs in this child population?

Participant 2 16:42
Oh, my goodness. Well, a lot of things. I mean, I think social media is a huge one right now. Just that's like a whole issue in and of itself. But I think there's a lot of bullying, that leads to a lot of depression and anxiety. And like, I think, I think for sure, like systemic racism leads to a lot of mental health needs, I think, in similarly like historical trauma, community trauma, like community violence, those kinds of things. And then I think I mentioned this, but I think it's like cyclical like there's parts of our population that don't have access to meet their basic needs. And then like, they're more vulnerable to have other bad things happen. And then that impacts their mental health. And so I think it's kind of like this pattern of like, we don't have the resources to help people support their basic needs, and then they're going to be worse off with regard to their mental health.

Emily Pedersen 17:43
Yeah. And then the last question, in your experience, what kinds of support do children typically have during hospitalization?

Participant 2 17:54

Well, I mean, there's like three different buckets. So when I think about hospitalization for mental health for kids, there's inpatient mental health over in St. Paul. And in that setting, they have access to psychiatry daily, they have family therapy, they have individual therapy. And they have like they do, ideally get some peer support too with each other that group therapy. And that's more of an acute, like, you know, three to seven days to really stabilize, where they're at and make sure they're not acutely unsafe and still having wanting to hurt themselves. And then on like more of a nonacute side, so like, if they're here for a medical issue, but they have other mental health concerns, or a history of mental health. We do screenings around that, like when they get admitted, the nurses are asking, you know, do you have any concerns about safety? Do you have any mental health concerns? So they usually catch a lot of those, like if a parent or a patient speaks up and says, Yeah, I'm concerned about this, then they'll get social work involved, and then social work, kind of direct it to the appropriate people, whether that's psychology or psychiatry, or sometimes we'll meet with them and do a lot of like, you know, processing or coping and helping them with coping skills, given whatever the situation is. And then the kids who are like stuck here, like just awaiting the county to help them find placement. Those kids, you know, they'll have a one-to-one CSA, so they'll have someone in their room to kind of help redirect them. But ultimately, like, what do we I mean, sometimes I see psychiatry and psychology that that would be great. Sometimes we can make referrals for them to get tutoring while they're in the hospital if they're here for a prolonged period of time. But often, that's hard too because it's like these kids need structure and routine, but they also push back on that because that's like one of the only things they can control. You know, and so it's like, how much do we fight to make them follow the schedule versus just like keeping them safe while they're here which is our ultimate goal? Yeah. And then there's like activities, you know, through child's life and those kinds of things to help them just do like normal things throughout the day.

Emily Pedersen 20:12
Yeah. Awesome. Thank you. Well, that's all the questions that I have. But is there anything else that you feel like would be? Like, good to share? Good to talk about?

Participant 2 20:23
Yeah, I don't think so. No, I think I think those are all really important questions. And yeah, no, I don't have any other follow-up.

Emily Pedersen 20:41

Thank you so much for your time.

Appendix E

Participant 3 Transcript

Emily Pedersen 0:00
Thank you for taking this time to speak with me. Um, I am, as I said, I'm Emily. I'm a senior psychology major at Macalester. And this studies for my honors projects that I'm doing. And yeah,

Participant 3 0:17
Are you float volunteer?

Emily Pedersen 0:19
yeah, I am in the inpatient. Yeah, I really like it. I love, love my role.

Participant 3 0:32
Nice. Well, there's so many I'm pretty new to the PICU. But there's so many volunteers that it's a little hard to, like, get to know the volunteers. But yeah,

Emily Pedersen 0:45
definitely, um, did you have a chance to look through the consent form that I sent you? Awesome. Perfect. So just to go over a couple things. I just want to remind you that this is recorded. However, the video portion of this won't be like used for anything, it's just the audio that will be used for later transcription and analysis. And then also you'll be you'll remain anonymous throughout the entire process, and the recordings will be kept private. And then also, you have the right to withdraw from the study at any time or refrain from answering any questions that you don't want to. With this, Do I have your verbal consent to move on in the interview process? Yes, ma'am. Awesome. Perfect, so we can jump right into the questions. So basically, all of the following questions will focus on the psychological and social well-being of children experiencing hospitalization because of chronic illness. And obviously, as your role it fits right into this. So how would you describe your role specifically relating to this identified population?

Participant 3 2:20
Yes. Okay, cool. Um, so as a child life specialist, my role with this population is really to support both patient and family coping in the hospital environment. Should I add more to that, like, specifically what I do?

Emily Pedersen 2:42

If you want, you can otherwise, I mean, parts, of your role might come up in the later questions too.

Participant 3 2:48
Sure. I would say that in the ICU setting in the PICU. It is a lot of like, family support, and translating medical information into developmentally appropriate information for whether it's a patient or a sibling is really a major role.

Emily Pedersen 3:10
And then what kinds of mental health needs Have you witnessed while working with this population of children?

Participant 3 3:17
Yeah, I would say the main thoughts that came up were like depression and anxiety. I would also say PTSD, specifically from medical experiences, are the main things that come to mind like depression often after being hospitalized for like, a really, really long time.

Emily Pedersen 3:45
Do you have any examples of what has helped children work through or relieve their mental health concerns?

Participant 3 3:53
Yes, I would say rapport building is major. I'm thinking a lot of like, older, like school age and adolescents and teens. I think. I'm trying to make sure I'm not answering a future question. But I think it's interesting from our perspective because we often get referred from like nursing staff or doctors like, Oh, they're, like down, they're in a funk. Maybe showing some signs of depression. But from our perspective, as child life specialist, it's like, but is it developmentally appropriate, like if you were 13, and you'd been in the hospital for two months, you might have a bad day or, you know, maybe you start snapping at your parents or the nurse or whatever, like to us that is completely developmentally appropriate. I think, obviously, some of my role is helping alleviate that but it's still gonna happen and that's like, okay, and nothing for major concern. But I would say a big thing is like having rapport built because especially my mind goes to the older kids like Having a new face coming in and being like, let's talk about your depression, like, really doesn't make much as much of an impact as if you have like a really good relationship. So I think, for most of my other questions I'm going to focus on, like, how it can help when you do have like a longer-standing relationship, if that makes sense.

Emily Pedersen 5:21
Um, what gaps or challenges have you seen or heard about that you believe should be addressed?

Participant 3 5:30
I have heard, you know, if we do have a kid who gets referred to or consulted to psychology, I've heard that like, oh, it could take weeks for them to come by kind of thing. And then that kind of goes back to like, having a psychologist visit in the hospital, once a week, like might not be as helpful as like, what they really need. So I definitely feel like there are gaps in like, how much come in? How many mental health resources do we have for like, not the mental health unit if that makes sense? Or like if it is a behavioral health patient or a mental health patient coming in with suicidal ideation? Like, yes, they're gonna get visited by those people more regularly than just like, chronic kids who have been here for weeks and weeks and weeks and are showing signs of depression, like they might have to wait longer. And I don't know, it'd be interesting, like the effectiveness of like, those sessions when it's a brand new person walking in the door. So those are the things that come to mind.

Emily Pedersen 6:32
Yeah. And then what gaps are challenges have you personally experienced while meeting a hospitalized child's mental health needs?

