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Therapeutic Alliance between Bereaved Parents and Physicians in the Pediatric Intensive Care Unit

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Abstract

Objective: Therapeutic alliance is the collaborative bond that develops between patients/families and healthcare providers. Our objective is to determine the extent of therapeutic alliance bereaved parents perceive to have occurred with their child's physicians during their child's pediatric intensive care unit (PICU) stay, and associated factors.

Design: Multicenter observational study.

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Setting: Eight children's hospitals affiliated with the Collaborative Pediatric Critical Care Research Network.

Participants: Parents ≥18 years of age whose child died in a PICU (including cardiac ICU).

Interventions: Bereaved parents completed the Human Connection Scale (HCS), a 16-item measure of therapeutic alliance, six months after their child's death. HCS scores range from 16 to 64 with higher scores indicating greater alliance. Parents provided sociodemographic data, and medical records were reviewed for the child's clinical characteristics.

Measurements and Main Results: Two hundred and thirty-three parents of 157 deceased children responded to the HCS with ≥80% item completion. Among parents, 146 (62.7%) were female, 155 (66.5%) were White and 46 (19.7%) Black, 175 (75.1%) were married, and 209 (89.7%) had at least a high school education. Among children, median age at time of death was 5.9 years (IQR 0.64, 13.9 years) and 114 (72.6%) died after limitation or withdrawal of life support. Mean HCS score was 51.4 ± 11.1 for all parents, 52.6 ± 9.0 for White parents and 47.0 ± 13.7 for Black parents. In multivariable modeling predicting HCS scores, race was the only parent or child characteristic in the final model. HCS scores were significantly different (−4.56, 95%CI −8.53, −0.6, p=0.025) between Black and White parents with items about trust, caring and honest communication showing the greatest mean difference.

Conclusions: Among parents bereaved in the PICU, therapeutic alliance with physicians is moderately high. Future research should identify strategies to strengthen therapeutic alliance with Black parents and examine the role of alliance on bereaved parents' health outcomes.

Keywords

Therapeutic alliance; bereavement; parent; physician; child; race; pediatric intensive care unit

INTRODUCTION

Approximately 43,000 children die annually in the United States affecting the health and wellbeing of many families (1). Childhood death often gives rise to an intense grief among parents. Bereaved parents are at high risk for disorders such as complicated grief, anxiety, depression, posttraumatic stress, insomnia, substance abuse, and physical morbidity (2–6). Complicated grief, a persistent and impairing form of grief, has been suggested to occur in as many as 60% of bereaved parents 6 months after their child's death in a pediatric intensive care unit (PICU) and persist in 40% at 18 months (7,8). Little is known about interventions to prevent these health outcomes in bereaved parents, and even less is known about the role PICU physicians may play in bereaved parents' ability to adjust to their child's death.

Therapeutic alliance is a multifaceted construct reflecting the strength and quality of the relationship between a patient and their physician, or in the case of pediatrics, parents and their child's physician (9). Elements of therapeutic alliance include a mutual sense of trust, caring, respect, collaboration, and understanding. Therapeutic alliance was first described in the psychotherapy literature as an empathic bond between patient and therapist and is considered a key aspect of successful psychotherapy for both adults and children (10–12).

Therapeutic alliance has demonstrated benefits in many serious childhood disorders including anorexia nervosa, autism, obsessive compulsive disorder, cancer, and arthritis (13–17), although it has not been well studied in pediatric critical illness. In adult ICUs, alliance between informal caregivers and physicians has been shown to be strongly correlated with patient-centeredness and poorly correlated with psychological distress among caregivers (18). In adult oncology settings, caregiver-physician alliance has been associated with better caregiver experiences with their relative's end-of-life care (19), and patient-physician alliance has been associated with better mental health among caregivers during bereavement (20).

Parents facing their child's death in the PICU often rely on their child's healthcare providers for support and guidance. Needs of bereaved parents in PICUs include compassion, trust, honest communication, and respect (21–23); all of these are attributes of therapeutic alliance. The extent of therapeutic alliance and factors that affect therapeutic alliance between parents and physicians near the time of a child's death in the PICU are not well understood. The aim of this study is to determine the extent of therapeutic alliance that bereaved parents perceive to have occurred with their child's physicians during the child's PICU stay. We hypothesized that the extent of therapeutic alliance reported by parents may be influenced by parent and/or child attributes and characteristics of the child's clinical course.

