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Post-Intensive Care Syndrome: Comparison of Educational Interventions to Educate Parents of Children Hospitalized in the Pediatric Intensive Care Unit at St. Louis Children's Hospital

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Abstract

Background: Family members of children hospitalized in the pediatric intensive care unit (PICU) can develop cognitive, psychological, and physical manifestations of post-intensive care syndrome (PICS). Targeted education to help parents/caregivers recognize the signs and symptoms of PICS may result in better awareness of the syndrome and greater willingness to seek and receive support during their child's PICU admission.

Objective: to evaluate three targeted PICS educational interventions to increase PICS awareness among parents/caregivers in the St. Louis Children's Hospital (SLCH) PICU.

Results: A total of 62 parents/caregivers received one of three educational interventions: informational brochures (n=22), scripted informational conversation (n=20), or three-minute educational video (n=20). An additional 19 bedside nurses completed surveys to describe how each educational intervention affected daily work flow. Changes in parental/caregiver PICS fund of knowledge was evaluated using Fischer's exact test. All three educational interventions were associated with a significant improvement in understanding of PICS, with no single intervention being superior. Nursing surveys indicated that work flow was minimally disrupted using PICS education and that all interventions were perceived to be important and useful.

Conclusions: Targeted educational interventions led to improvement in knowledge about PICS among parents/caregivers and were well supported by PICU nursing staff. Thus, providing support for a sustainable implementation of PICS education in the SLCH PICU.

Introduction

In recent years, investigators in the United States and Europe have identified significant mental health complications in patients and their families during and after intensive care unit (ICU) stays. Long-term follow-up assessments show that up to 80% of ICU survivors experience emotional trauma (Colville, Orr & Gracey, 2003; Colville, Kerry & Pierce, 2008; Colville, 2008; Davydow, Richardson, Zatzick, & Katon, 2010; Elison, Shears, Nadel, Sahakian & Garralda, 2008). According to Davidson, Harvey, Schuller, & Black (2013), one-third of family members of ICU patients suffer signs and symptoms of depression and about 70% experience signs and symptoms of anxiety. In many cases, these symptoms meet DSM-IV criteria for post-traumatic stress disorder (PTSD), anxiety, and depression (Balluffi et al., 2004; Bronner, Knoester, Bos, Last & Grootenhuis, 2008). In recent years, these symptoms have been conceptually organized under the umbrella term "post-intensive care syndrome" (PICS). Needham et al. (2012) describe PICS as new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute care hospitalization. PICS can be applied to not only a survivor but also to his or her caregivers and family members. This concept encompasses the effects of critical illness on acute and chronic psychological morbidity among patients' family members and has been coined "post-intensive care syndrome-family" (PICS-F). Symptoms experienced by family members can include but are not limited to, sleep deprivation, anxiety, depression, complicated grief and PTSD. Symptoms of PICS and PICS-F can persist for months or years after the initial ICU admission.

In the past two years, the Society of Critical Care Medicine (SCCM) has lead efforts to support adult ICU programmatic efforts to educate families about PICS and PICS-F, provide structured psychological support for patients and their families during the ICU admission, and develop longitudinal ICU recovery programs that include psychological counseling. Despite this, to date, there are few published accounts of a standard approach to the identification and management of PICS and PICS-F in the PICU setting.

The PICU at St. Louis Children's Hospital (SLCH) cares for over 2,000 critically ill children every year. Our current practice makes no mention of the risk of PICS or PICS-F, and we provide no standardized assessment nor treatment for families experiencing the emotional and mental health problems associated with their child's ICU admission. Early identification and management of PICS and PICS-F is important and necessary. Given the rates of symptoms described in the literature, as many as a thousand SLCH PICU families will experience mental health problems related to their child's PICU stay each year.

Problem and Purpose Statement

Family members of children hospitalized in the pediatric ICU (PICU) can develop cognitive, psychological, and physical manifestations of post-intensive care syndrome (PICS). In the 2015 annual Society of Critical Care Medicine Presidential address, Craig Coopersmith highlighted PICS as a clinical imperative for the critical care community, adding that there remains a lack of comprehensive education and management of PICS (Coopersmith, 2015). More lacking is how we address PICS with families when the patient is a child. Our study team, Stephanie Esses, MSN, RN, CPNP; Dr. Mary E.

Hartman, MD, MPH; Ashley Rodemann, MSW, LCSW; Sara Small, MSW, implemented targeted educational interventions to achieve parent/caregiver awareness of PICS in the St. Louis Children's Hospital (SLCH) PICU.

The study aimed to develop three PICS education strategies for parents/caregivers, assess the efficacy of each approach as a PICS educational intervention, and to determine the feasibility and acceptability of each strategy among the staff and leadership of the SLCH PICU. The study and preliminary work outlined are part of a larger team effort to develop the first comprehensive PICU Recovery Program in the United States.

Review of Literature and Summary

After an extensive literature review, a table (Appendix A) was developed selecting articles that best described children, family, and caregivers with signs and symptoms related to PICS and PICS-F. The table recognizes authors who addressed post-discharge PICS symptoms and treatment as well as those who addressed caregiver needs through needs assessment research. The literature review began with a search of "PICS" in UpToDate. After analyzing articles and original sources cited, a PubMed search was conducted using the terms: "Post Intensive Care Syndrome" OR "Post-Intensive Care Syndrome" OR "Post-Intensive Care Rehabilitation." From this, the following databases and search terms were used:

PubMed: (post intensive care syndrome* OR post-intensive care syndrome* OR post-intensive care rehabilitation*) OR (("Cognition Disorders"[Mesh] OR "Cognition Disorders" OR Cognitive Impairment* OR Cognitive Deficit* OR Cognitive Defect* OR "physical problems" OR physical issue* Or physical symptom* OR "Depression"[Mesh]

OR "Depressive Disorder"[Mesh] OR depression* OR depressive OR "Anxiety"[Mesh] OR anxiety* OR "Stress Disorders, Post-Traumatic"[Mesh] OR post traumatic stress disorder* OR PTSD[tiab] OR "Posttraumatic Neuroses" OR Posttraumatic Stress Disorder* OR "Post-Traumatic Neuroses")) AND (("Intensive Care Units"[Mesh] OR intensive care unit* OR ICU[tiab]) AND ("post discharge" OR "post-discharge" OR postdischarge OR ICU survivor*))

Embase: ('post intensive care syndrome' OR 'post-intensive care syndrome' OR ‘post-intensive care rehabilitation’) OR (('cognitive defect'/exp OR ‘cognition disorder’ OR (cognitive NEAR/1 (defects OR deficit* OR disability OR disorder* OR dysfunction OR impairment*)) OR (physical NEAR/1 (problem* OR issue* OR symptom*)) OR 'depression'/exp OR depression OR 'anxiety'/exp OR anxiet* OR 'posttraumatic stress disorder'/exp OR ('post traumatic' NEAR/1 stress) OR PTSD:ti,ab OR 'posttraumatic neurosis' OR 'posttraumatic psychic syndrome' OR 'posttraumatic psychosis' OR 'trauma and stressor related disorders' OR ‘traumatic stress’) AND ('intensive care unit'/exp OR 'intensive care unit’ OR ICU:ti,ab) AND ('post discharge' OR 'post-discharge' OR postdischarge OR ‘ICU survivor’))

CINAHL: "post intensive care syndrome" OR "post intensive care syndromes" OR “post-intensive care rehabilitation” OR ((MH "Cognition Disorders") OR "cognitive defect" OR (MH "Delirium, Dementia, Amnestic, Cognitive Disorders") OR “cognition disorder” OR “cognitive deficit” OR “cognitive disability” OR “cognitive dysfunction” OR “cognitive impairment” OR “physical problem” OR “physical issues” OR “physical symptoms” OR (MH "Depression") OR "depression" OR (MH "Anxiety Disorders") OR "anxiety" Or (MH "Stress Disorders, Post-Traumatic") OR "post

traumatic stress disorder" OR PTSD OR “traumatic stress”) AND ((MH "Intensive Care Units") OR (MH "Intensive Care Units, Pediatric") OR "intensive care unit") AND (“post discharge” PR “post-discharge” OR postdischarge OR “ICU survivor”)

Cochrane: ("post intensive care syndrome" or "post-intensive care syndrome" or "post-intensive care rehabilitation") OR ((([mh "Cognition Disorders"] OR (cogniti* NEAR/1 (defects OR deficit* OR disability OR disorder* OR dysfunction OR impairment*))) OR (physical NEAR/1 (problem* PR issue* OR symptom*)) OR [mh "depression"] OR [mh "depressive disorder"] OR depression OR [mh "anxiety"] OR anxiety OR [mh "Stress Disorders, Post-Traumatic"] OR ("post traumatic" NEAR/1 stress) OR PTSD OR (traum* NEAR/1 stress)) AND ([mh "intensive care units"] or (“intensive care unit”) AND ("post traumatic”) Summary of Findings

Initial results of this literature search identified 130 articles in PubMed, 121 articles in Embase, 18 in CINHAL, and 50 in Cochrane. After removing redundant search results, a total of 273 unique articles remained. Those titles were then reviewed for relevancy. The remaining 13 works constituted the final search results and were read in their entirety for inclusion in this report.