Participant 3 6:43
It would be really how helpful if there were like two of me on a unit because I'm thinking of a girl actually specificly, who's here right now who's been here for a little over a month. And I do have like, really great rapport with her. And I try to see her every day because I know, like, the mom will be like, Oh, she just really wants to, like girl chit-chat time. And I know that that is really beneficial for her mental health, which has struggled while she's here. But unfortunately, there are days that I definitely can't go spend time with her or I can just like wave and say hi, but I gotta like, move along. So I think in my role, it would just be really nice to have lower like patient ratios, like I'm responsible for, like, seeing or managing or prioritizing, like 35 beds. And I think in child life school, they say that what like one to 15 is like more ideal ratio, where like, you're still busy. And you know, they're still high needs, but like, it's not to the point where, yeah, I'm just kind of flying to like, what are the highest needs? And I tried to prioritize to like seeing her because I know that that is important. But yeah, more me more of like, if there

were more psychologists that could actually build rapport as well. Those would help.

Emily Pedersen 7:58
Yeah, definitely. In an ideal scenario, what would happen to fully address the mental health needs, you've observed, you've touched on this a little bit, but I don't know if you have any more to expand on.

Participant 3 8:09
I also, I think, like more group time, group opportunities could be beneficial, just to reduce some of the isolation because I think that is a big factor. So in an ideal scenario, like, we'd have a playroom on the PICU, so we have playrooms on the other floors but not the PICU. And not even a playroom, but maybe just like a better like group space where I could have like team group or you know, whatever. And an ideal scenario, and nobody would be on like isolation precautions. But unfortunately, that does happen. But I do think that would really help in some of these situations, both. I think when I think of depression, in these cases, I would relate that a lot of the time to isolation and like being in the same four walls. And then when I think of like anxiety in this chronic illness population, it's like, the constant medical cares, whether that's pokes or dressing changes, or whatever. And so like, I think group, group time, peer time, could be very helpful for both those things, because you know, you're like, not alone in the medical side. Yeah, and that's what like these age groups really need like they'd normally be at school. And so they're missing out on a lot of that, but I wish we had kind of a better setup for that.

Emily Pedersen 9:35
Yeah. A follow-up from that question are the playrooms on the other floors, Because I know what sixth and seventh floor have the playrooms, or something like that, like seventh and eighth, seventh and eighth. Are those well utilized by the patients?

Participant 3 9:51
yeah. Yeah. And I would say they're more geared towards like little ones like toddler age. They have started doing music therapy. Groups once a week for like that younger age, but again, it's like teenagers might not want to go to that space. Honestly, just like a big, bright room with light and chairs and table, you know, like anything like that would not only be beneficial for patients but also for family members too so. Yeah, I mean, you could make like a teen kind of group work in

there, but I think some of them when, yeah, and I love the environment as well. Yeah, yeah.

Emily Pedersen 10:29
Um, do you have any ideas for additional services to support this population's mental well-being?

Participant 3 10:41
Um, gosh, I think I don't know, as far as like, the resources or the services they get while they're here. Pretty much every family, especially if it's a chronic illness gets checked in with social work, Child Life, and sometimes spiritual care. So like a chaplain. So I think that's all great. I think, psychology, it really is just a consult basis for chronic kids non like mental health. Yeah. So I think it could be nice if there were like, protocols, like, I can't remember, if CV like they might have started, like, if you're on the heart transplant list, I might just be making this up. On the record, I know I'm on the record, but it's like, if you're on like a transplant list, and you're gonna you know, that, that then signifies that you're gonna be here a long time you like automatically get a psychology consult, so that it's not up to like the discretion of the bedside nurse or whoever to like, make a consult. So maybe if it's like, Oh, if you got diagnosed with I don't know. I don't know. I don't know if oncology because a lot of times are longer terms or oncology, too. So I'm not sure if anyone has these, like, order sets, but it's kind of like when you're diagnosed with something, you automatically get referred to psychology would be cool. And then there just have to be more psychologists at the hospital. Yeah.

Emily Pedersen 12:10
Definitely. Um, and then do you foresee any logistical challenges to implementing these additional support services? Yeah,

Participant 3 12:18
Yeah. money and time. So yeah, I mean, we could definitely use another childhood specialist. We could use another social worker, we could use my psychology. But I mean, just all of those things. Money. Yeah.

Emily Pedersen 12:34
Do you think that you said psychology is another one that I could have? Like, like be more integrated into like the care? Right? Do you think that department would be open to that? Like, would they like to be more?

Participant 3 12:48

I have no idea. I've never met anyone from psychology here. I've just seen, like, for example, the patient I've been referencing did get a psychology referral. I think they've seen her three or four times in like a month. I've never seen them. I have no idea if that's something that's like been brought up. Yeah, the impression to me is just like, they require like a legit console. And they'll come when they can and it might be next week or whatever. So I'm not sure.

Emily Pedersen 13:24
Interesting. Okay. Those are all the like, first part questions that we need to cover. But then the first additional question is, in your professional experience, what factors do you believe contribute to the origin of mental health needs in this child population?

Participant 3 13:42
so I kind of touched on that with like, isolation, feeling different from their peers, like missing a lot of school and normal life that they should be participating in. And then as far as like, the anxiety or like medical PTSD side of things. I mean, as a child life specialist, you can literally tell in a procedure, like let's say it's an IV start in the emergency department or something, but you can kind of tell the moment that this is becoming like, traumatic, and the kid just feels like they have no control. You know, they're being pinned down. They're yelling, like, Stop, please get off me. But we keep doing that, you know, you just feel it and that is heavy. So that's where my role exists, where we try to mitigate that as much as we can. It still happens even when we're in the room but I feel like in order to reduce because a kid with a chronic illness, they're probably coming in for that first IV start well, how does that go? If we can, like keep things on a positive coping and they have the skills to cope with their chronic illness in any procedures that results in? But if we start off the bat, like their first IV start goes horribly That's just setting it up for failure. So I think it's important to have, again, just coming from my perspective, like child specialists in the emergency department, frontlines, you know, meeting those kids right away. And getting involved early, like, let's say, let's say like a new a chronic illness would be like diabetes. So like, let's say, the kid, has new diabetes and is starting to have their first like finger pokes and insulin shots in the PICU. And they're losing their mind, well, then it's important for the nurse to call and let me know about that. So that we can kind of nip that in the bud because that could just lead to so many coping and mental health eventually challenges if we don't kind of give them the tools early on, if that makes sense.

Emily Pedersen 15:48

It does make sense. Perfect. And then in your experience, what kinds of support do children typically have during hospitalization?

Participant 3 15:58
Yeah, so I guess like the typical day of a chronically ill child would be like, obviously, they have the medical support. So they're probably having at least like if you're a chronic illness, you might be serviced by like three or four different teams, meaning like maybe neuro and GI and whatever. So you're having medical teams coming in and out. And then in between those moments. Social Work, who's typically, a lot of times focus more on like the adults in the room and like, do you have your parking? Does everyone have their work notes? Like that kind of thing? Child life, I would love to say we can see every kid, but we can't, because we need more of us. But you know, we try to make sure that they have activities to help with that like distraction. And normalization while they're here. They might have volunteers stopping by to play with them. Dogs, they love dog visits. So Chaplin will usually get called if there's like religious needs or desires from the family. Yeah. Yeah, that's those are all the people that might come by and probably on a daily basis.

Emily Pedersen 17:12
Um, and then. So like, in a follow-up to that, what role does like the family play in helping the child through their hospitalization?

