

DNP Portfolio Executive Summary  
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The Doctor of Nursing Practice (DNP) program of study has allowed me to broaden, enhance and advance my clinical and leadership skills in a manner that exemplifies evidence-based, ethical, and advanced practice nursing. Throughout my career, I have constantly valued and sought more knowledge. The DNP program has proven to be the ultimate source of knowledge acquisition, assimilation, and advancement.

Reviewing the current literature for writing clinical case reports provided new information for consideration and integration into clinical practice. My clinical competency has been enhanced by thoughtful evaluation and reflection of my existing practice. Expanding my clinical knowledge base related to substance use disorders has been an invaluable supplement to my pain management practice, and residency hours have provided an opportunity to further develop my skills in caring for patients at risk.

For me, the ultimate enactment of advanced practice is clinical inquiry. To be always asking why or how, requires that I look for the latest information, innovative ways to improve care, and opportunities to lead and role model expert advanced practice nursing. Over the course of my career, I have had many opportunities to be involved with initiatives to improve the health and health outcomes for individuals, groups, and entire populations. However, because of the academic and scientific rigor of my clinical inquiry project (Evaluating the Effect of a Pain Resource Nurse Program on Barriers to Pediatric Pain Management), I have developed a better understanding of the assessment, implementation, evaluation, and information dissemination processes necessary to make worthwhile contributions to nursing knowledge and practice.

Through systematic evaluations of health policy and organizational systems I have gained a greater understanding of the depth, breadth, and significance these have on the comprehensiveness, equality, and effectiveness of health care delivery. I have been challenged to, and see the benefit of looking beyond the local influences and factors and to be aware of national and global perspectives and influences.

Developing this portfolio to showcase my learning and growth experience has provided guidance and direction throughout the program of study. I have improved my clinical knowledge through the case studies, my leadership knowledge through the clinical inquiry project, and my organizational systems and policy understanding through evaluations of local regional, national, and global influences of health care. Going through the process of having a manuscript accepted for publication has prepared me to more effectively disseminate this and future knowledge.

Disparities in healthcare abound, but particularly for children in pain. DNP preparation has given me additional skills to function more effectively (professionally and personally) as a clinician, change agent, and advocate in my healthcare system, community, and nationally to change this paradigm. Today, our children face significant challenges on the road to adulthood and my mission is to decrease the number of children whose functionality is diminished by pain.

When I enrolled in the DNP program, I hoped to be challenged to look at situations/opportunities more critically and methodically, and to move my nursing practice to a higher level. That hope has been satisfied by being exposed to a variety of highly qualified classmates and faculty with advanced knowledge and skills.

Running head: PEDIATRIC PAIN MANAGEMENT BARRIERS AND PRN PROGRAM

Barriers to Pediatric Pain Management and Impact of the Pain Resource Nurse Program

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## Background

When children are hospitalized, they are most often faced with the experience of acute pain. However, they may also be exposed to procedural pain and endure chronic or end of life pain. Among hospitalized children, the prevalence of clinically significant pain may be as high as 60% (Walker & Wagner, 2003). Hospitals admit thousands of children each year, and yet despite the American Pain Society (APS) and American Academy of Pain Medicine (AAPM) (Ferrell et al., 2001) identifying children as being at risk for under treatment of pain, it is well documented that pain is not properly managed in this vulnerable population (Beyer, 2000; Ellis, O'Connor, Cappelli, Goodman, Blouin, & Reid, 2002; Sheidler, McGuire, Grossman, & Gilbert, 1992; Sutters et al., 2004). Untreated or poorly treated pain impacts every system in the human body and can lead to impaired healing, delayed recovery, prolonged hospitalization, exacerbation of illness or injury, and in some cases death (Schechter, Berde, & Yaster, 2003; Pasero, Paice, & McCaffery, 1999).

There are many barriers which negatively impact and contribute to the under treatment of pain in children. These factors include: knowledge and attitudes of nurses (Clarke, French, Bilodeau, Capasso, Edwards, & Empoliti, 1996; Ferrell, McGuire, Donovan, 1993; Hamers, Abu-Saad, van den Hout, & Halfens, 1998; Hester, 1993; Manworren, 2000); characteristics of nurses (Abu-Saad & Hamers, 1997; Clarke, et al., 1996; Fuller, 1996; Griffin, Polit, & Byrne, 2007; Horbury, Henderson, & Bromley, 2005; Wilson, 2007); child characteristics; amount of analgesia administered by nurses (Fuller, Neu, & Smith, 1999; Hall-Lord, & Larsson, 2006; Hamers, Abu-Saad, Halfens, & Schumacher, 1994; Horbury, et al., 2005; Vincent & Denyes, 2004); and multi-faceted barriers such as the patient/family, health care providers, and health care delivery systems (American Medical Association (AMA), 2006; APS, 2006; Czarnecki et al, 2008; Gunnarsdottir, Donovan, & Ward, 2003; McCaffery, 1999; Vincent & Denyes, 2004).