METHODS

Design and setting

This multisite observational study was conducted across eight children's hospitals affiliated with the *Eunice Kennedy Shriver National Institute of Child Health and Human Development* Collaborative Pediatric Critical Care Research Network (CPCCRN) between September 2016 and March 2019. The study was approved by the University of Utah institutional review board (IRB) serving as a central IRB for the CPCCRN.

Participants

Parents, defined as biological parents and/or legal guardians, were eligible for participation if their child died in a PICU (including cardiac ICU), were English or Spanish speaking, and at least 18 years old. One or more parents of each deceased child were eligible to participate. Medical records of the deceased children were reviewed to obtain parents' contact information and primary language for the purpose of recruitment.

Data Collection

Eligible parents were mailed surveys in English or Spanish 6 months after their child's death. If completed surveys were not returned within one month, telephone contact was attempted to offer the parents the option of completing the survey by telephone. If the household was successfully contacted by telephone but the survey was not completed, the parent was categorized as a refusal to participate. If the household could not be contacted by telephone after 3 or more attempts, the parent was categorized as unable to contact. For parents who completed surveys, their deceased child's medical records were further reviewed to collect information about the child's characteristics and clinical course. All parent information was collected by self-report.

Outcomes

The primary outcome was the extent of therapeutic alliance as assessed by the Human Connection Scale (HCS) (9). The HCS is a 16-item measure originally designed to evaluate therapeutic alliance between adult cancer patients and oncologists. The scale assesses (1) physician understanding of patient concerns, (2) mutual caring and respect, (3) patient understanding of information, (4) patient trust in physician, and (5) collaboration. Cronbach's α has been reported as 0.9 and validity demonstrated by positive association with related measures including acceptance of terminal illness (9). For this study, the HCS was adapted to evaluate therapeutic alliance between bereaved parents and their child's PICU physicians by changing the phrase "your doctor" to "your child's doctor(s) in the ICU." Responses are reported on a 4-point scale (1 = not at all, 4 = a great deal). Summed scores range from 16 to 64; higher scores indicate greater therapeutic alliance.

Independent variables

Independent variables included parental sociodemographics and attachment style, and child clinical characteristics. Parental sociodemographics included gender, age, race, ethnicity, marital status, education, relationship to the deceased child, and number of surviving children. Relationship to the deceased child was categorized as biological parent or other legal guardian.

Parental attachment style was assessed using the Revised Adult Attachment Scale (Revised-AAS) - Close Relationship Version (24,25). The Revised-AAS is an 18-item measure that evaluates an individual's general orientation to close relationships. Cronbach's α has been reported to range from 0.768 to 0.855 across subscales (25), and validity demonstrated by positive association with related measures (26). Responses are reported on a 5-point scale ranging from 1 (not at all like me) to 5 (very much like me). Scoring was performed to obtain subscale scores along two dimensions of attachment: avoidance and anxiety (24). Scores for attachment-related avoidance and anxiety are a mean of the relevant items and range from 1 to 5. Higher scores indicate more avoidance or anxiety, respectively, whereas lower scores indicate less avoidance or anxiety and thus, more secure attachment.

Child clinical characteristics included gender, age at time of death, cause of death, trajectory of death, mode of death, and PICU and hospital lengths of stay. Cause of death was categorized as cardiac, respiratory, malignancy, sepsis/multiple organ failure, neurologic, trauma, or other. Mode of death was categorized as limitation/withdrawal of life support, brain death, or unsuccessful cardiopulmonary resuscitation (CPR). Trajectory of death was categorized as sudden unexpected death, death from a potentially curable disease, death from a lethal congenital anomaly, or death from a progressive condition with intermittent crises (27).