Participant 3 17:24
Right. Well, that's a good question. Because it's kind of like how does the parents sometimes rub off on the patient, like, if the parent is incredibly anxious and pacing around their room and getting mad at staff or like, definitely seen some of those where that's not going to help like the coping of the patient? granted a lot on my unit, a lot of times the child is, like, sedated, maybe has a breathing tube and is sedated, so they're not aware of like that. But I would say family members can be very helpful if they're, like, supportive in like, "No, we're gonna pick something fun to do today". Or, like, I know, this girl who has been here for a month and has kind of been low like mom is like, nope today, we are getting out of the room, like you can pick where we go, you know, just like are encouraging. To break out of those kind of like slumps that kids sometimes get in. siblings, if they have siblings that can come visit that I think brings like a whole fresh, like light to the room and is normal because of okay, what's your guys's favorite like board game you play at home, like, I'll bring that and then facilitate that you like get some family time, some like normal, normal time. I mean, it's important to know that they're always the child's greatest support, whether they're being

helpful at the moment or not, and that's who the child is gonna go home with. So like, if there are challenging family situations, like we're not going to fix or like solve that. That's what they're going home with. So in my role, it's a lot of like, making sure parents know how to appropriately explain what's going on to the kid. Because if a parent doesn't know, they might either not tell the kid anything, or maybe way over-explain. So like, if I can kind of educate them on like, what diabetes is or whatever, so that they can keep informing the kid because chances are, you know, I might teach the kid while they're here, but then they'll go home and not, you know, in one ear out the other and so, yeah, kind of preparing parents on how to support their kid with whatever is going on.

Emily Pedersen 19:29
Yeah, awesome. Um, well, that's all the questions that I had planned, but is there anything else that you would like to note or anything that you felt should be talked about?

Participant 3 19:42
No, I think I drove home the points about like, I think there are good services set up. It's just that like, as with most healthcare areas, like everyone's stretched so thin, and like not anytime soon, that we're going to have a ton of extra money laying around So that's just kind of the main thing like whenever coming up with like great ideas for new services. Typically, the barrier is going to be money.

Emily Pedersen 20:37
Well, thank you so much for your time. I really appreciate you taking this moment to speak with me and to help me with my research.

Appendix F

Participant 4 Transcript

Participant 4 0:30
I can tell you about my job position.

Emily Pedersen 0:36
Perfect. Um, well first I do need to like remind you, I don't know if you had a chance to look at the consent form. Yeah, I just have to remind you that this is recorded, but that the recording will be kept private and anonymous, and then that you also have the right to withdraw from the study or refrain from answering any questions at any time if you would like. And with that, Do I have your verbal consent to move forward with the interview?

Participant 4 1:03
You have my verbal consent. Yes, perfect.

Emily Pedersen 1:08
Then we can jump right into the questions. But basically, all of the questions focus on the psychological and social well-being of children that are experiencing hospitalization because of chronic illness. Yeah, but so how would you describe your role specifically relating to the identified population?

Participant 4 1:28
My role is to provide normative play opportunities to hospitalized patients and support developmental goals

Emily Pedersen 1:54
did I lose you for a second? Okay. Okay. I think you're back.

Participant 4 2:05
Okay. Okay. Okay, did you hear any of that

Emily Pedersen 2:08
I got the first part of it, the normative play part and then you cut out. Okay.

Participant 4 2:12
I would say my role is to support well-being through normative play. So I play a lot with the kiddos. I do art with them. And then I provide them with art and

games and books, just things that typical kids need. To stay happy. Stay engaged. I would say that sounds best.

Emily Pedersen 2:51
Awesome. Um, what kinds of mental health needs Have you witnessed while working with this population of children?

Participant 4 2:59
Yeah, so I work with a variety of different patients. I work on the hematology oncology floor so blood and cancer disorders, and then I work on the cardiovascular unit or the heart unit. And as far as the cardiovascular unit, I would say, the most prominent mental health needs are with patients who are awaiting transplant so they're waiting for a new heart and we have two patients right now, who live in the hospital and jazz for almost a year and half a year and you see mental health needs. So like we're having discussion with one of them. Three years old, and showing signs of depression. Just because of the monotony of the day-to-day and especially in healthcare, there are so many in the healthcare field. There's so many moving parts and when monotony is sometimes unavoidable due to staffing and lack of opportunities to change routine. So from those like super super long-term patients, boredom and the lack of stimulation definitely lead to a decline in emotional health. And then they're also at risk for developmental delays or just being a little bit behind their peers when it comes to developmental progress just because they're not in the same social settings, the same opportunities to play and interact with peers. And then, on the hematology-oncology floor, there are also some random behavioral health rooms mixed in there. And so like that leads me down two different paths. I would say with the behavioral health kids, this is how to like, make it not related to the behavioral health already existed. I would also say boredom, lack of autonomy. A lot of these patients have one-to-ones so that you have to sit in the room with them because they're at risk of self-harm or leaving the facilities we do have some runners and that can just be kind of suffocating. To people. As well as these patients are also the most restricted in what they can have for activities so they can't have certain items. And as far as my role will be like interacting with a teen, a teenager and be like, Hey, do you want playdough or Model Magic or crayons because you can't have markers or pencils? So I think that's without super easy solutions because there are unfortunately valid reasons why these restrictions are put into place. Yeah. And then yeah, I'd say with oncology and then we also have a big sickle cell population. I would say also, just like depression, boredom or, not even depression, but just like apathy, low Anhedonia. is seen when they're here for a long time.

Emily Pedersen 7:41
Yeah, those are good, great things to note.

Participant 4 7:46
That was very thorough.

Emily Pedersen 7:49
Um, do you have examples of what has helped children work through or relieve their mental health concerns?

Participant 4 8:02
I think having staff meetings. Everybody getting on the same page has been helpful. So when we already see really evident signs of patients starting to show mental health concerns, then like the care team will get together and talk about what we're seeing and then come up with solutions. So kind of everybody voicing what they're witnessing. And then a lot of times this is like, how can we provide variety for these patients? So we bring patients down to what's called the sibling play area, and it's designed for siblings of patients to come down and play. But it's just a space that provides novelty, I would say novelty is a big one. Just something different than what they're doing all day every day because a lot of these patients are just stuck in like a 10 by 10 room for indefinitely. So just like getting them out of that room, if that is safe and appropriate, and providing them different opportunities. is helpful.

Emily Pedersen 9:34
and then what gaps or challenges have you seen or heard about that you believe should be addressed?

Participant 4 9:53
I would say limited staffing. I think this is a problem everywhere in the world, especially in the healthcare field and hospitals like we're short-staffed, and that limits our abilities to like provide this novelty to patients. Because if we don't have the nursing to like, have a nurse be one-to-one with a patient. Then that can limit the patient's opportunities to go out and like seek this novelty I say I don’t think there’s space for those patients who aren't in dire crisis or don't need support like I what I observe is sometimes we wait until there's a crisis in order to start making these changes. Instead of me taking action right away. Because it's time-consuming. It requires a lot of staffing occasionally, and I think there is a gap there.

Emily Pedersen 11:47
And what gaps or challenges have you personally experienced while meeting a hospitalized child's mental health needs?

