IDENTIFICATION AND RESPONSE TO PARENT DISTRESS BY MEDICAL PROVIDERS IN THE PEDIATRIC INTENSIVE CARE UNIT

by

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ABSTRACT

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During hospitalization in the pediatric intensive care unit (PICU), approximately 25-60% of parents experience clinical levels of distress (i.e., traumatic stress, anxiety, and depression). Despite this, PICU providers rarely refer parents to formal psychological services, and parents describe room for improvement in provider response to their emotional needs. Difficulty identify and/or responding to distress in parents may contribute to these deficiencies. The present study aimed to evaluate how medical providers identify and respond to parent distress in the PICU. Thirty-seven medical providers (78% female; 73% White) from the Children's Wisconsin PICU completed a semi-structured interview. Providers perceived supporting distressed parents as a shared responsibility with psychosocial providers and described several contributors to distress and strategies that align with previous research. There may be room for improvement in recognition of other contributors and strategies, self-efficacy, and use of external resources through psychoeducation, skill-building, and increasing presence of psychologists in the PICU.

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IDENTIFICATION AND RESPONSE TO PARENT DISTRESS BY MEDICAL PROVIDERS IN THE PEDIATRIC INTENSIVE CARE UNIT

Children admitted to the pediatric intensive care unit (PICU) require critical medical care for life-threatening conditions. Not surprisingly, patients' parents describe these experiences as extremely stressful (Colville & Pierce, 2012). As a result, a substantial proportion of parents experience distress both during and after hospitalization (e.g., Balluffi et al., 2004; Nelson & Gold, 2012). Parent distress during hospitalization is associated with negative short-term (e.g., reduced shared decision-making) and long-term (e.g., development of posttraumatic stress disorder; PTSD) consequences (Madrigal et al., 2018; Balluffi et al., 2004). Given these negative outcomes, there is a need to identify factors influencing parent distress in order to develop effective interventions to improve child and parent outcomes. Medical providers work in close and regular contact with parents during hospitalization and can provide both direct support and make referrals to appropriate external support services (e.g., psychologists). It is essential that medical providers are able to recognize and respond effectively to distress in order to support parents. The current study sought to evaluate medical provider identification of and response to parent distress in the PICU in order to identify areas for improvement within these domains.

PICU Background

More than 90,000 infants, children, and adolescents were admitted to a PICU in the United States in 2019 (*Virtual Pediatric System, LLC*, 2020). The PICU specializes in providing care for critically ill or injured youth, ranging from newborns to up to 21-year-olds, with about half of children under two-years of age (Namachivayam et al., 2010). These children require critical medical care for life-threatening conditions; a review of 54 PICUs reported the primary reasons for admission as respiratory (33%) and neurologic (23%) conditions, with 10% related to trauma and 40% to pre- or post-operative care (Edwards et al., 2012). The majority of children (70%) have at least one pre-existing chronic health condition (Edwards et al., 2012). For about half of patients, discharge occurs within two days of admission, resulting in a relatively short PICU stay; the average length of stay is five days for children admitted to the PICU, suggesting that those discharged after two days are typically hospitalized for significantly longer (Edwards et al., 2012). Due to advancements in treatment, the PICU mortality rate has decreased from 11% in 1982, to 5% in 2006, and to a current rate of about 2% (*Virtual Pediatric System, LLC*, 2020; Namachivayam et al., 2010). Regardless of length of stay and this relatively low mortality rate, parents experience stressful circumstances prior to, during, and after their child's hospitalization in the PICU.

Most (70%) PICU admissions are non-elective as opposed to planned post-operative admissions (Edwards et al., 2012). Therefore, the majority of parents do not expect to have a child admitted to the PICU and thus are likely unprepared for hospitalization both emotionally and practically (e.g., caring for other children, missing work). Often, hospitalization is immediately preceded by a traumatic event (e.g., car accident/fall), or parents might have agonized over whether to bring their child in (e.g., as they have progressive difficulty breathing from a viral infection). Many parents have described that the transition to the PICU, such as the drive to the hospital, is extremely stressful (Colville et al., 2009). Given that patients are primarily admitted to the PICU from the emergency department (45%) or the operating room/procedure suite (34%), many parents have also already begun to deal with hospital-related stressors or serious medical procedures prior to their PICU stay (Edwards et al., 2012).

Once hospitalized in the PICU, parents describe stressful circumstances related to the child's illness and ongoing treatment, alteration in their parenting role, and the PICU environment. While survival rates have increased, most childhood deaths that occur in inpatient hospital settings occur in the PICU (Carter et al., 2004). This may partially explain why many parents overestimate the possibility of their child's death and worry that their child may die (Rodríguez-Rey et al., 2018; Balluffi et al., 2004). Most parents describe this uncertainty and worry about the child's outcome to be stressful (Hagstrom, 2017; Jee et al., 2012). Stressors continue throughout treatment as many (65%) children undergo invasive procedures such as intubation and mechanical ventilation, which involves placing a tube down the throat and using a machine to facilitate breathing (Namachivayam et al., 2010). Parents reported that witnessing these types of medical procedures and observing their child's appearance and discomfort is stressful (Colville et al., 2009; Hagstrom, 2017). Additionally, parents describe feelings of helplessness and a change in their role as a parent due to an inability fulfill their child's needs (Jee et al., 2012; Simeone et al., 2018). Many parents also report balancing the competing demands of being physically present with other family members at home versus with the patient at the hospital to be stressful (Hagstrom, 2017). Finally, parents are not only subject to stressors related to their own child but also experience stress related to the general PICU environment. Specifically, parents describe anxiety due to witnessing events in the PICU (e.g., alarms, coding) even when unrelated to their child and recognize the critical state of both their child and others in the PICU (Colville et al., 2009).

While discharge from the PICU signals improvement in the child's medical state, transitioning to a new setting and managing on-going treatment needs contribute to continued stressful circumstances after leaving the PICU. For most families, their stay in the hospital continues after discharge from the PICU, as approximately 80% of children are discharged to another hospital setting, and only 16% are discharged directly home (Edwards et al., 2012). For those discharged to another ward, they need to adjust to a new environment and continue to manage the stressors associated with hospitalization. Many parents describe this transition to be stressful, as they lose contact with staff they had established relationships with and experience a reduction in staff presence (Colville et al., 2009). Once the child has returned home, they often demand new and increased caregiving responsibilities from parents without the support of the PICU environment and staff. This is due to the fact that the increased survival rates have been accompanied by a corresponding increase in child morbidity and decrease in child quality of life post-discharge (Namachivayam et al., 2010). Specifically, an increasing number of children demonstrate moderate-to-severe disability and persisting physical complaints (e.g., pulmonary and neurological problems) after discharge (Knoester et al., 2008). Further, parents may have increased anxiety that whatever initially brought their child into the PICU might happen again and that they need to be vigilant to avoid this. In fact, many parents report that they are more anxious about their child's health after a PICU hospitalization (G. Colville et al., 2009). Unfortunately, this worry is somewhat warranted as one in ten of these children will be readmitted to the PICU unexpectedly within the first year of discharge, leaving families to experience all of these stressors again (Edwards et al., 2018).

Parent Psychological Outcomes

Given these extremely stressful circumstances, it is not surprising that many parents experience psychological distress during and after discharge from the PICU. For the purposes of this study, psychological distress is conceptualized as experiences of traumatic stress, anxiety, and/or depression given their high comorbidity and shared underlying constructs of dysphoria and negative affect (Grant et al., 2008; Byllesby et al., 2016). This includes acute stress disorder (ASD), which is characterized by experiencing, witnessing, or learning about a trauma (i.e., actual or threatened death, serious injury, or sexual violation) and experiencing symptoms of traumatic stress, including intrusive distressing memories of the event, negative mood, avoidance of trauma-related stimuli, inability to remember important aspects of the trauma, and/or hypervigilance, within one month of the trauma (American Psychiatric Association, 2013). PTSD is defined by very similar symptomatology as ASD, but PTSD differs in time since the trauma such that symptoms of traumatic stress must continue or begin at least one-month post-trauma exposure.

During PICU hospitalization, about 32% of parents meet criteria for ASD (Balluffi et al., 2004), and on average demonstrate the same level of ASD symptoms as patients admitted to the PTSD unit of a psychiatric hospital (Auerbach et al., 2005). After discharge, about 11-21% of parents develop diagnosable PTSD (Nelson & Gold, 2012), compared to 6.8% of the general population (Kessler et al., 2005). PICU parents are also more likely to develop PTSD than parents of children in general pediatric wards (Rees et al., 2004), which suggests that there are unique factors related to PICU hospitalization that result in greater risk for PTSD than general hospitalization. Regarding symptoms of anxiety (e.g., worry, feeling tense), previous research suggests 26-60% of parents experience extreme anxiety during hospitalization (Stremler et al., 2017; Needle et al., 2009), and about one-fourth of parents continue to experience long-term anxiety after discharge (Bronner et al., 2009; Colville & Pierce, 2012; Rothschild et al., 2020). Finally, about half of parents experience symptoms characteristic of major depression (e.g., depressed mood, loss of interest or pleasure) during hospitalization (Fauman et al., 2011; Stremler et al., 2017), and 16-24% reported clinically significant depression at 3 months post-discharge (Bronner et al., 2009; Rothschild et al., 2020).

While a substantial subset of parents experience short- and long-term psychological distress, families demonstrate varying outcomes after their child's injury or illness (Muscara et al., 2015; Price et al., 2016). Price et al. (2016) outlined the Integrative (Trajectory) Model of Pediatric Medical Traumatic Stress, which describes four trajectories of family traumatic stress: resilient, recovery, chronic, and escalating (see Figure 1). Most families are considered resilient such that they demonstrate expected increases in traumatic stress in response to their child's illness or injury but then show a return to typical levels while the child undergoes acute medical care (i.e., PICU hospitalization). Fewer families fall within the recovery group in which they demonstrate higher and longer lasting levels of traumatic stress that eventually decline after discharge from care. The smallest number of families demonstrate chronic or escalating levels of traumatic stress in which traumatic stress is maintained or increased after discharge from the PICU, respectively.

Families in the recovery, chronic, and escalating groups experience short- and long-term negative consequences for both the child and parent. During hospitalization, parent distress impacts their ability to make decisions and care for their child, which may affect the child's health outcomes. Previous research suggests that mood and anxiety impact decision-making preferences, such that relatives of patients in the ICU who are more anxious and depressed prefer a more passive decision-making role (Anderson et al., 2009). In the PICU, the emotional state of both the parent and child can hinder shared decision-making (Boland et al., 2019a; Madrigal et al., 2018), which is a well-established component of patient-centered care (Barry & Edgman-Levitan, 2012). Parents have also reported their own emotions to be a barrier to participating in the care of their child undergoing day surgery (Chapados et al., 2002), which is likely heightened in the PICU setting given the higher intensity of care.

Parental distress also impacts long-term outcomes for both the parent and child. Specifically, parent symptoms of ASD during hospitalization predict subsequent development of PTSD (Balluffi et al., 2004a), which is associated with poorer financial (Walker et al., 2003), physical health (D'Andrea et al., 2011; Löwe et al., 2011; Mikuls et al., 2013), and cognitive outcomes (Woon et al., 2017). The child's experience also predisposes them to mental health sequelae such as PTSD (Nelson & Gold, 2012), and previous research suggests that maternal PTSD is correlated with child PTSD nine months after discharge from the PICU (Bronner et al., 2008). Finally, parent mental health also correlates with child health-related quality of life six years after pediatric injury (Sluys et al., 2015). This suggests that mitigating parent distress could improve parent and child mental and physical health outcomes. Therefore, is it critical to find effective ways to support parents through the stressful circumstances in the PICU in hopes of minimizing these negative outcomes for both the child and parents.

Hospitalization serves as an important opportunity for intervention to reduce these adverse outcomes. Notably, the majority of parents report that the PICU hospitalization was the most stressful time of their child's illness or injury (Colville & Pierce, 2012). Additionally, heightened symptoms of ASD and lower resilience during hospitalization have been associated with long-term PTSD, depression, and anxiety (Balluffi et al., 2004a; Rothschild et al., 2020), which suggests that promoting resilience during hospitalization may result in improved outcomes. Parents can also be more easily connected to psychosocial resources (e.g., chaplains, social work, psychology) during hospitalization, given that these supports are often more easily accessed in the hospital setting.