Statistical Analysis

For the HCS and Revised-AAS measures, scores were calculated based on available data if at least 80% of the items in each measure were completed. For the HCS score, which is a sum of the responses to each of 16 items, the total sum of completed item responses was multiplied by 16 and divided by the total number of items completed. For the Revised-AAS score, which is a mean of 18 items, the mean of the completed items was determined. If less than 80% of items were completed for either measure, the score was considered missing. Individuals with missing HCS scores were excluded from all analyses.

Data are summarized using frequencies and percentages for categorical variables, and means, standard deviations, medians, interquartile ranges, minimums and maximums for continuous variables. To account for the fact that more than one parent of the same deceased child could participate in the study, and the characteristics and survey scores of parents of the same child are likely correlated, linear mixed models were used with child as the random effect to identify variables associated with HCS scores. Candidate variables were determined by univariable linear mixed models. It was predetermined that variables with a p-value ≤ 0.2 in the univariable analyses would be candidate predictors for the model selection. To construct the final model, manual backward selection was performed on the multivariable mixed model containing the candidate predictors until all remaining predictors had a p-value ≤ 0.1.

RESULTS

Surveys were mailed to 710 families six months after their child’s death. One or more parents from 159 (22.4%) families responded to the survey, 181 (25.5%) families refused and 370 (52.1%) could not be contacted. In total, 237 parents responded to the survey; two were later found to be ineligible because their child died in a location other than a PICU. Of the remaining 235 parents, 200 (85.1%) responded in English by mail, 22 (9.4%) in English by telephone, 10 (4.3%) in Spanish by mail, and 3 (1.3%) in Spanish by telephone. Surveys were returned by mail or completed by telephone a median of 7.6 months (IQR 6.9, 8.8 months) after the death. Two parents were excluded from all analyses because less than 80% of HCS items were completed. There were 14 parents for whom the HCS was scored in the presence of missing data. Of these, 7 were missing one response, 6 were missing two responses, and one was missing three responses. The final data set included 233 parents of 157 deceased children.

Of the 233 included parents, 146 (62.7%) were female, 155 (66.5%) were White and 46 (19.7%) Black, 175 (75.1%) were married, and 209 (89.7%) had at least a high school education (Table 1). Two hundred and fifteen (92.3%) were biological parents and 42 (18.0%) had lost their only child. Mean HCS score was 51.4 ± 11.1. Revised-AAS avoidance score was 2.6 ± 0.7 and anxiety score was 2.1 ± 1.0.

Of 157 deceased children, 86 (54.8%) were male and median age at time of death was 5.9 years (IQR 0.64, 13.9 years) (Table 2). Cause of death was cardiac for 40 (25.5%), sepsis or multiple organ failure for 30 (19.1%), neurologic for 25 (15.9%) and respiratory for 24 (15.3%). Trajectory of death was sudden and unexpected for 48 (30.6%). Mode of death was limitation or withdrawal of life support for 114 (72.6%), brain death for 24 (15.3%), and unsuccessful CPR for 19 (12.1%). Median PICU length of stay was 6.6 days (IQR 2.2, 21.8), and hospital length of stay was 8.7 days (IQR 2.4, 35.0 days).

Based on univariable analyses, the following characteristics were candidate predictors of parental HCS scores (Supplemental Digital Content 1): parent race (p = 0.062), child trajectory of death (p = 0.124), child mode of death (p = 0.113), and hospital length of stay (p = 0.122). Backward selection resulted in a simple mixed model with parent race as the only predictor (Table 3). HCS scores were significantly different (−4.56, 95%CI −8.53, −0.6, p=0.025) between Black and White parents. HCS items about trust, caring and honest communication showed the greatest mean difference between Black and White parents (Table 4). Items about coping and offering of hope were among the lowest scored for all parents.

DISCUSSION

Our study is the first to evaluate therapeutic alliance between parents of children who died in a PICU and their deceased child's PICU physicians, and explore parent and child characteristics associated with therapeutic alliance. The extent of therapeutic alliance reported by bereaved parents, on average, appears to be moderately high although individual scores varied widely. Therapeutic alliance for Black parents was lower than for White parents with the greatest differences in the areas of trust, caring and honest communication. Medical mistrust and poor communication have been described as factors contributing to racial differences in parental decision making during pediatric end-of-life care (28–31).