Participant 4 12:05
I would say some of my challenges actually have been like outside of work. Working with the mental health population unlike hospitalized children it's hard to fully turn off when you leave work. It's hard to like drive out of the parking ramp and try to forget and compartmentalize kind of some of the stuff that you see and not being able to talk to people outside of work, or like debrief and obviously a confidential HIPAA, HIPAA-approved way just because it's an interesting job and we see a lot of people's worst days and a lot of trauma. And then I think just overall in health care. There is a kind of attitude, like because this is everybody's learning. I don't know if we take time to be like, actually, that was really hard. Because somebody like, has seen this case before and they're like, oh, yeah, I've seen it before. It is not new. It's not scary. It's not hard to me. Where you might be like actually, that was the first time I've seen that and now I don't feel like I can complain about it because everybody else seems super fine about it.

Emily Pedersen 13:54
In an ideal scenario, what would happen to fully address the mental health needs that you've observed?

Participant 4 14:08
I would say in an ideal scenario, one place to start and one kind of qualm that I'd have about some mental health needs, because I think this is the case at most hospitals, unfortunately, but a lot of behavioral health patients actually wear like rest kind of rust, orange, rust, red scrubs. And they look, unfortunately, kind of similar to an orange jumpsuit. Yeah, and I know that's to make them easily identifiable. So that like, if they did run out of the hospital, it would be able to be seen and no other department wears that color scrubs like kind of all the other colors seem to be taken to different departments, but I'm like that feels unnecessary. So that's just a weird niche one. But I would say more to fully address mental health communities I would say more maybe like more holistic support. And more staff or smaller staff-to-patient ratio so that each patient could be follow up more closely because like also what you see as patients start to stay here longer like especially the behavioral health patients like they have free access to order whatever food they want. And like if a 12-year-old, has to order whatever food they want, they're not going to make healthy choices which makes mental

health worse when you're not fueling your body appropriately and you're not moving, which I think makes things worse. So like having them meet with you know, a dietician so that you know, somebody is not just sort of existing off of brownies and chicken nuggets for an indefinite period of time. Yeah, like very personalized care. I think addresses a lot of needs.

Emily Pedersen 17:09
Yeah. Um, and then you've talked about like additional staff, like do you have any ideas for additional services like to support this population's mental well-being, and then like, what department would like more staff be needed?

Participant 4 17:35
I would say definitely the Social Services Well, okay. For some of the patients that's nursing, for example, like with the kiddos awaiting transplant, they need a nurse with them in order to leave their room. And sometimes, a nurse has three patients so they're like, No, I can't take this patient out of their room because I have to, like, be giving this patient feeds and get this patient medicine in 15 minutes so they don't have time. So definitely nursing. And then I would say

probably, definitely social work. I think social workers that are consistently spread very thin and that makes it that incentivizes like to be putting out fires, like, unless a patient is actively in an acute crisis, like you're gonna be pushed to the back burner and a lot of these mental health issues are gonna go unaddressed. And I would also say child life because I think we do provide a lot of the novelty and the fun stuff and I know like I am split between upwards of 70 patients and can only do so much as my like prioritization list. But I do think that that leads to not getting as good of care as I could in an ideal world. Where we have an abundance of staff. Yeah, definitely think nursing. Yes. And then social services.

Emily Pedersen 19:40
Awesome. Do you see any or do you foresee any logistical challenges to implementing additional support services?

Participant 4 19:55
Just I think I think it's just money. From the hospital side. Like I know our department. Most social service departments really has to fight to like, prove their place in a hospital and like hospitals, aren't super willing to hire more staff and pay more staff. If it's like, that verge of like, essential were like, yes, theoretically, a hospital could function without somebody as my job like, I'm not a surgeon. I'm not a nurse. I'm not a physical therapist, but you would see all of these mental

health like the well-being of children and the patients and the families would suffer at the expense of that, but I think it's hard to convince the healthcare field of the necessity of psychosocial departments, like child life Yeah. And then I know Masonic Children's Hospital actually cut their department of like music therapy, and child life like, just as an example of like hospitals don't like if it's departments have to be cut to psychosocial needs that are like here to improve the mental well being of patients are often the first to go because they're not like providing the drugs and the medicine and the treatment.

Emily Pedersen 22:06
I didn't know that about the Masonic Children's Hospital. Um, yeah. And then, I guess I have two other questions. If you have like a couple more minutes. In your professional experience, what factors do you believe contribute to the origin of mental health needs for like hospitalized children? Yeah, I mean, we already kind of touched on this a little bit. But yeah.

Participant 4 22:41
So is this like while they're in the hospital or patients before they get to the hospital?

Emily Pedersen 22:49
It's really while they're in the hospital. So like the children who are in like the inpatient wing.

Participant 4 22:58
Awesome. Realizing fact Check me on if it was Masonic Children's Hospital, I'm pretty sure it was. That's okay.

I think yes, I think boredom a lack of novelty a lack of purpose. Honestly, like is, you know, a lot of these kids get their purpose from school. Or, or just like how any adult, any person needs to feel like they're contributing to the world in some extent, whether that's like being a friend or making art or like giving Valentines to your classmates. I don't often still do that, but just like contributing to this world in some way. And that is limited and a lot of these patients are just stuck in their room. boredom, lack of novelty like I've always said, I think that's huge play is incredibly crucial. And art is incredibly crucial to the well-being of children. But sometimes there's only so much you can do like when you're awake and in a bed for 12 hours a day. And also, beyond the psychosocial needs, like pain and discomfort, all of these patients feel really, really bad. And if you're sick and in so much pain for so long, you're not going to be having a good time. And then I

would say also like the trauma anxiety that comes up as we go along with procedures. That's not something I've really touched on but like some of these like patients awaiting a heart transplant. They have to go through daily dressing changes, which is not comfortable or fun, or especially a child. They don't have their autonomy. It's just non-existent. And yeah, just as having a sick body weighs on patients, whether they have like the conscious words to say that or if it's just that they know it and they feel it. And they can't express it because maybe they're three.

Emily Pedersen 26:14
Um, and then in your experience, what kinds of support do children typically have during hospitalization?

Participant 4 26:23
I'd say they have the support most of the time of the family. Sometimes that's not the case, unfortunately. And so, I would say despite all that staff is very supportive. I think we have a lot of really, really wonderful staff who go above and beyond for a lot of the children here. And really like if they have the means and capabilities to help a patient and support a patient, they really will. There is a psychologist here to work with the patients and then the families, as well as social workers are huge and will go way above and beyond to support families. Yeah, I think it's just in an ideal universe like we would just have magically three times as many of those people as we have so that every patient could be as supportive as possible.

Emily Pedersen 27:52
You said that patients usually have the support of their families, but that's not always the case. Could you talk a little bit more about that?

Participant 4 28:00
Yeah, definitely. So you see a variety of patients. So some of the patients we have our waiting shelter placements, so they are foster youth, maybe homeless, so their family is not in the picture and they are a citizen of the state or the county. Or a lot of patients have come from a politically correct term, dysfunctional families. So like we have a number of patients who I know like when they're admitted, they're admitted, like certain patients who I know are going to be alone all the time. Because their parent doesn't necessarily have the ability to show up. For them or provide for them. That can be a result of a lot of different things. Sometimes, parents have four other kids at home and have to work full time and it's just not a possibility to drop everything and be at the hospital. That's a very, very real

reality. Sometimes that is because a parent is maybe struggling with addiction and kind of lives a very dysfunctional life and isn't able to show up for their child, as would be wanted in an ideal universe. Sometimes patients are estranged from their families. We also have like so a unique thing about children's hospitals, not really anything but we see patients like there have been I've seen 24-year-olds I've seen up to 30-year-olds like so we've got like some 20-year-olds who are estranged from their family and don't necessarily have that support system in place. So yeah.