Previous research suggests that increasing psychosocial support during hospitalization can improve psychological outcomes. Specifically, discussing their own feelings during hospitalization has been associated with less posttraumatic stress in parents (Colville & Gracey, 2006). In mothers with preterm infants in the neonatal ICU, trauma-focused cognitive behavioral therapy during hospitalization resulted in decreased PTSD, depression, and anxiety at 6 months after their child's birth relative to parents who received only one informational session (Shaw et al., 2014). Additionally, greater fulfillment of hospital (e.g., provider availability and compassion), family (e.g., babysitting services), and community (e.g., social support) needs is associated with fewer symptoms of depression and increased participation in child's care (Jones et al., 2017). This provides hope that greater fulfilment of these needs and increased early psychosocial support during hospitalization could lead to improved parental psychological outcomes.

The Role of Medical Providers

PICU medical providers are uniquely situated to identify, monitor, and address parent distress given the frequency of their interactions with families. In nearly all PICUs (94%), an attending physician facilitates patient care (Odetola et al., 2005). Many PICUs also include nurses, nurse practitioners, and fellows. However, the most recent reports suggest that the majority of PICUs do not have dedicated psychologists within their unit to provide direct psychological consultation and intervention services (Colville, 2001), making medical providers the front-line for identifying and addressing distress and connecting parents with resources. Furthermore, providing support to parents in the PICU is in-line with pediatric medicine's movement toward family-centered care, which includes providing formal and informal support to patients and families ("Family-Centered Care and the Pediatrician's Role," 2003). Providers have the opportunity to support parents through both their use of formal (e.g., psychologists) and informal (e.g., through daily interactions) psychosocial supports during hospitalization.

However, previous research suggests that there is room for improvement in provider support of distressed parents during hospitalization.

Regarding formal supports, a large discrepancy exists between parent levels of distress during hospitalization (i.e., 25-60%) and referral rates to psychology. Tunick et al. (2013) found that only about 2% of families were referred to pediatric psychology in one PICU, with most referrals originating from social work (34%) and nursing staff (28%), followed by physicians (17%). Furthermore, results indicated that physicians were more likely to make referrals regarding *patient* psychiatric concerns whereas social work and nursing staff were more likely to make referrals related to parent and family psychological needs. While psychological consultation requests have increased over time, requests for services for parents are still relatively rare and focus primarily on adjustment concerns rather than symptoms of anxiety and depression (Piazza-Waggoner et al., 2013). In summary, physicians appear to rarely make referrals for formal psychological services, and when they do, it is more likely to be for patient concerns rather than family concerns.

In addition to connecting parents with formal resources, the daily behavior of medical providers throughout hospitalization likely impacts parent psychological outcomes and therefore serves as another important point of intervention. In fact, parents who felt less accepted by, interpersonally close to, and emotionally supported by physicians demonstrated poorer emotional adjustment (Auerbach et al., 2005). Additionally, when parents felt cared for by medical providers (e.g., asking how they are coping), they felt better prepared to care for their child (Ames et al., 2011). Therefore, promoting provider behaviors that facilitate positive experiences in these domains could improve child and parent outcomes. However, another study found that while parents noted their practical needs (e.g., housing, reduced parking fees) to be well met by providers, they described their own emotional needs to be not fully addressed by the hospital staff during hospitalization (Foster et al., 2017).

It is therefore important to examine potential explanations for these low referral rates and unfulfilled parent needs. It is possible that providers demonstrate difficulty in identifying distressed parents; however, provider conceptualization of parent distress has not been fully evaluated and characterized in the literature. Even if providers accurately identify distressed parents, challenges in responding to parent distress may hinder effective intervention, which has not been thoroughly explored. There may be incongruence between parent reported needs and strategies used by providers to identify and support distressed parents, and/or low provider self-efficacy in supporting distressed parents may hinder effective intervention.

Medical Provider Identification of Parent Distress

It is important to understand how providers identify parent distress and their knowledge of known risk factors because in order to respond to parent distress, they must first recognize it. Previous research lends support to the hypothesis that medical providers may have difficulty identifying which individuals are highly distressed. Specifically, one study of PICU fellows indicates that they generally have moderate recognition of parent anxiety (i.e., 62% accuracy), but they are more likely to rate parent anxiety as high if their child is receiving mechanical ventilation (Needle et al., 2009). Furthermore, oncologists demonstrate low recognition of severe *patient* distress, and their recommendations for supportive counseling have not correlated with patient reported distress but rather progressive disease (Söllner et al., 2001). Tunick et al. (2013) found that PICU *patient* referrals were associated with longer hospitalizations, unanticipated admissions, previously healthy status, and a higher mortality rate. These findings suggest that providers may rely heavily on medical-related cues in their evaluation of distress and allocation of resources, but provider identification of *parent* distress warrants additional exploration.

In addition to evaluating the cues that providers rely on to identify distressed parents, it is also important to examine provider-reported risk factors for and correlates of distress to evaluate how well they correspond to known risk factors. Previous research has evaluated how several experiences during hospitalization relate to distress during and after hospitalization. Pre-existing factors such as having received previous professional psychosocial care and experienced more previous stressful life events (e.g., death of a loved one, divorce) have been associated with PTSD after discharge (Bronner et al., 2010). During hospitalization, decreased social support and living further from the hospital are associated with increased anxiety and depression (Stremler et al., 2017).

Regarding factors related to the child's illness, Balluffi et al. (2004) suggests that perceived severity of child's illness is associated with ASD during hospitalization and predicts long-term PTSD. Objective illness severity, however, has inconsistently been related to distress; while some studies report no correlation with anxiety and ASD during hospitalization and long-term PTSD (Balluffi et al., 2004a; Needle et al., 2009), another reports a positive relationship between objective illness severity and symptoms of PTSD about one month after discharge (Rothschild et al., 2020). Interestingly, previous research suggests that mechanical ventilation is associated with increased anxiety during hospitalization (Needle et al., 2009) but decreased long-term anxiety and posttraumatic stress and increased posttraumatic growth (Colville & Cream, 2009; Rothschild et al., 2020). While mechanical ventilation may signal a more severe illness and result in increased distress initially, once acute life threat has been removed after discharge, the increased support and decreased escalations in care resulting from mechanical ventilation during hospitalization may be protective in the long-term. Longer length of stay has been associated with long-term PTSD (Rees et al., 2004) as well as depression and anxiety (Rothschild et al., 2020). Nonelective and unexpected admissions have been associated with ASD during hospitalization and long-term PTSD (Balluffi et al., 2004; Colville & Pierce, 2012). If providers can identify and intervene on these known correlates and risk factors, parent distress during and after hospitalization could be mitigated or prevented. Therefore, it is important to evaluate the congruence between provider-reported and empirically supported risk factors.

Medical Provider Response to Parent Distress

After identification, incongruence between the strategies used by providers and what parents need and/or low self-efficacy regarding supporting distressed parents may hinder effective responses to parent distress. Several studies have evaluated parent needs and preferences surrounding provider behavior in the PICU. Specifically, parents indicate a strong need for more information (Simeone et al., 2018), with honest, open, timely, and understandable information (Jee et al., 2012). Many parents report that good quality communication from the medical team helps to reduce stress (Diaz-Caneja et al., 2005). In addition to these communication needs, parents desire an active role in the treatment process and a partnership of trust with the medical team such that the medical providers and parents reciprocally rely on each other for their expertise (Ames et al., 2011; Simeone et al., 2018). More change in one's role as a parent is associated with higher anxiety (Lisanti et al., 2017), and parents describe opportunities for participation as helpful in reducing stress (Diaz-Caneja et al., 2005). Parents also describe the importance of access to their child (Harbaugh et al., 2004; Jee et al., 2012), encouragement to get respite, staff presence to answer questions, and reassurance of the normalcy of their child's behavior (Ames et al., 2011).

Previous research focused on parent report indicates many of these needs are inconsistently met by providers. Specifically, many parents feel that these communication needs are poorly addressed during hospitalization, reporting a lack of information and explanations about the child's condition and treatment (Auerbach et al., 2005). Additionally, parents report their active participation needs to be inconsistently fulfilled by providers (Hill et al., 2018). It is possible that providers may use strategies that are not congruent with parents needs and preferences. Notably, the majority of studies focus on parent reported contributors to stress and fulfilment of needs; however, minimal research has focused on provider awareness of the importance of these domains. Overall, parents report several needs related to provider behavior during hospitalization, and in many cases, there remains room for improvement.

Low provider self-efficacy in supporting distressed parents may also hinder provider support of distressed parents. In this context, self-efficacy describes a provider's belief in his or her capacity to execute the behaviors necessary to support distressed parents. Bandura's theory of self-efficacy outlines three key components of an individual's perception of their own self-efficacy: perceived importance, outcome expectancy, and efficacy expectation (Bandura, 1977). Perceived importance describes the evaluation of the importance of their own ability to achieve the desired goal (i.e., reduce parent distress). The outcome expectancy describes an individual's belief that a given behavior will lead to the expected outcome. The efficacy expectation describes an individual's belief in their ability to perform the target behavior. These components determine whether or not the individual will engage in the target behavior. Deficits in any of these domains would undermine their likelihood of intervening.

Components of Bandura's theory have been informally incorporated in studies of medical provider use of psychological resources, but this literature has largely focused on outpatient primary care providers' (PCPs) use of formal psychological services. Previous research suggests PCPs perceive provider confidence to be a barrier to arranging behavioral health services for their patients (Beacham et al., 2012). A lack of provider confidence may undermine the provider's efficacy expectations and therefore impede their willingness to intervene. Furthermore, previous research suggests PCPs may not perceive behavioral health services to be helpful (Green et al., 2017), which could undermine their outcome expectancy and ultimately dissuade their use of these services. Previous research with PCPs suggests that increased training and education is associated with increased likelihood of collaboration with mental health providers (Green et al., 2017) and that this type of training is generally well-received by PCPs (Beers et al., 2017). While some elements pertaining to Bandura's theory of self-efficacy have been noted in previous studies with PCPs, the theory has not been holistically applied to medical providers nor explored within PICU providers specifically. Given the distinct characteristics of the PICU setting, including life-threatening conditions, absence of pre-existing relationships with patients, and lack of integrated psychologists, it is important to evaluate PICU provider self-efficacy and receptivity to training as it likely differs from that of PCPs.

The Present Study

Parents of children admitted to the PICU are at heightened risk for experiencing distress during hospitalization, which affects their ability to care for their child and predicts long-term adverse psychological outcomes for parents and children. Medical providers are uniquely situated to provide additional informal and formal support to prevent and mitigate distress. However, very little is known about how PICU medical providers identify and respond to parent distress during hospitalization. The present mixed-methods study utilized semi-structured qualitative interviews to better understand this. Knowledge gained from this study will aid in the development of interventions targeting areas for additional support as identified by PICU medical providers.

First, the present study aimed to characterize provider perceptions and identification of parent distress during their child's PICU hospitalization. Given previous research indicating that provider ratings of parent anxiety were correlated with mechanical ventilation, it was hypothesized that providers would frequently describe relying on medical cues, such as illness severity, to identify parent distress. Second, the present study aimed to evaluate provider response to parent distress in the PICU. Given that previous literature suggests parent needs during PICU hospitalization are inconsistently met, it was hypothesized that there would be moderate congruence between provider reported strategies to support distressed parents and parent reported needs. Further, it was hypothesized that providers would describe deficiencies more frequently than proficiencies in their self-efficacy, in terms of perceived importance, outcome expectancy, and efficacy expectation in supporting distressed parents. Finally, the present study sought to evaluate provider decision-making surrounding the use of external psychosocial supports (e.g., psychology and palliative care). Given that provider counseling referrals for patients were correlated with progressive disease, it was hypothesized that providers would frequently describe using external resources when medical prognosis is more severe.

Method

Participants

All critical care nurse practitioners (NPs), medical fellows, and attending physicians from the PICU at Children's Wisconsin (CW) were invited to participate in the present study. Thirty-seven critical care providers (78% female, 73% White) participated, with >80% participation from each group. See Table 1 for full demographic information. Eligible members of the present study’s research team were excluded. CW’s PICU is a 72-bed facility with three floors including cardiac, surgical, and medical ICU subunits and has approximately 2,000 admissions a year. Notably, this PICU currently uses a consultation and liaison model of incorporating psychology rather than having an integrated psychology program with dedicated psychologists. This PICU also has social workers, child life specialists, and chaplains available for psychosocial support.

Participants were not compensated for their participation and had the opportunity to participate during their scheduled work hours. They were informed that the goal of the study was to improve training and education for PICU medical providers as well as improve care for PICU families.