Of the 13 articles, three constituted systematic searches. One such article, by van Buesekom, Bakhshi-Raiez, de Keizer, Dongelmans & van der Schaaf (2016), reviewed qualitative and quantitative studies in PubMed and CINAHL from database inception until June 2014. The aim was to provide a broad overview of ICU caregiver reported hardships to make recommendations on which burdens require further assessment in this population. The most common reported outcomes were psychosocial burdens with the prevalence of anxiety at 15-24%, depression at 5-36%, and PTSD at 35-57% after six

months' post-discharge. An additional four articles were cohort studies examining PTSD, PICS, and acute stress syndrome. A single randomized control trial was highlighted as part of the literature review. In this study, caregivers received a psychoeducational tool, outlining the possible psychological reactions in children and parents, and a phone call to address each family's post-discharge experience. As a result, parents who received the intervention reported lower post-traumatic stress symptoms in themselves and fewer emotional and behavioral difficulties in their children (Als, Nadel, Cooper, Vickers, & Garralda, 2015).

Literature demonstrates anxiety and depression are significant symptoms experienced by patients and caregivers post-discharge from an ICU (Elliott et al., 2014). Preventative and therapeutic measures for post-intensive care syndrome-family have not been formally evaluated. Ward-Begnoche (2007) asserts research in risk and resiliency factors for pediatric patients and their caregivers is still underdeveloped. To date, there are few publications exploring the provision of psychological support for families with a child in the PICU (Als, Nadel, Cooper, Vickers & Garralda, 2015). With fewer accounts of a standard approach to the identification and management of PICS in the PICU setting. Those reports that do exist have demonstrated variable benefit, with improvements in mental health symptoms often failing to justify follow-up clinics (Colville, Cream & Kerry, 2010; Samuel, Colville, Goodwin, Ryninks & Dean, 2015). A consistent limitation in these programs, however, is that none offered a systematic approach to educating families about mental health symptoms they might expect during their child's PICU admission and in most studies mental health services did not begin until after PICU discharge. We believe our approach is novel in that it provides a comprehensive program

of education and support that begins during the PICU admission. Unlike other investigators, our study team has already conducted a needs assessment in the PICU at SLCH, identifying the baseline understanding and acceptance of mental health services among our families.

Prior Work

From June to September 2014, a SLCH study team consisting of two PICU social workers, a PICU nurse practitioner and a PICU physician, conducted a survey of PICU patients and their families to understand family perceptions related to their PICU experience and the subsequent impacts on their mental health functioning. The team conducted in-person interviews with 30 parents (22 mothers, 8 fathers) to explore what types and level of mental health services families were aware of, using, or open to receiving. All families had children admitted to the PICU for a minimum of 24 hours at the time of the interview. Half of the participants were in their first admission to the PICU, 13 had been admitted to the SLCH PICU previously, and two had prior PICU admissions at other local ICUs. Parents were asked a series of needs/needs met questions using the Critical Care Family Needs Inventory (Molter, 1979) and Needs Met Inventory (Kosco & Warren, 2000). From this, parents were asked to identify on a one to four scale their needs and how well they were met. Parents responded a median rate of three when asked how important it was to discuss their feelings, and a two with how well that need is currently met in the PICU. Following the inventory, parents were asked a series of open-ended questions about their PICU admission.

The majority (83%) of parents were previously unaware of the potential risks for mental health problems that often accompany ICU care, but readily acknowledged the

difficulty and stressors that accompanied their own child's PICU admission. Almost three-quarters of parents (73%, n=22) stated that they would be open to receiving follow-up services to assist with coping and managing stress, but 14 of 22 parents reported they would not be open to 'counseling.' We believe these data indicate that our families have a limited understanding of the mental health component of PICS, but have a strong desire for more information and mental health services. They also indicate that while our families wish to receive support for the early symptoms of PICS, they do not want to discuss the symptoms or treatment in traditional mental health terms.

Framework

Our current study sought the best way to talk with families about the emotional and mental health stressors of having a child in the PICU, the most effective way to introduce the term "post-intensive care syndrome" (PICS), and educate families about PICS symptom recognition and management. We did this by comparing three education strategies using the Practical, Robust Implementation and Sustainability Model (PRISM) framework (Feldstein & Glasgow, 2008). Each strategy was evaluated with respect to the elements of consideration within this framework, including:

Program: Assesses the actual intervention, with specific attention paid to the perspectives of both our PICU providers (i.e. usability, repeatability, and observability of results) and patients (i.e. patient-centeredness, access, privacy, usability, and burden)

External environment: Relates the intervention to other institutional and community resources, and considers the role of reimbursement (if relevant)

Implementation and sustainability infrastructure: Considers the presence of adopter training and support, a dedicated team, ability to share best practices, ability to track performance data, and a plan for sustainability

Recipients: Considers characteristics of both the organization (i.e. organizational culture, clinical leadership, data and decision support, staffing, and incentives) and parents/caregivers (i.e. pre-existing knowledge and beliefs, competing demands and disease burden).

We chose three strategies because they represented a variety of education approaches, including auditory, visual and experiential learning. The three strategies selected were: (1) Brochures handed to participants to read, (2) a conversation with a study team member using a loosely outlined script, or (3) a three-minute video for viewing. All participants, no matter the intervention, received the brochures. However, to ensure that all families had access to emergency mental health resources at any point in their hospital stay, the participants in the non-brochure intervention groups received the printed material after their post-intervention survey.

Methods

Our study team had three specific aims when conducting this study:

Aim 1: To develop three tailored PICS education strategies for families in the SLCH PICU.

Aim 2: To assess the efficacy of each education strategy as a PICS educational intervention.

Aim 3: To assess the acceptability of each education strategy for full implementation in the SLCH PICU.

Aim 1 was achieved over a three-month period, during which the brochures, script and video were created. After a literature review and sharing the results with the study group, work began on drafting the brochures and video script. As part of the process, we invited a parent of a former PICU patient who suffered from PICS, to help with suggestions and refine the material. The brochures were sent to the Family Resource Center (FRC) at SLCH to evaluate for content and reading ease. Once approved by the FRC, multiple meetings with SLCH's marketing team helped to further refine the brochure content and pictures. Following two draft revisions, the brochures were sent to our printers. The SLCH PICU covered the cost of printing, which was $200 for 400 brochures. The video script was review and edited by our study group multiple times before final approval and was recorded with the use of SLCH's videographer at no cost to our team. The video was then downloaded to our purchased portable tablet. The conversational script was developed from the brochures and video to reflect the flow and content of both.

In Aim 2, study subjects included PICU parent/caregivers who were randomized to receive one of the three educational interventions (brochure, video, or conversation with study team member) (Appendices B, C & D). After the consent process, each parent/caregiver was provided a brief, pre-intervention PICS knowledge assessment by a study team member. The survey consisted of eight items to elicit the parent/caregiver's familiarity with the term 'post-intensive care syndrome,' its signs and symptoms, and how to seek help for associated symptoms. Items on this assessment were scored on a 3-point Likert-type familiarity scale with responses ranging from "1-never heard of" to "3-very familiar" with a neutral/no opinion and an "I do not wish to answer" option.

Parents/caregivers were also asked to complete a nine-item demographic survey (Appendix E). These items address the participant's relationship to the patient, sex, age, marital status, education level, type of insurance, employment status, proximity to the hospital, and previous trauma in the past twelve months. This data was collected to understand our family population for the future development of the PICU Recovery Program to address PICS. After educational strategy deployment, a similar fund of knowledge survey was provided to parents/caregivers as the post-intervention survey (Appendix F). Our sample size goal was 20 participants in each educational intervention. We exceeded our sample size goal, with 20 to 22 participants per intervention.

To assess the acceptability of each education strategy in Aim 3 for full implementation in the SLCH PICU, study subjects included bedside PICU nurses. Bedside nurses caring for children whose parents were participating in the PICS educational study were asked to complete a survey (Appendix G) to gather more information with focus on the PRISM Framework. A total of 19 bedside nurses completed the 19item survey. Again, items on this assessment were scored on a 3-point Likert-type familiarity scale with responses ranging from "1-never heard of" to "3-very familiar" with a neutral/no opinion and an "I do not wish to answer" option.

Inclusion and Exclusion Criteria

Patient families eligible for participation were 18 years of age or older, English speaking adult parent/caregivers of children who have been admitted to the PICU for a minimum of 24 hours and are expected to survive their PICU stay. Only bedside nurses of participating families were eligible for participation in Aim 3 of the study.