### *Strategies to Overcome Barriers*

Many different strategies have been used to overcome barriers to pain management. One such strategy is improving nurses' knowledge through the Pain Resource Nurse (PRN) Program which develops staff nurses as pain management experts on their units. In 1992, Ferrell and colleagues at The City of Hope in Duarte, California (Ferrell, Grant, Ritchley, Ropchan, & Rivera, 1993) developed this educational program. This or closely adapted programs have since been implemented in hospitals around the United States (US) and have been reported to be effective (Ellis, et al., 2007; McCleary, Ellis, & Rowley, 2004; Paice, Barnard, Creamer, & Omerod, 2006). The program consists of developing unit based experts via didactic training covering topics such as pain assessment, pharmacologic management, non-pharmacologic management, types of pain (acute, surgical, end of life, and special populations), psychosocial-spiritual aspects of pain, patient education, and caring for the professional caregiver. Case study, skills application, and role play are utilized to develop clinical decision making and leadership skills as the PRN nurses also serve as role models, provide education and consultation, and act as change agents for improving pain management. Critical attributes of the PRN nurses are related to increased self efficacy and include augmented pain knowledge, improved assessment and communication skills, and enhanced leadership and empowerment.

Other strategies used to decrease barriers to pain management include utilization of evidence based guidelines, state wide initiatives, institution wide pain committees, quality improvement projects, and patient education programs (Clarke, et al., 1996; Dahl, Gordon, Ward, Skemp, Wochos, & Schurr, 2003; Gunnarsdottir, et al., 2003; Pasero, Gordon, McCaffery, & Ferrell, 1999). Though experts espouse the value of these efforts, they all agree that multiple strategies (including the PRN Program) are required for measurable and sustained success.

Doernbecher Children's Hospital (DCH) is a university based teaching hospital and clinic system providing tertiary care for children ages 0-18 on nursing units such as intensive care, intermediate care, neonatal intensive care, emergency care, hematology/oncology, medical/surgical, and a multitude of general and specialty care outpatient clinics. Clinical experience, a survey of DCH RNs, and family satisfaction reports indicate there are several barriers to the delivery of optimal pain management at Doernbecher.

As the Clinical Nurse Specialist whose role involves providing direct patient care, working with nurses and multidisciplinary providers, and guiding institutional standards and policies, it is clear to me DCH has barriers similar to what is reported in the literature. This has been confirmed by the results of a recent survey of DCH RNs regarding perceived barriers to pain management. Overcoming barriers is a complex and multidisciplinary challenge. The PRN Program may be an influential grass roots approach to drive the change for an organizational commitment to value optimal pain management and improve clinical practice. As a Doctor of Nursing Practice (DNP) student with my leadership role and expertise in pain management, I am well prepared and positioned to champion the values inherent to relieving pain; evaluate the evidence supporting clinical standards and guidelines, the safety and efficacy of pain management practices, and the effectiveness of nursing training programs; begin removing barriers to the delivery of optimal pain management; and empowering the staff nurses to do many of these activities.

The purpose of this program evaluation is to determine the effectiveness of the PRN Program for reducing barriers to optimal pain management and improving family pain satisfaction scores on DCH's Pediatric Acute Care Center (PACC). In order to do this, following questions are posed:

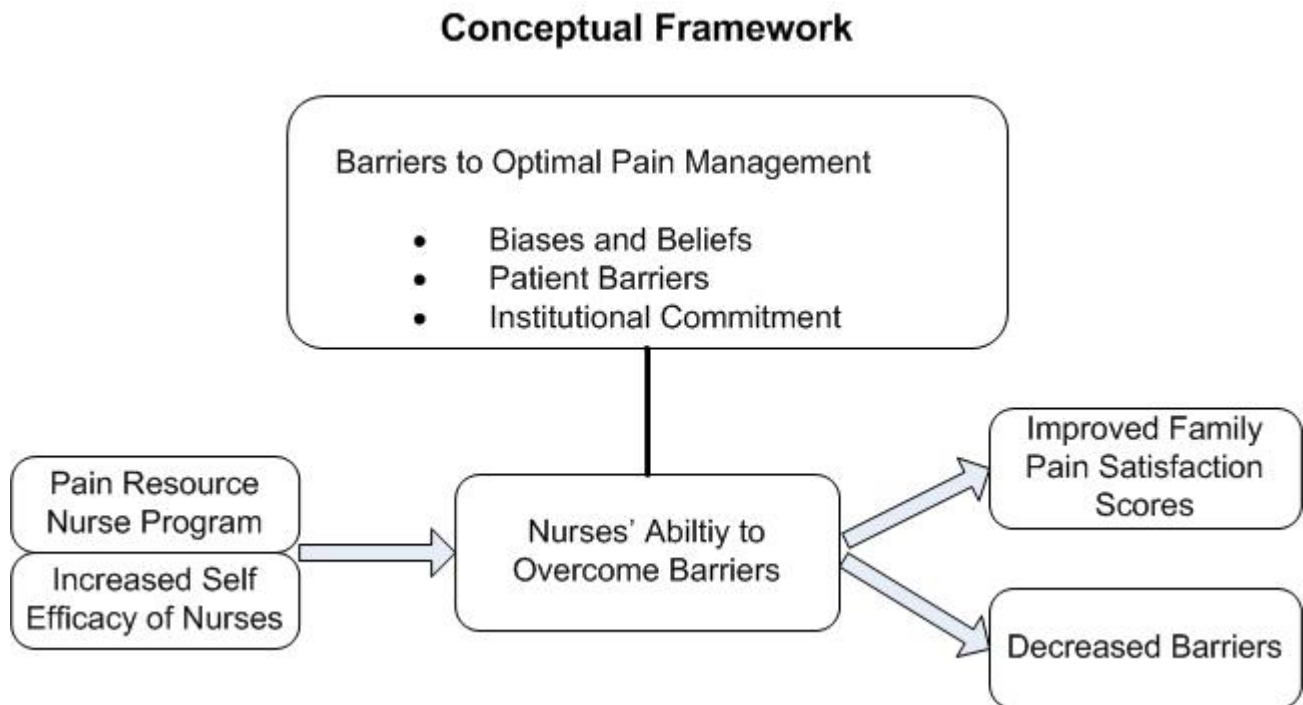
1) What are the most frequent perceived barriers to providing optimal pain management identified by the Pediatric Acute Care Center (PACC) RNs at Doernbecher Children's Hospital's (DCH),

2) Does the Pain Resource Nurse (PRN) Program decrease barriers to pain management on the PACC, and

3) Does the PRN Program improve PACC family satisfaction scores?

### Conceptual Framework

A conceptual framework was developed to guide this project which will identify barriers, evaluate interventions, and focus additional clinical inquiry. Although it is recognized there are multiple complex barriers to providing optimal pain management, the concepts of interest for this clinical inquiry project are perceived barriers to pain management, nurses' abilities to overcome those barriers, and family satisfaction with pain management during hospitalization. See Figure 1.



*Figure 1.* Evaluation of the Pain Resource Nurse Program Outcomes

After extensive review of the literature, optimal pain management is broadly defined as the appropriate, safe, effective, and evidence based treatment of pain.

Barriers are defined as any factor which diminishes or prevents the delivery of optimal pain management. There is extensive literature on such barriers and they are generally grouped into three broad categories which are: barriers within the health care delivery system (hospital, local, regional, and national policy, standards, and laws), barriers related to health care professionals (knowledge, beliefs, and behaviors), and patient and family barriers (knowledge, communication, and disease process) (AMA, 2006; APS, 2006; Czarnecki et al, 2008; Ferrell, Grant, et al., 1993; Gunnarsdottir, Donovan, & Ward, 2003; McCaffery, 1999; Polkki, Laukkala, Vahvilainen-Julkunen, & Pietila, 2003; Vincent & Denyes, 2004).

Family satisfaction with pain management can be assessed in many ways, both formal and informal. Nursing and administrative staff may have conversations with families who are informally reporting dissatisfaction or satisfaction with pain management. These personal stories can be powerful, but they do not lend themselves to measurement. More formal pain satisfaction measures have been developed by nursing units, health care systems, professional organizations, and health care consulting businesses. Two well known consulting firms whose focus is using standardized and comparable methods to measure health care performance are NRC Picker and Press Ganey. Tools used by these companies to measure family satisfaction have been designed and tested to report scores from minimal to maximal levels of satisfaction. For the purpose of this project, family pain satisfaction will be defined as the scores from specific pain items reported by the consulting firms of NRC Picker and Press Ganey.