Medical mistrust is well documented among Black Americans and likely rooted in American history (32–34). Lasting effects of prior atrocities from personal or learned experiences remain today and are linked to disparities in preventative healthcare (35,36), treatment adherence (37,38), and patient satisfaction (39). Black parents have reported decreased trust in physicians caring for their children (40). Research suggests that trust in physicians improves among Black parents when there is greater continuity of care and use of a partnership-building communication style (41).

Poor medical communication may be another barrier to therapeutic alliance between Black Americans and physicians, further perpetuating feelings of mistrust and discrimination (41–43). High quality communication during clinical encounters may improve health outcomes regardless or race or ethnicity (44). In a study of breast feeding promotion, Black mothers voiced their desire for personal connection with healthcare providers, and preferred providers who would listen, empathize and offer encouragement (45). A study by October et al, which included a high percentage of Black parents (64%) in the PICU, demonstrated that parent-provider interactions with more patient-centeredness, such as a higher proportion of empathetic statements, question asking, and emotional talk, positively influenced parent satisfaction despite the severity of their child's illness (46). Perhaps pediatric intensivists who utilize patient-centered communication will have more success at establishing stronger alliances with Black parents, though this warrants further investigation within the PICU.

Perceived discrimination is another barrier to therapeutic alliance reported by Black Americans (43,47,48). The HCS measure used in our study does not include items about discrimination *per se*; therefore, it is unknown whether bereaved parents perceived discrimination from PICU physicians. Prior research suggests that perceptions of discrimination, mistrust, and poor communication by Black Americans are inter-related (43). Black Americans have perceived discrimination when their symptoms or problems were dismissed, when they felt disrespected, or when their perspectives were not acknowledged during clinical encounters (43). Conversely, perceived discrimination can be minimized and therapeutic alliance strengthened when providers develop multicultural competence, express a belief in equality and empowerment, and demonstrate empathy, positive regard, and genuineness (49).

Other parent and child characteristics evaluated in our study were not significantly associated with therapeutic alliance. Attachment represents the basic framework characterizing how a person thinks, feels and behaves in close personal relationships (50). Two fundamental dimensions of attachment are avoidance and anxiety. Individuals with high attachment-related avoidance tend to have a negative view of others and prefer not to rely on others. Those with high attachment-related anxiety tend to have a negative self-image and worry that others will not be available to them. Individuals low on avoidance and low on anxiety have more secure attachment and are more comfortable being close to others, depending on others, and having others depend on them. We evaluated the association between parent attachment and therapeutic alliance because prior research on adult patient-provider relationships suggests that some patients attribute attachment functions to healthcare providers, and that a patient’s dissatisfaction with a provider may be influenced by attachment insecurity (51). We expected that parents with more secure attachment would report greater therapeutic alliance with their child’s physicians although this was not observed. Similarly, characteristics of the child’s death such as cause, trajectory, or mode of death were not significantly associated with alliance.

Whether therapeutic alliance between bereaved parents and PICU physicians has a positive impact on parents’ bereavement experiences is not well understood; however, prior research suggests that parents have many informational, emotional, and other needs near the time of their child’s death and often rely on their child’s healthcare providers to help meet these needs (21,22). HSC items reflecting physician inquiries about parent and family coping, and the offering of hope were scored lowest by parents suggesting these needs were not well met. Future research should investigate relationships between therapeutic alliance and bereaved parents’ health outcomes, as well as the influence of race on these relationships.