Procedures

All study procedures were reviewed and approved by the Washington University in St. Louis (Appendix H) and the University of Missouri in St. Louis (Appendix I) institutional review boards. Recruitment took place between January and February 2017, with the assistance of our study team members. All participants, including bedside nurses, showed willingness to participate in the study by verbal informed consent (Appendix J).

Data Analysis

Data Analysis for Aim 1: None necessary.

Data analysis for Aim 2: Parental/caregiver PICS fund of knowledge pre- and post-educational intervention was evaluated using Fischer's exact test; specifically looking at responses of "somewhat familiar" and "very familiar."

Data analysis for Aim 3: Final analysis of the three education strategies considered the elements of the PRISM Framework. Components included the external environment, cost and resource requirements of each strategy (collected in Aim 1); the program, measured by the efficacy of the education strategies themselves (collected in Aim 2); the implementation and sustainability infrastructure, measured by PICU nursing's perceptions of the PICU culture and its readiness to adopt this education program (collected in Aim 3); and the recipients of the education, focusing on parent/caregivers' perceptions of the usefulness, usability and acceptability of each strategy (collected in Aim 3). Upon completion of this analysis, results were presented to SLCH PICU staff and leadership for consideration of permanent implementation of the recommended strategy in the SLCH PICU.

Parent/Caregiver Results: Demographic Data

The study included a total of 62 participants (Table 1), of which 21 were male, and 41 were female. Most respondents were ages 25-34 years (47%), with the next largest group being ages 35-44 years (21%). Half of the respondents were employed full-time, and 25% of participants were stay at home parents.

Table 1: Sample Characteristics

Table 1. Sample Characteristics (*N*=62)	
Demographics	*n* (%)
Age:	
15 to 24 years	6 (10)
25 to 34 years	29 (47)
35 to 44 years	13 (21)
45 to 54 years	6 (10)
55 to 64 years	8 (13)
Marital status:	
Single, never Married	12 (19)
Married or domestic partner	40 (65)
Widowed	7 (11)
Divorced	2 (3)
Separated	1 (2)
Employment status:	
Full-time worker	31 (50)
Part-time worker	9 (15)
Unemployed	3 (5)
Stay at home parent	16 (26)
I do not wish to answer	3 (5)

Table 1. Sample Characteristics (*N*=62)

Insurance:	
Commercial (Private)	37 (61)
Medicaid (Government)	20 (33)
Military	2 (3)
Uninsured	2 (3)
Highest Level of Education Completed:	
Did not complete high school	4 (7)
High school diploma/GED	11 (18)
Some college	17 (27)
College degree	20 (32)
Master's degree	9 (15)
Doctorate degree/Advanced graduate work	1 (2)
Travel Time from Home to Hospital:	
Less than 30-minute drive	16 (26)
30 to 60-minute drive	18 (29)
60 to 90-minute drive	10 (16)
Over 90-minute drive	18 (29

Of these participants, 56% (35/62 respondents) were mothers, 31% (19/62 respondents) were fathers, 6% (4/62 respondents) were grandparents, 3% (2/62 respondents) identified as an aunt/uncle, 2% (1/62 respondents) were foster parents and 2% (1/62 participants) identified as other. The "other" self-identified as a patient's sister.

Participants were asked, "Have you ever heard about symptoms of depression, anxiety, grief, and/or post-traumatic stress disorder (PTSD) related to a stay in the

intensive care unit?" 36 participants (58%) responded "No," and 25 participants replied "Yes." However, when asked, "Do you know what post-intensive care syndrome (PICS) is?" over 67% (42/62 participants) replied, "Never heard of."

When participants were asked "What is your interest and willingness to return to St. Louis Children's Hospital to participate in follow-up rehabilitation therapy, medical care, and/or counseling services," over 56% (35/62 respondents) reported "likely interested" or "very interested." When asked "What is your interest and willingness to participate in massage services, therapy services, meditation services, and/or receive wellness passes to the gym while your loved one is hospitalized in the Pediatric Intensive Care Unit," over 70% reported "likely interested" or "very interested."

Parent/Caregiver Results: Frequency Data

A Fischer's exact test was conducted to compare post- to pre-intervention PICS fund of knowledge for parents/caregivers of children hospitalized in the PICU at SLCH. Comparisons were made using "somewhat familiar" and "very familiar" with the post- compared to the pre-intervention survey data. There was a significant difference in scores between the pre- and post-educational intervention for all three educational interventions. No one educational intervention was superior to any of the others regarding new knowledge gained by study participants.

Table 2: Brochures, Conversation, and Video P-values
Brochures:

Survey Questions n=22	Pre-Intervention n (%)	Post-Intervention n (%)	p-value
Do you know what PICS is?			
Never heard of	17 (77)	2 (9)	
Neutral/No opinion	0	0	
Somewhat familiar	5 (23)	7 (32)	0.0002
Very familiar	0	13 (59)	
Do you know the signs and symptoms of PICS?			
Never heard of	17 (77)	3 (14)	
Neutral/No opinion	0	0	
Somewhat familiar	3 (14)	3 (14)	< 0.0001
Very familiar	2 (9)	16 (72)	
Are you aware of a Hospital PICU Support Program?			
Never heard of	19 (86)	4 (19)	
Neutral/No opinion	1 (5)	0	
Somewhat familiar	2 (9)	3 (14)	< 0.0001
Very familiar	0	14 (67)	
Do you know how to contact a social worker?			
Never heard of	8 (38)	3 (14)	
Neutral/No opinion	1 (5)	0	
Somewhat familiar	3 (14)	2 (10)	0.01
Very familiar	9 (43)	16 (76)	
Are you aware of resources to help with the management of PICS?			
Never heard of	19 (86)	2 (9)	
Neutral/No opinion	0	0	
Somewhat familiar	3 (14)	5 (23)	< 0.0001
Very familiar	0	15 (68)	

Conversation:

Survey Questions n=20	Pre-Intervention n (%)	Post-Intervention n (%)	p-value
Do you know what PICS is?			
Never heard of	11 (55)	1 (5)	
Neutral/No opinion	1 (5)	0	
Somewhat familiar	7 (35)	9 (45)	0.0004
Very familiar	1 (5)	10 (50)	
Do you know the signs and symptoms of PICS?			
Never heard of	13 (65)	3 (15)	
Neutral/No opinion	0	0	
Somewhat familiar	6 (30)	8 (40)	0.003
Very familiar	1 (5)	9 (45)	
Are you aware of a Hospital PICU Support Program?			
Never heard of	15 (79)	2 (10)	
Neutral/No opinion	1 (5)	0	
Somewhat familiar	3 (16)	7 (35)	< 0.0001
Very familiar	0	11 (55)	
Do you know how to contact a social worker?			
Never heard of	0	0	
Neutral/No opinion	2 (10)	0	
Somewhat familiar	5 (25)	4 (20)	0.5
Very familiar	13 (65)	16 (80)	
Are you aware of resources to help with the management of PICS?			
Never heard of	13 (65)	2 (11)	
Neutral/No opinion	1 (5)	0	
Somewhat familiar	4 (20)	9 (47)	0.001
Very familiar	2 (10)	8 (42)	

Video:

Survey Questions n=20	Pre-Intervention n (%)	Post-Intervention n (%)	p-value
Do you know what PICS is?			
Never heard of Never heard of	14 (70)	1 (5)	
Neutral/No opinion	1 (5)	0	
Somewhat familiar	4 (20)	8 (40)	< 0.0001
Very familiar	1 (5)	11 (55)	

Survey Questions n=20	Pre-Intervention n (%)	Post-Intervention n (%)	p-value
Do you know the signs and symptoms of PICS?			
Never heard of	15 (75)	1 (5)	
Neutral/No opinion	1 (5)	0	
Somewhat familiar	3 (15)	8 (40)	< 0.0001
Very familiar	1 (5)	11 (55)	
Are you aware of a Hospital PICU Support Program?			
Never heard of	14 (70)	2 (10)	
Neutral/No opinion	1 (5)	1 (5)	
Somewhat familiar	4 (20)	7 (35)	0.0003
Very familiar	1 (5)	10 (50)	
Do you know how to contact a social worker?			
Never heard of	1 (5)	0	
Neutral/No opinion	2 (10)	0	
Somewhat familiar	9 (45)	9 (45)	0.2
Very familiar	8 (40)	11 (55)	
Are you aware of resources to help with the management of PICS?			
Never heard of	14 (70)	2 (10)	
Neutral/No opinion	2 (10)	0	
Somewhat familiar	2 (10)	5 (25)	< 0.0001
Very familiar	2 (10)	13 (65)	

Nursing Results: Frequency Data

Bedside nurses were approached to participate in a survey after their patient's parent/caregiver completed the post-intervention survey. A total of nineteen nurses participated in the survey. When discussing compatibility, over 84% (16/19 respondents) responded "very" to the following questions: (1) Teaching families about PICS is compatible with my work flow, (2) I think using the PICS educational tools fit well with the way I like to work, and (3) Using the PICS educational tools fits into my work style. Over 81% (13/16 respondents) of nurses reported "yes" to "Before handing out the PICS educational tools, I was able to properly read/watch/listen to the material." With

assessment of ease of use, over 88% (16/18 respondents) responded “very” to “The PICS educational tools are clear and understandable.” Over 77% (14/18 respondents) responded “very” to “I believe that it is easy to introduce the educational tools” and over 94% (17/18 respondents) answered “very” to, “Overall, I believe in the PICU Recovery Program.” 84% (16/19 respondents) felt “the PICS educational tools are useful to families,” and 100% of respondents reported “very” to, “Patients and families will benefit from the educational tools and a program to address PICS.” Lastly, the organizational climate was addressed with over 94% (18/19 respondents) of nurses responding “very” to, “Our organization seeks new and innovative ways to connect with patients and their families” and “Our organization promotes programs that promote health and well-being for patients and their families” (Figure 5).