Using barriers and family satisfaction scores as measures, this program evaluation project will assess the effectiveness of the PRN Program in improving nurses' abilities to overcome barriers. It is

posited that improving nurses' abilities to overcome barriers will decrease the number and/or intensity of perceived barriers to optimal pain management and fewer barriers will result in improved family satisfaction scores.

## Review of Literature

### *Under Treatment of Pediatric Pain*

Despite significant advances in the field of pain management, pain in children continues to be under treated. In their review article, Walker and Wagner (2003) report the literature indicates the prevalence of clinically significant pain in hospitalized children may be as high as 60%, only about 60% of pediatric hospitals have pain management standards, and of the 60%, only 15% indicate those standards are followed 80% or more of the time. Walker and Wagner go on to say knowledge in the field of pediatric pain management has advanced greatly yet the translation to clinical practice continues to lag.

Ellis et al. (2002) reported their descriptive study found that a "substantial number of children had unacceptably high levels of pain" (p. 267) and that "nurses are assessing pain accurately but not using the assessment information to take action" (p. 268). The limitations of this study are not insignificant. The pain measurements were done in single eight hour (9:00 a.m. to 5:00 p.m.) period on week days, sample size varied because patients were unavailable at all measurement points (two hour intervals), and pain intensity was measured by self report of the children, parental report, or health professional report. The tool used by the children to measure intensity (color analog scale) is a metric not currently in common use due to concerns about validity and reliability. They conclude their results are comparable to what is reported in the literature.

Acetaminophen with codeine is one of the most commonly used analgesics for mild to moderate postoperative pain in children. Sutters et al. (2004), in a randomized three group treatment



( $n=80$ ) study showed this standard treatment analgesic did not provide adequate relief for children following tonsillectomy whether the medication was given on a scheduled basis with routine post operative instructions, given on a scheduled basis with RN coaching, or given on an as needed basis. Limitations of this study include a single surgical population (tonsillectomy) was used, data were collected using a parent completed home diary, and subjects were 6 to 15 years of age. Despite the limitations, it can be concluded continued use of suboptimal analgesics further contributes to the under treatment of pediatric pain.

Beyer (2000), using a small ( $n=21$ ) convenience sample reported 71% of the sample were in moderate to severe pain at time of study interview which occurred during hospitalization for a veno-occlusive event related to sickle cell disease. Though this study may not be representative of the overall hospital experience for these patients nor can it be generalized beyond the study institution, it is indicative that a significant under treatment of pain exists in this population.

Sheidler, et al. (1992) used four clinical vignettes to examine nurses' decision-making skills related to analgesic administration. Of the 708 responses provided by 177 participants attending an oncology conference, only 26% were correctly answered. All four vignettes were answered incorrectly by 29% of the sample and 44% of the sample answered only one vignette correctly. The vignettes had been written specifically for this study and covered changes in routes of analgesic administration, specific analgesic and doses administered, and a combination of route, analgesic, and dose. These findings may indicate patients in pain may not receive adequate analgesia. The ability to make generalizations from this study is limited as the vignettes were based in cancer care, not tested for clinical relevance and accuracy, and they were not specific to pediatric nurses.

The available literature supports Walker's and Wagner's (2003) report that despite significant increases in knowledge of pediatric pain management, translation to clinical practices is lagging.

### *Barriers to Pain Management*

As an intervention follow-up, a survey was developed by Ferrell and colleagues (1995) which included verbiage regarding barriers to improving pain management from the 1994 Agency for Health Care Policy and Research's (AHCPR) Management of Cancer Pain Guideline. There were 14 perceived barriers to pain management that fell into three categories of problems related to the health care system, problems related to health care professionals, and problems related to patients (Ferrell, Dean, Grant, & Colluzi, 1995).

In a study designed to describe factors which promote and hinder nurses' use of nonpharmacological methods to relieve surgical pain, Polkki, et al. (2003) identified five factors that promoted the use of nonpharmacological pain relieving methods and five factors that hindered their use by pediatric nurses. The factors that were seen as hindering were the nurse's insecurity, beliefs regarding the expression of pain, workload/time constraints, limited use of pain alleviation methods, and work model/patient turnover. This descriptive study was done in a pediatric hospital in Finland, had a 99% response rate to a Likert-type questionnaire and a final *n* of 162. The factors identified have the familiar underpinnings of barriers related to health care systems, health care providers, and patients.

