Reducing Postintensive Care Syndrome – Pediatrics in the Child with Congenital Heart Disease by Addressing Delirium

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Abstract

Advances in healthcare are decreasing mortality but increasing morbidity. As a result of the advanced treatment, recognition of a cluster of long-term complications known as postintensive care syndrome – pediatrics, or PICS-p, has developed. PICS-p impacts four areas of health: psychological, cognitive, physical, and social. The literature revealed best practices for reducing PICS-p complications in patients with congenital heart disease (CHD). Based on the standard bundle for best practices to prevent PICS-p, the ABCDEF bundle, a quality improvement project was conducted with an emphasis on identifying and recognizing delirium in the child with CHD while admitted to an inpatient cardiology unit. Nurses caring for these patients were invited to attend an education session regarding PICS-p and delirium, including how to accurately score for delirium using the Cornell Assessment of Pediatric Delirium (CAPD) (Traube et al., 2014) tool. Pre and post tests were given prior to and after the educational session to assess baseline CAPD and PICS-p awareness. Scores were compared to assess knowledge acquisition. CAPD scores were tracked, and three separate points were chosen to be measured. Data analysis showed an increase in CAPD scoring and an overall reduction of CAPD scores by nearly 50%. Increased CAPD scoring and reduction in overall scores decrease a patient's risk of developing PICS-p related to delirium once they are discharged. Additionally, an increase in nursing awareness of PICS-p and delirium can benefit patients with overall delirium reduction.

Keywords: Postintensive Care Syndrome-pediatrics, delirium, CAPD scores, congenital heart disease

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Mortality in the pediatric population has decreased substantially with advancements in medical technology and treatment options. With the improvement in medical technology, more children are being treated for severe illness, injuries, and congenital defects than in decades prior. Pediatric cardiovascular intensive care unit (CVICU) admissions often come with invasive ventilatory support, sedation and analgesia medications, prolonged decreased mobility, and an increased risk for delirium. These necessary treatment components are not without long-term complication risks after discharge. As a result of decreasing mortality, morbidity has increased.

Problem Statement

Pediatric patients are often treated in the CVICU and cardiac step-down units for extended periods of time. Modalities of care frequently include intubation and mechanical ventilation, requiring sedation and analgesia medications (Ekim, 2020; Hartman et al., 2020; Tang et al., 2021; Watson et al., 2018).

It is no longer sufficient to only measure mortality as a mark of success in the pediatric population given the high levels of care and treatment they receive. In recent years, a new clinical syndrome has emerged called postintensive care syndrome-pediatrics (PICS-p) because patients are surviving and experiencing long term consequences contributing to intensive care unit (ICU) morbidity. Ekim (2020) defines PICS-p as new or worsening impairment in physical, cognitive, or mental health status after critical illness, that persists beyond hospitalization. These new or worsening impairments can hinder the success of treatment for patients and increase suffering in the post-hospital course.

Purpose and Rationale

Patients with congenital heart defects (CHD) treated in the CVICU and cardiac step-down unit are already at a high risk for significant physical and cognitive complications because of their cardiac pathology. The surgical procedures, medical treatments, and potential complications also increase their risk for developing PICS-p. The purpose of this paper is to establish the significance of the compounding complications associated with care in the CVICU and step-down unit and explain the importance of identifying and treating delirium to reduce PICS-p complications.

Background and Significance

The recognition of PICS-p is a relatively new concept in the pediatric population even though PICS has been widely studied and diagnosed in adult populations for the last two decades. The Society of Critical Care Medicine (SCCM) (n.d.) has a global initiative known as THRIVE that provides resources and education for ICU survivors and their families. While this information and initiative is designed for adult patients, the information is applicable to pediatric ICU patients and their families. Pediatric patients treated in ICU settings suffer many of the same psychological, cognitive, physical, and sleep disturbance complications seen in adult ICU survivors (Ekim, 2020; Fink et al., 2020; Hartman et al., 2020; Herrup et al., 2017; Tang et al., 2021; Watson et al., 2018).

One of the complications increasing the development of PICS-p in pediatric patients is delirium. The incidence of pediatric delirium (PD) among patients with an ICU stay greater than 48 hours can be as high as 69% (Ista & van Dijk, 2020). Common treatments increasing the development of PD include restraint use, sleep schedule disruption, mechanical ventilation,

benzodiazepine exposure, and poorly treated pain. Delirium scoring using the Cornell Assessment of Pediatric Delirium (CAPD) tool can identify patients positive for delirium, allowing for the quick initiation of treatment (Staveski et al., 2020; Traube et al., 2014).

Pediatric Cardiovascular Intensive Care Unit Patients

Critical congenital heart defects (CCHD) are anomalies that arise during the development of the fetal heart. Fetal developmental abnormalities can impact the structure of the heart through valve, vessel, or heart chamber malformations (Centers for Disease Control and Prevention [CDC], 2023). Many of these patients will require life-saving surgery within the first few days of life, along with several other surgeries, procedures, and hospitalizations throughout their lives (American Heart Association, 2022). Patients with CHD will require critical care treatment in the CVICU for a varied length of time depending on the severity of their condition and any complications in treatment (CDC, 2023).

Prior to their surgeries, patients with the most severe CHDs require continuous medication infusions via central lines to maintain hemodynamic stability. Many also require respiratory support, either through noninvasive measures or through mechanical ventilation. Because of the very tenuous state of these neonates, or the level of support they require, many parents are unable to participate in normal newborn care they would otherwise be a part of, like diaper changes and feeding. There can be a severe sense of loss of what the expected newborn period should be (A. Estravit, personal communication, March 10, 2023).

PICS-p Complications

Families with loved ones undergoing care in the CVICU experience exceptional emotional and physical stressors. With the knowledge of PICS in adults, and the stressors

caregivers experience and report, it can be assumed that those same conditions will impact the pediatric population. Herrup et al. (2017) summarized multiple studies that looked at patients after pediatric intensive care unit (PICU) admissions, some as short as eight hours. One of the first complications assessed was sleep disturbance and fatigue. The study found that 72% of PICU patients were at risk for sleep disorder after discharge. In other areas they reported that 49% of critically ill children (n=150) had affected mobility up to one year post discharge. Cognitively, many patients of varying ages self-reported difficulty in school that was corroborated by their teachers in follow up surveys. Surveys showed more deterioration in academic performance in patients treated for sepsis, resulting in long-term difficulty and attention problems.

Given these significant findings in PICU patients, it is important to identify those patients at greatest risk for complications early and intervene prior to discharge. Those who spent significant time mechanically ventilated, on long term sedation and analgesia infusions, or with extended limited mobility were at significant risk of PICS-p (Ekim, 2020; Fink et al., 2020; Hartman et al., 2020; Herrup et al., 2017; Turkel, 2017; Watson et al., 2018).