Table 3: Nursing Survey

Nurse Survey Questions n=19	Somewhat n (%)	Very n (%)
Compatibility		
Teaching families about PICS is compatible with my work flow	2 (11)	16 (84)
I think using the PICS educational tools fit well with the way I like to work	2 (11)	16 (84)
Using the PICS educational tools fits into my work style	3 (16)	16 (84)
Trialability		
Before handing out the PICS educational tools, I was able to properly read/watch/listen to the material	3 (19)	13 (81)
Ease of Use		
The PICS educational tools are clear and understandable	0	16 (89)
I believe that it is easy to introduce the educational tools	3 (17)	14 (79)
Overall, I believe in the PICU Recovery Program	1 (6)	17 (94)
Learning how to distribute the PICS educational tools is easy	1 (6)	16 (89)
The environment I work in makes it difficult to use the PICS educational tools	4 (22)	5 (28)
The wording used in the educational tools is clear and unambiguous	0	15 (83)
Perceived Usefulness		
I think the PICS educational tools are useful for families	2 (11)	16 (84)
The PICS educational tools enhance my effectiveness in discussing how parents can help themselves	5 (26)	12 (63)
I find the PICS educational tools useful	2 (11)	15 (79)
Patients and families will benefit from the educational tools and a program to address PICS	0	19 (100)
Organizational Climate		
Our administration is willing to take a chance on a good idea	1 (5)	17 (89)
Our organization seeks new and innovative ways to connect with patients and their families	1 (5)	18 (95)
Our organization promotes programs that promote health and wellbeing for patients and their families	1 (5)	18 (95)
	Yes	No
It does not matter what I think about the PICS educational tools, I will be expected to hand them out	5 (26)	14 (74)

Discussion

In this study, an evaluation of three educational strategies to talk to parents/caregivers of pediatric ICU patients about post-intensive care syndrome (PICS) was completed. The results suggest that when families are educated about PICS, their understanding of the syndrome, its signs and symptoms, how to contact a social worker, self-management techniques, and knowledge of resources increases. However, there was not enough data to suggest that one intervention was more superior in educating individuals than another.

Being that there is no statistically significant difference between the interventions, our team looked at the strategies through the lens of the PRISM framework. Evaluation within this model considers the elements of program, external environment, implementation and sustainability, infrastructure, and recipients' needs. From a programmatic standpoint, and with data from the nurse surveys, our study team would recommend the nursing staff be a part of future education. By training the staff to hand out the brochures with a brief discussion on the topic, the PICU's relative competency and fund of knowledge would be maintained. Though adopter training and support would be necessary, the burden to workflow would be minimal. The cost of two brochures, which participants received, was fifty cents. From this standpoint, the video appears to be the most economical choice because it does not require explanation and is on a pre-purchased iPad. However, there are some drawbacks of the iPad/video strategy. With the use of a single iPad for education, there would likely be a bottleneck effect in efforts to educate multiple families or if the iPad is not functioning properly, families will lack timely education. From an infection control standpoint, this intervention could have

a negative effect and be costly. This educational intervention also limits nursing's ability to educate families, resulting in loss of staff knowledge and likely loss of interest as well. The conversation educational intervention, though effective, would likely require a more significant time commitment from staff and the parent/caregiver would not be left with something tangible to reference later. Face-to-face education would be the most cost prohibitive option considering time and staffing costs. After careful examination of each educational intervention, our team recommends use of brochures for future education. Pamphlets provide a tangible resource throughout a family's admission and after discharge home. The production cost is minimal and can be covered within the SLCH PICU budget.

Limitations

There is no way of judging whether the process of pre-testing influenced the post-test results, as there was no baseline measurement against groups and no group remained completely untreated. Participants were randomized to an intervention and there was no baseline assessment of learning preferences or reading ability. Participants were not isolated from one another and it cannot be determined if participants talked to other participants concerning the study. Also, participants may have answered the post-intervention survey in a manner that reflected learning to please the study team.

Conclusion and Future Directions

ICU admission, and a new significant healthcare problem may have long-term psychological effects on both children and parents/caregivers. An early educational intervention provides parents/caregivers improved knowledge of PICS, available resources to aid coping, and understanding of how to gain access to help both in- and out-

patient. Evaluation of educational interventions to educate parents of hospitalized children in the PICU at SLCH has demonstrated PICS educational tools to be associated with a significant improvement in understanding of PICS. Furthermore, nursing surveys indicated that work flow was minimally disrupted using PICS education and that all interventions were perceived to be important and useful. With this study, we propose the continued development of the PICU Recovery Program and full implementation of the brochure handouts for all SLCH PICU caregivers.

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*References found on the literature table in Appendix A

Appendix A

Literature Table

Author/Year	**Focus/ Purpose**	**Conceptual/ Theoretical Framework**	**Paradigm and Methods**	**Context/ Setting/ Sample**	**Findings**	**Gaps/ Limitations**
Balluffi et al. (2004)	-Measure prevalence of parental acute stress disorder (ASD) and PTSD and assess associations among demographic, situational, and illness factors and severity of symptoms	-Pediatric Risk of Mortality (PRISM) score -ASD Scale and PTSD Checklist -Additional questions concerning worry on a 5-point-Likert-type scale	-Prospective cohort study	-38 bed PICU, urban children's hosp.	-Traumatic stress symptoms common among parents may persist long after discharge	-Single PICU setting -No assessment of ethnicity, race or SES (all factors that carry varying risk of developing PTSD)
Als, L.C., Nadel, S., Cooper, M., Vickers, B., & Garralda, M.E. (2015)	-To assess feasibility and pilot a supported psychoeducational tool to improve parent and child mental health following	-Parents received a psychoeducational tool, outlining the possible psychological reactions in children and parents, and a phone call to address each family's post-	-Feasibility assessment and single-center, parallel group, pilot RCT.	-A PICU in an acute care hospital in London, UK	-The feasibility and pilot RCT provided valuable information on the intervention and trial design for a full RCT -Parents who received the intervention reported lower post-traumatic stress symptoms in	-The feasibility pilot RCT was performed at a single center -The sample size fell short of its target

Author/Year	**Focus/ Purpose**	**Conceptual/ Theoretical Framework**	**Paradigm and Methods**	**Context/ Setting/ Sample**	**Findings**	**Gaps/ Limitations**
	discharge from a PICU	discharge experience.			themselves and fewer emotional and behavioral difficulties in their children	
van den Born-Van Zanten, S.A., Dongelmans, D.A., Dettling-Ihnenfeldt, D., Vink, R., van der Schaaf, M. (2016)	-Describes the level of caregiver strain and posttraumatic stress-related symptoms in relatives of ICU survivors	-Relatives of ICU survivors, mechanically ventilated for > 48 hours in the ICU, were asked to complete a questionnaire 3 months after discharge -Symptoms of PTSD and caregiving concerns were assessed using the Trauma Screening Questionnaire and the Caregiver Strain Index (CSI)	-A cohort study	-12 bed adult ICU	-Relatives of ICU survivors could experience strain 3 months after hospital discharge and are at risk of developing PTSD-related symptoms	-No information collected on the relatives' previous psychosocial status or previous caregiving tasks -A large proportion of patients and caregivers declined the invitation to visit the post-ICU clinic
Farley, K.J., Eastwood, G.M., &	-Study aimed to ascertain the incidence and severity of	-Patients received the EuroQol-5D and Hospital Anxiety and	-A single center cohort study of all patients	-Single hospital ICU, 27 patients	-ICU survivors report impaired quality of life with most experiencing	-Small patient sample size -Single center study