Vincent and Denyes (2004), drawing on the 1994 AHCPR guidelines and Ferrell's work, developed a 13-item instrument which solely focused on barriers to optimal pain management. The tool was used to quantify nurses' abilities to overcome barriers to optimal pain management in relation to knowledge, attitudes, characteristics (nurse and child), and the amount of analgesia administered. The four most frequently reported barriers in the Vincent study stemmed from the physician, the child, and the parents, and were "inadequate or insufficient physician medication orders," "children's reluctance to report pain," "parents' reluctance to have children receive medications," and "children's

reluctance to take pain medications” (p. 181) (Vincent, 2005). Limitations of this study, which was reported in two journals, include convenience sampling ( $n=67$ ) of nurses, pain levels were measured during a six hour block, and the majority (80%) of the child subjects were experiencing pain from surgery.

Building on the work by Vincent and Denyes (2004), Czarnecki et al. (2008) made slight modifications to the 13-item instrument and completed a survey of RN staff in their 250 bed pediatric teaching hospital. Respondents ( $n=272$ ) identified the following top five barriers: inadequate or insufficient physician orders, insufficient premedication orders prior to procedures, insufficient time allowed to pre-medicate prior to procedures, low priority given to pain management by medical staff, and parents’ reluctance to have patients receive pain medications. The investigators then did a principle component factor analysis which highlighted the components of institutional commitment, nurses’ biases and beliefs, and patient barriers. These components also appear to follow the categories of barriers related to health care systems, health care providers, and patients identified by Ferrell et al. (1995).

#### *Knowledge and Attitudes as Barriers*

Knowledge deficits related to pain management persist despite a plethora of literature providing current and emerging information in the field. Changes to nursing education (basic and continuing) focusing on pain management have yet to yield significant changes in clinical practice.

Hester (1993) wrote in her expert opinion, “improving knowledge and clinical judgment skills of nurses regarding pain” (p. 131) would potentially alleviate the inadequacies of pain management in children. Ferrell, McGuire, and Donovan (1993) also were of the same opinion, and to facilitate quantifying nurses’ knowledge and attitudes developed the Survey of Knowledge and Beliefs Regarding Pain. This tool was developed using 23 questions to measure knowledge, beliefs, and

combined knowledge/beliefs scores. The scores discriminated in the direction predicted between the novice and expert nurses with students having the lowest scores and the pain experts having the highest score. Construct validity was verified by a panel of pain experts. Eighteen of the 23 items had greater than or equal to 90% agreement in appropriate word and content. The other five questions ranged from 60 to 80% agreement and were revised based on feedback from the panel. Content was deemed to measure both knowledge and beliefs. The tool was then used in a survey of nursing faculty at 14 baccalaureate nursing schools in the US. Based on responses from 498 faculty members, Ferrell et al. speculated that one in ten faculty members were teaching outdated or inappropriate material on pain and pain management. This study is more than 15 years old and many advances have since been made in the knowledge of pain and its treatment. However, the literature does not indicate nursing practices related to pain management have made similar advances.

In their 1997 review of the literature and comparison of the surveys used over the years 1988 to 1995, such as the Nurses' Knowledge and Attitude Survey (NKAS), McCaffery and Ferrell reported some areas of nurses' knowledge showed improvement (assessment, opioids dosing, and the likelihood of addiction) though deficits remained (importance of patient's self report of pain and opioid titration). They deemed the NKAS continues to be a valid and reliable assessment tool but point out the limitation of survey methodology generally being a single point in time. Additional limitations of this review are that surveys reviewed were those developed by the authors, surveys were modified over time, and potential sampling bias. Nurses completing the surveys reviewed are not likely representative of practicing nurses as they are likely more motivated to learn about pain or care for populations known to experience significant pain (cancer and end of life).

Hamers, Abu-Saad, van den Hout, and Halfens (1998) in their review of the literature indicated nurses' knowledge and attitudes regarding pain relief methods contributed to the insufficient

administration of analgesics. The review was started using four classic citations regarding insufficient medication administration for children's pain and Medline was searched for additional literature using the snowball method. This review is limited in current applicability given its age and methodology.

Clarke, et al. (1996) used the Nurses' Knowledge and Attitude Survey in their study evaluating the impact of RN education and characteristics on knowledge, attitudes, and clinical practice. The sample for this study was 120 RNs from nine various units of a large university affiliated teaching hospital with the highest response rate (94%) from the oncology unit. They made a significant observation regarding the appropriateness of this tool for nurses not caring for cancer patients. The oncology unit in their study had the highest mean score on the survey and Clarke et al. point out that one third of the questions on the survey are specific to cancer pain. They recommended modification to the survey that would allow it to be more applicable to pain management in general. Their study also described how nurses' characteristics (e.g., age, work experience, personal experience with pain) and education (basic and continuing) levels impacted clinical practice including documentation. Based on their findings, their recommendations included continued and repeated education regarding pain management principles, wide spread distribution and utilization of evidence based guidelines, and implementation of PRN programs. This study's results were consistent with findings previously reported in the literature, but cannot be generalized beyond their organization.