Nonpharmacological Delirium Treatment

Aside from medications to treat delirium, there are several nonpharmacological interventions that can reduce the development of delirium and decrease the severity and duration. Maintaining natural sleep/wake cycles, massage, promoting good sleep, listening to music, early mobilization, avoiding overstimulation, and encouraging family presence are all nonpharmacological treatment options for preventing and treating delirium in all patients (Ista

& van Dijk, 2020; Michel et al., 2022). These methods are easy to implement by nursing as part of their bedside cares.

Decrease PICS-p Complications

Early identification of those at greatest risk for PICS-p can help implement nursing bundles quickly and work to reduce PICS-p complications. Studies show some of the best ways to identify those at risk is through effective, standardized screening, early mobility practices, and adherence with effective bundles in nursing practice (Mejia, 2017).

Through acknowledgement of the ABCDEF bundle, nursing and medical staff can help reduce PICS-p complications for their patients. The components of the ABCDEF bundle include assessing, preventing, and managing pain, both spontaneous awakening and breathing trials to extubate quickly and safely, choice of analgesia and sedation, delirium assessment and prevention, early mobility and exercise, and family engagement and empowerment (Lin et al., 2023). Managing these elements can promote healthy transition from intensive care to step-down unit to discharge and beyond.

Common Themes

From the literature, it is evident that the complications from critical care treatment can be life altering for both patients and families and persist well beyond the discharge period. These complications do not account for the complications related directly to their condition. Following the ABCDEF bundle and focusing on identification, treatment, and reduction of delirium in patients with CHD, providers and nursing staff can work to reduce the development of PICS-p and the complications associate with it.

Internal Data

A free-standing pediatric hospital in the Southwest region of the United States has separate, dedicated CVICU and cardiology inpatient step-down floors. The CVICU is a 24-bed unit and cares for all patients with CHD that are admitted for surgical intervention, surgical complications, or overall worsening condition related to their heart defects. There is also a 24-bed step-down unit that cares for less critical patients or those preparing for discharge. The mission of this facility is patient and family centered, encouraging family participation in cares and medical decisions. This facility receives patients from multiple states in the Southwest region and is the only cardiac program in the state, resulting in hundreds of admissions each year. The level and volume of care the facility provides makes the goal of reducing long-term complications directly related to inpatient care paramount to its mission and goals.

PICO Question

A review of the literature led to the development of the clinically relevant PICO question: In pediatric patients that received treatment for congenital heart disease *(P)*, how does educating nurses on delirium and implementing a nonpharmacological nursing bundle *(I)* compared to current practice *(C)* reduce delirium scores, thereby reducing PICS-p complications *(O)*?

Search Strategy

An exhaustive literature search was conducted using the research databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, and Academic Search Premier. Because of the very recent recognition of PICS-p within the medical community, use of Boolean terms within the databases did not increase the number of articles returned. All three databases provided at least one article that contributed to the development

of the PICO question. Additional literature searches for pediatric delirium were conducted using the same three databases.

Keyword Selection

Keywords used across the three databases included: *postintensive care syndrome, post-intensive care syndrome, PICS-p, PICS, congenital heart defects, delirium, pediatric delirium, CAPD, CVICU*, and *PICU*. In the literature there were different presentations of the word postintensive. Some sources presented it as hyphenated; others left it as one word. For the sake of literature search, both options were entered. As mentioned above, the already limited field of search results became even more limited when too many of the keywords were used at once. Limiting the use of the keywords to *postintensive care syndrome* and *pediatrics* yielded the best field of related articles across all three databases.

Initial and Final Search Yields

The search for *post-intensive care syndrome AND pediatrics* with a year range of 2019 to present in CINAHL yielded 23 results, ten results in Academic Search Premier, and 78 in PubMed. Those numbers decreased to a range of zero to 11 across all databases when additional Boolean search terms were added beyond those listed above. Because of the larger number of results from PubMed, instead of narrowing search terms, advanced search options were used to include only studies that were randomized controlled, clinical trial, and meta-analysis. This reduced the results to three articles.

Of the combined total 111, critical appraisal was performed on 18 articles that were considered primary research, and ten were selected for further review. Of those ten, two were

randomized control trials, three were cohort studies, two were correlational, and three were systematic reviews.

Limitations, Inclusion, and Exclusion Criteria

The inclusion criteria concentrated on studies published from 2019 to present. Some were published from countries outside the United States, and they were included, but those that did not have English translations were not considered. While the main purpose of the literature search was to find information on pediatric PICS, there was some widening of the scope of research to include general adult related PICS to strengthen the evidence since pediatric literature is limited. Many of the articles returned were not primary research, and although they provided excellent information for the literature review, they were not considered in the critical appraisal.

Critical Appraisal and Synthesis of Evidence

The quality and level of evidence was evaluated and determined using rapid critical appraisal (RCA) tools (Melnyk & Fineout-Overholt, 2019). A combination of both qualitative (Appendix A, Table A1) and quantitative (Appendix A, Table A2) studies were included in evaluation and synthesis tables (Appendix A, Table A3) because of the evidence regarding the impacts of PICS-p on patients and families.

The studies evaluated had a wide range of the number of participants. The total number of participants ranged from 14 in one study to 183 in another. The demographics varied greatly from being measured in inpatient units, to outpatient clinics, using adult participants because of the limited pediatric studies, to those featuring pediatric participants. Some of the studies were single event studies, where others were conducted over a period of months. One-third of

them measured the impact on three of the four paradigms of a PICS-p diagnosis, while another one-third of them measured two of the four paradigms. One measured only one, and two others did not specify which of the paradigms their study impacted or measured.

Discussion

The impact of inpatient treatment is long-lasting and goes well beyond when a patient is discharged from the hospital. To improve long-term outcomes, hospitals need to acknowledge these potential complications and the risk of developing PICS-p in their patients. Providing nursing staff education on PICS-p and the ways to address it while patients are still admitted can help reduce the associated long-term complications. It can also help to create nursing bundles that can be incorporated into their daily cares to prevent PICS-p. Arming them with the knowledge is the easiest way to reduce long term complications.

Theoretical Framework Application

As mentioned, children with CHD are CVICU patients for a lifetime because of the complexity and nature of their anatomy and physiology. They will undergo treatment for their chronic condition indefinitely as there is no cure for CHD, only palliation surgical options. As a result, the concept framework of the chronic care model (CCM) was chosen because of its applicability and ability to demonstrate the addition of community services to aid in patient's treatment (Appendix B, Figure B1). The initial framework was designed in 1996 and has since been able to adapt with the changing healthcare landscape. For instance, chronic care treatment can now include telehealth medicine, and self-care can include wearable diagnostic technology (Berwick, 2019), both items used in the treatment of patients with CHD. Telehealth options can increase the likelihood some families will be adherent with follow up

appointments. The CCM can continue to adapt and apply to chronic care treatment as the ability to treat chronic conditions improves.