Strengths of this study include the multicenter design and racial, ethnic and geographic diversity of the participants. Limitations include the low response rate; however this is typical of parental bereavement research and likely due to bereavement-related distress and the burden of research participation (2,3,6–8,22,23). This study was part of a larger project on parental health outcomes during bereavement and no formal power analysis was performed for the outcome of therapeutic alliance. Parents with strong alliances with physicians may have had greater motivation to participate and may be over-represented in the research. Alternatively, parents with strained relationships may have been more likely to participate as a means of providing feedback. Parents who participated were more often married and more highly educated than the general US population. These factors limit the generalizability of our findings. Characteristics of non-responders, such as race, are unknown because only parental inclusion criteria and contact information were obtained from the medical records of children whose parents did not participate. The HCS scale was developed and validated for use with adult cancer patients and their oncologists, and adapted for use with PICU physicians. Parents likely interacted with several intensivists and subspecialists during their child’s PICU stay; hence, their responses may indicate a general sense of alliance rather than alliance with any specific provider. Therefore, the extent to which parents’ perceptions of alliance relate to the intensivist, other specific provider, or the team as a whole is unknown. Parents completed the HCS approximately 6 months after their child’s death and recall bias may have influenced their responses. Parents’ perceptions of therapeutic alliance likely depend not only on parent and child characteristics but also on the characteristics of the physician with whom the alliance is formed. Physician characteristics and their perceptions of therapeutic alliance were not assessed. Specifically, the extent to which racial discordance between parents and physicians contributed to parents’ assessments of alliance was not evaluated.

CONCLUSIONS

Therapeutic alliance between bereaved parents and PICU physicians is moderately high; however, it is lower for Black parents than White parents. Future research should identify strategies to strengthen therapeutic alliance with Black parents, as well as examine the role of therapeutic alliance on bereaved parents’ health outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Parent Characteristics

Characteristic	Overall (N = 233)
Gender	
Male	87 (37.3%)
Female	146 (62.7%)
Age (years)	
Mean (SD)	38.5 (10.41)
Median [IQR]	37.0 [30.7, 46.1]
Race	
White/Caucasian	155 (66.5%)
Black	46 (19.7%)
Asian	5 (2.1%)
American Indian/Alaskan Native	3 (1.3%)
Native Hawaiian or Other Pacific Islander	0 (0%)
More than one race	3 (1.3%)
Other	16 (6.9%)
Not reported	5 (2.1%)
Ethnicity	
Hispanic or Latino	35 (15.0%)
Non-Hispanic or Latino	192 (82.4%)
Not provided	6 (2.6%)
Education	
Some high school or less	22 (9.4%)
High school graduate or GED[a]	60 (25.8%)
Vocational school or some college	64 (27.5%)
College degree or higher	85 (36.5%)
Not provided	2 (0.9%)
Marital Status	
Married	175 (75.1%)
Single	56 (24.0%)
Not provided	2 (0.9%)
Relation to Child	
Biological parent	215 (92.3%)
Other guardian	18 (7.7%)
Additional Children	
None	42 (18.0%)
One	78 (33.5%)
Two	50 (21.5%)
Three or more	62 (26.6%)
Not provided	1 (0.4%)
6 Month Revised-AAS Avoidance Score[b]	

Characteristic	**Overall (N = 233)**
Mean (SD)	2.6 (0.73)
Median [IQR]	2.7 [2.1, 3.2]
Min, Max	1.0, 4.6
6 Month Revised-AAS Anxiety Score[c]	
Mean (SD)	2.1 (1.00)
Median [IQR]	1.8 [1.2, 2.7]
Min, Max	1.0, 5.0
6 Month HCS Score[d]	
Mean (SD)	51.4 (11.09)
Min, Max	16.0, 64.0

[a] GED is General Education Diploma.

[b] Revised-AAS Avoidance Score is Revised Adult Attachment Scale – Avoidance Score. Value is mean of item responses.

[c] Revsied-AAS Anxiety Score is Revised Adult Attachment Scale – Anxiety Score. Value is mean of item responses.

[d] HCS is The Human Connection Scale. Value is sum of item responses.

Table 2.