None of the above studies were specific to pediatric nurses so Manworren and Hayes (2000) modified the NKAS to reflect pediatric pain management standards. The modified tool was called the Pediatric Nurses' Knowledge and Attitudes Survey Regarding Pain (PKNAS) and contained 42 items. Content validity was established by a national nursing panel of pediatric pain experts. The original tool author (B. Ferrell) verified the consistency of concepts between the NKAS and PKNAS. Manworren and Hayes then administered the survey with responses from 247 staff at large pediatric teaching

hospital. After analysis of the descriptive data, it was concluded the PKNAS is a valid tool for the identification of pain management knowledge deficits in pediatric nurses.

Though some variability is noted in all of these studies, it appears knowledge deficits related to pain management generally persist. Continued efforts must be made to address these deficits so nurses are practicing with accurate knowledge and information

#### *Lack of Nursing Empowerment as a Barrier*

Extensive literature exists documenting that education alone is not enough to change clinical practice. The overarching principle of the PRN Program is to improve nursing practice related to pain management and this writer believes empowerment and effective communication techniques are critical to the ability of the PRN Program to positively influence practice. Manojlovich (2007) posits that nurses who have a sense of empowerment and expertise are more effective at influencing others (“expert power, p. 15”) resulting in improved patient outcomes. Maxfield, Grenny, McMillan, Patterson, and Switzler (2005) in their report *Silence Kills The Seven Crucial Conversations for Healthcare* say their “study shows that healthcare workers who are confident in their ability to raise these crucial concerns observe better patient outcomes, work harder, are more satisfied, and are more committed to staying (p. 3).”

#### *Health Care System Barriers*

There are a broad range of barriers that are reported to come under the health care system category though there are limited studies that quantify the impact of these systems barriers. The barriers may be as global as societal attitudes related to poverty, culture, addiction, and substance abuse and legal barriers which include restrictive laws and regulations around controlled substances commonly used for pain management, or as focused as which medications are allowed on hospital pharmacy formularies (Schechter, Berde, & Yaster, 2003). Failure of health care systems to make pain

relief a priority and lack of accountability for pain management practices are major barriers (APS, 2006). Managed care processes may limit access to pain specialists, comprehensive pain management facilities and certain medications (Ferrell et al., 2001). Reviewing the literature on health care system barriers is not relevant to this project.

### *Patient/Family Barriers*

Patient/family barriers are multiple and complex. These barriers can include age, sex, socioeconomic status, and educational level. Race and ethnicity can influence where patients seek care and the quality of care received (Iwashyna, Curlin, Christakis, 2002; Kahn, et al., 1994). Communication difficulties (cultural, language, cognitive, etc.) between patients/families and health care providers and concerns about risk of addiction, abuse, or diversion (Sullivan & Egel, 2005) may also act as barriers to receiving optimal pain management. The patient's disease process may present a barrier if it complicates appropriate assessment and management. Unresolved anxiety, grief, anger, misconceptions, concerns, biases, and beliefs are additional factors which can become barriers preventing patients from adequate pain management care.

### Guidelines for Pain Management

The American Academy of Pediatrics (AAP) and the American Pain Society their 2001 joint statement titled 'The Assessment and Management of Acute Pain in Infants, Children, and Adolescents', state "most acute pain experienced in medical settings can be prevented or substantially relieved" (p. 793), and recommend the anticipation of predictable painful experiences, appropriate interventions, and monitoring effects and processes accordingly. Other guidelines available are more disease focused and specific; however this statement appears to have set the stage and tone for the nearly 200 guidelines found when electronically searching the National Guideline Clearinghouse using the term 'pediatric pain.' Nearly 1000 guidelines were the result of a search using the word 'pain.' The

plethora of guidelines has not had the desired impact of improving pediatric pain management as indicated by the many current reports of continued under treatment in this population.

Empowering nurses is one approach to decreasing perceived barriers to pediatric pain management and it is the goal of this project to determine the impact of the Pain Resource Nurse Program on barriers perceived by nurses on the PACC at Doernbecher Children's Hospital and family pain satisfactions scores reported from children hospitalized on the PACC. Improvements in these areas will provide evidence, support, and motivation for the continuation and expansion of PRN Program to other nursing units at Doernbecher.