Implementation Framework

The Steven's Star Model of Knowledge Transformation (Appendix B, Figure B2) is an evidence-based project (EBP) model often used in healthcare to provide a framework for systematically developing and putting EBP concepts into practice. There are five steps, or points of a star, to the Steven's Star Model: knowledge discovery, evidence synthesis, translation into practice recommendation, implementation into practice, and evaluation (Stevens, 2013). In practice, the steps look like discovering primary research articles on a selected topic, synthesizing all available knowledge into a single statement, like a systematic review, translating that into action or creating EBP clinical practice guidelines, integrating that into practice, and evaluating the outcomes the change has on patients and health outcomes. This is applicable to creating change in navigating and working to have an impact on the prevalence of PICS-p by knowledge discovery, identifying ways to create change based in EBP, implementing them, and evaluating the impact they have on current patients as they are preparing for and discharged from the hospital, as well as future patients undergoing treatment in the CVICU.

Implications for Practice Change

Based on the evidence provided by the critical appraisal and the exhaustive literature search, an ideal way for hospitals to address PICS-p complications is through staff education on PICS-p. This education can focus on the ways their daily cares can impact or influence the development of PICS-p. Picking some of the elements of the ABCDEF bundle and ensuring there are steps and programs in place to address them can help prevent complications. Creating

nonpharmacological nursing bundles that can be implemented based on CAPD scores can help identify and treat delirium. By doing that well, it will help reduce PICS-p development and complications.

Creating educational resources for nursing can increase the awareness of the signs and symptoms of PICS-p, to better help recognize when something is a potential complication – like a change from the patient's baseline that could be attributed to the treatment course. Proper education and assessment would allow for recognition of changes to the patient in any of the four paradigms impacted by PICS-p: psychological, cognitive, physical, and social.

Potential Outcomes

The cost of adding educational resources for staff is minimal to the organization, but the benefits they could provide are exponential. CHD patients will always be placed in the CVICU and cardiac step-down unit for any hospital admission. If they come in with issues secondary to their cardiac anatomy, they will be back in the CVICU. Those repeat or bounce back admissions can cost the organization. Even more so than that, the cost to families to have to find care and resources long beyond their hospital admission is something that needs to be considered.

Helping nursing staff understand how they can reduce PICS-p with their daily cares is easy to implement and will have a substantial impact on patients. This not only benefits the child greatly by getting resources started early, but it allows for family centered care, which is in alignment with the organization's mission and values.

Methods

Based on the findings of the literature search and information gleamed from the background and significance discovery, it was evident that there is room for improvement in

the assessment and treating of pediatric delirium in the patient with CHD. Reduction in delirium occurrence should reduce the incidence of PICS-p and the associated complications.

Project Description

The goal of this DNP project was to improve nursing knowledge of delirium and to improve overall screening for delirium in CHD patients admitted to the step-down unit as a steppingstone for prevention of PICS-p. An educational session was offered that provided nursing staff the opportunity to learn about PICS-p and how their daily care of patients impacts the development of it, especially as it relates to delirium. Attendees completed a pre and post survey about their baseline knowledge of PICS-p and delirium prior to the education session, and after to assess knowledge acquired. After the session was completed and disseminated to other nursing staff in the CVICU and the cardiology step-down unit, CAPD scores were gathered from a chart audit process. CAPD scores were tracked for qualified patients and three various points (baseline, midpoint, and final) were obtained for data analysis. CAPD scoring was used as an adjunct for knowledge acquisition of the importance of delirium screening and prevention.

Participants and Setting

The goal for the project was to have at least 50 nurses attend the educational session via in person or through a virtual option. These are nurses that currently work in the CVICU or on the inpatient cardiology unit. The information was also disseminated to house-wide, critical care float pool, and PICU nurses for their knowledge as they often float to the cardiology unit and care for these patients.

It was projected to have between 25 and 100 patient charts to review that have baseline CAPD scores to track and analyze. This was dependent on the patient census during the time of data collection and nurse follow through with completing CAPD scoring.

Ethical Considerations and IRB Approval

Prior to beginning the implementation of the project, institutional review board (IRB) approval was required from the project site and Arizona State University (ASU). This process ensured that no patient harm would occur because of the project and that all ethical considerations are met to ensure subject safety. For this project, it was important that patients remained deidentified to protect their private health information, and only information deemed necessary for the data analysis was collected. The project was deemed a quality initiative and approved by both college and project site.

Instrument

The CAPD screening tool is a valid and reliable observational tool for screening delirium in the ICU and other inpatient units (Traube et al., 2014). The overall sensitivity of the CAPD is 94.1% with a specificity of 79.2%, indicating good internal consistency. The questions on the screening can be done and answered rapidly, allowing for quick identification of patients at risk for delirium (Traube et al., 2014).

There are eight questions on the CAPD, and they use a Likert scale for answers (Appendix C). The components assessed include: the child making eye contact with the caregiver, their actions being purposeful, the child being aware of their surroundings, do they communicate their wants and needs, are they restless, are they inconsolable, are they underactive while awake, and does it take a long time for them to respond to interactions? A

score of nine or greater indicates a positive screening for delirium. It is important to note that if a patient is highly sedated or receiving neuromuscular blockade, they cannot be accurately screened with the CAPD tool.

Data Collection

Data was collected via chart audits using an IRB approved chart audit form. This form accounted for independent patient identification numbers, plus tracking of their CAPD scores over time. The data collection tool allowed for the documentation of delirium treatment medications including scheduled or any as needed (PRN) medications. The data was collected on a secure, hospital network with a hospital issued computer that has encryption software for patient information safety.

Data Analysis Plan

At the end of the implementation phase, data was collected and analyzed. The pre and post nursing surveys were linked by randomly assigned identification numbers. The patients will also have their own identification number so that all private health information is deidentified. Pre and post surveys were compared for knowledge acquisition. The CAPD scores were tracked and measured over the course of data collection.

Budget

Most of the budget (Appendix D) accounted for the educational hours of the nurses attending the educational session. There was a small cost associated with printed materials for the pre and post surveys for those attending in person. The most important line item in the budget was the cost savings to the healthcare system with reduced development or worsening of delirium for the patient with CHD. By reducing the development of PICS-p and the

complications associated with it, a significant amount of money in reduced hospital stays, reduced readmission rates, and reduced need for services once discharged can occur for the hospital and the patients. No funding was received for the project.

Results

Data for this project was collected and analyzed in the Intellectus Statistics ™ software. Demographic data, baseline, midpoint, and final CAPD scores were run through descriptive statistics. Of the qualified patients, 11 had trackable CAPD scores. 45% were male (n=5), 55% were female (n=6). 81% were under 2 years old (n=9).