Author/Year	**Focus/** **Purpose**	**Conceptual/** **Theoretical Framework**	**Paradigm and Methods**	**Context/** **Setting/** **Sample**	**Findings**	**Gaps/** **Limitations**
Bellomo, R. (2016)	PICS symptoms in patients surviving prolonged ventilation and to describe their views regarding follow-up clinics	Depression Scale (HADS) via phone interview and were questioned on their views about the possible utility of a follow-up clinic	discharged alive after ventilation in an ICU for 7 or more days	were part of the study	significant psychological symptoms of depression and/or anxiety -Majority believed that a follow-up clinic would be beneficial	-No assessment of pre-ICU function
Al-Mutair, A., Plummer, V., Clerehan, R., & O'Brien, A. (2014)	-To identify the perceived needs of Saudi families of patients in the ICU in relation to their culture and religion	-Individual, semi-structured interviews of a purposive sample of 12 family members seeking to evaluate family members needs and experiences	-A descriptive exploratory qualitative study	-Eight mixed medical-surgical ICUs of eight major trauma hospitals in Saudi Arabia	-Study provided in-depth understanding of family members' experience of having a relative in the ICU and focused on unmet needs, particularly those related to culture and religion	-Small sample size -Inclusion of family members within 24 hours of admission to the ICU -Only family members present at the ICU were asked to participate -Family members of an ICU patient that died were not included in the study
Dow, B.L., Kenardy, J.A., Le Brocque, R.M., &	-Explores the diagnosis of PTSD in children and adolescents	-PTSD was assessed via diagnostic interview (Children's PTSD	-Face-to-face interview or by letter and	-59 children aged 6-16 admitted to the PICU for at least 8 hours	-Few differences seen in patterns of symptom presentation between school-aged	-Modest sample size

Author/Year	**Focus/** **Purpose**	**Conceptual/** **Theoretical Framework**	**Paradigm and Methods**	**Context/** **Setting/** **Sample**	**Findings**	**Gaps/** **Limitations**
Long, D.A. (2013)	following PICU admission -Explores the validity of the DSM-IV PTSD algorithm and alternative PTSD algorithm (PTSD-AA)	Inventory) 6 months following PICU discharge -All statistical analyses were performed using the Statistical Package for Social Sciences (SPSS 19.0)	follow-up phone call		children and adolescents -Use of PTSD-AA and no C3 is the most valid algorithm	
van Beusekom, I., Bakhshi-Raiez, F., de Keizer, N.F., Dongelmans, D.A., & vand der Schaaf, M. et al. (2016)	-Aim was to provide a complete overview of the types of burdens reported in informal caregivers of adult ICU survivors to make recommendations on which burdens should be assessed in this population	-Two independent reviewers used a standardized form to extract characteristics of caregivers and burdens -Quality of included studies assessed using the Newcastle-Ottawa and PEDro scales	-Systematic search in PubMed and CINAHL from database inception until June 2014 -Qualitative and quantitative studies reviewed	-Of the 2000+ articles, 28 were included in the literature review	-Most common reported outcomes were psychosocial burden -Six months' post-discharge prevalence of anxiety was 15-24%, depression 4.7-36.4% and PTSD 35-57.1%	-More high-quality studies needed to obtain accurate assessments of the prevalence and severity of burdens of informal caregivers suffer

Author/Year	**Focus/ Purpose**	**Conceptual/ Theoretical Framework**	**Paradigm and Methods**	**Context/ Setting/ Sample**	**Findings**	**Gaps/ Limitations**
	and which tools should be used to assess them					
Needham et al. (2012)	-Report on a 2-day SCCM conference aimed at improving the long-term outcomes after critical illness for patients and families	-SCCM members presented a summary of existing data regarding the potential long-term physical, cognitive and mental health problems after an ICU stay and the results from studies of post-intensive care unit interventions to address these problems	-Stakeholders provided reactions, perspectives, concerns and strategies aimed at improving care and mitigating long-term health problems	-Thirty-one stakeholders representing key professional organizations /groups, predominantly from North America, involved in the care of intensive care survivors	-3 themes emerged: 1) raising awareness and education, 2) understanding and addressing barriers to practice, and 3) identifying research gaps and resources	-An agenda to improve issues could not be developed w/in 2 days -Lack of representation from primary care providers, geriatricians, hospitalists, social workers, care coordinators, policymakers and payers.
Davydow, D.S., Zatzick, D., Hough, C.L., & Katon, W.J. (2013)	-Determine if in-hospital acute stress symptoms were associated w/ impaired 12-	-In-hospital symptoms assessed w/ Posttraumatic Stress Disorder Checklist-Civilian Version and post-ICU stay cognition	-Patients were enrolled prospectively interviewed before	-137 non-trauma patients without cognitive impairment or a dementia diagnosis who	-In hospital, acute stress symptoms were associated w/ greater impairment in 12-month performance	-Single center serving for study -Data only from patients who consented to participate in the study; can't characterize

Author/Year	**Focus/** **Purpose**	**Conceptual/** **Theoretical Framework**	**Paradigm and Methods**	**Context/** **Setting/** **Sample**	**Findings**	**Gaps/** **Limitations**
	mo. cognitive functioning among ICU survivors	was assessed with the modified Telephone Interview for Cognitive Status	hospital discharge and again via telephone at 12 months post-ICU	were admitted to an ICU for more than 24 hours	-impairment could be partially mediated by post-ICU PTSD	potential differences between the study cohort and all ICU survivors
Melhorn et al. (2014)	-Assess the effectiveness of rehabilitation interventions in adult post-ICU patients	-Comparative studies of rehabilitation interventions in adult post-ICU patients -Two reviewers extracted data and assessed risk of bias independently	-Systematic literature search in databases, reference lists and hand search - From 4000+ publications, 18 studies with 2,510 patients were included.	-Studies assessed 20 outcomes using 45 measures, covering various healthcare settings	-Positive effects seen for ICU-diary interventions for PTSD -More interventions for the growing number of ICU survivors needed	-Relevant studies may have been missed due to indexing limitations in the new field of post-ICU patient care -Only studies published in peer-reviewed journals were accepted, publication bias possible

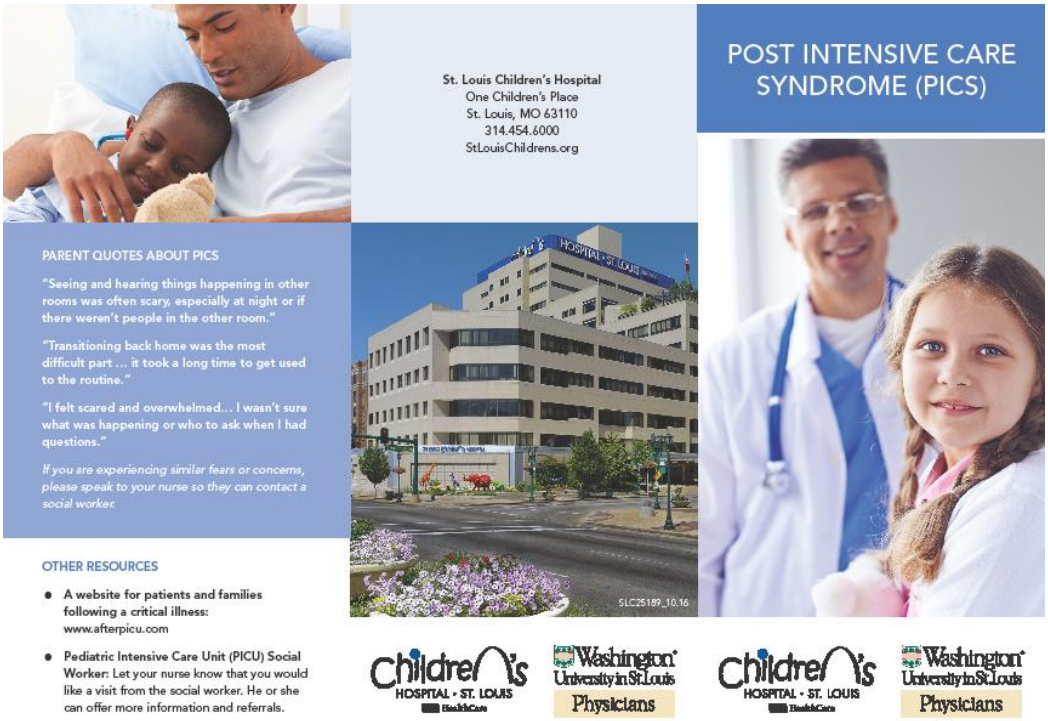
Author/Year	**Focus/** **Purpose**	**Conceptual/** **Theoretical Framework**	**Paradigm and Methods**	**Context/** **Setting/** **Sample**	**Findings**	**Gaps/** **Limitations**
Choi et al. (2014)	-Examines prevalence of caregiver self-reported fatigue, explores longitudinal trends in caregiver fatigue and compares caregivers' psycho-behavioral stress responses	-The Short-Form 36 Health Survey vitality subscale was used to measure caregiver self-reported fatigue -The Center for Epidemiologic Studies Short Depression Scale was used to measure depressive symptoms -The Brief Zarit Burden Interview-12 items was used to measure caregiver burden -The Caregiver Health Behavior 11-item scale was used to measure self-reported health risk behaviors in caregivers -The Pittsburg Sleep Quality Index was used to	-Secondary analysis using dataset obtained from a longitudinal study that explored bio-behavioral stress responses in family caregivers of critically ill adults who required prolonged acute mechanical ventilation	-49 pairs of caregivers and patients were recruited in a32 bed ICU in a tertiary academic medical center located in western Pennsylvania	-Caregivers who reported clinically significant fatigue also reported more depressive symptoms, health risk behaviors, and poorer sleep quality at ICU admission, which persisted over four months post-ICU discharge -Fatigue is common in caregivers of ICU survivors and potentially linked with caregivers' reports of psycho-behavioral stress responses	-Unable to obtain measures of fatigue from caregivers before the time of ICU admission or immediately after ICU admission -Sample was limited to caregivers of ICU survivors who were available at four months post-ICU discharge -10 of 28 caregivers (36%) reported the patient had one or more impairments in activities of daily living, requiring caregiver assistance, before the ICU admission