Procedure

The procedure for participant recruitment and data collection was approved by CW’s Institutional Review Board (IRB). An initial recruitment announcement was shared by email from the research team’s PICU medical providers. Participants were then recruited and scheduled via calendar invitation or email.

Study visits were conducted in a private room at CW for the convenience of the participants, or remotely via Teams video conferencing due to COVID-19 restrictions. Participants completed verbal informed consent, assuring them of the voluntary and confidential nature of the study. They then completed a brief demographic questionnaire. Next, participants completed a one-on-one semi-structured qualitative interview lasting approximately 45 minutes conducted by one of three trained graduate students. Throughout the interview, participants completed quantitative ratings of selected questions in real-time and subsequently explained their responses qualitatively. They then completed the Self-Efficacy questionnaire. Questionnaire and quantitative data were completed on an iPad for in-person appointments or via Qualtrics for virtual appointments.

Interviews were audio-recorded, de-identified, and subsequently transcribed. Approximately half of interviews were transcribed using TranscribeMe, an independent transcription company. Due to funding constraints due to COVID-19, the remaining interviews were transcribed using a three-step process: 1) initial automated transcription via Microsoft Word Dictation and 2) verification of the accuracy of transcriptions by a critical care administrative assistant or undergraduate research assistant, 3) two-thirds of transcriptions were reviewed by a second reviewer to ensure accuracy. Transcripts were then be transferred to QSR NVivo Software (NVivo, 2018), a qualitative software package, for thematic analysis. NVivo functions as a tool that facilitates the coding process detailed below.

In order to ensure interview quality, all interviewers worked under the supervision of the research team's qualitative research methods expert, Dr. W. Hobart Davies, and met with Dr. Davies weekly throughout data collection. Additionally, Dr. Davies reviewed a random selection of 20% of audio-recordings for each interviewer throughout data collection and provided feedback.

Measures

Demographics. Demographic questions collected background information, such as participant gender, race, ethnicity, profession, medical specialty, and years of experience.

Qualitative Interview. A semi-structured qualitative interview (See Table 2) was developed by the study's research team who have expertise in critical care, pediatric psychology, and qualitative research methods. The questions were developed specifically for the purposes of the current study and align with Bandura's theory of self-efficacy. After the scope of the project was defined (i.e., how PICU providers identify and respond to parent distress) in discussions as a full research team, four graduate students in clinical psychology generated 4-5 qualitative questions in four domains: recognition, attributions, action, and knowledge (i.e., awareness of resources). These initial questions were discussed as a small group with Dr. W. Hobart Davies' supervision and contribution. The number of questions was reduced, and the domains were redefined as the final areas of focus in the present study: 1) identification of parent distress, 2) response to parent distress, and 3) use of external resources. The initial interview guide was then circulated to the full research team and discussed in meetings. The interview guide was revised for clarity, relevance, and reduction of redundancy.

Three former PICU medical providers who do not meet inclusion criteria for the proposed study completed pilot and cognitive interviews. Feedback regarding participant burden and comprehension was requested from the providers during the cognitive interviews. The providers indicated that the length of the study was reasonable and that the semi-structured qualitative interview questions were relevant and well understood. Interviewers reported that the interview appeared to provoke rich, detailed narratives. The qualitative interview guide was adapted based on these pilot interviews in consultation with the research team, with changes such as adding transitional statements and changing the order of questions to address the natural flow of topics.

In addition to the qualitative questions, quantitative ratings of six selected qualitative interview questions regarding self-efficacy and interest in additional training were completed within the interview using a 4- or 5-point Likert scale.

Self-Efficacy Questionnaire. A measure was developed by the research team to evaluate provider self-efficacy in engaging in eight behaviors that previous literature (e.g., Geoghegan et al., 2016; Richards et al., 2017) indicated are helpful in reducing parent distress during hospitalization (See Table 3).

Data Analytic Plan

Initial Review of Transcripts. Given the conversational nature of interviews and since each question was coded separately, two graduate students first independently reviewed transcripts to relocate relevant answers provided outside of the target question to the corresponding question for coding purposes. Any discordance was discussed to consensus.

Coding of Qualitative Responses. Thematic analysis of the transcripts was conducted using the Delphi coding method (Holey et al., 2007) to describe recurrent themes discussed by participants related to each research question separately. Coding teams at the University of Wisconsin-Milwaukee consisting of 4-6 undergraduate and graduate students, with previous experience coding qualitative data using this method, conducted the coding. Once data collection has been completed, coders were blind to participant identity and carefully reviewed responses to each question to independently create a list of recurrent themes. There were no a priori number of categories. Then, the study team collectively established a list of categories with operational definitions specific to each question. Coders independently coded each response for the presence or absence of each category. Independent codes were compiled and compared across study team members. Responses that were below 75% agreement for each category were discussed as a group to reach 75% agreement.

This coding method was selected over interpretative phenomenological analysis (IPA) given that the interview questions were designed to elicit discrete answers within questions rather than relying on broad general questions to promote emergent themes across questions as is characteristic of IPA. The Delphi coding method produces discrete quantifiable data.

Quantitative Analysis. The frequency with which each theme was reported by the participants was calculated and evaluated in NVivo. Descriptive statistics were used to evaluate the frequencies of the ordinal data for quantitative questions using IBM SPSS Statistics Version 26. Given that quantitative questions were independent and were not compiled to compute any total scores, any missing data was excluded from the data analyses.

Statement of Positionality

Through explicitly examining our assumptions, worldviews, and positionality relative to the participants, we increased awareness of their potential impact on the research process (Hampton & Reeping, 2019). Qualitative interviews were conducted by three graduate students in clinical psychology with interests and experiences in pediatric psychology. While our student status, discipline, and personal research interests were not formally disclosed to participants, the study's focus on family distress in the PICU and our assumptions about medical settings (e.g., PICU is stressful) may have biased interviews. To minimize bias, we explicitly examined and discussed our positionality, utilized multiple coders, and during interviews, we sought to directly reflect participant's responses and only prompt for additional information or clarification. Furthermore, the first author (K.B.) is a white, cisgender female clinical psychology graduate student, not a medical provider, and lacks lived and clinical experience in the PICU. She holds the belief that pediatric psychology can play an important role in supporting distressed parents in the PICU. Finally, the research team is predominantly White, which significantly limits the diversity of perspectives incorporated into the development, implementation, and dissemination of the present study.

Results

Aim 1: Identification of Distress

Distress Prevalence (*N*=37). On average, participants estimated that 25% (*SD*=21, *Mdn*=43%) of parents present with a level of distress above the normal levels they experience in their day-to-day practice.

Cues (*N*=37). Participants described a variety of cues for identifying distressed parents: *Nonverbal, Emotional, Disengagement, Voice, Direct, Confusion, Distrust, Questions, Selfcare, Others' Perceptions,* and *Other.* See Table 4 for illustrative quotes.

Most commonly (84%), participants perceived *Nonverbal* cues, including body language (e.g., biting nails) and facial expressions (e.g., lack of eye contact), as indicators of parent distress. Many providers (46%) specifically noted *Crying* or tearfulness as nonverbal cues of distress. Most providers (81%) also described *Emotional* cues, including *Anger* (65%; displays of anger or frustration), *Sadness* (22%; feeling down or sad), *Dysregulation* (19%; difficulty regulating emotions), and *Anxiety* (14%; anxiety, nervousness, and worry).

About two-thirds (68%) of providers described *Disengagement* as an indicator of distress, defined as mentally or emotionally withdrawing or disengaging; this may include minimal to no talking or asking questions, being physically absent from the hospital, and/or minimal participation in the care or interactions with the medical providers.

About half (49%) of participants described cues related to the parent's *Voice* (i.e., tone, loudness, and pace of speaking voice), such as yelling. Approximately one-quarter to one-third of participants described cues including *Direct* (35%, parent directly verbalizes they are distressed), *Confusion* (30%; confusion or difficulty understanding medical information), *Distrust* (27%; questioning, doubting, or opposing the medical team and/or their decisions and care), and *Questions* (25%; how questions are asked and/or phrased, including high intensity or frequency of questions). Finally, 16% described *Selfcare* cues (i.e., neglect of own needs such as sleep, physical appearance) and 11% relied on *Other's Perceptions* (e.g., other team members, nurses) to provide insight about the level of distress.

Risk Factors/Correlates. Participants identified a range of contributors to parent distress: *Medical Factors* (*Admission Type, Illness Severity*), *External Factors*, *Medical Understanding*, *Internal Factors, Psychosocial Support, Communication, Cultural Factors, PICU Environment, Language,* and *Other.* See Table 5 for illustrative quotes.

Most participants (76%) identified *Medical Factors* as the primary contributor to parent distress, which included *Admission Type* (54%) and *Illness Severity* (54%). *Admission Type* incudes type of or reason for admission. Many providers described different experiences between parents with chronically ill children as compared to parents with a previously healthy child admitted to the PICU for the first time; they often noted differences due to unexpected nature and lack of familiarity with the PICU for previously healthy children. Regarding *Illness Severity*, these participants described the contributions of the severity or type of illness/diagnosis (e.g., rate of progression) and acuity of the condition.

Many participants (65%) recognized the contributions of *External Factors*, such as daily life responsibilities (e.g., other children, finances, work) and the stressors of being at the hospital (e.g., transportation, housing). About half (54%) noted *Medical Understanding* to be a contributor to distress; they described difficulty understanding and comprehending medical information and lack of familiarity with medical terminology, procedures, and the health care system. Relatedly, 32% noted that *Communication* (i.e., provider style of quality of communication and explanations, lack of keeping the family up to date) can contribute to distress. About half (46%) of participants described *Internal Factors* related to the parent's coping style and ability, pre-existing mental health conditions, feelings of guilt or lack of control, and/or distrust of the healthcare providers. Additionally, 38% described that lack of *Psychosocial Support* (e.g., interpersonal relationships) or the impact of hospitalization on social relationships can contribute to distress.

Fewer participants noted the impact of *Cultural Factors* (14%; cultural beliefs, race and ethnicity), the *PICU environment* (14%; noise, beeping machines, many people in the room), and *Language* (8%; language barriers, requiring interpretive services) on distress.

Aim 2: Response to Distress

Perceived importance. The large majority (81%) of participants reported that it is *Very* important that they are able to support distressed families (See Figure 2). When asked to explain their response, participants (*N*=35) primarily described *Child Care* (40%) and *Role* (37%) as reasons for the importance. *Child Care* included a belief that providing support to parents will aid in the medical care and outcomes of the child, with 11% explicitly mentioning the importance of supporting parents through decision-making processes or in building rapport. *Role* consisted of responses noting that supporting distressed families is part of their job as a provider; they may see themselves as the frontline person responsible for this given their frequent interactions, and/or they may view the model of care as providing care for the whole family. *Medical Responsibilities* (23%) taking precedence over addressing parent distress in some situations was also described when addressing the importance of supporting distressed parents. See Table 6 for additional, less frequent (<17%) themes and illustrative quotes.

Strategies & Outcome Expectancy. Providers used a variety of strategies to support distressed families: *Listen, Explain Medical Information, Assess Needs, Use Resources, Nonverbals, Validate, Reassure, Social Support,* and *Other*. See Table 7 for illustrative quotes. Many participants (65%) described *Listening* (i.e., being present and available to be engaged and listen to the family talk and express concerns), *Explaining Medical Information* (i.e., explaining medical information to improve medical understanding, communicating clearly), and *Assessing Needs* (i.e., assess needs or reasons for distress, evaluate and ask about family needs and wants). About half (54%) described *Using Resources,* defined as relying on other resources (e.g., nurses, psychology) and facilitating those connections. One-third of participant described using *Nonverbal* strategies, including use of nonverbal communication and body language (e.g., adjust physical level, hugging) and/or changing the physical setting (e.g., room, location).

Fewer participants (14%) described *Validation* (i.e., acknowledging that their emotions and experiences are valid, normalizing their experience) and *Reassuring* the family that they are doing everything they can and that the child's health is what is most important to them. Finally, 8% of participants described encouraging *Social Support* from family, friends, or community.

Most providers (76%) felt these strategies were *Moderately* helpful in reducing parent distress (See Figure 2).

