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Effect of a Trauma Informed Care Tool in a Pediatric Cardiac Intensive Care Unit

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A thesis submitted to the graduate school at the University of Missouri-St. Louis in
partial fulfillment of the requirements for the degree

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Abstract

Problem: Parents of infants less than one-year-old with complex congenital heart disease (CCHD) experience significant stress while their child is admitted to the pediatric cardiac intensive care unit (PCICU), often resulting in trauma to parents and their families.

Trauma informed care (TIC) seeks to minimize the impact of emotional trauma and it acknowledges previous trauma an individual may have experienced.

Methods: The purpose of this quality improvement (QI) project was to assess the thrive guide's ability to decrease parental stress in the pediatric cardiac intensive care unit (PCICU). The aim was to decrease parental Perceived Stress Scale (PSS) scores by 10% in parents of infants with CCHD during a twelve-week implementation period. The thrive guide is a TIC tool developed at the project site that is created in collaboration with the family to aid staff in providing TIC. Data was collected from a large, pediatric tertiary care center in a pediatric cardiac intensive care unit.

Results: Analysis included *t*-tests and an ANOVA on pre/post PSS mean scores. A correlation and regression analysis were completed on parental satisfaction surveys of the thrive guide. All analyses were not significant except for the regression analysis which had a p -value = 0.03 showing there is enough evidence to show that there is a positive relationship between a parent's satisfaction survey and the reduction of their PSS score. The average reduction of PSS scores was 12.34%.

Implications for practice: Limitations include a small sample size. Clinical significance supports the use of the thrive guide in the PCICU. Recommendations include widening the inclusion criteria, expanding TIC to the cardiac floor, and expanding staff education of TIC.

Keywords: Trauma informed care, pediatric cardiac intensive care unit, trauma.

Effect of a Trauma Informed Care Intervention in a Pediatric Cardiac Intensive Care Unit

According to the Centers for Disease Control and Prevention (CDC) congenital heart defects affect approximately one percent of births per year in the United States (Centers for Disease Control and Prevention [CDC], 2020). Of that one percent, one in four babies with a congenital heart defect are considered to have complex congenital heart disease (CCHD) and will require surgical intervention or another procedure in their first year of life (Lisanti et al., 2017). Currently, a large amount of literature exists in the neonatal intensive care unit (NICU) and in the pediatric intensive care unit (PICU) settings exploring parental stress as well as previously experienced trauma, and their effects on the child and parent during hospital admission (Lisanti et al., 2017). Less evidence exists focusing on the unique stressors of parents of infants in the pediatric cardiac intensive care unit (PCICU) with CCHD, and these stressors' long-term effects on the parent and child. Studies completed in the NICU setting have shown a NICU admission can result in toxic stress negatively affecting the hypothalamic-pituitary-adrenal axis. This situation can lead to poorly controlled cortisol secretion, which can ultimately have detrimental long-term effects on parents and infants (Sanders & Hall, 2018). It can be reasoned that parents of infants with CCHD admitted to the PCICU have a similar stress response as parents of NICU patients. There is some evidence showing that parents of infants with CCHD experience a significant amount of stress and parental role alteration when their child is admitted to the PCICU, and it has been shown these parents experience more stress if their child is less than a year old (Lisanti et al., 2017). Parents of infants with complex congenital heart disease requiring surgical intervention

experience significant levels of stress which can result in re-traumatization to the parents and their families.

Childhood trauma results in a wide variety of psychobiological problems (Marsac et al., 2016). *Medical trauma* is defined as emotional trauma. The Adverse Childhood Experiences (ACE) study shows a strong correlation between childhood trauma, or what the study refers to as adverse childhood experiences, and adult risk factors associated with high morbidity and mortality in adulthood; trauma informed care attempts to provide care with this relationship in mind (Felitti et al., 1998; Sanders & Hall, 2018). *Trauma informed* care is defined as the implementation of care by healthcare providers to minimize or prevent the impact of emotional trauma. Trauma informed care also acknowledges previous trauma patients, and their families, may have experienced, including toxic stress or adverse childhood experiences. Trauma informed care aims to minimize the potential for medical care to cause trauma or trigger trauma reactions, resulting in overwhelming their coping mechanisms and potentially end in maladaptive behaviors (Marsac et al., 2016; Sanders & Hall, 2018). It acknowledges distress, emotionally supports the family, encourages healthy coping strategies, and provides anticipatory guidance for the trajectory of the hospital admission and beyond (Marsac et al., 2016; Sanders & Hall, 2018).