Table 1
Interview 1 Themes and Codes

Theme	Quotes	Codes
Mental health struggles facing hospitalized children	1. "So medical anxiety actually could be one of those, like, maybe it's not, it doesn't have a specific diagnosis to it. But yeah, we see it all the time. But it definitely affects children's mental health" 2. "...we see a lot of children with like needle phobia or, you know, really catastrophizing" 3. "So we see a variety, I think there's, you know, and there's no one size fits all with, when it comes to like, the children's like mental health" 4. "So it could be they're experiencing anxiety over, you know, medical procedures, while my next patient might be experiencing, maybe none of that they kind of have their routine drill down. They know, they know why they're here, but kind of the just depression of the isolation of being in the hospital setting, and then time and time again, if we're talking about chronic patients, depending on you know, what if they have to be admitted time and time again, okay, what does that look like?"	● Medical Anxiety ● Depression ● Isolation ● Loneliness ● Parents ● Age

	5. "…have some of that peer-to-peer support, have some of that socialization, that all help encourage normal growth and development, and meanwhile, is also helping them forget that they're in the hospital for a little while. And therefore I'm, you know, helping with decreasing their feelings of isolation and loneliness, or you know, missing their class in normal, normal classroom activity time. They get to instead come to this group time that can be really supportive for them." 6. "...due to precautions in the hospital, really only those on standard precautions, which is like our most most basic precautions in the hospital, meaning they don't have anything contagious, that they can come down to that group time, but unfortunately, those that are on specific precautions, they are not able to join for that group activity time." 7. "And so there's, there's that, from the family experience, you that can cause stress on parent caregivers, and then therefore, the child's can pick up on those stressful emotions from the parents."	

	8. "...you know, that have to experience the hospital life, especially if they're here for a long time, you know, they might have jobs at home, they might have, you know, children, the patients have siblings at home." 9. "...is that child alone, like families and caregivers, like I said, they might live far away, they might have kids at home, other kids at home, like have jobs during the day" 10. "we look at prioritizing age too. So okay, like there is research on, like, Who's more likely to have effects from medical experiences. So based on prioritizing if I have two IVs, weighing on at the same time, if there's a team going on with an IV or a school-aged child if we are going to go to that school-aged child first. And so that could be you know, an age could be a factor two, and just prioritization."	
Hospital-based support for hospitalized children	*Child Life* 1. "A lot of that, you know, that is promoting child life. So are we, you know, do we have enough time to go in ahead of time and teach about the procedure that's about to happen or teach a lot of diagnosis teaching."	● Education about procedures and diagnosis ● Facilitated peer support ● Sibling support

	2. "And a lot of times, it's that education, of like, well, what part of the body is not doing its job? Why does that happen? Even if it's an answer that like, well, we don't know why it happens to some kids and not to other kids yet, or we don't know why that part of the body just stops working? That is an answer. 3. "...providing that education is huge for decreasing medical anxiety, there is research on that in child life textbooks" 4. "We have scheduled group time. So helping kids you know, feel more connected to their peers, increasing normal growth and development through providing accessible activities for all." 5. "Child Life, social work, psychology, volunteer services, you know, there's research on volunteers making a positive impact on the patient, family hospital stays just increasing that normal experience having playtime." a. Star Studio b. Welcome desk - "welcome desk staff making families feel invited and creating, you know, a warm	● Volunteers ● Family resource center ● Child life ● Psychology ● Social work

	and welcoming environment when they first initially check-in" 6. "Yeah, are there siblings involved too, so are siblings present? There we also a part of our work focuses on sibling support. So not just that child, but also you know, the sibling and their mental health needs and well-being as well and to try to continue those normal routines for them." 7. "volunteers, I like to point out too just because that's my other main job here. So having volunteers, that's where it's readily available is phenomenal" 8. "We're fortunate, both of our campus hospitals, we have Ronald McDonald Houses, for families in, you know, intensive care units or, you know, referred to by social work, they can use those spaces to grab something to eat, or just take a break and unplug or the family resource center that can print things out or get things notarize, things that they need to like, get on their way if they need like school documentation sent out their way." 9. "There's music therapy, that is really, I mean, I've just	

	been blown away by some of their sessions and what they can do that really, you know, they really impact to the mental well-being of children in the hospital setting too.” 10. “...or I think of with my patients with diabetes, okay, like, we would provide them with books that they can read to help with like adjustment, to taking insulin to getting finger pokes” 11. “We have support groups, for children. So whether there is an outlet for children with a loved one who has passed away, and then there is a facet for children with diabetes, they can come to our support group.” 12. “I think social work helps with a lot of, you know, if they need further resources beyond, you know, like, beyond medical, yeah, as well, they helped me those social needs as well outside of the hospital setting make referrals.”	
Other support for hospitalized children		
Gap/Challenges to optimal care	1. “I think there can be a lot more research out there there is some a lot of our Child	● Dated research ● Lack of resources

	Life, particular ones are very, very dated." a. "But I do think there could there could be benefits to, you know, increasing education and research, or at least different topics of, you know, what helps a child's well-being while they are in the hospital with, you know, diagnosis, whether it's a new diagnosis or, you know, a diagnosis of years ago, and they're, you know, they're in for various reasons pertaining to their chronic illnesses." 2. "So sometimes it's resources, sometimes it comes down to like, what resources do we have? And what can we utilize, depending on what the goal is, right? So I know in, like, smaller hospital experience, the budget looks very different." 3. "So we just only have so many staff here. So we are only able to cover so many patients in a day. So maybe it's like, you know, one kiddo could use an extra TLC, but meanwhile, we	• Budgeting issues • Lack of staffing • Triaging

	have four different procedures going on down the hallway. That is what makes it a challenge too. there's one of us on the units, and we can't be in four places at one time.” 4. “But in terms of challenges, I think it does, again, come down to that also impacts timing, like, so if we have less staff, we're just not going to be able to see every single patient in one day. I know, I worked full house here on Saturdays for a while. Yeah, and, you know, a full house for one person, you just have to prioritize.” a. “Okay, where, you know, is there a death, dying, or bereavement going on today? What procedures are going on today? Who's going to surgery so I can provide that preparation? Whether it's, you know, and then assessing to Okay, we have all these things going on today? Has this child had surgery before? Where am I most needed?” 5. “But, I, one thing that comes to mind in terms of when I'm jumping back to that	

	diabetes, population divert heavily with, there's a huge barrier and costs for insulin.” 6. “And therefore to so just just finding free or inexpensive resources would be super helpful for the for any of these families”	
Barriers to improving care	1. “You know, all for the like, you know, social work, child life all of these ones that I'm thinking of we're not billable services. And that's where that's where that there's that difference between like services like occupational therapy or physical therapy, we are not a billable service.” 2. “I think that's where that financial barrier sets in. And that's where I, you know, I would imagine there's limitations to like staffing that we could have.”	● Financial/money