Efficacy Expectations. Most providers (84%) were *Moderately* confident in their ability to support distressed parents (See Figure 2). Participants described similar reasons for their perceptions of helpfulness and confidence: *Ability* (80%), *Control* (69%), and *Feedback* (37%). See Table 8 for illustrative quotes. Regarding *Ability*, 57% of participants described that there is *Room for Improvement* in their ability to support distressed parents, such that they note limited capabilities, resources, or experience and that there is room for improvement in these abilities. About half (51%) of participants expressed that they do feel *Skilled* in their abilities and skills in supporting distressed parents.

Regarding perceptions of *Control*, 60% of participants noted that there are *Uncontrollable Factors* that they cannot fully address to reduce all distress, including external factors (e.g., non-medical) and stress due to the stressful and/or high intensity nature of the PICU environment. On the other hand, 34% of providers noted that there are *Controllable Factors* that they can address within the PICU environment (e.g., sitting down, communicating clearly). Finally, regarding *Feedback*, 37% expressed *Uncertainty* about the helpfulness of strategies due to difficulty interpreting family cues and/or lack of feedback. Contrarily, 29% expressed that their strategies were helpful because they have received *Positive Feedback* directly (i.e., verbal praise) or indirectly (i.e., cues, body language) from families or other hospital staff.

Almost all providers reported that it is *Moderately* (65%) to *Very* (30%) feasible to support parents during a hospital stay (See Figure 2). Regarding barriers to supporting distressed parents, almost all participants (81%) described *Provider Time*, defined as provider availability, time, and workflow (e.g., obligations to other patients) and the PICU census and acuity. Participants less commonly (<33%) endorsed other barriers (e.g., Resources, Disengagement, Lack of Control). See Table 9 for additional themes and illustrative quotes.

Training. Most participants were *Moderately* (41%) to *Very* (49%) interested in receiving more training about how to support distressed families (See Figure 2).

Self-Efficacy Questionnaire. Participants reported variable confidence and importance of the eight behaviors listed in the self-efficacy questionnaire (see Figures 3 and 4). Participants rated partnering with the family, referring to behavioral health services, recommending time away, and coordinating care as less important than the remaining items (49-54% rated as *Very* important). They rated ensuring understanding, individualizing communication, asking about emotional well-being, and evaluating and fulfilling needs as more important (68-89% rated as *Very* important). Of these behaviors rated as more important, they primarily reported *Moderate* confidence (54-62%) with 3-35% reporting *Very* confident. Notably, participants demonstrated the least confidence in evaluating and fulfilling needs.

Aim 3: Use of External Resources

Responsibility. When asked about who role it is to directly work with the family to manage their distress between inpatient medical providers and psychosocial providers (*N*=37), most participants (81%) viewed it as *Equally* the role of medical team and psychosocial providers (See Figure 5). When asked to expand upon this, participants primarily recognized the *Expertise* (40%) psychosocial providers offer related to psychosocial support, that they can help with *Logistical* (23%) needs (e.g., childcare), and that they have more *Time* (20%) to focus on distress. Participants cited the reasons for involving medical providers in addressing distress including that they can provide the *Medical Information* (69%), that they are the *Frontline* (40%) for identifying and supporting distressed parents, and that their frequent *Presence* (34%) with parents allows them to support them. See Table 10 for illustrative quotes.

When asked about whose role it is to directly work with families to manage their distress between long-term care teams and the PICU medical providers (*N*=36), 56% of participants reported that it was *Somewhat More the Long-Term Care Teams'* role, and 39% reported that it was *Equally* both team's role (See Figure 5).

Use of Psychologists. Participants (*N*=37) reported that when they perceive a parent to be distressed, they involved psychology about 42% of the time on average (*SD*=31%, *Mdn*=50%). Participants considered a variety of factors when deciding whether or not to ensure psychology in involved for patients or families: *Distress Level, Family Openness, Medical Factors (Illness/Injury, Length of Stay), Provider Prompt, Family Prompt, Provider Ability, Mental Health History, Social Support, Psychology Workload,* and *Other.* Notably, 8% did not describe any factors because they never or always involve psychology. See Table 11 for illustrative quotes.

Many providers (60%) described relying on the parent's *Distress Level* (i.e., severity of symptoms of distress, including unexpected reactions) and impact of distress on the parent, child (including medical care), and/or family functioning, including behaviors that are potentially harmful to themselves or their families. About half of participants reported that they consider the family's *Openness* and/or willingness to meeting with psychology. Some providers (46%) described considering *Medical Factors,* with 41% describing *Illness/Injury* factors such as the type of injury/illness (e.g., trauma, cancer), chronicity of the condition/illness, prognosis and severity of illness/injury, and 16% considered *Length of Stay* (LOS) of the hospitalization, with most suggesting they are less likely to involve psychology for shorter LOS. Participants (38%) also described relying on *Provider Prompts* from other care providers (e.g., nurse, psychology, social work) who prompt or suggest involving psychology. Thirty percent relied on *Parent Prompts,* where the family expresses interest or asks directly about involving psychology. Participants (30%) described *Provider Ability*, involving psychology once they feel the family's need exceed their ability to help them (e.g., family continues to be distressed after provider attempts to support them). Fewer providers considered family's past *Mental Health History* (22%; history of mental health concerns and/or previous involvement with psychological treatment), *Social Support* (11%; the family's level of social support), and *Psychology's Workload* (8%; access to psychology, unsure of psychology's ability to see more clients).

Discussion

Summary of Findings & Relation to the Literature

The present study evaluated PICU medical provider perspectives on identifying and addressing parent distress in the PICU in order to reduce the high prevalence of anxiety, depression, and traumatic stress experienced by parents with a child in the PICU (Yagiela et al., 2019). Regarding identification of distressed parents, results suggest that providers recognize that a substantial portion of parents experience distress in the PICU, with providers reporting an average of 25% of parents experiencing higher than typical levels of distress compared to the 26-60% of parents described in the literature (Yagiela et al., 2019). Providers described utilizing a variety of cues to identify distressed parents, primarily relying on nonverbal (e.g., crying), emotional (e.g., anger), disengagement, and voice cues. Participants also identified a variety of risk factors and correlates of distress, primarily describing medical factors (e.g., illness severity, admission type), external factors (e.g., finances), poor medical understanding and communication, internal factors (e.g., lack of control, previous mental health conditions), and lack of psychosocial support.

These reported contributors are consistent with previous research that suggests perceived severity of illness, admission type, home-life balance, communication, helplessness, previous mental health conditions, and lack of social support contribute to distress (Abela et al., 2020; Yagiela et al., 2019). However, providers did not express awareness that parents' subjective assessments of medical severity is more closely associated with distress than objective medical severity (Yagiela et al., 2019). Furthermore, only a few providers recognized the contributions of the general PICU environment and witnessing their child undergo medical procedures (Abela et al., 2020).

Regarding provider responses to parent distress, providers described the use of a variety of strategies and reported moderate self-efficacy. First, providers perceived supporting distressed parents as their role and as a very important part of their job. They recognized that parent distress can impact the patient's medical care (Boland et al., 2019b; Chapados et al., 2002; Madrigal et al., 2018) and cited this as a critical reason for the importance of being able to support distressed parents. Therefore, perceived importance is not a barrier for PICU medical providers in supporting distressed parents in the PICU.

Regarding strategies used, providers primarily reported that they listen, explain medical information, assess parent needs, and rely on external resources (e.g., psychologists). These strategies aligned with many parent reported needs from the literature, including the desire for providers to listen to them, answer questions, and address their concerns (Richards et al., 2017) and the need to be well informed (Abela et al., 2020). However, providers did not note use of some strategies reported by parents to be important, such as promoting active participation in their child's care as a partnership (Ames et al., 2011; Simeone et al., 2018). Therefore, providers may not be aware of or recognize the importance of this behavior for parents. In fact, partnering with the family was rated lower in importance than other strategies on the self-efficacy questionnaire.

While providers emphasized the importance of good communication to reduce parent distress (e.g., individualizing communication, ensuring understanding), they appeared only moderately confident in executing these strategies, which may align with parents' reports that these needs are not fully addressed (Auerbach et al., 2005). While providers endorsed assessing parents needs as a frequent and important strategy, they also reported variable confidence in evaluating parent emotional well-being and coordinating efforts to fulfill those needs. It is possible that providers may have some discomfort regarding assessing emotional well-being. Providers reported that lack of training in supporting distressed parents was a barrier and expressed interest in receiving more training, and they recognized the limits of their psychosocial skills by reporting that there is room for improvement. Providers did express feeling a lack of control over some aspects of parent distress, including external factors and that parents will always have at least some distress due to having a child in the PICU. Furthermore, they noted that they lack feedback on their performance in supporting distressed families, creating uncertainty over the efficacy of their strategies. There may be room to improve provider's outcome expectancies and efficacy expectations. In addition to these barriers related to self-efficacy, providers described *time* to be the primary barrier to supporting distressed parents, consistent with previous research (Bartel et al., 2000).

Overall, providers most commonly reported moderate self-efficacy with few participants endorsing high or low self-efficacy; moderate self-efficacy is likely the optimal amount of self-efficacy to promote interest and performance in responding to distressed parents in the PICU. Bandura (1997) suggests that at least a moderate amount of self-efficacy is necessary to sustain interest in an activity and that high self-efficacy can actually decrease interest in engaging in an activity, which has been supported empirically (Silvia, 2003). Research suggests high self-efficacy may also reduce feedback seeking (Sherf & Morrison, 2019). Therefore, most PICU providers likely demonstrate an optimal level of self-efficacy in supporting distressed parents such that most perceived themselves as moderately confident in their abilities and that their strategies are moderately helpful in reducing distress but many also described room for improvement in these domains.

Regarding use of external resources, providers appeared to see these resources as key in supporting distressed parents, with many reporting use of external resources as a strategy for supporting distressed parents. Most providers viewed supporting distressed parents as a shared responsibility with psychosocial providers, reiterating that providers view this as a very important part of their role and that they value the contributions of psychosocial providers. Providers primarily see their role as providing the medical information; their rationales for their involvement also included that they are the frontline providers and frequently interact with families throughout their stay. They reported that psychosocial providers offer expertise that medical providers lack and assist in addressing logistical needs (e.g., transportation). Providers also reported that when a long-term care team is involved, they perceived the long-term care team to hold more responsibility for directly addressing parent distress than the PICU medical providers.

Despite perceived importance of psychosocial resources, providers may be underutilizing psychology as a support for distressed parents in the PICU. On average, they reported that they ensured psychology was involved about 41% of the time when they perceive a family to be distressed. They primarily considered the following when deciding whether or not to ensure psychology was involved: the severity and impact of the distress, parent openness, medical factors (e.g., illness/injury type, length of stay), prompting from other providers or the parent themselves, and when they perceive parent's needs to exceed their ability to support them themselves. The emphasis on medical factors is consistent with previous research indicating that PICU patient referrals to psychology were associated with longer hospitalizations, admission types, and higher mortality expectations (Tunick et al., 2013a). These results suggest that perceived importance does not appear to be a barrier to involving psychology; therefore, there must be other barriers to involving psychology more frequently. Some providers did note that resource availability (e.g., time of day, weekends) is a barrier to supporting distressed parents. It is possible that providers may rely more heavily on social work or other psychosocial resources first, who may be more likely to ultimately refer to psychology (Tunick et al., 2013a). Furthermore, if providers rely on other providers to prompt involvement of psychology, there may be a diffusion of responsibility.

Clinical Implications

Reducing parental distress during PICU stays has the potential to enhance parent and family well-being, reduce the likelihood of long-term emotional distress (Balluffi et al., 2004b), and even improve medical outcomes (Sluys et al., 2015). These findings have important clinical implications for improving PICU medical providers' abilities to identify and support distressed parents and to increase use of psychosocial resources. Given the substantial barrier of medical provider's limited time, interventions should focus on aiding provider identification of parents at-risk for distress, improving the way in which providers conduct their medical responsibilities (e.g., communication), and increasing use of psychosocial supports (e.g., psychologists) rather than relying on providers to implement psychological interventions. Given that participants reported that they are interested in receiving more training about how to support distressed parents, many expressed that there is room for improvement in their abilities, and participants did demonstrate lack of awareness of some important areas of parent distress, providers may benefit from additional training on identifying and responding to distressed parents. These interventions should include both psychoeducation about parent distress in the PICU and skill building exercises. These types of trainings with PCPs have been successful in increasing collaboration with mental health providers (Green et al., 2017).