The CAPD scores were run through an ANOVA test. A Friedman test was run as supplemental analysis after one or more of the assumptions in the ANOVA test were violated. The Friedman test examined whether the medians of the three selected points of CAPD scores were equal. The results were significant based on the chi square equation, $\chi^2(2) = 9.33$, indicating significant differences between the median values. This showed a significant response in CAPD scores decreasing once nurses received education on CAPD and delirium. The median baseline CAPD score was 10.91, for midpoint CAPD the median was 7.55, and for the final CAPD the median score was 4.36.

Impact of the Project & Sustainability

The constant reminder to nurses to complete their CAPD scoring helped increase the number of patients that received delirium scoring. This also led to nursing awareness of how their cares impacted the development of delirium and resulted in increased delirium scoring. Better capturing delirium early allows for better treatment and prevention of worsening conditions for a prolonged period, and the potential development of PICS-p. Increasing the

conversation around delirium in pediatric patients has improved the scoring and nursing knowledge.

Continuing that education is the crux of the sustainability of this project. All current nurses have received and been made aware of the PICS-p and delirium education. From this point out, the education should be included in new hire classes for the CVICU and the cardiology step-down unit. New hire nurses received trainings in a systems-based manner, and the education on PICS-p and delirium would fit appropriately into the neurology course they receive, ensuring all nurses on both units are well educated and exposed to proper delirium scoring.

Discussion

Despite the recognition of delirium in pediatrics being relatively new, there is evidence to support that it is a significant problem in intensive care units and inpatient units. For delirium to be addressed, it must be properly identified and screened for. Implementing and ensuring proper education on delirium is the first step in helping with prevention. It is easy in the pediatric population to misidentify delirium because other conditions, like drug withdrawal, pain, or general baby fussiness can make delirium identification challenging. Knowing the anchor points and components of the CAPD screening tool ensures that the provider or bedside nurse can differentiate between conditions.

Limitations and Barriers Encountered

Despite strong evidence in CAPD score reduction, there was limited nurse participation in the educational sessions, resulting in a limited data set for pre and post surveys. Additionally, it was exceedingly difficult to get nurses to initiate the CAPD scoring for all qualified patients,

especially on the cardiology unit verses the CVICU. This difficulty was met with multiple email reminders and in person follow up, but the struggles for buy-in continued.

Another barrier was the nature of patients treated in the CVICU and on the cardiology unit. They often have clinical changes resulting in frequent transfers between the CVICU and the step-down unit. These transfers often result in escalation of treatment resulting in exposure to delirium provoking management, thus increasing their risk for delirium development. Tracking the CAPD scores of these patients could be impacted by the transfers and their scoring could be altered by the treatments they received.

Recommendations for Further Study

Continuing to track and monitor CAPD scores for patients is going to help ensure that the units are doing what they can do reduce the development of PICS-p through addressing delirium. Because delirium is a significant problem even in pediatric patients, it is good practice to consistently screen and track these scores. Surveying nurses should be extended to the residency courses new hires take to continue ensuring adequate exposure to this information.

Conclusion

PICS-p is a potentially serious, life-long collection of complications secondary to treatment in the CVICU and inpatient unit. While many of these treatments are necessary for survival in a critical time, there are ways to mitugate them and potentially reduce the risk of developing PICS-p. By educating bedside nurses about PICS-p and the complications associated with it, interventions can be put into place. One such way is bringing awareness to delirium in the pediatric patient and how simple measures can be implemented to reduce it. Patients with CHD will always require care and treatment in the intensive care unit at this institution, so

finding ways to reduce complications will ensure they have the best possible outcome once they are discharged from the hospital.

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Appendix A

Evaluation and Synthesis Tables

Table A1

Evaluation Table for Qualitative Studies

Citation	**Theoretical/ Conceptual Framework**	**Design/ Method/ Purpose**	**Sample/Setting**	**Major Themes/Studies Definitions**	**Measurement/ Instrumentation**	**Data Analysis**	**Results/ Findings**	**Level of Evidence; Application to practice; Generalization**
Esses, S. A. et al. (2019). Post-intensive care syndrome: Educational interventions for parents of hospitalized children **Country**: USA **Funding**: Costs were covered by the hospital the study was conducted at: St. Louis Children's Hospital	PRISM	**Design:** SR, RCT **Purpose:** To establish the ideal method of education for parents of hospitalized children in the PICU on signs and symptoms of post-intensive care syndrome: pediatrics.	***n*=** 62 total caregivers **Brochures**: 22 **Conversation**: 20 **Video**: 20 **Demographics:** Demographic questionnaire including: relationship to patient, sex, age, marital status, education level, type of insurance, employment status, proximity to hospital, and previous trauma	**RQ1:** How familiar are parents with PICS-p? **RQ2:** Can parents appropriately identify signs and symptoms of PICS-p? **RQ3:** What is the ideal educational method for teaching parents about PICS-p? **RQ4:** How does educating parents impact the day/role of the nurse?	**Data Collection:** 1: Demographic questionnaire 2: Pre and post intervention tests 3. Nursing survey	Qualitative analysis Evaluation using the PRISM framework	**RQ1:** Brochure: 77% had never heard of PICS-p Conversation: 55% had never heard of PICS-p Video: 70% had never heard of it PICS-p **RQ2:** Brochure: 77% pre had no idea the s/s; post 73% very familiar with s/s Conversation: 65% pre had no idea the s/s; post 45% very familiar with s/s	**Level of Evidence**: Level I **Strengths**: Well designed, included nursing, strong qualitative design **Weakness**: Small sample size, limited to PICU, excluded patients old enough to comprehend **Feasibility**: Easily replicable at other hospitals/units, easy to expand sample size **Application:** Identified ideal

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Bias: Potential bias because all authors are employees at the hospital where it was conducted.			**Setting:** the PICU at St. Louis Children's Hospital in St. Louis, MO **Exclusion:** Parents < 18 years old, non-English speaking, PICU admissions < 24h **Attrition:** 0%				Video: 75% pre had no idea the s/s; post 55% very familiar with s/s **RQ3:** The brochure educational strategy has the greatest likelihood of successful and sustainable implementation. **RQ4:** Nursing survey showed workflow was minimally disrupted during PICS-p education and all 3 methods were viewed as important and useful.	educational method for parents and impact on nursing who will be at the bedside after researchers leave and might be fielding questions:
Annamalai, M. R. (2022). Post-intensive care syndrome in a heterogenous pediatric population. **Country**: USA **Funding**:	Item response theory	**Design:** Retrospective cohort review **Purpose:** Measure the incidence of PICS-p among children who received critical care treatment and evaluate patient characteristics	***n* = 183** **Demographics:** Age, PICU admission time, survived hospitalization **Setting:** The PICU at The Children's Hospital of San Antonio	**RQ1:** What was the preadmission FSS score? **RQ2:** What was the discharge FSS?	**Tools:** FSS scores **Validity/ Reliability:** FSS is valid and reliable, but a limitation in this study. It does not account for 2 of 4 domains in the PICS-p paradigm.	Linear regression was used to analyze the relationship between change in FSS and independent factors. Both one and two tailed t-	1 in 5 children treated in the PICU develop PICS-p. Lower preadmission FSS scores, increased number of procedural interventions, increased LOS, fewer ventilation free days were all	**Level of Evidence:** Level IV **Strengths**: Easy to duplicate or complete at other centers. Utilizing the FSS is using a validated tool. **Weakness**: Using only FSS leaves out 2 of the domains of PICS-p which