Table 2
Interview 2 Themes and Codes

Theme	Quotes	Codes
Mental health struggles facing hospitalized children	1. "...families that come in with a medical issue, but have other co-occurring needs, you know, like anxiety or housing concerns, or, you know, trauma histories, domestic violence, physical assaults, that kind of stuff" 2. "So working on our inpatient units upstairs mostly med surg, and I work a lot with kids with type one diabetes. So anytime they're admitted, we'll do psycho socials and kind of follow them just because we know there's a lot of co-morbidity between like depression and chronic health conditions." 3. "And I think, too, you know, I do see a lot of kids up on the floors that have specific like medical trauma, and that impacts their ability to engage in cares, or like, they might get kind of burned out of doing some of the cares that that, that they need to, it's kind of a cycle of like, they're there has a medical condition, which causes them to feel, you know, lonely or anxiety or burnt out, and then they don't take care of it, which makes them feel worse."	• Anxiety • Trauma histories • Housing concerns • Domestic violence • Physical assaults • Type 1 diabetes • Depression • Comorbidity • Burnout • Loneliness • Medical trauma • Bullying • Social media • Systemic racism • Community trauma • Cyclical mental health needs

	4. "I think social media is a huge one right now. Just that's like a whole issue in and of itself. But I think there's a lot of bullying, that leads to a lot of depression and anxiety. And like, I think, I think for sure, like systemic racism leads to a lot of mental health needs, I think, in similarly like historical trauma, community trauma, like community violence, those kinds of things. And then I think I mentioned this, but I think it's like cyclical like there's parts of our population that don't have access to meet their basic needs. And then like, they're more vulnerable to have other bad things happen. And then that impacts their mental health."	
Hospital-based support for hospitalized children	1. "...a social worker does a lot of things. they can get called for, you know, families that come in with a medical issue, but have other co-occurring needs, you know, like anxiety or housing concerns, or, you know, trauma histories, domestic violence, physical assaults, that kind of stuff. But then the other big thing that we do in the emergency room would be crisis, mental health assessments…" 2. "So working on our inpatient units upstairs mostly med surg, and I work a lot with kids with	*Social work* ● Mental health assessments ● Crisis management ● Psychosocial assessments ● Case management ● Support for parents

	type one diabetes. So anytime they're admitted, we'll do psycho socials and kind of follow them just because we know there's a lot of comorbidity between like depression and chronic health conditions." 3. "...it is working directly with kids, especially if they're older and sometimes it is working more with parents to try to help them identify like, how do they want to help their kids cope with this? What are the resources? What are the barriers and then just providing like support overall because it can be really challenging." 4. "So for those kids, you know, I think what helps them is having really consistent support people, whether that's Child Life, or psychologist coming to see them and we do that often for kids is has psychology and psychiatry, like partner with social work. And in those settings, it's often like we kind of triage, like, I'll take parents, psychology will take the kid and psychiatry will address the medication piece. So that access to being able to get psychiatry or therapy in the hospital has been really helpful." 5. "I think having like routine is also helpful for kids to know what to expect, and consistent responses from us at the	• Childlife • Psychology • Psychiatry • Creating routine • Nurses • Tutoring

	hospital is also helpful for them to kind of at least know that they're safe, and like feel like because a lot of kids, you know, if they're depressed or suicidal like they don't, they don't feel safe and a lot of settings." 6. "And then on like more of a non-acute side, so like, if they're here for a medical issue, but they have other mental health concerns, or a history of mental health. We do screenings around that, like when they get admitted, the nurses are asking, you know, do you have any concerns about safety? Do you have any mental health concerns? So they usually catch a lot of those, like if a parent or a patient speaks up and says, Yeah, I'm concerned about this, then they'll get social work involved, and then social work, kind of direct it to the appropriate people, whether that's psychology or psychiatry, or sometimes we'll meet with them and do a lot of like, you know, processing or coping and helping them with coping skills, given whatever the situation is." 7. "Sometimes we can make referrals for them to get tutoring while they're in the hospital if they're here for a prolonged period of time. But often, that's hard too because it's like these kids need structure and routine, but they also push back on that	

	because that's like one of the only things they can control. You know, and so it's like, how much do we fight to make them follow the schedule versus just like keeping them safe while they're here which is our ultimate goal?" 8. "And then there's like activities, you know, through child's life and those kinds of things to help them just do like normal things throughout the day."	
Other support for hospitalized children		
Gap/Challenges to optimal care	1. "But the problem is that we don't have enough services for everyone." 2. "Yeah, I think yeah, I think, you know, especially in like rural areas, but even in the metro, there's just super long wait time so it can be really hard to get into somebody to get treatment. Um, and then I think there's not enough people who are trained in like trauma-specific modalities to help kids address like, specifically trauma, but like EMDR, or some of those other ones. It's just Yeah, people, I hear people all the time that are from Greater Minnesota that are like we've been on waitlist for like six months, and just can't get in or there's not something that's like	• Lack of hospital services/ resources • Waitlists for care outside the hospital • Lack of trained individuals • Lack of community resources • Post-hospitalization support • Triaging

	feasible for them to drive to. Yeah. But telehealth telehealth has helped a lot.” 3. “I think, lack of available community resources. And in that sense, like, lack of ability for us to come up with a safe discharge plan is, is hard. And then there's certain things that like kids can't get while they're in the hospital, like we can't do psychological testing, like we can't bill for neuro-psych testing or get that done while they're in the hospital.” 4. “If we meet them, and we think that they would benefit from like a PCA or, you know, respite, or any kind of waiver services to help them they, the county says that they have to be out of the hospital before they'll do that assessment. And so their families can't really get those extra support. So they do that. And yeah, same with neuro-psych. Testing. Like, there's just we don't have anybody that does neuro-psych testing on the inpatient side.” 5. “Yeah, this was one of the ones I didn't have an answer for when I was looking at it. But I think first off, I think I think having more time and having more like staffing and time and like, financial support, because often we're just like, triaging, we're like jumping from one crisis to the next. And kind of	

	prioritizing these based on things in the hospital as far as like being a social worker and trying to address those needs." 6. "...having more time dedicated to each family would help I think having more access to outpatient follow up would be helpful." 7. "Like sometimes we can get kids to see psychology or psychiatry when they're here. But then they can't get established with anybody in their community. And so they just kind of stop their meds." 8. "And then I think another thing that would be helpful is to have more of like a wraparound kind of model, like, like, somebody who can follow them, from their admission to like, make sure that this safety plan is followed and to make sure that there's continuity, so more like somebody who could follow them out into the community after they've been in an inpatient setting to kind of provide that like, crisis stabilization." 9. "I think having space in this setting like there's not a lot of green space or outdoor safe space. And I feel like that's also a piece that contributes to a lot of adolescent mental health." 10. "we don't have the resources to help people support their basic needs, and then they're going to	

	be worse off with regard to their mental health.”	
Barriers to improving care	1. “There's lots of barriers. Just like from a billing perspective.” 2. “Yeah. So funding to those areas” [social work, psychiatry, psychology] 3. “Yeah, it's like, who's licensed the bill? What things can we get done when somebody else is billing? Like, the payment part of it, like the funding is a really big barrier to because there's all these different players.”	• Billing • Funding