Psychoeducation and use of screening tools could likely improve identification of distressed parents. Regarding psychoeducation, it may be helpful to share information about the prevalence of distressed parents to ensure awareness of the prevalence of the problem. It would also be helpful to ensure that all providers are aware of known risk factors and correlates, with an emphasis on risk factors and correlates not described by providers in this study (e.g., PICU sights and sounds, witnessing medical procedures). It would be helpful to provide information about the current status of research on perceived and objective severity and distress. Specifically, providing information that objective indicators inconsistently relate to distress, whereas subjective severity consistently relates to distress (Yagiela et al., 2019); therefore, providers should be encouraged to rely on factors found to consistently relate to distress and avoid relying primarily on objective medical factors. Research suggests that parents may be overly pessimistic in their perceptions of illness severity; for example, studies have found that 26-46% of parents worry that their child might die (Balluffi et al., 2004a; Rodríguez-Rey et al., 2018b), compared to the 2% mortality rate (*Virtual Pediatric System, LLC*, 2020). Therefore, providers should evaluate parent's perceptions of the severity of illness and correct any overly pessimistic beliefs. Additionally, providers did not describe use of some strategies reported by parents to be important (e.g., encouraging active participation, partnering with the family); therefore, it is important to provide psychoeducation that parents have reported these behaviors to be helpful.

Use of brief screening tools may also be helpful in identifying parents most as risk to provide additional support and/or refer to psychology, especially given the number of medical decisions ICU providers must already make independent of identifying distressed parents and determining how to respond. Specifically, intensivists make over 100 critical care decisions daily (McKenzie et al., 2015). Therefore, brief screenings may remove additional burden from providers on identifying and referring distressed families, reduce human bias in identification and referrals, and improve outcomes for families. Previous research has found that the Posttraumatic Adjustment Scale and Distress Thermometer have been effective in identifying families at risk for long-term distress (Liaw et al., 2019; Samuel et al., 2015). Furthermore, Liaw et al. (2019) found that using screening tools increased patient satisfaction with emotional support and decreased the number of calls to security for distressed families by 50%.

Interventions focused on skill building related to working with families in the PICU and responding to distressed parents may also be beneficial. Specifically, while providers endorsed that providing medical information and communication were frequent and important strategies, they demonstrated variable confidence in ensuring the family understands the information they provide and individualizing communication. Although many expressed that assessing parent needs and listening to parents were frequent and important strategies, they also demonstrated variable confidence in their ability to assess parent's psychosocial needs and coordinate efforts to fulfill them as well as asking them about their emotional well-being and listening to their concerns. Simulation sessions and role-play may be helpful to increase parent engagement in discussion, improve provider expression of empathy, limit use of technical jargon, and improve parent satisfaction with provider communication (see Kodjebacheva et al., 2016 for systematic review of child-parent-medical provider communication interventions).

Interventions should focus on addressing reported barriers to efficacy expectations and outcome expectancy by providing strategies to reduce feelings of lack of control and decreasing uncertainty over their helpfulness. Providers reported lack of control over external factors (e.g., parents having other sick family members) contributing to distress. When providers experience these feelings of helplessness related to external stressors, it may be most helpful to refer families to social work and/or psychology to develop coping strategies and/or address external stressors. Social work may be able to help problem-solve any external stressors than can be addressed. When stressors cannot be changed, acceptance-based strategies, cognitive reframing, and relaxation training can be facilitated by psychologists to reduce feelings of stress (Doupnik et al., 2017).

Many providers also expressed that it is not possible to reduce all of parent distress given the stressful nature of the PICU; these perceptions align with Integrative (Trajectory) Model of Pediatric Medical Traumatic Stress (Price et al., 2016), such that almost all parents will demonstrate a normative increase in distress during hospitalization. Therefore, it may be useful to share this model with providers and validate that almost all families will have some level of distress that may not decrease until after hospitalization. However, experiences during hospitalization can contribute to whether they go onto the resilient, recovery, chronic, or escalating trajectories. This information would validate provider's concern but also may increase their feelings of agency over improving long-term outcomes of families.

Providers also reported that lack of direct and indirect feedback results in uncertainty over the utility of their strategies. To address this, the discussed training programs should incorporate individualized feedback. Feedback from colleagues regarding communication and psychosocial skills should also be encouraged throughout clinical work. Research suggests that regular multidisciplinary work shift evaluations in which staff discuss how the work day went have improved communication and decreased emotional exhaustion (Sluiter et al., 2005). Incorporating a focus on discussing support of distressed parents into this model may be helpful in providing more formal feedback to providers about their abilities and reducing uncertainty.

Interventions should also focus on increasing use of psychosocial resources given that providers valued the expertise of psychology and viewed supporting distressed parents as a shared responsibility with psychosocial providers but appeared to underutilize psychologists. Many providers reported that they rely on parent openness or parent prompting to involve psychology. While it is certainly important to respect parent's autonomy to refuse involvement of psychologists, it may be helpful to provide parents with brief psychoeducation about the importance of addressing their mental health concerns during hospitalization given that they may be hesitant to focus on themselves while their child is critically ill. Providers should share information about the importance of addressing their own mental health in order to provide the best care to their child and to improve parent and child physical and psychological outcomes after hospitalization (Bronner et al., 2008; Chapados et al., 2002; Madrigal et al., 2018). Furthermore, providers should certainly support parents when they ask for psychological services themselves, but it is important to also offer psychological support because parents may not be aware of resources available, there may be stigma, and they may not see focusing on themselves as important during this time. Additionally, many providers described use of other provider's perceptions to prompt use; in this case, it would be important to have a clear expectation of responsibility to avoid diffusion of responsibility such that each provider believes another provider will refer the parents to psychology. Finally, providers reported relying on medical factors to decide whether or not to ensure psychology is involved; again, providers are encouraged to evaluate subjective perception of illness severity and rely more heavily on this factor rather than relying primarily on objective medical factors.

Furthermore, integrated psychology models have been increasing in the children's hospital setting, such that clinics (e.g., hematology/oncology, gastroenterology) have an embedded, dedicated psychologist to work with their patients and families (Kazak & Noll, 2015; Moser et al., 2014; Samsel et al., 2017). This model would allow for an increased presence of psychology in the PICU to address concerns quickly and frequently, which would be beneficial given that about 50% of patients are discharged after two days (Sands et al., 2009). This model would allow providers to rely on psychologist colleagues to also possess some of the medical expertise necessary to provide further explanations as needed. This would reduce the need for parents to leave the PICU floor, which many report to be a major stressor (Jee et al., 2012) and may increase openness to focusing on their own mental well-being.

Providers suggested that long-term medical teams (e.g., specialty clinics) may hold more responsibility for supporting distressed parents in the PICU. This may be due to long-term care providers having pre-existing relationships and rapport with parents, more psychosocial training, and/or more time. For example, pediatric palliative care (PPC) providers have increased skills and time for family support (Mercadante et al., 2018). Research suggests that PPC improves health-related quality of life, emotional well-being, and family communication and satisfaction as well as reduces child and family anxiety (Hancock et al., 2018; Hays et al., 2006; Weaver et al., 2018). Given these physical and psychological benefits, improving integration of pediatric palliative care in the PICU may also improve psychological outcomes for parents. Three models for integrating pediatric palliative care into the PICU should be considered, ranging from promoting core PPC competencies in all PICU providers to utilizing PPC providers as consultants, depending on the institution's infrastructure (e.g., available resources) (Morrison et al., 2018). When aiming to increase use of PPC, it is important to be aware of and address several barriers to use of PPC, including myths and misconceptions about PPC (e.g., PPC is too expensive, PPC is only for end-of-life) (Friedrichsdorf & Bruera, 2018; Liben et al., 2008). PPC educational programs have been found to improve PICU nurses' knowledge of and attitudes toward PPC (Haut et al., 2012) and are likely important to integrate into provider trainings regarding support of distressed parents.

In considering clinical implications related to improving communication and support of distressed parents in the PICU, it is important to note that PICU parents from minoritized races and ethnicities report worse experiences than white parents. For example, of parents with a child in the PICU, parents from minoritized races are more likely than white parents to experience instances when they felt doctors did not listen to them and are more likely to experience or observe discrimination in healthcare (DeLemos et al., 2010) and are less likely to report that their bedside nurses spent enough time speaking with them and less likely to receive communication from the medical team in their preferred setting (Zurca et al., 2020). Therefore, interventions should promote awareness of disparities in quality of care for minoritized parents and utilize a framework of cultural sensitivity and humility to address them. Use of simulation (Ndiwane et al., 2017) and reflexive journaling (Hughes et al., 2020) interventions may be helpful.

Limitations & Future Directions

While this study advances our understanding of providers' experiences working with distressed patients and families, there are important limitations to acknowledge and to address in future research. First, only NP, fellow, and attending physician perspectives were represented. While this perspective is invaluable given the amount of time providers spend with families, it is also important to directly assess patient and family perspectives on how they would like providers to respond and any barriers in involving psychology, as this may differ from provider perspectives. It would also be useful to evaluate other PICU providers' perceptions about identifying and supporting distressed parents given different responsibilities and experiences. For example, bedside nurses interact with families more frequently (Butler et al., 2018) and are more likely to refer parents to psychologists (Tunick et al., 2013a). It is particularly important to evaluate these perspectives given that many participants reported utilizing prompts from other providers to ensure psychology is involved; this will allow for a better understanding of perceptions of role and responsibility in supporting distressed parents.

While the present study provided rich descriptions of patient, family, and provider experiences using qualitative interviews, quantitative data evaluating this topic is needed to address limitations of self-report (e.g., social desirability). Participants frequently expressed difficulty responding to questions prompting percentage estimations (e.g., percent of distressed parents, percent of time ensuring psychology is involved). Therefore, expanding upon quantitative studies such as Tunick et al. (2013b), which evaluated the percent and patterns of referrals to psychology for patients and parents in one PICU, by including data regarding involvement of other psychosocial providers (e.g., social work) and evaluating these patterns across multiple PICUs would significantly improve understanding of use of psychosocial resources in PICU. Furthermore, it would be useful to ask medical providers more detailed questions about the role of social workers in supporting distressed parents. Additionally, providers may have responded in a socially desirable way during interviews (e.g., suggesting more willingness and interest in identifying and respond to distressed parents), especially if the interviewer's positionality as a psychology student was known; therefore, these results may overestimate self-efficacy in this area. Using objective tools to evaluate identification of distressed parents would also allow for comparison between parent and provider report in future studies. This would provide additional information about provider ability to accurately identify distressed parents. Currently, this type of work has only been conducted focusing on provider recognition of anxiety (Needle et al., 2009); therefore, future research should expand this work to symptoms of depression and traumatic stress.

Only one PICU was represented, and therefore, results may not generalize to other PICUs with different populations and psychological support models. Additionally, the sample of participants and the research team are predominantly white. Notably, 100% of the NPs were white females, which reflects similar demographics in the broader field (Sipe et al., 2009). Additionally, racial disparities exist in the PICU such that African American children have a greater risk for PICU admission than non-white Hispanic children (Turner et al., 2011), and child poverty correlates with PICU admission rates (Andrist et al., 2019), due to systemic racism and inequity contributing to health disparities. The significant mismatch in demographics between the present study's research team and participants as compared to the PICU population is problematic and may result in a biased interpretation and response to minoritized PICU parent distress as well as lack of representation of their experience. It is critical to increase representation within the present study's research team and within PICU medical teams to reduce systemic racism contributing to health disparities present in the PICU. Incorporating and centering patient and family perspectives in future research utilizing a patient centered outcomes research approach (Frank et al., 2014) will also ensure research is meaningful and important to patients and caregivers.

Conclusions

PICU medical providers can play a vital role in identifying and supporting distressed parents in order to reduce long-term psychological sequalae. Interventions should focus on providing psychoeducation about parent distress in the PICU, building skills related to communication and promoting active participation in their child's medical care, and increasing use and presence of psychologists in the PICU. Future research should evaluate parent perspectives on provider response to their distress and barriers to seeking support from psychologists.