Much work has been done to improve the care of children in pain. Never the less, much of what is reported in the literature is descriptive in nature and lacking in measurement of outcomes. It is well known there is a significant lag between new evidence and changing practice. In the current healthcare environment, demonstrating consistently improved outcomes in the form of decreased patient morbidity and mortality and increased cost effectiveness (specifically in reimbursement) may more rapidly drive change. The next steps in this area involve rigorous evaluation of pediatric pain management practices in relation to patient and health care system specific outcomes.

## Methods

### *Clinical Inquiry Design*

The following questions will be asked to perform this program evaluation:

1) What are the most frequent perceived barriers to providing optimal pain management identified by the Pediatric Acute Care Center (PACC) RNs at DCH?

2) Does the PRN Program decrease nurses' perceptions of barriers to pain management on the PACC?

3) Does the PRN Program improve family pain satisfaction scores?



Inquiry design for the first question is descriptive. A descriptive, prospective, longitudinal design will be used to answer each of the other two questions which have different samples (question 2 sample is PACC nurses and question 3 sample are families returning satisfaction surveys after discharge from the PACC). See Appendix A for design diagram and table of variables. These designs were chosen to allow comparison of barriers and satisfaction scores after implementation of the PRN Program to baseline data collected in April 2008, and to assess the program's impact on decreasing nurses' perceived barriers to optimal pain management. Convenience sampling will be used for both the RN and family samples. Randomization is not feasible as the initial measures were convenience sampling and I do not have access to individual responses on the satisfaction survey. This study design does not control for variables other than the PRN Program that may influence perceived barriers which is an additional design limitation.

### *Setting*

DCH is a 150 bed, university based, teaching hospital providing tertiary care for children ages 0-18. Nursing units of care include intensive care, intermediate care, neonatal intensive care, medical/surgical, hematology/oncology, and a multitude of general and specialty care outpatient clinics. The setting for this project will be a medical/surgical unit called the PACC. The PACC has 48 patient beds, and is staffed by 75 RNs who are supported by certified nursing assistants and health unit coordinators (secretarial/administrative support staff). This unit is budgeted for 12,300 patient days which is a more accurate reflection of unit workload than number of admissions and length of stay (LOS). Staffing ratios are consistent with national standards National Association of Children's Hospitals and Related Institutions (NACHRI) for similar University Healthcare Consortium (UHC) pediatric hospitals. Ratios are four patients to one RN (4:1) on the 7:00 a.m. to 3:00 p.m. and 3:00 p.m. to 11:00 p.m. shifts, and four to five patients per RN (4-5:1) on the 11:00 p.m. to 7:00 a.m. shift. This

is based on 10.13 hours of care per patient day (HPPD). The charge nurse does not take patients on the PACC. Staff retention, resulting in a low turnover rate, is high on the PACC.

The PRN Program is congruent with the DCH mission which highlights family-center care, education and training of healthcare professionals, and setting new standards of care for children in Oregon, the Pacific Northwest and worldwide. Significant support for implementation of the PRN Program comes from the nursing administration. Interactions with staff on the PACC indicate that many are eager to improve clinical practice related to pain management. This is supported by feedback from the PACC's Unit Based Nursing Practice Council (UBNPC) which is part of the hospital's shared governance model.

Challenges to overcome in the project setting include cost and recent major system technology changes. Since the baseline data were collected, there has been a multi-phased conversion from paper to electronic medical record requiring extensive training, as well as a major software conversion for electronic mail (e-mail) communication. These changes have required a significant amount of flexibility and effort from the staff. Cost is not insignificant for implementation of the PRN Program given its length (16 hours), the need to provide coverage for the RNs who are being trained, the cost of educational materials, and the promotional costs.

### *Sample*

The first sample of interest is the RN staff working on the PACC. This unit was chosen as the site for this project as it is the largest unit, represents the broadest cross-section of patients and RNs at DCH, and because of the variety of patients the greatest number and variety of multidisciplinary and specialty health care teams. Convenience sampling of PACC RNs was used for purposes of the baseline survey and will be repeated for the post-intervention survey. The baseline sample includes responses from just over one third of the staff ( $n=28$ ). Recruitment for the post-intervention survey will

match the procedure used for the baseline survey. An email, with an electronic link to the survey and weekly (total of four weeks) reminders, will be sent to all PACC RNs ( $n=75$ ). The only exclusion criteria will be non-English speakers as the survey is only available in English. I am on the PACC on a daily basis and have the full support of DCH nursing leadership to evaluate the effectiveness of the PRN Program. Therefore, no major issues with access to the sample group are anticipated.