Table 3
Themes and Codes for Interview 3

Theme	Quotes	Codes
Mental health struggles facing hospitalized children	1. "I would say the main thoughts that came up were like depression and anxiety. I would also say PTSD, specifically from medical experiences, are the main things that come to mind like depression often after being hospitalized for like, a really, really long time. 2. "We often get referred from like nursing staff or doctors like, Oh, they're, like down, they're in a funk. Maybe showing some signs of depression. But from our perspective, as child life specialist, it's like, but is it developmentally appropriate, like if you were 13, and you'd been in the hospital for two months, you might have a bad day or, you know, maybe you start snapping at your parents or the nurse or whatever, like to us that is completely developmentally appropriate." 3. "I think, like more group time, group opportunities could be beneficial, just to reduce some of the isolation because I think that is a big factor."	• Depression • Anxiety • PTSD • Isolation • Medical Anxiety • Feeling different than peers • Lack of autonomy • Novelty of the hospital/treatments • Parents

	4. "And an ideal scenario, and nobody would be on like isolation precautions. But unfortunately, that does happen." 5. "When I think of depression, in these cases, I would relate that a lot of the time to isolation and like being in the same four walls. And then when I think of like anxiety in this chronic illness population, it's like, the constant medical cares, whether that's pokes or dressing changes, or whatever" 6. "Yeah, and that's what like these age groups really need like they'd normally be at school." 7. "...isolation, feeling different from their peers, like missing a lot of school and normal life that they should be participating in. And then as far as like, the anxiety or like medical PTSD side of things. I mean, as a child life specialist, you can literally tell in a procedure, like let's say it's an IV start in the emergency department or something, but you can kind of tell the moment that this is becoming like, traumatic, and the kid just feels like they have no control. You know, they're being pinned down. They're yelling, like, Stop,	

	please get off me. But we keep doing that, you know, you just feel it and that is heavy." 8. "Because it's kind of like how do the parents sometimes rub off on the patient, like, if the parent is incredibly anxious and pacing around their room and getting mad at staff or like, definitely seen some of those where that's not going to help like the coping of the patient."	
Hospital-based support for hospitalized children	1. "So as a child life specialist, my role with this population is really to support both patient and family coping in the hospital environment." 2. "I would say that in the ICU setting in the PICU it is a lot of like, family support and translating medical information into developmentally appropriate information for whether it's a patient or a sibling is really a major role." 3. "I would say rapport building is major." 4. "I think, obviously, some of my role is helping alleviate that [the funk discussed above] but it's still gonna happen and that's like, okay, and nothing for major concern." 5. "But I would say a big thing is like having rapport built	*Child life* ● Coping support ● Family support ● Medical information translation ● Mitigation of medical trauma ● Education ● Social work ● Psychology ● Spiritual life

	because especially my mind goes to the older kids like Having a new face coming in and being like, let's talk about your depression, like, really doesn't make much as much of an impact as if you have like a really good relationship.” 6. “Pretty much every family, especially if it's a chronic illness gets checked in with social work, Child Life, sometimes spiritual care. So like a chaplain. So I think that's all great. I think, psychology, it really is just a consult basis for chronic kids non like mental health.” 7. “So that's where my role exists, where we try to mitigate that as much as we can 8. If we can, like keep things on a positive coping and they have the skills to cope with their chronic illness in any procedures.” 9. “And getting involved early, like, let's say, let's say like a new chronic illness would be like diabetes. So like, let's say, the kid, has new diabetes and is starting to have their first like finger pokes and insulin shots in the PICU. And they're losing their mind, well, then it's important for the nurse to call and let me know about that. So that we	

	can kind of nip that in the bud, because that could just lead to so many coping and mental health eventually challenges if we don't kind of give them the tools early on." 10. "Yeah, so I guess like the typical day of a chronically ill child would be like, obviously, they have the medical support. So they're probably having at least like if you're a chronic illness, you might be serviced by like three or four different teams, meaning like maybe neuro and GI and whatever. So you're having a medical teams coming in and out. And then in between those moments. Social Work, who's typically, a lot of times focus more on like the adults in the room and like, do you have your parking? Does everyone have their work notes? Like that kind of thing? Child life, I would love to say we can see every kid, we can't, because we need more of us. But you know, we try to make sure that they have activities to help with that like distraction. And normalization while they're here. They might have volunteers stopping by to play with them. Dogs, they love dog visits. So Chaplin will usually get called if	

	there's like religious needs or desires from the family." 11. "So in my role, it's a lot of like, making sure parents know how to appropriately explain what's going on to the kid. Because if a parent doesn't know, they might either not tell the kid anything, or maybe way over-explain. So like, if I can kind of educate them on like, what diabetes is or whatever, so that they can keep informing the kid because chances are, you know, I might teach the kid while they're here, but then they'll go home and not, you know, in one ear out the other and so, yeah, kind of preparing parents on how to support their kid with whatever is going on."	
Other support for hospitalized children	1. "And so like, I think group, group time, peer time, could be very helpful for both those things, because you know, you're like, not alone in the medical side." 2. "Family members can be very helpful if they're, like, supportive in like, "No, we're gonna pick something fun to do today". Or, like, I know, this girl who has been here for a month and has kind of been low like mom is like, nope today, we are getting out	• Peer support • Family • Siblings

	of the room, like you can pick where we go, you know, just like are encouraging. To break out of those kind of like slumps that kids sometimes get in." 3. "...siblings, if they have siblings that can come visit that I think brings like a whole fresh, like light to the room and is normal because of okay, what's your guys's favorite like board game you play at home, like, I'll bring that and then facilitate that you like get some family time, some like normal, normal time."	
Gap/Challenges to optimal care	1. "If we do have a kid who gets referred to or consulted to psychology, I've heard that like, oh, it could take weeks for them to come by kind of thing. And then that kind of goes back to like, having a psychologist visit in the hospital, once a week, like might not be as helpful as like, what they really need. So I definitely feel like there are gaps in how many mental health resources we have for like, not the mental health unit." 2. "It would be really how helpful if there were like two of me on a unit because I'm thinking of a girl actually is specific, who's here right now	● Resources ● Staffing ● Time ● More playrooms ● Connection between departments

	who's been here for a little over a month. And I do have like, really great rapport with her. And I try to see her every day because I know, like, the mom will be like, Oh, she just really wants to, like girl chit-chat time. And I know that that is really beneficial for her mental health, which has struggled while she's here. But unfortunately, there are days that I definitely can't go spend time with her or I can just like wave and say hi, but I gotta like, move along. So I think in my role, it would just be really nice to have lower like patient ratios, like I'm responsible for, like, seeing or managing or prioritizing, like 35 beds." 3. "And I think in child life school, they say that what like one to 15 is like more ideal ratio, where like, you're still busy." 4. "But yeah, more me more of like, if there were more psychologists that could actually build rapport as well. Those would help." 5. "I also, I think, like more group time, group opportunities could be beneficial, just to reduce some of the isolation because I think that is a big factor. So in an ideal scenario, like, we'd have a playroom on the	

	PICU, so we have playrooms on the other floors but not PICU. And not even a playroom, but maybe just like a better like group space where I could have like team group." 6. "Yeah, and that's what like these age groups really need like they'd normally be at school. And so they're missing out on a lot of that, but I wish we had kind of a better setup for that." 7. "Yeah. And I would say they're [the playrooms] more geared towards like little ones like toddler age. They have started doing music therapy. Groups once a week for like that younger age, but again, it's like teenagers might not want to go to that space. Honestly, just like a big, bright room with light and chairs and table, you know, like anything like that would not only be beneficial for patients but also for family members too so." 8. "So I think it could be nice if there were like, protocols, like, I can't remember, if CV like they might have started, like, if you're on the heart transplant list, I might just be making this up. On the record, I know I'm on the record, but it's like, if you're on like a transplant list, and	

	you're gonna you know, that, that then signifies that you're gonna be here a long time you like automatically get a psychology consult, so that it's not up to like the discretion of the bedside nurse or whoever to like, make a consult." 9. "So I'm not sure if anyone has these, like, order sets, but it's kind of like when you're diagnosed with something, you automatically get referred to psychology would be cool. And then there just have to be more psychologists at the hospital." 10. "We could definitely use another childhood specialist. We could use another social worker, we could use my psychology." 11. "I've never met anyone from psychology here. I've just seen, like, for example, the patient I've been referencing did get a psychology referral. I think they've seen her three or four times in like a month. I've never seen them. I have no idea if that's something that's like been brought up. Yeah, the impression to me is just like, they require like a legit console. And they'll come when they can and it might be next week or whatever."	