Author/Year	**Focus/ Purpose**	**Conceptual/ Theoretical Framework**	**Paradigm and Methods**	**Context/ Setting/ Sample**	**Findings**	**Gaps/ Limitations**
		measure caregivers' sleep quality				
Jensen, J.F., Thomsen, T., Overgaard, D., Bestle, M.H., Christensen, D., & Egerod, I. (2015)	-Evaluate the impact of routine follow-up consultations vs. standard of care for ICU survivors on quality of living and on anxiety, depression, PTSD, physical ability, cognitive function and return to work	-This systematic review follows the preferred reporting items for systematic reviews and meta-analyses guidelines (PRISMA) -Two reviewers extracted data and assessed quality independently	-Systematic literature review from 5 databases, reference lists, citation traction, and ongoing/unpublished trials -Randomized controlled trials investigating post-ICU consultations	-From 1,544 citations, fiver trials were included (855 patients) -ICU patients were 18 and above -Individual-based and group-based interventions regardless of setting were included (home, clinic, online, etc.)	-Follow-up consultations that informed patients about their ICU stay failed to affect quality of life (QOL), anxiety, depression, physical and cognitive function, and return to work -Significant reduction in the risk of new onset PTSD at 3-6 mos after ICU discharge in patients receiving follow up	-Poor effect of follow-up consultations on QOL may be due to the generic nature of the SF-36 and EQ-5D questionnaires -Post-ICU follow-up is still poorly indexed in the literature review and a broad range of synonyms were used -Inconsistencies in the setup of the follow-up programs (times, setting, theoretical stance, etc.), challenging generalization -A few of the studies were small and one likely underpowered, posing a threat to the internal validity of the review
Choi et al. (2015)	-Describe depressive symptoms and	-Shortened Version of Center for Epidemiologic	-Secondary analysis, using the	-Analyzed data from 39 ICU survivors who	-Younger age, being female, and experiencing a	-Small sample size

Author/Year	**Focus/** **Purpose**	**Conceptual/** **Theoretical Framework**	**Paradigm and Methods**	**Context/** **Setting/** **Sample**	**Findings**	**Gaps/** **Limitations**
	anxiety in ICU survivors and explore symptoms based on individual care needs and discharge disposition for 4 months post-ICU discharge	Studies-Depression 10 items were used to measure depressive symptoms -Shortened Profile of Mood States-Anxiety scale was used to measure anxiety -Activities of daily Living and Instrumental Activities of Daily Living were used to determine patient's care needs at each time point	data from a study that explored bio-behavioral stress responses in family caregivers of ICU survivors who underwent mechanical ventilation	self-reported measures of depressive symptoms and anxiety	shorter ICU stay resulted in higher anxiety scores at 2 weeks -Depressive symptoms were common throughout the 4 month follow up period -Worsening depressive symptoms and anxiety when cares needs were moderate or high	-Recruitment from a single medical ICU in an academic medical center -Attrition due to mortality was high, further reducing sample size -Analysis does not have sufficient power to detect longitudinal changes or differences between variables

Appendix B

Sample Brochure



PARENT QUOTES ABOUT PICS

"Seeing and hearing things happening in other rooms was often scary, especially at night or if there weren't people in the other room."

"Transitioning back home was the most difficult part … it took a long time to get used to the routine."

"I felt scared and overwhelmed… I wasn't sure what was happening or who to ask when I had questions."

If you are experiencing similar fears or concerns, please speak to your nurse so they can contact a social worker.

OTHER RESOURCES

- **A website for patients and families following a critical illness:** www.afterpicu.com
- **Pediatric Intensive Care Unit (PICU) Social Worker:** Let your nurse know that you would like a visit from the social worker. He or she can offer more information and referrals.

St. Louis Children's Hospital
One Children's Place
St. Louis, MO 63110
314.454.6000
StLouisChildrens.org

POST INTENSIVE CARE SYNDROME (PICS)

Children's HOSPITAL • ST. LOUIS
Washington University in St. Louis Physicians
Children's HOSPITAL • ST. LOUIS
Washington University in St. Louis Physicians

PICU PARENT QUOTES

"One of the most helpful things was figuring out who to talk to."

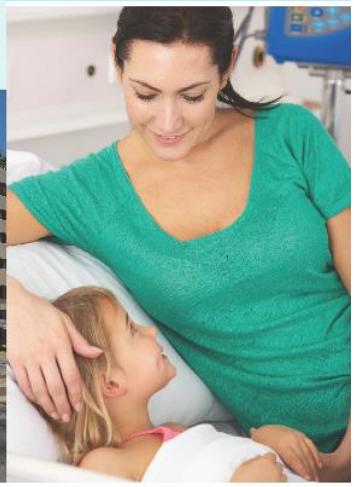
"It was difficult to figure out where to sleep or other basic routines once my child was admitted."

"Living so far away from the hospital made everything even more difficult."

You are not alone, St. Louis Children's Hospital is here to help.

St. Louis Children's Hospital
One Children's Place
St. Louis, MO 63110
314.454.6000
StLouisChildrens.org

PEDIATRIC INTENSIVE CARE UNIT (PICU) RECOVERY PROGRAM



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Children's HOSPITAL • ST. LOUIS
Washington University in St. Louis Physicians

Appendix C

Video Script

Hi, Welcome to Saint Louis Children's hospital Pediatric Intensive Care Unit. We would like to take a few minutes to talk to you and your family about PICS, which is post intensive care syndrome, and what it means for you and your loved one. Health care professionals once thought patients who returned home after a critical illness returned to how they were before. However, stories from patients and families with profound struggles after hospitalization have taught us that any stay at an intensive care unit is a very troubling and stressful time for you and your child. We now know that many children and their families return home very different than they were before.

Research shows that up to a half of children and their parents will develop at least one symptom of post intensive care syndrome at some point in their recovery. PICS is a cluster of health problems that may develop during and after your child's stay in the hospital. Your child may experience changes to their brain, body and emotions. Some of these changes can be physical such as weakness, fatigue, changes in memory, attention and problem solving (showing up as learning problems) or emotional problems such as sadness, unpredictable or uncontrollable outbursts, or your child having a hard time reconnecting with friends and family members

Even family members can experience physical and emotional symptoms of PICS such as anxiety, depression, and extreme grief. This is called PICS-family.

Recovery from a serious illness only begins in the hospital. For many families, life does not return to normal after hospital discharge. Symptoms can persist for weeks, months or over a year. Some of these changes will be noticeable after you and your child have been discharged home.

Family members may experience symptoms including stress, anxiety, and depression. It is not uncommon to have feelings of being overwhelmed, changes in your sleeping or eating, irritability or moodiness, loss of enjoyment in activities and isolation and loss of social connections.

As we recognize the impact stress can have on our lives, we can start to develop skills to cope. Helpful coping strategies while in the hospital can include:

Acknowledging you have been through a traumatic event. Journaling your feelings can help.

Connecting with others, such as getting support from family, friends or your spiritual leader. St. Louis Children's hospital offers a variety of support, all of which is available at your request.

Taking care of yourself. Make sure you get adequate sleep, nutrition and time away from your child's bed. We offer a family waiting room, cafeteria, garden and Ronald McDonald room to allow for time away.

Encourage your children to talk about their feelings. We offer child life services to talk to your children through age appropriate play and music therapy.

Appendix D
Conversation Outline

Welcome family to the PICU

Discuss terms PICS and PICS-F

Outline what research has demonstrated (i.e. over half of children and their parents will develop at least one symptom of PICS at some point in their recovery and research show patients and family members may have profound struggles after hospitalization)

Address signs and symptoms of PICS

Discuss the cognitive, emotional and psychological changes in simple terms (i.e. cognitive: changes in memory/attention or problem solving difficulties, emotional: uncontrollable outbursts/having a hard time reconnecting with friends or family, psychological: extreme grief, symptoms of depression or anxiety)

Address helpful coping strategies parents/caregivers can employ while their child is still in the hospital

Acknowledging you have been through a traumatic event. Journaling your feelings can help.