The projects' purpose was to assess the thrive guide's ability to decrease parental stress in the PCICU. The Iowa Model of Research-Based Practice to Promote Quality Care was the chosen framework to guide the project. The aim of the project was to decrease parental Perceived Stress Scale scores by 10% in parents of infants with CCHD after the implementation of the trauma informed care tool during the twelve-week

implementation period. The primary outcome measure for the project was parental Perceived Stress Scale scores. The secondary outcome measures were parental reported tool satisfaction and PCICU staff reported satisfaction of the thrive guide. The project question for this project was: what is the effect of implementing a trauma informed care tool on parental Perceived Stress Scale score within the twelve weeks of the implementation period?

Literature Review

Three search engines, including PubMed, CINAHL, and Google Scholar, were searched to complete the literature review. The literature review's key terms and phrases included *trauma informed care*, *pediatric*, *intensive care*, *ICU*, *stress*, *parent**, and *cardiac*. The Boolean operators used were OR and AND. The initial search generated 360 results matching the search terms and phrases. Inclusion criteria were studies from 2014-2021, studies published in English, and studies including infants with CCHD requiring cardiac surgery. Most of the studies selected were published in the last five-years to gather the most recent evidence except for one publication. This publication is a classic publication. Exclusion criteria for the publications included those where infants with complex congenital heart disease did not require surgery and those not published in the English language. After applying the inclusion and exclusion criteria, 49 publications were generated and of those, 11 publications were chosen for this literature review.

The Adverse Childhood Experiences (ACE) study was conducted in 1998 and is a large reason for the adoption of trauma informed care within health care systems (Felitti et al., 1998; Goddard, 2021; Kassam-Adams et al., 2015; Koita et al., 2018; Moss et al., 2019; Weiss et al., 2017). The purpose of the ACE study was to determine if a

relationship exists between health risk behaviors disease in adulthood, exposure to emotional abuse, physical abuse, sexual abuse, and household dysfunction during childhood (Felitti et al., 1998). These exposures are what the study refers to as Adverse Childhood Experiences (ACEs) (Felitti et al., 1998). The ACE study found there is a strong dose correlation between the number of exposures to ACEs and the increase of risk factors for several of the leading causes of death in adults. One of the ACE study recommendations is to implement interventions aimed at reducing the prevalence of ACEs. This recommendation in the study promotes the implementation of trauma informed care into healthcare settings.

In recent years, trauma informed care within pediatric healthcare has been being adopted in increasing rates. Of the studies completed in this setting, all but one of them found during the literature review are qualitative in nature (Kassam-Adams, 2015; Lisanti, Golfenshtein, Medoff-Cooper, 2017; Marsac et al., 2016; Moss et al., 2019; Stokes et al., 2017; Strait & Meagher, 2020; Weiss et al, 2017). These qualitative studies supply rich information about health care workers', pediatric patients, and their parents' knowledge, understanding, attitudes, and the overall use of trauma informed care within healthcare. This comprehensive understanding is one of the strengths of this research method. Despite this, these studies fail to create objective results making generalizing their findings to other settings difficult. This is one of the weaknesses of this available evidence. A systematic review completed by Bargeman et al. (in press) discusses the need for trauma informed care interventions in the pediatric setting to be operationalized. This systematic review calls for more studies in the pediatric population that are quantitative in nature to better establish trauma informed care as a treatment model that

can be consistently measured (Bargeman et al. in press). Another study completed by Goddard (2021) also discusses the need to operationalize trauma informed care into practice further emphasizing the importance of creating evidence with measurable outcomes.