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The Children's Hospital of San Antonio, Baylor College of Medicine **Bias**: None		and critical care interventions associated with the development of PICS-p	**Exclusion:** Patients in PICU for < 4 days, over the age of 18 years, did not survive hospitalization. **Attrition:** 0%			tests and Wilcoxon rank-sum tests were used. Fisher's exact test was used.	associated with PICS-p.	could alter results significantly. Small sample size. **Feasibility**: Easily replicated, low cost due to retrospective chart reviews.
Rohr, M. (2021). Piloting an ICU follow-up clinic to improve health-related quality of life in ICU survivors after a prolonged intensive care stay (PINA): Study protocol	Benner's novice to expert theory	**Design:** MM, RCT pilot **Purpose:** The concept for an ICU follow-up clinic was developed and will be tested in a pilot randomized controlled trial, to evaluate the feasibility and	***n* = 100** Intervention Arm = 50 Control Arm = 50 **Demographics:** >18 years old, ICU duration more than 5 days, SOFA score > 5, expected survival time	**RQ1:** Is a post-ICU specialty clinic beneficial in identifying/treating PICS? **RQ2:** How does the follow up clinic improve patient health?	**Tools:** Standardized questionnaires: Mini-Cog, PHQ-8, GAD-7, PTSS-10. **Validity/ Reliability:** The questionnaires are frequently used and valid.	Group allocation will be masked. The treatment effect to be assessed using analysis of covariance according to the intention-	A post-ICU specialty clinic works to improve the quality of life and management of PICS symptoms by getting patients to specialists that can help with complications.	**Level of Evidence:** Level II **Strengths**: The participatory nature of the program. **Weakness**: The follow up period too short, and the effects of the intervention might

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for a pilot randomized controlled trial. **Country**: Germany **Funding**: Innovation Fund of the Federal Joint Committee **Bias**: None		additionally the potential efficacy.	greater than 6 months **Setting:** University of Regensburg, Germany **Exclusion:** < 18yo, not expected to survive 6 months, unable to complete questionnaires, or have insufficient German language skills. **Attrition:** 0%			to-treat principle.		appear only after the follow-up prior of 6 months. **Feasibility**: Feasible in many instances.
Atkins, E. K. (2020). Families' experiences of life in the year after a child's critical illness: Navigating the road to a "new normal". **Country**: London, UK	Grounded theory	**Design:** Add on interviews following a qualitative study **Purpose:** Wanted to add to the literature on the psychological impact on families of a PICU admission.	***n* = 18 families** ***n* = 9 children** **Demographics:** White British, Asian British. **Setting:** The interviews were conducted in the homes of the participants, with one or both	**Theme 1: Just getting through.** Families reflected on feeling they didn't have space or time to think about or understand what they were going through and were just trying to survive.	**Tools:** The interview questions were created based on literature and clinical experience of the researchers. **Validity:** There's no official validity of the questions they created on their own.	Grounded theory, a rigorous qualitative methodology.	Main points to consider: 1) psychosocial adaptation usually beings after the child has largely recovered physically. 2) value exists in communicating with each other to put their story and experiences together. 3) with	**Level of Evidence:** Level V **Strengths: I**nsight from both parents and patients. **Weakness:** Underrepresentation of minorities. Families of younger children, less than 5, were not included.

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Funding: Not included **Bias**: None			parents and the child present. **Inclusion:** PICU stay of more than 24 hours, child aged 5 to 16 years, admission in the previous 8 to 18, and biological parent available to take part. **Exclusion:** Those admitted for nonaccidental trauma or palliative care. **Attrition:** 18/39 = 46%	**Theme 2: A changed person.** Several parents reported becoming more protective of their child post PICU discharge. The patients reported feeling their identity of themselves had shifted as well. **Theme 3: Striving for normality.** Most families assumed life would return to normal after discharge, but many found that their normal had shifted based on the condition their child was discharged in.			time and resources, most will make a good recovery and move on but 4) this journey may take longer than they expect. And finally, 5) concepts of the "old normal" and the "new normal" early on may be helpful to families.	**Feasibility:** Is feasible in any location and can be easily replicated to further the field of knowledge.
Hauschildt, K. E. (2022). Hospital discharge summaries are insufficient following ICU stays: A qualitative study **Country**: USA	Attribution theory	**Design:** Semi structured interviews with PCPs **Purpose:** To understand and identify what other information PCPs would benefit from	***n* = 14** **Demographics:** 11 board certified internal medicine MDs and 3 board certified family medicine MDs (2 with additional certifications in	**Theme 1:** ICU course of hospitalization is often missing from discharge summary template. **Theme 2:** Discharge	**Tools:** RADaR (rigorous and accelerated data reduction) **Validity:** RADar is a valid tool used by creating tables and spreadsheets.		It is important to increase the information about PICS for effective follow up by outpatient providers, as these are the ones that will see and care for the patient after discharge.	**Level of Evidence:** Level VI **Strengths:** It extends previous research showing vital information is often missing. **Weakness:** It was a single system study,

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Funding: Dr. Iwashyna provided funding for transcriptions. **Bias**: None		receiving post ICU discharge.	pediatrics). Women = 12, men = 2. White = 8, African American, Middle Eastern, Asian = 6. **Setting:** Clinics across Southeast Michigan, connected to a hospital wide health system. **Exclusion:** Recruitment was done via email and after 14 interviews they had achieved response saturation. **Attrition:** 0%	summary is too wordy/too vague.				focusing on the physicians' experiences with patients discharged from academic hospitals. **Feasibility:** Recreation of this study would be easy to accomplish across the US.
Hampton S. F. (2022). Interprofessional education module on post-intensive care syndrome for internal medicine residents.	Conditions of Learning	**Design:** Single-site pilot education program **Purpose:** To improve internal medicine residents' knowledge of interprofessional	***n = 65*** **Demographics:** Internal medicine residents that work in ICUs with physical, occupational, speech therapists	**Precourse Knowledge:** 15% got 1 question correct on preassessment, 32% got 2 correct, 35% got 3 correct, 18% got 4 correct, 0 got all 5 questions correct. 77% of	**Tools**: A 5 point Likert scale exam was provided precourse to determine the knowledge base. 5 question quiz about the fundamentals of and treating PICS. Postcourse	Objective knowledge gain was measured using a paired one-tailed t-test analysis of pre and postcourse assessment	Providing short, direct educational sessions to residents improved their knowledge and understanding of treating PICS, as well as how to do it as a interprofessional	**Level of Evidence:** Level IV **Strength:** Using virtual platforms and videos provide high yield and interactive experiences to a large audience, and may be reproducible with minimal effort.