Connecting with others, such as getting support from family, friends or your spiritual leader. St. Louis Children's hospital offers a variety of support, all of which is available at your request.

Taking care of yourself. Make sure you get adequate sleep, nutrition and time away from your child's bed. We offer a family waiting room, cafeteria, garden and Ronald McDonald room to allow for time away.

Encourage your children to talk about their feelings. We offer child life services to talk to your children through age appropriate play and music therapy.

Ask for help. Let others know if you need help with meals, errands or house chores. Talk to your physician, nurse practitioner, social worker or chaplain about support and resources.

Address how parents/caregivers can get social work involvement and what services they can offer

Summarize what PICS and PICS-F

State the mission of St. Louis Children's Hospital

Remind the parent/caregiver that they can access the provided educational brochures for more information

Appendix E
Pre-Intervention Survey

How are you related to the infant/child?

Mother (biological/adoptive)

Father (biological/adoptive)

Grandparent

Aunt/Uncle

Foster parent

Other (please list):

I do not wish to answer

What is your gender/gender identification? Please circle

Male

Female

I do not wish to answer

What is your age? Please circle

15-24 years old

25-34 years old

35-44 years old

45-54 years old

55-64 years old

65-74 years old

75 years or older

I do not wish to answer

What is your marital status? Please circle

Single, Never Married

Married or Domestic Partner

Widowed

Divorced

Separated

I do not wish to answer

What is your employment status? Please circle

Full time worker (employee)

Part-time worker (employee)

Unemployed

Stay at home parent

Retired

Other (please list):

I do not wish to answer

What type of insurance does your family carry?

Commercial (Private)

Medicaid

Military

Uninsured

I do not wish to answer

What is the highest level of education you have completed? Please circle

Did Not Complete High School

High School Diploma/GED

Some College

College Degree

Master's Degree

Doctorate Degree/Advanced Graduate Work

I do not wish to answer

What is your drive time from your home to this hospital? Please circle

Less than 30-minute drive

30 to 60-minute drive

60 to 90 minutes (1 to 1 ½ hours)

Over 90 minutes (over 1 ½ hours)

I do not wish to answer

Have you experienced any of the following in the last 12 months? Please circle

Serious accident of illness/medical procedure (of yourself or loved one)

Previous hospitalization (of yourself or loved one)

Grief/loss

Financial burden (i.e. unemployment, loss of job, inability to pay bills)

Martial conflict/Separation/Divorce

Displacement from home

Witness or victim of abuse (emotional, physical or sexual)

Witness to or victim of violence

Substance abuse (yourself or loved one)

Household mental illness

Incarcerated (yourself or household member)

I do not wish to answer

Have you ever heard about symptoms of depression, anxiety, grief, and/or post-traumatic stress disorder (PTSD) related to a stay in an intensive care unit? Please circle No

Please read each question and circle a number that corresponds with your level of understanding.

1 = Never heard of

2 = Somewhat familiar

3 = Very familiar

4 = Neutral/No opinion

Do you know what post-intensive care syndrome (PICS) is?

1 2 3 4 I do not wish to answer

Do you know the signs and symptoms post-intensive care syndrome?

1 2 3 4 I do not wish to answer

Are you aware of this hospital's Pediatric Intensive Care Unit Recovery Program?

1 2 3 4 I do not wish to answer

Do you know how to contact a social worker?

1 2 3 4 I do not wish to answer

Do you know how you can self-manage stress?

1 2 3 4 I do not wish to answer

Are you aware of resources to help with management of PICS?

1 2 3 4 I do not wish to answer

Please read each question and circle a response that corresponds with your level of understanding.

St. Louis Children's Hospital cares about my child and my family

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

St. Louis Children's Hospital wants to help my child and my family recover after leaving the intensive care unit

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

Appendix F
Post-Intervention Survey

What is your interest and willingness to return to St. Louis Children's Hospital to participate in follow-up rehabilitation therapy, medical care, and/or counseling services? Please circle.

Not Interested

Somewhat Interested

Not sure

Likely Interested

Very Interested

I do not wish to answer

What is your interest and willingness to participate in massage services, therapy services, meditation services, and/or receive wellness passes to the gym while your loved one is hospitalized in the Pediatric Intensive Care Unit?

Not Interested

Somewhat Interested

Not sure

Likely Interested

Very Interested

I do not wish to answer

Who in your family, do you think, would benefit from these services? Please circle one or more choices.

Mother (biological/adoptive)

Father (biological/adoptive)

Grandparent

Aunt/Uncle

Foster parent

Sibling (please list ages):

Other (please list):

I do not wish to answer

Please read each question and circle a number that corresponds with your level of understanding.

1 = Never heard of

2 = Somewhat familiar

3 = Very familiar

4 = Neutral/No opinion

Do you know what Post-Intensive Care Syndrome (PICS) is?

1 2 3 4 I do not wish to answer

Do you know the signs and symptoms of PICS?

1 2 3 4 I do not wish to answer

Are you aware of a Hospital PICU (Pediatric Intensive Care Unit) Support Program?

1 2 3 4 I do not wish to answer

Do you know how to contact a social worker?

1 2 3 4 I do not wish to answer

Do you know how you can self-manage stress?

1 2 3 4 I do not wish to answer

Are you aware of resources to help with management of PICS?

1 2 3 4 I do not wish to answer

Before you received the brochures (and/or the video or conversation), did you know what post-intensive care syndrome (PICS) was?

1 2 3 4 I do not wish to answer

Please read each question and circle a response that corresponds with your level of understanding.

I understood the information provided in the brochures

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

The language and writing was clear in the brochures

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

I understood the information provided in the video (DO NOT answer if you did not see a video)

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

The conversation I had with a healthcare provider on PICS was clear and I understood the information (DO NOT answer if you did not have a conversation)

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

St. Louis Children's Hospital cares about my child and my family

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

St. Louis Children's Hospital wants to help my child and my family recover after leaving the intensive care unit

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

I have gained enough knowledge about post-intensive care syndrome (PICS) to teach someone who is not familiar with the term

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

I feel there are resources that are available to address my concerns of post-intensive care syndrome (PICS).

Never Slightly Not Sure/No Opinion Quite Extremely I do not wish to answer

Appendix G
Nurse Survey

Please read each question and circle a number that corresponds with your views.

1 = Never

2 = Somewhat

3 = Very

4 = Neutral/No opinion

Compatibility:

Teaching families about PICS is compatible with my work flow

1 2 3 4 I do not wish to answer

I think using the PICS educational tools fit well with the way I like to work

1 2 3 4 I do not wish to answer

Using the PICS educational tools fits into my work style

1 2 3 4 I do not wish to answer

Repeatability:

Before handing out the PICS educational tools, I was able to properly read/watch/listen to the material

Yes -or- No I do not wish to answer

I was permitted to hand out the PICS educational tools and answer questions

Yes -or- No I do not wish to answer

Ease of Use:

The PICS educational tools are clear and understandable

1 2 3 4 I do not wish to answer

I believe that it is easy to introduce the educational tools

1 2 3 4 I do not wish to answer

Overall, I believe in the PICU Recovery Program

1 2 3 4

Learning how to distribute the PICS educational tools is easy

1 2 3 4 I do not wish to answer

The environment I work in makes it difficult to use the PICS educational tools

1 2 3 4 I do not wish to answer

The wording used in the educational tools is clear and unambiguous

1 2 3 4 I do not wish to answer

Perceived Usefulness:

I think the PICS educational tools are useful for families

1 2 3 4 I do not wish to answer

The PICS educational tools enhance my effectiveness in discussing how parents can help themselves

1 2 3 4 I do not wish to answer

I find the PICS educational tools useful

1 2 3 4 I do not wish to answer

Patients and families will benefit from the educational tools and programs to address PICS

1 2 3 4 I do not wish to answer

Organizational Climate:

It does not matter what I think about the PICS educational tools, I will be expected to hand them out

Yes -or- No I do not wish to answer

Our administration is willing to take a chance on a good idea

1 2 3 4 I do not wish to answer

Our organization seeks new and innovative ways to connect with patients and their families

1 2 3 4 I do not wish to answer

Our organization promotes programs that promote health and well-being for patients and their families

1 2 3 4 I do not wish to answer

Appendix H

Washington University IRB Approval

IRB ID #: 201610149

To: Mary Hartman

From: The Washington University in St. Louis Institutional Review Board,

WUSTL DHHS Federalwide Assurance #FWA00002284

BJH DHHS Federalwide Assurance #FWA00002281

SLCH DHHS Federalwide Assurance #FWA00002282

Re: St. Louis Children's Hospital Post-Intensive Care Syndrome (PICS) Education Strategy Assessment

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Approval Date: 12/12/16

Next IRB Approval

Due Before: 11/16/17

Type of Application:	**Type of Application Review:**	**Approved for Populations:**
☐ New Project		☐ Full Board: ☐ Children
☐ Continuing Review	Meeting Date:	☐ Signature from one parent
☒ Modification ☐ Signature from two parents		☒ Expedited
	☐ Exempt	☐ Prisoners

☐ Facilitated ☐ Pregnant Women, Fetuses, Neonates

☐ Wards of State

☐ Decisionally Impaired

Criteria for approval are met per 45 CFR 46.111 and/or 21 CFR 56.111 as applicable.