The implementation of trauma informed care interventions as well as research on parental stress in the intensive care pediatric population have mostly taken place in the NICU setting. (Coughlin, 2017; Sanders & Hall, 2018). These studies occurring in this setting is one of the weaknesses of this literature review, as there is much less evidence focusing on trauma informed care in the PCICU. While most of this evidence exists in the NICU setting, some evidence does exist exploring parental stress in the PCICU setting. These studies show parents of infants with CCHD experience significant levels of stress and trauma, and one of the studies showed parents of infants less than one year old requiring surgical experience more stress than parents in the same setting with a child older than one year old (Franck et al., 2010; Lisanti et al., 2017). The strengths of these studies exploring parental stress in parents of infants with CCHD is their quantitative research design. One study conducted by Lisanti et al. (2017) evaluated maternal stressors and their stress responses through validated instruments. These instruments are the Parental Stressor Scale: Infant Hospitalization (PSS: IH) and the State-Trait Anxiety Inventory (STAI). These validated instruments allow future studies to utilize these tools to further the evidence of parental stress in the PCICU to fathers or other guardians and not only mothers of infants with CCHD. This would allow for the evaluation of their stress levels with a validated tool allowing for more information other than only maternal stress. The weakness of this evidence includes the lack of the total number of studies

evaluating parental stress of parents of infants with CCHD in the PCICU and the effect of this stress over time. A systematic review conducted by Woolf-King et al. (2017) emphasizes the need for more research on the effects of this stress and its severity in patients and their parents in the PCICU. The systematic review also emphasizes the need for developing interventions that can be practically implemented in the PCICU to minimize stress and long-term mental health problems that may develop from it and demonstrates the need for the implementation of trauma informed care interventions (Woolf-King et al., 2017).

The Iowa Model of Research-Based Practice to Promote Quality Care was the chosen framework to guide the project. This framework focuses on “triggers” for evidence-based practice and in this project the trigger is high parental stress in the PCICU. The project evaluated the effect of a trauma informed care tool on this stress. The model then aids health care practitioners in solving the identified “trigger” or clinical problem through the implementation of evidence-based practice (Hanrahan, 2019). These “triggers” then allow for the Iowa Model of Research-Based Practice to Promote Quality Care algorithm to be initiated within the healthcare organization, where the project will be implemented. Along with this, this model specifically focuses on pilot testing and this project design was a pilot study making it an appropriate model to guide this project (White et al., 2021).

In summary, evidence exists highlighting high levels of parental stress in the PCICU. The ACE study shows a strong dose correlation between exposure to ACEs and adult health risk factors and is the basis for the development of a trauma informed care approach within some healthcare settings and the use of trauma informed interventions.

There is currently a gap in the evidence on the effects of high levels of parental stress in the PCICU and its long-term and traumatic effects on the parents, infants, and entire families. There is also a gap in the evidence focusing on strategies to minimize parental stress and trauma for parents of infants with CCHD. This information helps to guide the development of trauma informed care interventions within this population. The current evidence for the adoption of trauma informed care in the pediatric intensive care patient population, has mostly been implemented in the NICU setting or is a qualitative design method. This furthers the gap in the evidence focusing on the effects of a trauma informed care intervention of infants within the PCICU requiring surgery within their first year of life. The Iowa Model of Research-based Practice to Promote Quality Care was the chosen framework to guide this project and is particularly valuable as it specifically focuses on pilot testing. Parents of infants with CCDH in the PCICU should receive care to minimize stress and trauma, which was a major goal of this project.

Methods

Design

This quality improvement (QI) project utilized a pretest-posttest design (Grove & Gray, 2019). Quantitative data regarding Perceived Stress Scale (PSS) scores were collected on ten parents prior to implementing the tool to gather baseline parental PSS scores. Data regarding PSS scores at the time of implementation of the tool and demographic information were collected on all participants. PSS scores were collected again on all participants seven days after implementation of the tool. At the time of the second PSS, parents completed a survey on their satisfaction with the thrive guide and had an opportunity to share their opinions on the thrive guide. At the completion of the

project period PCICU staff were asked to complete a satisfaction survey of the tool, including opportunity for them to share their opinions on the tool.

Setting

This project occurred in a large, pediatric tertiary care center, in a pediatric cardiac intensive care unit in the metropolitan Kansas City area.

Sample

This project used a purposive convenience sample including parents of patients under one year of age with a complex congenital heart defect diagnosis admitted to the PCICU. Parents of any age were included in the project. Patients who have an existing thrive guide were excluded from the project. A unique alphanumeric identifier was created and applied to each patient to deidentify them. The identifier was the patients' first and last initials and their date of birth. This created a unique eight-digit identifier. A master list of coded identifiers and patients' names and email addresses was stored in a password-protected file on the organization's internal server.