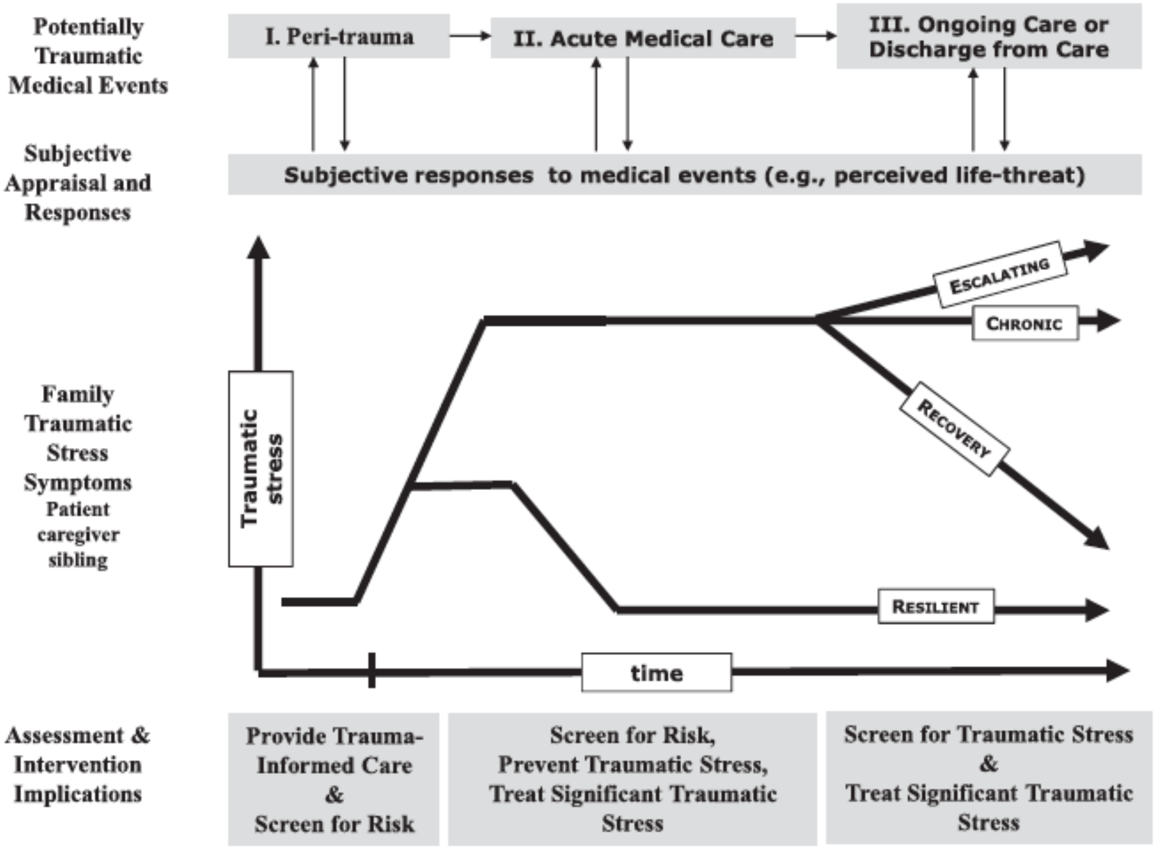

Figure 1. Integrative (Trajectory) Model of Pediatric Medical Traumatic Stress

Note. Reprinted from "Systematic Review: A Reevaluation and Update of the Integrative (Trajectory) Model of Pediatric Medical Traumatic Stress", by Price et al., 2015, *Journal of Pediatric Psychology, 41*, p. 93.

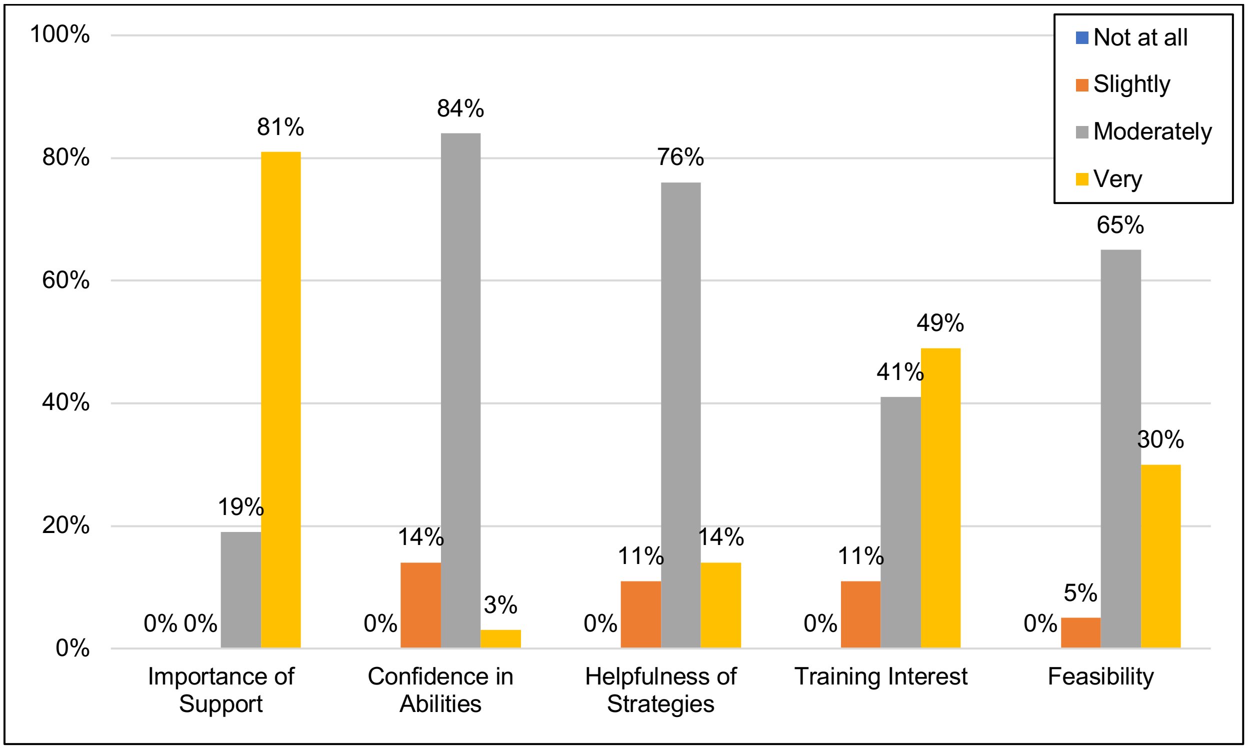

Figure 2. Self-efficacy quantitative data and training interest

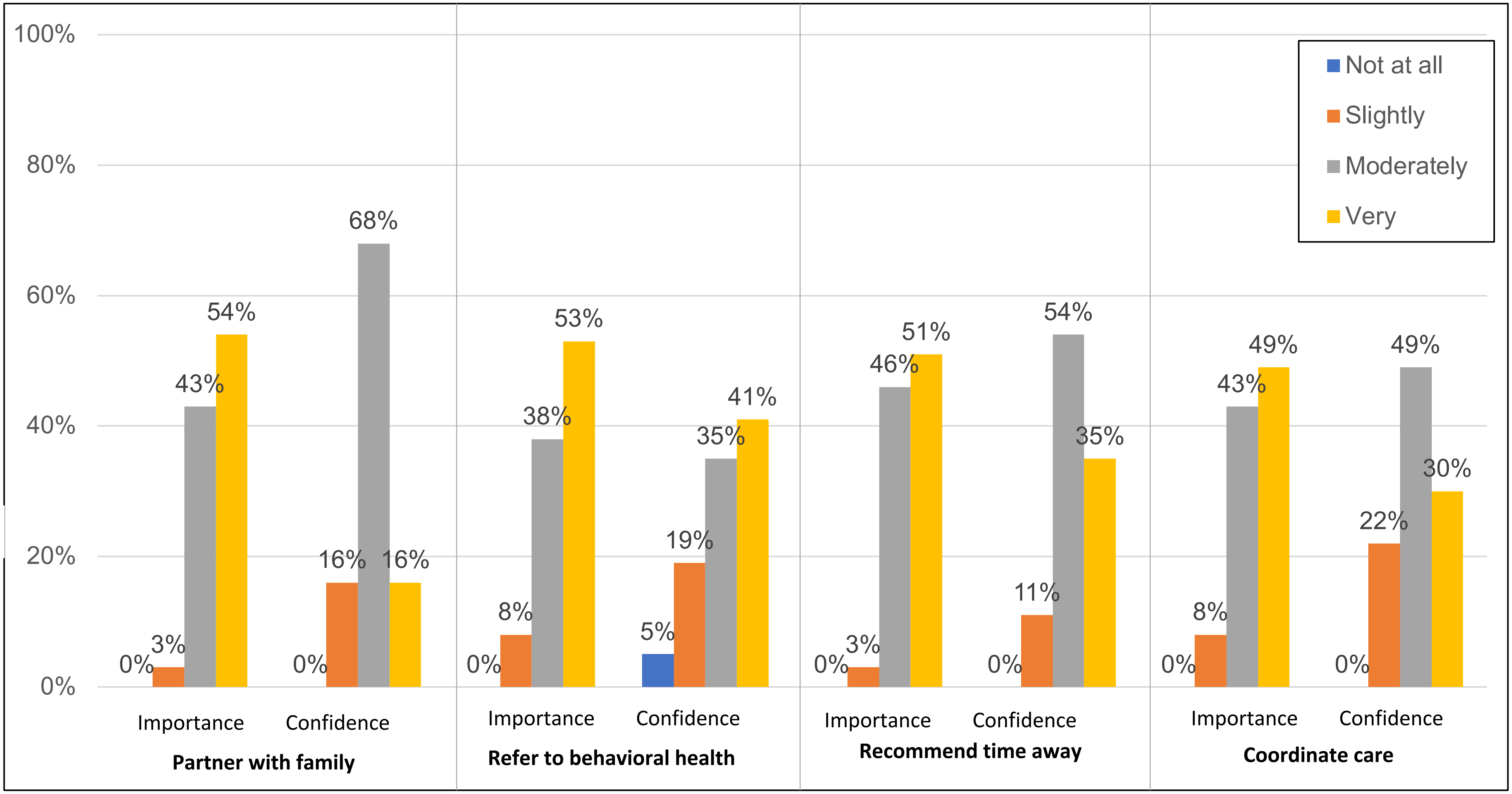

Figure 3. Items rated as lower importance on self-efficacy questionnaire

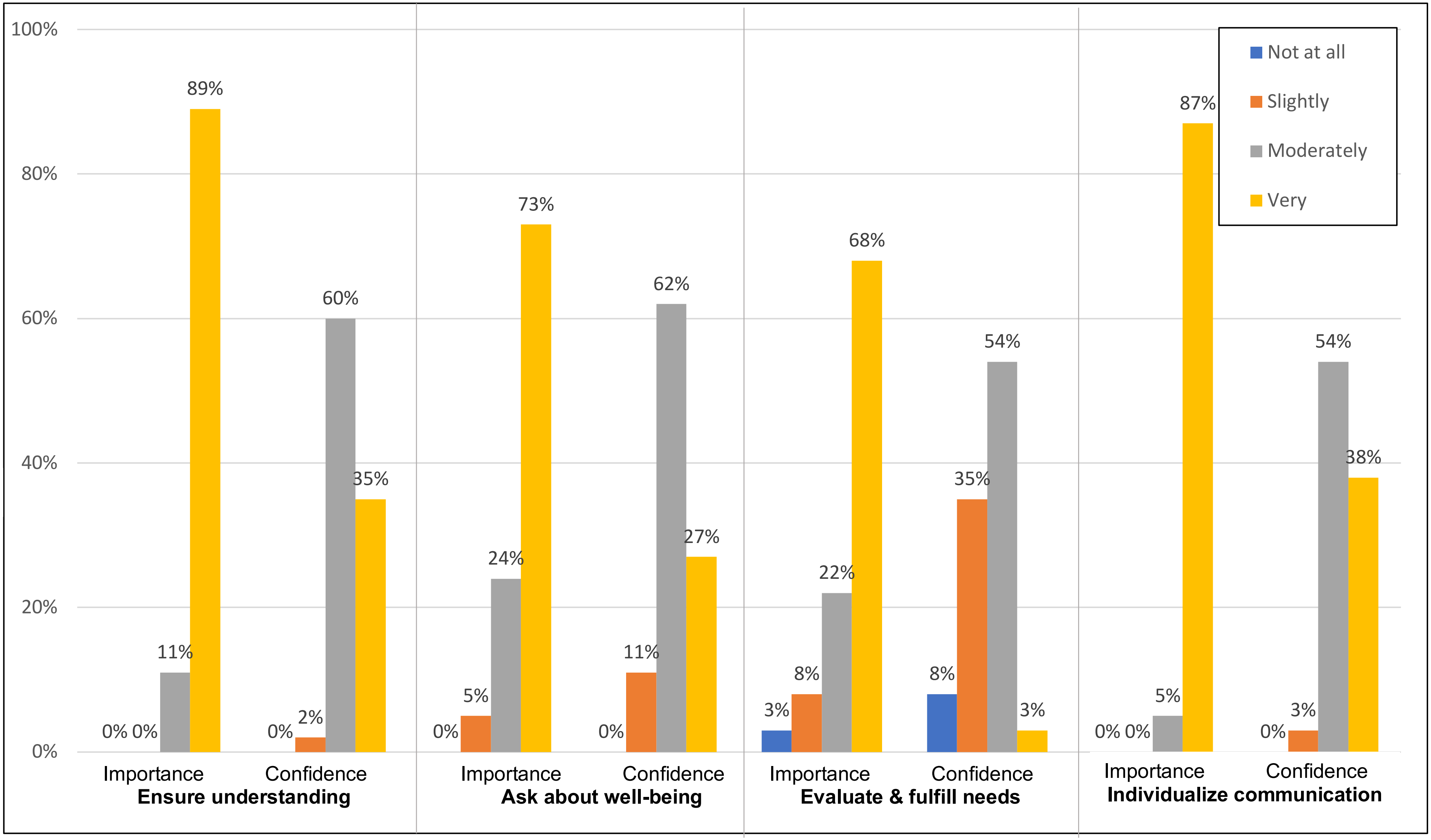

Figure 4. Items rated as high importance with lower confidence on self-efficacy questionnaire