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Country: USA **Funding**: University of Washington **Bias**: Potential selection bias was possible due to being rolled out at a single institution.		roles in the ICU and their confidence in managing PICS	**Setting:** ICU in Washington **Exclusion:** **Attrition:** 52% completed both pre and postcourse assessments	respondents rated themselves as either not very or not at all confident in PICS knowledge. **Postcourse Knowledge:** 9% got 2 correct, 18% got 3 correct, 41% got 4 correct, and 32% got all 5 correct. 94% rated themselves as somewhat or very confident after the course.	exams were also given. **Validity**: Likert scale questionnaires are excellent methods of information gathering and knowledge base rating.	scores. A McNemar statistical test was performed to see if their confidence significantly changed. A *P* value <0.05 was considered significant, and *P* <0.001.	collaborative team.	**Weakness:** There was only a 50% response rate in evaluations and that restricted generalizability and making results prone to selection bias. **Feasibility:** This is easily feasible at many centers. Doing it with virtual education modules allows for a wide casting of participants.

Table A2

Evaluation Table for Quantitative Studies

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Citation	**Theoretical/ Conceptual Framework**	**Design/ Method/ Purpose**	**Sample/Setting**	**Variables**	**Measurement/ Instrumentation**	**Data Analysis**	**Results/ Findings**	**Level of Evidence; Application to practice; Generalization**
Yuliarto, S. (2022). The risk factors of the functional status, quality of life, and family psychological status in children with postintensive care syndrome: A cohort study. **Country**: Indonesia **Funding**: Nil **Bias**: None	Assessing quality of life for patients and families after treatment in the PICU	**Design:** Analytical observational prospective cohort study **Purpose:** Assess the functional status and QOL for pediatric patients admitted to the PICU > 24h at baseline and 3-month post discharge intervals	***n* = 45** **Demographics:** Gender, age, family composition, socioeconomic status, **Setting:** The PICU at Saiful Anwar General Hospital; PICU patients 1 month to 18 years old, admitted for > 24h **Exclusion:** < 1 mo old, > 18 yrs, admitted for < 24 hours to the PICU **Attrition:** 0%	**IV1:** Admission and time in the PICU **DV1:** Functional status **DV2:** Quality of life **DV3:** Family Depression, Anxiety, and Stress score **Definitions:** FSS shows the condition of 4 domains: cognition, psychiatric, social, physical.	**Tools:** 1. TISS tool 2. FSS tool 3. PedsQL tool 4. DASS tool 5. Family interviews **Validity/ Reliability:** TISS: Found to be valid and reliable for clinical studies FSS: Highly valid and reliable for clinical trials and studies PedsQL: Excellent validity and reliability; can be used in clinical trials. DASS: found to have good internal validity and reliability.	Normality tested with Shapiro-Wilk test. Homogeneity by Levene's test Comparison of pre-and 3-month post: dependent *t*-test Bivariate association tested by Mann-Whitney, Kruskall-Wallis test, or Spearman's correlation test	**DV1:** Significant difference ($p < 0.001$) in children's functional status before and 3 mos after ICU. **DV2:** Significant difference ($p < 0.001$) in children's QoL before and 3 mos after ICU. **DV3:** Majority of the families developed depression, anxiety, and stress during and shortly after the ICU admission.	**Level of Evidence**: Level IV **Strengths**: Close follow up of families, with broad range of testing/score assessments. **Weakness**: Very small sample group, single center study, homogenous demographics **Feasibility**: Easily replicated, low cost **Conclusion**: Occurrence of PICS can decrease functional status of patients and impact their QoL.

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Jennings, M. L. (2021). Effect of animal assisted interactions on activity and stress response in children in acute care settings. **Country**: USA **Funding**: The Louis Family Foundation, Arizona Cardinal Charities, and PetSmart Charities **Bias**: Dr. Granger is the founder and president of Salimetrics, the company that conducted the testing		**Design:** RCT **Purpose:** Determine the effects of AAI on activity and stress response.	**AAI Group**: ***n*** = 44 **Wait list control**: ***n*** = 36 **Demographics:** Gender, age, ethnicity, had a pet in the house **Setting:** The PICU, CVICU, and hematology oncology units at a tertiary children's hospital in Arizona **Exclusion:** Patients taking glucocorticoids, catecholamines, alpha- or beta-adrenergic blockers, and anticholinergic agents, isolation precautions, mechanical ventilation, sedation, medical complications, fear/allergy to dogs, mouth or swallowing issues, scheduling conflicts with procedures,	**IV: AAI** **DV1:** Cortisol reactivity **DV2:** Activity level **DV3**: Mood	**Tools:** 1. Cortisol testing prior to AAI visit and again at 5, 20, and 60 min after end of visit 2. Lansky play performance/activity tool at baseline and 1- and 3-hours post visit 3. Modified Wong-Baker faces scale to measure mood **Validity/ Reliability:** Lansky play performance is a valid and reliable play performance activity measure for kids. The Wong-Baker faces scale for mood rates the mood from "best feeling" to "worst feeling."	A power analysis was conducted based on repeated measure ANOVA design. They used a two tailed test for detecting intervention effects. Linear regression was used to examine if AAI group predicted children's activity level.	**DV1:** The control group had higher levels of cortisol with respect to time, where children in the AAI group showed a decrease in cortisol levels with respect to time. **DV2:** AAI group differed significantly in change in activity level. Activity levels were higher for children in the AAI group than children who did not receive the visit. **DV3:** Significant interaction	**Level of Evidence:** Level I **Strengths**: Easy to replicate at other centers, easy to increase the population group size for further testing. **Weakness**: Medical team interruptions which could have impacted the children's mood/attitude/activity levels. It could have also impacted the dog's reactions during AAI. Due to the time component it was hard to be completely blind as participants could figure out which group they were in. **Feasibility**: Easily replicated, low cost **Conclusion**: There are short term benefits of AAI for children in critical