Approval Process

This project was submitted to the Institutional Review Board (IRB) of the project site as well as the University of Missouri – St. Louis IRB.

Data Collection/Analysis

This project investigator completed data collection. Prior to implementation of the QI project, ten parents completed the PSS. No patient identifying information was gathered on these participants. This was a convenience sample and provided baseline data of parental perceived stress of parents who have a child admitted to the PCICU prior to the implementation of the thrive guide QI project. Prior to implementation of the thrive

guide, parents will complete the PSS. This was done via an electronic survey platform made within the organization's applications. In this survey form, parents were asked to list their child's name, their child's birthdate, and their email address. Seven days after the thrive guide interview, parents completed another PSS and at a satisfaction survey on the thrive guide tool. At the end of the project implementation period, project site staff who utilized the thrive guide completed a satisfaction survey. A paired t-test using the SPSS software was used for data analysis of parents PSS.

Procedure

Project site staff education was completed in January 2022 to provide education about the thrive guide tool and its use. Implementation will occur February 2022 and go over a 12-week period.

The thrive guide was implemented on all patients who met inclusion criteria and agree to be in the project. A handout with information of the thrive guide was given to all parents who were approached about the thrive guide. If a family did not want to be included, they could decline with no negative repercussions. A trained project site employee conducted the interview in collaboration with the patient's family to create a thrive guide specific to each patient and their family in the project. The thrive guide was then a part of the patient's electronic medical record (EMR) and accessible to project staff provided care for that patient. The thrive guide was in the M-Pages section of the EMR or could be found in the documents section of the EMR under screenings. Staff handed-off during bedside report that a patient has a thrive guide and utilized the information learned from the guide in the care they provided for the patient and their family. A thrive guide had to be created within four days of admission to the PCICU. If

the guide is not created by then, the patient and their family were excluded from the project.

Results

Parental sample demographics are shown in table 1 as well as the pre-PSS and post-PSS data. PSS scores ranging from 0-13 indicate low perceived stress, scores ranging from 14-26 indicate moderate perceived stress, scores ranging from 27-40 would be considered high perceived stress. Fifteen parents completed the pre-PSS, 4 parents completed the post-PSS. A total of 5 thrive guides were created with one parent being lost to follow up for the post-PSS. Therefore, a total of 4 thrive guides were included in the post-PSS data analysis. The average pre-PSS score is 19.8, with a standard deviation of 7.79, while the average post-PSS score is 16.25 with a standard deviation of 4.35. The average reduction in PSS was found to be 12.34%. To examine the variance between the pre- and post-PSS data, two one-tailed t-tests were performed on the pre-PSS and post-PSS data of parents that went through the thrive guide project. The p-value of a one-tailed paired t-test was found to be 0.20, while the p-value of a one-tailed unpaired t-test was found of 0.40. The variance of the Pre-PSS is 60.74, and the variance of the post-PSS is 18.92. Since these are not within 150% of each other, a one tailed Heteroscedastic t-test was conducted, resulting in a p-value of 0.13. Next, an Analysis of Variance (ANOVA) was conducted on the pre and post populations to further examine if a difference of the variances existed between the populations, which evaluated to having a p-value of 0.34.

Parent satisfaction scores of the thrive guide were collected using four questions pertaining to the thrive guide. The survey questions were evaluated using a Likert scale from a range of 1-5 with 1 being very unsatisfied and 5 being very satisfied. The average

parent satisfaction response score was 4.43 across all questions, with a standard deviation of 0.76. A linear regression was done to examine the reduction in PSS scores with respect to the parent's personal satisfaction with the thrive guide. The correlation coefficient was found to be 0.9326. The linear regression analysis between a parent being satisfied with the trauma informed care communication tool and their reduction in PSS found to have a slope of 1.83, with an r squared value of 0.87. The p-value of the slope being positive, non-zero was found to be 0.03.

Sixteen PCICU nurses were surveyed on their satisfaction and use of the thrive guide in their patient care. See table 3 for staff survey results.

Discussion

The aim of the project was to decrease parental PSS scores by 10% in parents of infants with CCHD after the implementation of the trauma informed care tool during the twelve-week implementation period. This project achieved said goal as the average reduction in PSS score was 12.34%.