MATERIALS APPROVED

Consent/Assent Materials:

Consent & Assent Forms

Informed consent IRB updated.rtf

Questionnaires:

Subject Data Collection Instruments

PICS Post-Intervention Questionairre.rtf

PICS Nursing Questionairre.rtf

PICS Pre-Intervention Questionnaire Edited.rtf

This approval has been electronically signed by IRB Chair or Chair Designee:

Melanie Koleini, MS

12/12/16 1120

Appendix I
UMSL IRB Approval

Office of Research Administration
One University Boulevard
St. Louis, Missouri 63121-4499
Telephone: 314-516-5899
Fax: 314-516-6759
E-mail: ora@umsl.edu

DATE: January 21, 2017

TO: Stephanie Esses

FROM: University of Missouri-St. Louis IRB

PROJECT TITLE: [993975-2] PICS Education Strategies

REFERENCE #:
SUBMISSION TYPE: New Project

ACTION: APPROVED

APPROVAL DATE: January 21, 2017
EXPIRATION DATE: January 20, 2018

REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # *7*

The chairperson of the University of Missouri-St. Louis IRB has reviewed the above mentioned protocol for research involving human subjects and determined that the project qualifies for expedited review under Title 45 Code of Federal Regulations Part 46.110b. The time period for this approval expires one year from the date listed below. You must notify the University of Missouri-St. Louis IRB in advance of any proposed major changes in your approved protocol, e.g., addition of research sites or research instruments.

You must file an annual report with the committee. This report must indicate the starting date of the project and the number of subjects to date from start of project, or since last annual report, whichever is more recent.

Any consent or assent forms must be signed in duplicate and a copy provided to the subject. The
principal investigator must retain the other copy of the signed consent form for at least three years following the completion of the research activity and they must be available

for inspection if there is an official review of the UM-St. Louis human subjects research proceedings by the U.S. Department of Health and Human Services Office for Protection from Research Risks.
This action is officially recorded in the minutes of the committee.
If you have any questions, please contact Carl Bassi at 314-516-6029 or bassi@umsl.edu.
Please include your project title and reference number in all correspondence with this committee.

Appendix J
Informed Consent Document

INFORMED CONSENT DOCUMENT

Project Title: St. Louis Children's Hospital Post-Intensive Care Syndrome (PICS) Education Strategy Assessment

Principal Investigator: Mary Hartman

Research Team Contact: Stephanie Esses 314-454-4775

This consent form describes the research study and helps you decide if you want to participate. It provides important information about what you will be asked to do during the study, about the risks and benefits of the study, and about your rights and responsibilities as a research participant. By signing this form, you are agreeing to participate in this study.

- You should read and understand the information in this document including the procedures, risks and potential benefits.
- If you have questions about anything in this form, you should ask the research team for more information before you agree to participate.
- You may also wish to talk to your family or friends about your participation in this study.
- Do not agree to participate in this study unless the research team has answered your questions and you decide that you want to be part of this study.

WHAT IS THE PURPOSE OF THIS STUDY?

This is a research study. We invite you to participate in this research study because healthcare professionals once thought patients and parents who returned home after a critical illness returned to how they were before. However, research shows that up to half of children and their parents/caregivers will develop at least on symptom of post-intensive care syndrome (PICS).

PICS is a cluster of health problems that may develop during or after your child's stay in the hospital. You or your child may experience changes in your/their brain, body and/or emotions. This study offers information about PICS and helps you better understand the symptoms and how to address your concerns.

The purpose of this research study is to inform families/caregivers about post-intensive care syndrome (PICS) through selected learning strategies and assess the ability of the information to produce the intended result of educating individuals about PICS.

WHAT WILL HAPPEN DURING THIS STUDY?

After consenting to the study, you will be provided with a pre-intervention survey. This survey asks questions to better assess your background as well as questions related to post-intensive care syndrome (PICS). You are free to skip questions or stop answering questions at any time. A study team member is happy to read the questions to you and fill out the survey or you can complete it in private

After completing the survey, you will be provided with one of three educational interventions. The educational material will consist of either a 1) brochure, 2) brochure and a conversation with a study team member, or 3) brochure and a three-minute video. You will be able to review the information on your own time.

A study team member will arrange a time that is best for you to return and provide a post-intervention survey after you review the information. After the second survey, the study is complete. Again, you are free to skip questions or stop answering questions at any time. A study team member is happy to read the questions to you and fill out the survey or you can complete it in private.

HOW MANY PEOPLE WILL PARTICIPATE?

Approximately 300 people will take part in this study conducted by investigators at Washington University.

HOW LONG WILL I BE IN THIS STUDY?

If you agree to take part in this study, your involvement will last for approximately 24-72 hours, depending on when you are able to complete reading/viewing the educational materials and take a post- intervention survey. However, you are free to stop participating in the study at any time.

Visits with the study team members will last less than 30 minutes. And will be limited to time spent reviewing the consent form and providing study materials.

WHAT ARE THE RISKS OF THIS STUDY?

You may experience one or more of the risks indicated below from being in this study. In addition to these, there may be other unknown risks, or risks that we did

not anticipate, associated with being in this study.

Participants may be troubled by the information included in the PICS education strategies, and education about the possible long-term consequences of critical illness in childhood may be distressing to parents/caregivers.

Breach of Confidentiality

One risk of participating in this study is that confidential information about you may be accidentally disclosed. We will use our best efforts to keep the information about you secure. Please see the section in this consent form titled *"How will you keep my information confidential?"* for more information.

WHAT ARE THE BENEFITS OF THIS STUDY?

You may or may not benefit from being in this study. Ideally, we hope that you will benefit from this study by receiving educational material to help assist you in recognizing and treating symptoms of post-intensive care syndrome (PICS).

However, we hope that, in the future, other people might benefit from this study because St. Louis Children's Hospital cares for over 2,000 critically ill children every year. Our current practice makes no mention of the risk of post-intensive care syndrome (PICS) and we provide not current treatment for patients and family members experiencing symptoms. Building on this study, we hope to identify the best educational strategy to address PICS and to later develop a comprehensive program to address PICS both in the hospital and on an out-patient basis.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will not have any costs for being in this research study.

WILL I BE PAID FOR PARTICIPATING?

You will not be paid for being in this research study.

WHO IS FUNDING THIS STUDY?

The University and the research team are not receiving payments from other agencies, organizations, or companies to conduct this research study.

HOW WILL YOU KEEP MY INFORMATION CONFIDENTIAL?

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people such as those indicated below may become aware of your participation in this study and may inspect and

copy records pertaining to this research. Some of these records could contain information that personally identifies you.

- Government representatives, (including the Office for Human Research Protections) to complete federal or state responsibilities
- University representatives, to complete University responsibilities
- Washington University's Institutional Review Board (a committee that oversees the conduct of research involving human participants) and Human Research Protection Office. The Institutional Review Board has reviewed and approved this study.

To help protect your confidentiality, data will be collected by Dr. Hartman and her study team members. All data will be collected and stored in such a manner to keep all patient information private. No patient, parent/caregiver or PICU bedside nurse personal identifiers will be collected as part of the study.

All surveys will be anonymous.

If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

IS BEING IN THIS STUDY VOLUNTARY?

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. Any data that was collected as part of your participation in the study will remain as part of the study records and cannot be removed.

If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

What if I decide to withdraw from the study?

You may withdraw by telling the study team you are no longer interested in participating in the study.

Can someone else end my participation in this study?

Under certain circumstances, the investigator might decide to end your participation in this research study earlier than planned. This might happen for no reason or because in our judgment, it is no longer of benefit for you to continue.

WHAT IF I HAVE QUESTIONS?

We encourage you to ask questions. If you have any questions about the research

study itself, please contact: Stephanie Esses at 314-454-4775. If you feel that you have been harmed in any way by your participation in this study, please contact our primary investigator, Dr. Mary Hartman, at 314-286-2163

If you have questions, concerns, or complaints about your rights as a research participant please contact the Human Research Protection Office at 660 South Euclid Avenue, Campus Box 8089, St. Louis, MO 63110, 1-(800)-438-0445, or email hrpo@wustl.edu. General information about being a research participant can be found on the Human Research Protection Office web site, http://hrpo.wustl.edu. To offer input about your experiences as a research participant or to speak to someone other than the research staff, call the Human Research Protection Office at the number above.

This consent form is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by agreeing to participate in this study.