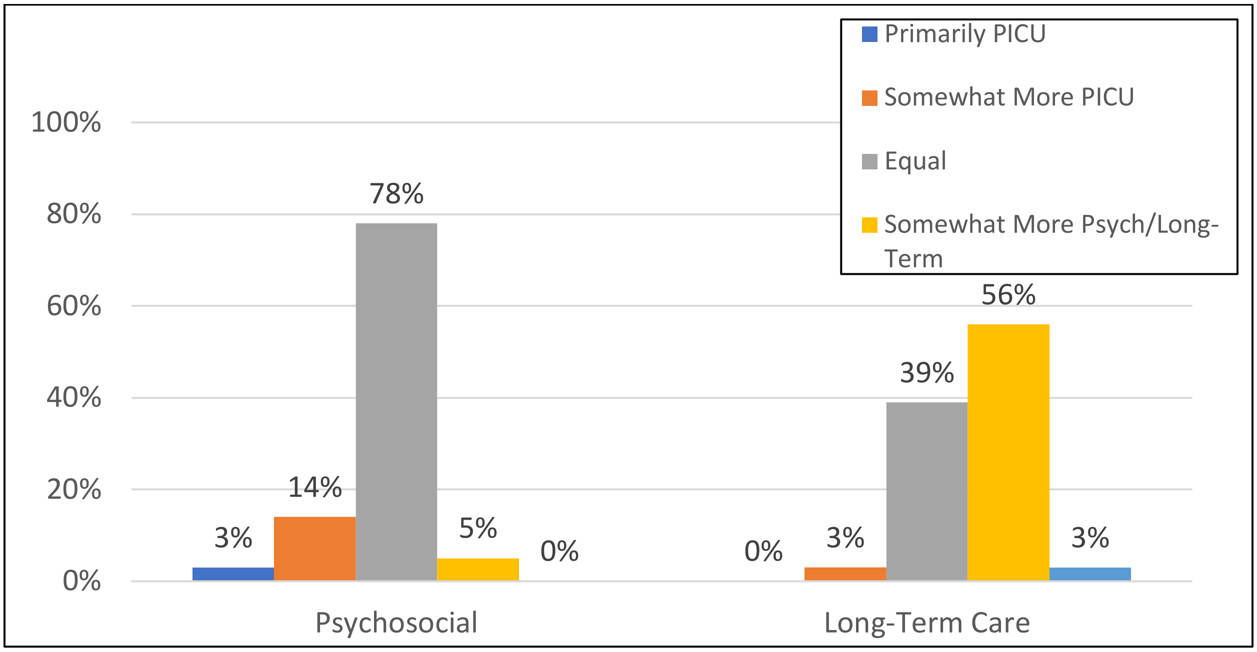

Figure 5. Perceived role of PICU medical providers vs. external providers in supporting distressed parents

Table 1. Participant Demographic Information

Variables	**Total (*N*=37)**	**NPs (*N*=12)**	**Fellows (*N*=13)**	**Physicians (*N*=12)**
	***N* (%)**	***N* (%)**	***N* (%)**	***N* (%)**
Gender				
Female	29 (78%)	12 (100%)	8 (62%)	9 (75%)
Male	8 (22%)	0 (0%)	5 (38%)	3 (25%)
Race				
White	27 (73%)	12 (100%)	8 (62%)	7 (58%)
Asian	5 (14%)	0 (0%)	2 (15%)	3 (25%)
African American/Black	2 (5%)	0 (0%)	0 (0%)	2 (17%)
Other	1 (3%)	0 (0%)	1 (8%)	0 (0%)
Prefer not to answer	2 (5%)	0 (0%)	2 (15%)	0 (0%)
Ethnicity				
Hispanic or Latinx	2 (5%)	0 (0%)	2 (15%)	0 (0%)
Not Hispanic or Latinx	35 (95%)	12 (100%)	11 (85%)	12 (100%)
	***M* (SD) [range]**	***M* (SD) [range]**	***M* (SD) [range]**	***M* (SD) [range]**
Years of Experience				
Total Clinical	13 (10) [3-39]	14 (8) [5-31]	5 (1) [3-6]	19 (11) [7-39]
Current role	7 (9) [0-34]	8 (6) [1-20]	1 (1) [0-3]	13 (12) [3-34]
PICU	9 (9) [0-33]	10 (7) [1-21]	2 (1) [0-3]	15 (11) [3-33]
CW	8 (9) [0-37]	10 (5) [3-20]	2 (1) [0-5]	14 (12) [3-37]

Table 2. Semi-Structured Qualitative Interview Guide

Construct	Interview Question
Aim 1. Identification of Distress	
Cues	- What indicates to you that a family is distressed?
Prevalence Perception	- In your experience, about what percentage of families present with a level of distress above the normal levels that you experience in your day-to-day practice?
Risk Factors/Correlates	- What factors do you think contribute to a family's distress?
Aim 2. Response to Distress	
Perceived Importance	- How important is it for you to be able to support distressed families?[c]
Outcome Expectancy	- What strategies do you use to support a family when they are distressed? - How helpful do you think these strategies are in reducing family distress?[c]
Efficacy Expectations	- How confident are you in your ability to support distressed families?[c] - What are the barriers or challenges to supporting distressed families?
Training	- Rate how interested you would be in receiving more training about how to support distressed families[c]
Aim 3. Use of External Resources	
Psychosocial Providers	- For this question, the PICU medical team refers to any inpatient medical providers (e.g., NPs, fellows, attendings), and psychosocial providers refers to any mental health professionals such as social workers and psychologists. Whose role is it to directly work with the family to manage their distress?[a]
Long-Term Care Teams	- If the family is involved with a long-term care team, whose role is it to directly work with the family to manage their distress?[b]
Psychology	- For a family who you perceive to be distressed, about what percentage of the time do you ensure that psychology is involved? - What factors do you consider when deciding whether or not to ensure Psychology is involved for patients or families?

Note. a-c indicate questions answered both quantitatively and qualitatively. Scales listed below.
a: Primarily the medical team, Somewhat more the medical team than the psychosocial providers, Equally the medical team and psychosocial providers, Somewhat more the psychosocial providers than the medical team, Primarily the psychosocial providers
b: Primarily the medical team, Somewhat more the medical team than the long-term care team, Equally the medical team and long-term care team, Somewhat more the long-term care team than the medical team, Primarily the long-term care team
c: Not at all, Slightly, Moderately, Very

Table 3. Self-Efficacy Questionnaire

	If your goal is to reduce family distress, how important would it be for you to do each of the following?:				**How confident are you in your ability to do each of the following?:**			
	Not at all	Slightly	Moderately	Very	Not at all	Slightly	Moderately	Very
1. Partner with the family to negotiate the role they want to play in their child's care.	1	2	3	4	1	2	3	4
2. Ask the family about their emotional well-being and listen to their concerns.	1	2	3	4	1	2	3	4
3. Evaluate the family's psychosocial needs and coordinate efforts to fulfill those needs.	1	2	3	4	1	2	3	4
4. Make a referral to behavioral health services.	1	2	3	4	1	2	3	4
5. Oversee the providers working with the family and coordinate their care.	1	2	3	4	1	2	3	4
6. Ensure that the family fully understands information you provide to them.	1	2	3	4	1	2	3	4
7. Recommend time away from the hospital for the family.	1	2	3	4	1	2	3	4
8. Individualize communication based on the family's needs and preferences.	1	2	3	4	1	2	3	4

Table 4. Indicators of Parent Distress (*N*=37)

Themes / Subthemes	*N* (%)	Illustrative Quotes
Nonverbal	31 (84%)	"It's their nonverbal cues….they might be like wringing their hands, they might be not making good eye contact"
Crying	17 (46%)	"It could be crying. It could be sniffling."
Emotional	30 (81%)	"They can get emotional."
Anger	24 (65%)	"I think we have families that can get angry, and I think that's often a sign of maybe not distress in the typical way. It's maybe not the most obvious. They may want it to come off as they're just advocating for their child. But I think that's a sign that they're in unfamiliar territory and maybe putting up barriers in other ways."
Sadness	8 (22%)	"…and sadness would be like big red flags"
Dysregulation	7 (19%)	"Emotional lability, so crying one minute, angry the next."
Anxiety	5 (14%)	"The most common one I feel is anxious. They're extremely anxious just because they've never—if it's a child that's never been ill, then it's a lot of anxiety."
Disengagement	25 (68%)	"At times, you can also see that they can be withdrawn from their child, so not really able to kind of process what's going on, so being a little bit more reserved and withdrawn. Sometimes they also don't, in that regard, they are also a little bit withdrawn with the medical staff too, not really asking questions, not really actively participating in care and rounds and things."
Voice	18 (49%)	"You can kind of hear that pressure in their voice. So the tone that they use."
Direct	13 (35%)	"Sometimes they just straight up tell you that this is not an enjoyable experience, as you can imagine."
Confusion	11 (30%)	"They might ask kind of the same question in a little bit different way maybe because they're not understanding or again, processing everything we're telling them."
Distrust	10 (27%)	"Maybe not trustworthy of the health system or providers, there -- when they question everything you're doing and um kind of are defensive more than trying to work with you as you know in the team"
Questions	9 (24%)	"I would think that usually the questioning is usually a bit more intense or they have a lot of questions."
Selfcare	6 (16%)	"Not sleeping, not taking care of themselves and…not taking care of their families."
Others' Perceptions	4 (11%)	"And behavior with-- not just me, the feedback you receive from prior providers from nurses, from other ancillary staff like respiratory tappers, so physiotherapist, all of them. I think the whole team's idea about the family or their sense also makes it."
Other	16 (43%)	

Table 5. Perceived Risk Factors and Correlates of Parent Distress (*N*=37)

Themes / Subthemes	***N* (%)**	**Illustrative Quotes**
Medical Factors	28 (76%)	
Admission Type	20 (54%)	"If this is a first ICU stay. I think there's definitely a difference of a family who's used to a patient with chronic medical problems who's in and out all the time, and this seems within their norm of their previous stays, versus a previously healthy kid that maybe isn't your sickest patient on the unit, but it's a big change for the family. So I think that's two extremes of patients that you see."
Illness Severity	20 (54%)	"Probably the severity of their child's illness is the biggest determinate of that."
External Factors	24 (65%)	"Other outside stressors, whether you have other children at home, um, your relationships, things like that, finances, all those things."
Medical Understanding	20 (54%)	"I think their understanding of the patient's condition, the prognosis, the um treatment, their perhaps their own familiarity with health care, medical conditions,"
Internal Factors	17 (46%)	"Some of it's their own coping mechanism, or if they feel that, I think that the lack of control. You don't have control the situation or what's going on with their child."
Psychosocial Support	14 (38%)	"um to some extent how much support they have in terms of their own family network,"
Communication	12 (32%)	"I think lack of communication, too, obviously is a big one. Like providers aren't communicating very well exactly what is happening or what they're doing can cause distress as well."
Cultural Factors	5 (14%)	"The other is also their cultural background too. Many families have their, especially families from other parts of the world with different cultures and their beliefs, all those things can I think impact how they respond in these different situations."
PICU Environment	5 (14%)	"Being in the ICU itself because it it is very different with all the monitors and the noises and then number of staff that are present especially when you first enter the PICU so that can be pretty distressing."
Language	3 (8%)	"I think also is sometimes language barrier can be a big problem too for families who didn't-- who do not understand English, who have to-- yes you can, interpreter services do help but sometimes um it is it still might not be perfect and that can affect."
Other	3 (8%)	