All 15 parents' pre-PSS scores were used as a representation of population of parents who have not used the thrive guide. To analyze the efficacy of the thrive guide, a comparison between the pre-PSS and post-PSS populations was done. A one tailed t-test was used to analyze if there was a significant difference between the two population's means in one direction, namely is the post-PSS scores lower than the pre-PSS. Since the ratio of the variance of the pre-PSS scores and the variance of the post-PSS score exceeds 1.5, there is evidence the pre- and post- have a different mean when considering the Heteroscedastic one sided paired t-test having a p-value of 0.13, however since the p-value is not less than 0.05, there is not enough evidential support to show that the pre-

PSS and post-PSS are from populations with a different variance. Next, an ANOVA test was used to examine this difference in means in a different way. The p-value of the ANOVA was 0.34, which again is not enough to be able to assert that there is a significant difference between the means of the two populations.

Since every p-value was greater than 0.05, none were able to show a significant difference between the means of the two populations, meaning it can be said that there is not a significant change in PSS for a parent using the thrive guide. However, it can be said that in every case, a parent's PSS score was not larger than their PSS score before the thrive guide.

An additional analysis was done to correlate a parent's perception of the survey and the magnitude of the impact the thrive guide had on their PSS score. A linear regression was done to examine the reduction in PSS scores with respect to the parent's personal satisfaction with the thrive guide. The correlation coefficient was found to be 0.9326, which shows there is a significant positive relationship between a parent's satisfaction of the thrive guide and the magnitude of the reduction of their PSS score. The linear regression analysis between a parent being satisfied with the trauma informed care communication tool and their reduction in PSS found to have a slope of 1.83, with an r squared value of 0.87, showing that the line of best fit is highly correlated to the data. The p-value of the slope being non-zero was found to be 0.03, which signifies that there is a significant positive relationship between a parent's satisfaction of the thrive guide and the reduction of their PSS score.

Lastly, PCICU staff were surveyed on their satisfaction and use of the thrive guide in their patient care. On average, PCICU nurses reported the thrive guide was

helpful in their ability to engage with parents, enhanced their ability to improve a parent's sense of safety, positively affected their level of trust with parents, improved their collaboration with parents, improved their ability to increase a parent's comfort in caring for their child, improved their ability to empower parents, and improved PCICU nurses' cultural humility to better understand the values of parents. On average, most of the nurses surveyed reported they utilized the thrive guide less than half of their shifts due to being they were not aware if their patient had a thrive guide created, or their patient did not have a thrive guide made. Anecdotally, staff reported the education of the thrive guide increased their knowledge of trauma informed care, and they anecdotally understand the value of a trauma informed care communication tool such as the thrive guide.

For implications for practice, with these two seemingly contradictory results, one showing there is no significant difference in PSS scores for a parent who had a thrive guide created, whereas the other shows that there is a moderately to very strong correlation to a parent's satisfaction with the survey, and the reduction of their PSS score, there is not a definitive assertion to be made on the efficacy of the thrive guide. This phenomenon is an instance of the Simpson's Paradox; however, a more controlled QI project would need to be done to provide further validation, namely including all admitted patients to PCICU in the project to have more samples from the pre thrive guide distribution. It must also be noted that the correlation between a parent's satisfaction with the thrive guide and their efficacy of it is a very natural result, as if the parent's PSS score was reduced, it is natural for the parent to look favorably towards the survey. Due to the confounding nature of the variables in the regression analysis of them having a

correlation coefficient of 1.83, the relative inference strength of the results is diluted, as opposed to the strength of argument from the t-tests ran.

Recommendations for further projects include widening the inclusion criteria to include all patients and their parents admitted to the PCICU. This would widen the scope of the project to establish a better understanding of the PSS score distribution for pre- and post-PSS scores and the potential differences between the two distributions. Another recommendation is to expand the project to include the cardiac floor. This project only took place in the PCICU and thus education to staff only included PCICU staff.

Expanding the project to include the cardiac floor staff could further benefit patients and their parents admitted to the hospital. Parental stress is likely most strongly correlated with the condition of their child, including questions evaluating the health status of their child could provide more data pertaining to PSS. Lastly, expanding staff education on the thrive guide would be beneficial to increase the use of it with this patient population.