Child Characteristics

Characteristic	Overall (N = 157)
Gender	
Male	86 (54.8%)
Female	71 (45.2%)
Age at time of death (years)	
Mean (SD)	8.0 (7.77)
Median [IQR]	5.9 [0.64, 13.9]
Min, Max	0.0, 38.7
Trajectory of Death	
Sudden unexpected death	48 (30.6%)
Death from progressive condition with intermittent crises	44 (28.0%)
Death from potentially curable disease	36 (22.9%)
Death from a congenital anomaly	29 (18.5%)
Mode of Death	
Limitation or withdrawal of life support	114 (72.6%)
Brain death	24 (15.3%)
Failed cardiopulmonary resuscitation	19 (12.1%)
Cause of Death	
Cardiac	40 (25.5%)
Sepsis or multiple organ failure	30 (19.1%)
Neurologic	25 (15.9%)
Respiratory	24 (15.3%)
Trauma	20 (12.7%)
Malignancy	13 (8.3%)
Other	5 (3.2%)
PICU length of stay (days)[a]	
Mean (SD)	22.3 (39.02)
Median [IQR]	6.6 [2.1, 21.8]
Min, Max	0.0, 209.2
Hospital length of stay (days)	
Mean (SD)	27.4 (42.50)
Median [IQR]	8.7 [2.4, 35.0]
Min, Max	0.1, 209.2

[a] PICU is pediatric intensive care unit.

Table 3.

Final Model of Predictors of The Human Connection Scale Scores

Characteristic[a]	**Estimate (95% CI)**	**P-value**[b]	**P-value**[c]
Parent Race			0.0617
White/Caucasian	Reference		
Black	−4.56 (−8.53, −0.60)	0.025	
Other[d]	0.25 (−3.73, 4.22)	0.90	

[a] N=215; Parents with missing data for any variable were excluded.

[b] P-value comparing Black/African American to reference or Other to reference.

[c] P-value for multivariable mixed model.

[d] The category Other collapses all races except White/Caucasian and Black due to small sample size.

Table 4.

The Human Connection Scale Items: Responses for Black and White Parents

Item	All Parents[a] (N = 215) Mean (SD)	White[a] (N = 150) Mean (SD)	Black[a] (N = 38) Mean (SD)
1. How often would you say your child's doctor(s) took the time to listen to your concerns in the ICU?	3.4 (0.80)	3.5 (0.73)[b]	3.1 (0.96)[b]
2. To what extent did your child's doctor(s) pay close attention to what you were saying?	3.4 (0.85)	3.5 (0.77)	3.0 (1.01)
3. To what extent do you think your child's doctor(s) saw your child as a whole person in the ICU?	3.4 (0.81)	3.5 (0.77)	3.2 (0.94)
4. How much did you like your child's doctor(s) in the ICU?	3.3 (0.90)	3.4 (0.80)	2.9 (1.14)
5. How much did you trust your child's doctor(s) in the ICU?	3.4 (0.89)	3.5 (0.74)	2.9 (1.13)
6. How thorough was your child's doctor(s) in the ICU?	3.4 (0.76)	3.5 (0.68)	3.1 (0.84)
7. How much did you respect your child's doctor(s) in the ICU?	3.5 (0.76)	3.6 (0.64)	3.2 (1.02)
8. How much did you feel your child's doctor(s) cared about your child in the ICU?	3.4 (0.82)	3.6 (0.72)	3.0 (0.97)
9. How much of the time would you say your doctor(s) was honest with you in the ICU?	3.4 (0.84)	3.5 (0.75)	2.9 (1.02)
10. To what extent did you feel comfortable asking the doctor(s) questions in the ICU?	3.5 (0.77)	3.6 (0.69)	3.3 (1.00)
11. How often did you understand the doctor's explanations and suggestions in the ICU?	3.3 (0.78)	3.4 (0.73)	2.9 (0.94)
12. How often did your doctor(s) ask how family members were coping with your child's illness or heath condition?	2.5 (0.99)	2.4 (0.90)	2.4 (1.15)
13. How often did your child's doctor(s) offer hope in the ICU?	2.5 (1.00)	2.4 (0.92)	2.5 (1.08)
14. How often did the doctor(s) ask how you were coping with your child's illness or health condition?	2.7 (0.98)	2.6 (0.94)	2.8 (1.01)
15. How concerned do you think your doctor(s) was about your child's quality of life?	3.3 (0.83)	3.4 (0.78)	3.0 (0.97)
16. How open-minded do you feel your child's ICU doctor(s) was?	3.1 (0.96)	3.1 (0.92)	2.8 (1.13)

[a] Scores are from parents included in the multivariable mixed model.

[b] Item response format is: 1=Not at all, 2=Somewhat, 3=Quite a bit, 4=A great deal.