	12. "Child life, I would love to say we can see every kid, we can't, because we need more of us."	
Barriers to improving care	1. "Yeah. money and time." 2. "I think there are good services set up. It's just that like, as with most healthcare areas, like everyone's stretched so thin, and like not anytime soon, that we're going to have a ton of extra money laying around So that's just kind of the main thing like whenever coming up with like great ideas for new services. Typically, the barrier is going to be money."	● Money ● Time

Table 4
Themes and Codes for Interview 4

Theme	Quotes	Codes
Mental health struggles facing hospitalized children	1. "And as far as the cardiovascular unit, I would say, the most prominent mental health needs are with patients who are awaiting transplant so they're waiting for a new heart." 2. "...Three years old, and showing signs of depression. Just because of the monotony of the day to day." 3. "So from those like super super long term patients, boredom and the lack of stimulation definitely leads to a decline in emotional health." 4. "And then they're also at risk for developmental delays or just being a little bit behind their peers when it comes to developmental progress just because they're not in the same social settings, the same opportunities to play and interact with peers." 5. "I would say also, just like depression, boredom or, not even depression, but just like apathy, low Anhedonia is seen when they're here for a long time." 6. "Just something different than what they're doing all day every day because a lot of these	• Depression • Monotony • Boredom • Developmental delays • Lack of autonomy • Anhedonia • Physical symptoms • Medical trauma • Medical anxiety • If parents are present

	patients are just stuck in like a 10 by 10 room for indefinitely.” 7. “I think boredom, a lack of novelty, a lack of purpose. Honestly, like is, you know, a lot of these kids get their purpose from school. Or, or just like how any adult any person needs to feel like they're contributing to the world in some extent, whether that's like being a friend or making art or like giving Valentines to your classmates. I don't often still do that, but just like contributing to this world in some way. And that is limited and a lot of these patients are just stuck in their room.” 8. “But sometimes there's only so much you can do like when you're awake and in a bed for 12 hours a day.” 9. “And also, beyond the psychosocial needs, like pain and discomfort, all of these patients feel really, really bad. And if you're sick and in so much pain for so long, you're not going to be having a good time.” 10. “And then I would say also like the trauma anxiety that comes up as we go along with procedures. That's not something I've really touched on but like some of these like patients awaiting a heart transplant. They have to go through daily dressing changes,	

	which is not comfortable or fun, or especially a child. They don't have their autonomy. It's just non-existent. And yeah, just as having a sick body weighs on patients, whether they have like the conscious words to say that or if it's just that they know it and they feel it. And they can't express it because maybe they're three." 11. "So like we have a number of patients who I know like when they're admitted, they're admitted, like certain patients who I know are going to be alone all the time. Because their parent doesn't necessarily have the abilities to show up." a. "Sometimes, parents have four other kids at home and have to work full time and it's just not a possibility to drop everything and be at the hospital." 12. "For example, like with the kiddos awaiting transplant, they need a nurse with them in order to leave their room. And sometimes, a nurse has three patients so they're like, No, I can't take this patient out of their room because I have to, like, be giving this patient feeds and get this patient medicine in 15 minutes so they don't have time."	

Hospital-based support for hospitalized children	1. “I would say my role is to support well-being through normative play. So I play a lot with the kiddos. I do art with them. And then I provide them with art and games and books, just things that typical kids need. To stay happy. Stay engaged.” 2. “I think having staff meetings. Everybody getting on the same page has been helpful. So when we already see really evident signs of patients starting to show mental health concerns, then like the care team will get together and talk about what we're seeing and then come up with solutions. So kind of everybody voicing what they're witnessing. And then a lot of times this is like, how can we provide variety for these patients? So we bring patients down to what's called the sibling play area, and it's designed for siblings of patients to come down and play. But it's just a space that provides novelty, I would say novelty is a big one.” 3. “So just like getting them out of that room, if that is safe and appropriate, and providing them different opportunities is helpful.” 4. “And art is incredibly crucial to the well-being of children.” 5. “I think we have a lot of really, really wonderful staff who go	*Childlife* ● Normative play ● Art ● Sibling play area ● Providing novelty

	above and beyond for a lot of the children here.” 6. “There are psychologists here to work with the patients and then the families, as well as social workers are huge and will go way above and beyond to support families.”	
Other support for hospitalized children	1. “I'd say they have the support most of the time of the family”	• Family support
Gap/Challenges to optimal care	1. “There's so many moving parts and when monotony is sometimes unavoidable due to staffing and lack of opportunities to change routine.” 2. “I would say limited staffing. I think this is a problem everywhere in the world, especially in the healthcare field and hospitals like we're short-staffed, and that limits our abilities to like provide this novelty to patients. Because if we don't have the nursing to like, have a nurse be one-to-one with a patient. Then that can limit the patient's opportunities to go out and like seek this novelty.” 3. “What I observe is sometimes we wait until there's a crisis in order to start making these changes. Instead of me taking action right away. Because it's time-consuming. It requires a	• Staffing • triaging/prioritizing

	lot of staffing occasionally, and I think there is a gap there.” 4. “...more maybe like more holistic support. And more more staff or smaller staff to patient ratio so that each patient could be follow up more closely.” 5. “I would say definitely the Social Services. Well, okay. For some of the patients that's nursing, for example, like with the kiddos awaiting transplant, they need a nurse with them in order to leave their room. And sometimes, a nurse has three patients so they're like, No, I can't take this patient out of their room because I have to, like, be giving this patient feeds and get this patient medicine in 15 minutes so they don't have time. So definitely nursing.” 6. “I think social workers that are consistently spread very thin and that makes it that incentivizes like to be putting out fires, like, unless a patient is actively in an acute crisis, like you're gonna be pushed to the back burner and a lot of these mental health issues are gonna go unaddressed.” 7. “And I would also say child life because I think we do provide a lot of the novelty and the fun stuff and I know like I am split between upwards of 70 patients and can only do so much as my like prioritization list.”	

	8. "Yeah, I think it's just in an ideal universe, like we would just have magically three times as many of those people as we have so that every patient could be as supportive as possible."	
Barriers to improving care	1. "I think it's just money. From the hospital side. Most social service departments really has to fight to like, prove their place in a hospital and like hospitals, aren't super willing to hire more staff and pay more staff." 2. "Theoretically, a hospital could function without somebody as my job like, I'm not a surgeon. I'm not a nurse. I'm not a physical therapist, but you would see all of these mental health like the well-being of children and the patients and the families would suffer at the expense of that, but I think it's hard to convince the healthcare field of the necessity of psychosocial departments, like child life."	● Money ● Appreciation