Table 6. Reasons for Importance of Supporting Distressed Parents (*N*=35)

Themes / Subthemes	***N*** **(%)**	**Operational Definition**	**Illustrative Quotes**
Child's Care	15 (43%)	Provider believes that providing support to these families will aid in the medical care and outcomes of the child during and/or after hospitalization	"On any given day, it can affect how I provide care to their child. And so being able to mitigate that and get past that so we can focus on the care of the child is very important. So I take it pretty seriously."
Rapport	4 (11%)	Providing support is important for developing a relationship with the family and/or gaining their trust	"I think you need the family to be on the same page as you for them to trust you, so I think that plays a big role in taking care of the child. So I think it's very important that the family is on the same page, and not in distress."
Decision-Making	4 (11%)	Describes importance of supporting families through decision-making process	"And if you don't manage the distress then making decisions from the family is very challenging."
Role	13 (37%)	Supporting distressed families is seen as a part of the job as a provider	"Just because I would say it's a big part of the job"
Medical Responsibilities	8 (23%)	Medical responsibilities may take precedence over addressing the family's distress in some situations	"That being said, though, sometimes, distressed families can actually pull away from us providing medical care to the child. So that's why I picked moderately and not very just because we are truly there to help get the best and safest care that we can. So that should be the main focus, taking into account that do-what-you-can to help bring the family to where you are and continue to aid in the kid's care."
Empathy	6 (17%)	Noted importance of supporting distressed families because of the intensity of the PICU environment; feeling empathy for the families	"I tell people my comment a lot is that I am walking with you on your journey through one of the worst days of your life, and I think that that is something that is a privilege that we have"
Resources	6 (17%)	Describes importance of providing family with resources or offering other supports to help them through their distress	"I need my resources to help me so that the social worker who is at the code, the nurses who are at the code, etc, to take on that role for the distressed family."
Other	10 (29%)		

Table 7. Strategies used to support distressed parents (*N*=37)

Themes	***N* (%)**	**Illustrative Quotes**
Listen	24 (65%)	“I try to have conversations with them where hopefully I'm mostly listening and answering their questions and concerns”
Explain Medical Information	24 (65%)	“Making sure they ask whatever questions they need answered or trying to explain things so that they can understand them”
Assess Needs	24 (65%)	“I try to address the concerns that we actually have. So there is usually an underlying concern somewhere. Amidst what they're saying or what sadness or grief or whatever they're having, and I try to find out what that is and see if I can help solve it.”
Resources	20 (54%)	“involving other teams that may be helpful for them you know be it a consultant versus somebody more on the psychology end if they need that.”
Nonverbals	12 (32%)	“Sometimes I'll um, like use touch, like I’ll put my hand on their shoulder”
Validate	5 (14%)	“And then I also think just, just offering -- just telling them that it's OK to be distressed that this is a stressful situation is also important, and that what they're feeling is not abnormal, and it's OK to feel that the way that they do”
Reassure	5 (14%)	“I think reassuring them that we're doing we're using some type of process to try to help us figure out answers”
Social Support	3 (8%)	“And then, "Is there family that you want to come be here with you?" I think is another question to ask families at that point in time because I'm just a stranger to them. So sometimes they need a little bit more outside support as well.”
Other	5 (14%)	

Table 8. Efficacy Expectations and Outcome Expectancies in Supporting Distressed Parents (*N*=35)

Themes / Subthemes	***N* (%)**	**Illustrative Quotes**
Ability	28 (80%)	
Room for Improvement	20 (57%)	“There's always room for improvement.”
Skilled	18 (51%)	“So the reason I say that is um innately it makes sense, um to me, and I've seen it work and so that's why I say very.”
Control	24 (69%)	
Uncontrollable Factors	21 (60%)	“And then at the end of the day their kid is really sick, so I'm sure that distress is not going to actually go away.”
Controllable Factors	12 (34%)	“I can't undo the new cancer diagnosis, I can't undo the trauma that happened to your child, but I can try and support the other things to try and bring the distress level down so that you can focus on your child and not on these outside problems.”
Feedback	13 (37%)	
Uncertainty	8 (23%)	“I mean I think I just don't ever know exactly what they take away from it.”
Positive Feedback	10 (29%)	“Most often we get feedback from either the family member - through a repaired or a improved relationship - or the bedside nurses, or, or in some meetings with when social work is there or other providers are there they provide you with feedback.”
Other	10 (29%)	

Table 9. Barriers and Challenges to Supporting Distressed Parents (*N*=37)

Themes	***N* (%)**		**Illustrative Quotes**
Provider Time	30 (81%)	Provider availability, time, and workflow (e.g., obligations to other patients); PICU census and acuity	"I think it just sometimes depends on how busy the medical team is. With how busy that unit is, for being pulled in 10 different directions with really sick patients. Sometimes we don't have as much time as we want to be able to sit down with each family and support them in that way."
Resources	12 (32%)	Lack of resources or resources unavailable (e.g., time of day, weekends)	"Other barriers I think would be time of day. So it's tricky in the middle of the night if we get a trauma patient in who is not going to make it to the morning, to get a child life specialist in to meet with the siblings to help with that. Chaplains are available 24/7. Translator or interpreter services are available 24/7, so that's helpful. But it can be some of the more ancillary services that are available, psychiatry or psychology, to help assist with working with the families."
Disengagement	12 (32%)	Family absent, disengaged, or withdrawn from the hospital and their child's care	"Their time availability as well. So especially if they're a withdrawn family and they're not around that much, it's hard to sometimes get in touch with them or things like that."
Lack Control	12 (32%)	Provider expresses lack of control over external family stressors and/or the child's illness and uncertainty	"Yeah I think they have a whole life outside of what's going on with their child at that moment so you know we can't intervene necessarily in all of that."
Family Demeanor	10 (27%)	Families who are "difficult", such as distrusting of the medical team, angry, or aggressive	"I think sometimes if a family has been particularly-- if they're manifesting their distress by being sort of a difficult, what we consider like a difficult family. They're very argumentative or distrusting of the medical team."
Rapport	10 (27%)	Difficulty connecting or establishing rapport with the family, may be due to workflow and discontinuity of providers throughout their care	"And I think for us in the ICU, this is the first time that you've met a family then you just don't have that relationship and so while you can try to build trust quickly, in some settings it just might not be enough for them to really feel the most supported."
Language	10 (27%)	Language barriers and challenges related to using an interpreter	"I think if there's obviously there's a language barrier that's always very difficult so that's even makes it worse trying to

			support families you can't talk to that I know I can see facial expressions and I can hear it word inflections but I have no idea what the words are saying."
Lack Training	10 (27%)	Provider level of knowledge, training, skill, and comfortability with identifying and supporting distressed families	"And I say that because I think there's-- I feel like the tip of the iceberg is what we see identify. [I think there is a huge layer of distress that [inaudible] the families that's not detected. " "there's just skill or not really knowing what to say to a family."
Cultural Considerations	6 (16%)	Differences in perceptions due to cultural factors (e.g., race, ethnicity, religion, and spirituality)	"And kind of maybe a lack of cultural or religious understanding"
Provider Mental Health	4 (11%)	Provider's own mental health, stress, and well-being	"You also have other patients that might also be stressed, and being able to provide that level of care to each stressed family can be very emotional for you."
Family Understanding	4 (11%)	Family's level of medical understanding	"Level of understanding from a communication standpoint I think is tricky…it's understanding where that level is and what's the best level to talk to the family."
Other	6 (16%)		

Table 10. Role of Psychosocial vs. Medical Providers in Supporting Distressed Parents (*N*=35)

Themes	***N* (%)**	**Operational Definition**	**Illustrative Quotes**
Psychology: Role & Reasons for Involvement			
Expertise	14 (40%)	Limits of medical provider training and role related to psychosocial support	"But then the medical team doesn't necessarily have the training and background to be able to provide that psychosocial support. So I think that's where those providers would come into play."
Logistics	8 (23%)	Help with logistical needs and resources (e.g., childcare, transportation, housing)	"I think if it's things like traveling to home or child care for other children at home, perhaps then the psychosocial is more helpful."
Time	7 (20%)	Psychosocial providers have more time to focus on distress	"And we don't have the time to sit down and talk to them. I think that's a big constraint for us although we may like to do that."
Coping	4 (11%)	Focus on providing comfort and psychosocial support (e.g., building coping skills) rather than medical care	"And certainly the social work and psychology can be more helpful with the coping strategies they might need."
Liaison	4 (11%)	Psychosocial providers can help facilitate communication and collaboration between family and medical providers	"And I think it's also again like I said the psychosocial providers who are going to help us work with the families and help identify specifics that we can help how we can help those families."
Other	1 (3%)		
PICU Medical Provider: Role & Reasons for involvement			
Medical Information	24 (69%)	Medical providers focus on providing the medical information, describing what's happening related to their child's care	"The PICU medical team can bring the medical updates for the patient to the family and really explain and support in those sort of difficult conversations"
Frontline	14 (40%)	Medical providers responsible for identifying distressed families and deciding whether and when to involve psychosocial supports (e.g., coordinating care); medical provider is primary caregiver for the family	"That is the role of the PICU medical team. So primarily the medical team has to make the choice, identify the problem, and make the decision that they need to call."
Presence	12 (34%)	Medical providers manage distress because they are frequently in contact with families throughout their stay and/or frequently interact with them at the bedside	"We're there every day, all day so I do think a majority of the need falls on us"
Other	2 (6%)		

Table 11. Factors considered when deciding whether or not to ensure psychology is involved (*N*=37)

Themes / Subthemes	***N*** **(%)**	**Operational Definition**	**Illustrative Quotes**
Distress Level	22 (60%)	Severity or impact of symptoms of distress	"I guess like if I perceive them to be distressed above a usual level… and that I personally decide to call." "I think patients if they come in and there's concerns for depression and self-harm and those kind of things then for sure I pretty much always consult them."
Parent Openness	19 (51%)	Parent willingness and/or openness	"I think also just the families themselves. I think whether or not they'd be open to it. I think sometimes we always-- we will essentially offer it and they might just refuse."
Medical Factors	16 (46%)		
Illness/Injury	15 (41%)	Type of injury/illness (e.g., trauma, cancer) or chronicity of condition/illness; prognosis	"Yeah, the like chronicity of their um diagnosis so like if they had the disease, that's going to take a couple years or end in palliative then definitely get psychology involved but if it's like something that acute like a, fractured something or a post-op then, probably not."
Length of Stay	6 (16%)	How long the family is the in the ICU or hospital	"If they're not in the unit very long, I either don't think about it or don't forget -- or forget about it and then like there are only there for a day. So I think the longer I take care of a kid the more likely it is for me to A: know they're distressed and B: get child psychology involved because I can see they're distressed and remember"
Provider Prompt	14 (38%)	Other care providers prompt or suggest involving psychology (nurse, psychology, social work)	"Usually, I get a lot of cues from nursing staff. I think that because they spend a lot more time with the patients and families, that a lot of the times they will suggest it and that can be very helpful, so I rely on them."
Parent Prompt	11 (30%)	Parent prompts consideration of psychology by expressing interest or asking directly	"And then, certainly, if they bring it up themselves then, of course, we'll involve other people."

Provider Ability	11 (30%)	Parents needs exceed provider ability to help them	"And then otherwise, um, I think if it's reaching a point where I feel like I'm not able to manage it effectively then I will consider it then too."
Mental Health History	8 (22%)	Parent has history of mental health concerns	"Sometimes you get like in his-- in like when you're getting like a history that there's kind of like a family history of mental health issues so then it kind of triggers me earlier in some of those cases."
Social Support	4 (11%)	Parent's level of social support	"A support system, I think is definitely -- so if I see a mom or a dad who has several, several people around them, a very strong support system. I'm probably less apt to um, ask psychology to be involved."
Psychology Workload	4 (11%)	Access to psychology	"Access. So part of that is understanding the workload of psychology."
No Factors	3 (8%)	Provider does not consider any factors because they forget that psychology can be involved, don't think about it, and/or doesn't have any factors because they never or always involve psychology.	"I guess I just never think about it."
Other	7 (19%)		

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