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			cognitive/behavioral issues. **Attrition:** 0%				between mood and group, indicating the children in the AAI group showed a more positive mood.	care. Repeated AAI visits may reduce children's stress and increase activity, and perhaps mobility, in critical care settings.
Martillo, M. (2021). Postintensive care syndrome in survivors of critical illness related to Coronavirus disease 2019: Cohort study from a New York City critical care recovery clinic. **Country**: USA **Funding**: Friedman Brain Institute and Bee Foundation, Neurocritical Care Society Incline Grant **Bias**:	Theory of Interpersonal Relations	**Design:** Single-center descriptive cohort study **Purpose:** Determine the characteristics of postintensive care syndrome in the cognitive, physical, and psychiatric domains in COVID-19 ICU survivors.	***n* = 45** **Demographics:** median age 54 years, 73% male, 91% met criteria for PICS diagnosis. **Setting:** Critical care recovery clinic at The Mount Sinai Hospital in New York City **Exclusions:** Participants who did not complete the self-report portion of the follow up were excluded **Attrition:** 121 patients met criteria; 72 were not seen in clinic; 28 couldn't be reached; 13 were in	**IV:** Admission to ICU **DV1:** Physical domain **DV2:** Cognitive domain **DV3:** Psychiatric domain	**Tools:** Telephone Montreal Cognitive Assessment, EQ-5D-3L for mobility, pain/discomfort, self-care, usual activities, anxiety/depression, Modified Rankin Scale, Dalhousie Clinical Frailty Scale, Neuro-QoL upper and lower function, Patient-Reported Outcome Measurement Information System Fatigue Item Bank, PHQ, PTSS Checklist, Insomnia Severity Index **Validity:** All of the tools used are valid and used frequently in research. They are	Study data were exported to REDCap, (research electronic data capture). Descriptive statistics were calculated.	**DV1:** 86.7% of participants reported at least one physical impairment. 30 patients had difficulties in mobility. 16 reported problems with self-care and 30 reported problems with usual activities. **DV2:** Of the 45 patients only 30 received a cognitive screening due to staff shortages	**Level of Evidence:** Level VI **Feasibility:** This study is feasible to be recreated in any ICU setting. **Conclusion:** 90% of ICU survivors reported symptoms affecting at least one PICS domain. The findings highlight the importance of planning for appropriate post-ICU care for patients who survive critical illness. The high prevalence of PICS suggests a need for rehab interventions and long-term monitoring.

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None			subacute rehabs; 11 in long-term care; 9 had expired. 49 total were seen in clinic, and 45 were included in the study. All 45 completed.		appropriate for this study and the goals. **Reliability:** They are all reliable and valid to be used in research. They help obtain the information required for the study.		during the pandemic. **DV3:** 48.9% of patients presented with psychiatric impairment, depression, followed by insomnia.	
Sidiras, G. (2019). Long term follow-up of quality of life and functional ability in patients with ICU acquired weakness – A post hoc analysis. **Country**: Athens, Greece **Funding**: Special Account for Research Grants **Bias**: None	Nursing Need Theory	**Design:** Prospective cohort study **Purpose:** To assess the QOL and functional ability of patients with ICUaW 6 months post hospital discharge.	***n* = 128** (assessed at ICU discharge) **Demographics:** patients ventilated > 72 hours, able to answer/follow at least 3 predetermined commands. **Setting:** Mixed medical-surgical 24 bed intensive care unit **Exclusions:** < 18 and > 85 years old, pregnancy, obesity, preexisting neuromuscular diseases, technical restrictions regarding NMES	**Intervention Group:** Received individualized rehabilitation regimen and NMES daily until hospital discharge **Control Group:** Received sham NMES along with usual care until hospital discharge	**Tools:** Handgrip dynamometry, Functional Independence Measure, SF-36 questionnaire, Nottingham Health Profile **Validity:** All of the tools used are valid. **Reliability:** All of the tools used are reliable and a good way to measure the intended outcomes of the study.	Normality of distribution was checked by Shapiro-Wilk test. Mann-Whitney U test was employed for between-group comparisons. Assessments repeated > 2 different times analyzed by ANOVA.	Patients with ICUaW had significantly worse QOL and functional ability at all time points. They showed significant improvement at the 6 month follow up, despite still remaining compromised.	**Level of Evidence:** Level IV **Feasibility:** Feasible for recreation and implementation. However, being observational doesn't allow for randomization. **Conclusion:** ICUaW is associated with persistent deficiencies in functional ability and QOL, leading to a prolonged period of recovery. Although global muscle strength improves, functional recovery takes time.

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			implementation (burns), terminal disease, pacemaker and trauma to the spine **Attrition:** 112 patients assessed at hospital discharge, 83 at the 3-month post discharge mark**,** and 62 at the 6 month mark. 45% lost to follow up through the entity.					

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Table A3

Synthesis Table

Study Author	Annamalai, M. R.	Atkins, E. K.	Esses, S. A.	Hamptom, S. F.	Hauschildt, K. E.	Jennings, M. L	Martillo, M.	Rohr, M.	Sidiras, G.	Yuliarto, S.
Year	2022	2020	2019	2022	2022	2021	2021	2021	2019	2022
Design/LOE	Cohort Study IV	SR Qualitative V	SR/RCT I	Cohort Study IV	Qualitative VI	RCT I	Qualitative VI	MM/RCT II	Cohort Study IV	Obs. Cohort IV
Demographics										
n subjects	183	18	62	65	14	80	45	100	128	45
ICU admission > 24h		X	X						X	X
ICU admission > 72h										
ICU admission minimum 4 days	X							X		
ICU admission minimum 7 days							X			
Did not indicate				X	X	X				
Setting										
PICU/CVICU	X		X			X				X
Adult ICU				X			X	X	X	
Outpatient Care		X			X					
Tools										
Parent/Family/Healthcare Education		X	X	X	X					
DASS										X
FSS	X									X
GAD-7								X		
PHQ							X	X		
PTSS							X	X		
SF									X	
SOFA								X		
TISS										X

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Study Author	Annamalai, M. R.	Atkins, E. K.	Esses, S. A.	Hamptom, S. F.	Hauschildt, K. E.	Jennings, M. L	Martillo, M.	Rohr, M.	Sidiras, G.	Yuliarto, S.
Year	2022	2020	2019	2022	2022	2021	2021	2021	2019	2022
QOL							X		X	X
Outcomes/ Themes										
PICS diagnosis	X	X	X	X	X		X			X
Impact on cognitive domain	X	X				X	X	X		X
Impact on physical domain	X	X				X	X	X	X	X
Impact on psychiatric domain	≠	X				X	X	X		
Impact on social domain	≠									