Conclusion

While the project question was empirically validated with at least a 10% reduction of PSS scores was achieved, the targeted reduction of the PSS score was not a significant reduction. Despite this, there was never an increase in parental perceived stress after the thrive guide was implemented. Despite a lack of significance, parents reported satisfaction with the thrive guide. PCICU nurses who completed the satisfaction survey reported satisfaction with the thrive guide tool, but responses also showed the need for increased education as some nurses reported not knowing what a thrive guide is or that a patient had one made.

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Table 1*Parent Demographic Information, Pre-PSS scores, Post-PSS scores*

Participant	Parental Age	Parental Sex	Ethnicity	Language	Pre- PSS	Post- PSS	Difference
1	41	Female	White	English	23	-	
2	31	Female	Hispanic/Latino	Spanish	17	17	0
3	29	Female	White	English	13	12	1
4	30	Female	White	English	24	22	2
5	32	Female	White	English	21	14	3
6	18	Female	Black	English	19	-	-
7	21	Male	White	English	14	-	-
8	28	Female	White	English	5	-	-
9	20	Female	White	English	27	-	-
10	28	Female	White	English	11	-	-
11	39	Female	White	English	25	-	-
12	32	Female	White	English	23	-	-
13	29	Female	White	English	14	-	-
14	32	Male	Black	English	24	-	-
15	26	Female	White	English	37	-	-

Table 2

Parental Satisfaction Scores of the Thrive Guide

Parent Participant	How Satisfied were you with the thrive guide?	How satisfied were you with the thrive guide interview?	How satisfied were you with staff having the information in the thrive guide available to them?	How would you rate communication between staff and you/your family?	Average Score
1	5	5	5	4	4.75
2	5	5	5	5	5
3	5	5	5	4	4.75
4	5	5	5	2	4.25

Table 3

Staff Satisfaction Scores

Respondent	How helpful is the information of the thrive guide on the impact of your ability to engage with the family?	The thrive guide affected your ability to improve a parent's sense of safety	The thrive guide positively affected your levels of trust with parents	The thrive guide positively affected collaboration or partnership with parents	The thrive guide positively affected your ability to increase a parent's comfort in caring for their child	The thrive guide has positively affected your ability to empower parents	How often did you read the thrive guide?	If you did not use the thrive guide, what was the reason?
1	2	1	1	1	1	1	1	4
2	3	2	2	1	1	1	1	
3	1	1	1	1	1	1	1	4
4	3	2	2	2	2	2	2	
5	1	1	1	1	1	1	1	4
6	3	2	1	2	2	2	2	
7	5	2	2	2	2	2	2	
8	2	1	2	1	1	2	1	4
9	2	1	1	1	1	1	1	4
10	3	1	1	2	1	1	1	4
11	3	1	1	1	1	1	1	2
12	1	1	1	1	1	1	1	4
13	2	1	1	1	1	1	1	4
14	2	1	1	1	1	1	1	2

15	3	2	2	2	2	2	2	2
16	3	1	1	1	1	1	1	2
Average response	2.4375	1.3125	1.3125	1.3125	1.25	1.3125	1.25	2.08

Note. Column two question is a Likert scale question with 1=very helpful, 2=helpful, 3=neutral, 4=unhelpful and 5= very unhelpful; column 3-7 asks staff whether they agree (1) or disagree (2) with the statement; column 8 is a Likert scale question with 1=every shift, 2=more than half the shifts, 3=half the shifts, 4=less than half the shifts, 5=never; column 9 numerical responses correlate to the following: 1=not aware of the thrive guide, 2=no easy access to the thrive guide, 3=it was not useful 4=other, 5=never.

Appendix A.

This is the thrive guide template.

Thrive Guide:

Thrive Guide offered: Healthcare offered a Thrive Guide
 Family declined a Thrive Guide

Relevant Family History and Information:
*Past experiences that could trigger upsetting memories
*Life situations that are contributing to current family stress
*Patient and family viewpoints, including medical and cultural considerations/preferences
Save UI

Coping Strategies/Information:
*Specific ideas/techniques that help family to cope
Save UI

Communication Tools:
*Most effective ways to provide medical information to patient/family
*Family preference for communication and inclusion in treatment planning process
*Patient/family preferred methods of receiving education
Save UI