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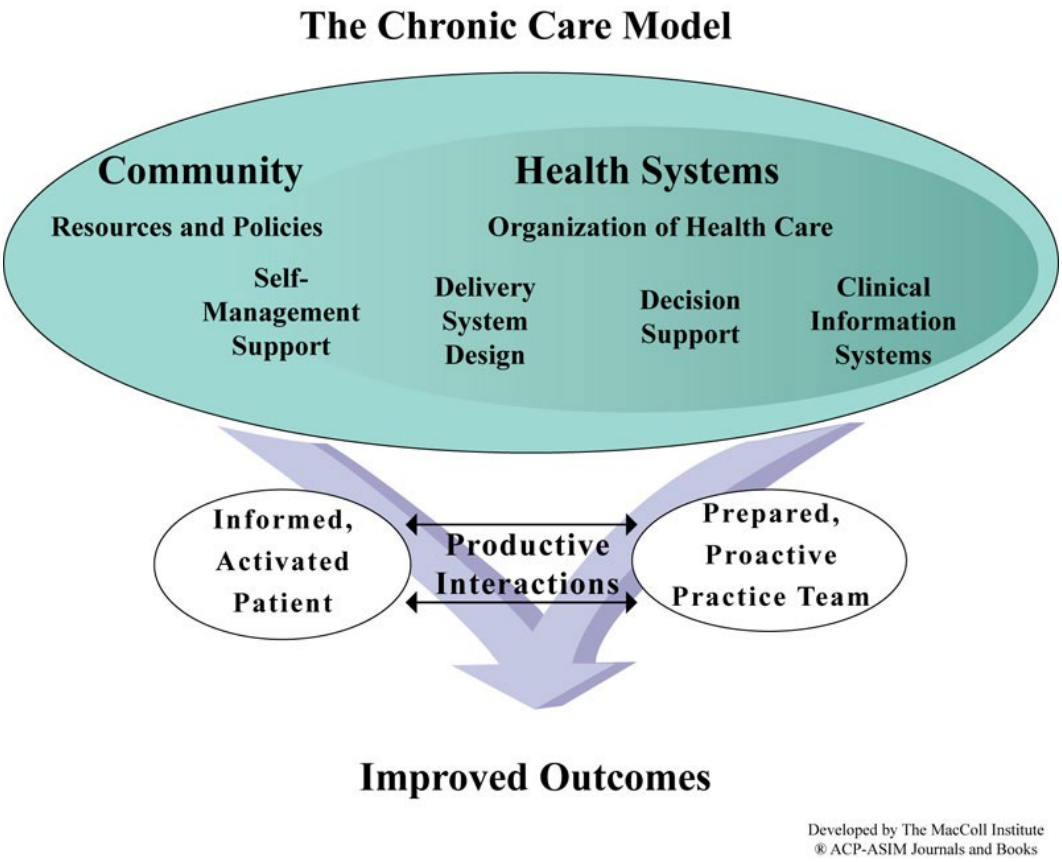
Appendix B

Models and Frameworks

Figure B1

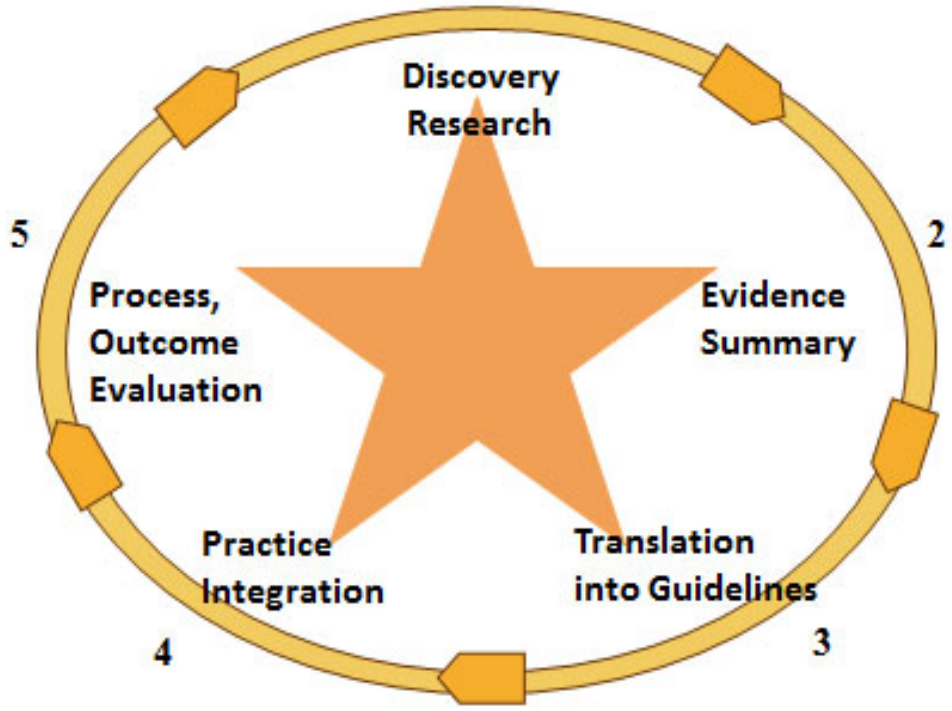
Chronic Care Model



(Institute for Healthcare Improvement [IHI], n.d.; Turner, 2018)

Figure B2

Steven's Star Model of Knowledge Transformation



Used with permission.

(Stevens, 2013)

Appendix C

CAPD Screening Tool

RASS Score ____ (if -4 or -5 do not proceed)

Please answer the following questions based on your interactions with the patient over the course of your shift:

	Never 4	Rarely 3	Sometimes 2	Often 1	Always 0	Score
1. Does the child make eye contact with the caregiver?						
2. Are the child's actions purposeful?						
3. Is the child aware of his/her surroundings?						
4. Does the child communicate needs and wants?						
	Never 0	Rarely 1	Sometimes 2	Often 3	Always 4	
5. Is the child restless?						
6. Is the child inconsolable?						
7. Is the child underactive—very little movement while awake?						
8. Does it take the child a long time to respond to interactions?						
					TOTAL	

(Traube et al., 2014)

Appendix D

Phase	Activities	Cost	subtotal	Total
Preparation	Design, print, and post promotional materials on unit (colored copies, 10 each)	$5		
	Have IT add method for tracking CAPD scores in SCM	$200		
	Design and print evaluation tools and handouts (50 of each)	$10		
	Meetings with Site Champion Mandy Richardson (1hr @ $50 avg x 5 mtgs)	$250		
	Meeting with CLNA re: delirium education (1hr @ $40 avg x 1 mtg)	$40		
	Meetings with Project Mentor Aimee Bucci (1hr @ $45 avg x 6 mtgs)	$270		
	Meetings with Dr. Glover (ASU statistician) (1hr @ $50 avg x2 mtgs)	$100	$875	
Delivery	Rented meeting space – utilize unit conference room	$0		
	Staff salary education hours (1hr @ $30 avg x 50 nurses)	$1,500		
	Medical provider salary for educational hours (1hr @ $60 avg x 10 providers)	$600		
	Light refreshments and supplies for educational session	$50	$2,150	
Evaluation	Email reminder to complete postsurvey if not done in person	$0		
	Student hours for data analysis ($0/hr)	$0		
	Future hours for data analysis ($25/hr x 10h/wk)	$250		
	Intellectus software – already accessible to student	$0	$250/wk	**$3,275**
Cost Savings	Reduced hospitalization due to early delirium recognition and treatment	$9,000 - $75,000		