The second sample of interest is families returning satisfaction surveys after discharge from the PACC. Baseline family satisfaction (NRC Picker) scores were obtained from a convenience sample of patients discharged from the PACC during the same month the baseline survey occurred (April 2008). Post-intervention family satisfaction will again be a convenience sample of patients discharged from the PACC during the same month the RN survey is conducted. However, post-intervention satisfaction scores will be received from Press Ganey due to the organization wide switch from NRC Picker to Press Ganey. Family satisfaction scores are reported monthly and readily available from DCH nursing leadership. Post-intervention data will be gathered one year after the baseline data were collected, and this will also be two months after the PRN Program is initiated.

### *Intervention*

The Pain Resource Nurse Program was developed and first used by Ferrell and colleagues at The City of Hope in Duarte, California (Ferrell, et al., 1993). It is an educational program focused on creating pain experts at the patient bedside. This or closely adapted programs have since been implemented in hospitals around the United States and Canada (McCleary, et al., 2004). The program consists of didactic training covering topics such as pain assessment, pharmacologic management, non-pharmacologic management, types of pain (acute, chronic, surgical, end of life, special populations), psychosocial-spiritual aspects of pain, patient education, case study and skills application, communication role play, and caring for the professional caregiver.

All staff nurses on the PACC received an email announcing the plan to offer the PRN Program and requesting those who were interested to submit a statement of interest and intent to participate. Fliers were also posted on the PACC with the same information (Appendix B). Seven RNs submitted statements and all were accepted into the Program.

For the purposes of this project, the program will be similar to the content outlines used by Ferrell et al. (1993) and McCleary et al. (2004). The course will involve 15 hours of didactic education, case study and skills application, and role play delivered over two eight hour days (Appendix C). The agenda was reviewed and supported by PRN Program experts Betty Ferrell and Debra Gordon (B. R. Ferrell and D. B. Gordon, personal communications, December 11, 2008). Local experts will present the content to participants in a classroom type setting.

In addition to the content mentioned above, sessions on empowerment, being change agents, and having crucial conversations will be provided.

Continuing education credits will be awarded to participants. On a monthly basis after completion of training, the participants will meet for one hour with pain management experts to review patient care, discuss successes and challenges, and to discuss current evidence (journal club format).

### *Measures*

#### *Barriers to Optimal Pain Management Survey*

Registered nurses entering the survey are asked to complete a 36 question survey titled Barriers to Optimal Pain Management which had been adapted with permission from the designer (Czarnecki, et al., 2008). The original measure was developed by Vincent and Denyes (2004) and included 18 items (barriers) designed to assess how much each barrier interfered with nurses' ability to provide optimal pain management. Each item is rated on a 10-point Likert scale with 0 = not a barrier and 10 = a major barrier. Content validity of the barriers measures was addressed by the original developer, an

instrument development scholar, and two pediatric nursing experts (Vincent and Denyes). The development process included extensive literature review, item construction, and pilot testing with an internal consistency alpha of 0.86 (Vincent and Denyes).

Adaptations by Czarnecki et al. (2008) included the addition of one barrier item related to nursing documentation format and free text space to allow nurses to describe what optimal pain management would look like, to list any barriers not specifically identified and make any other comments. A principle component factor analysis of the 19 barrier items was done by Czarnecki et al. which resulted in three subscales with Eigen values above 1 and factor loadings above 0.5. The three subscales identified were titled Institutional Commitment, Beliefs and Biases, and Patient Barriers. Four of the 19 items loaded into Beliefs and Biases (concern about children becoming addicted, concern about side effects of medications (other than addiction), concern about children becoming tolerant to analgesics, and limitations in my knowledge of pain management), seven of the 19 items loaded into Institutional Commitment (low priority given to pain management by medical staff, low priority given to pain management by nursing staff, low priority given to pain management by nursing management, inadequate or insufficient physician medication orders, insufficient time allowed to pre-medicate prior to procedures, insufficient pre-medication orders prior to procedures, insufficient resources to provide guidance/expertise in managing patients' pain), and three of the 19 items loaded in Patient Barriers (patients' reluctance to report/rate pain, patients' reluctance to take pain medications, parents' reluctance to have children receive medication). Five items did not load onto a subscale but were still considered important barriers to providing optimal pain management. One additional barrier measure was included in the current survey regarding timeliness/responsiveness from medical staff to the RN's concern about pain management. Scores are constructed as the mean for the items and high scores indicate the barrier is more highly perceived. The survey also gathers demographic

characteristics of the nurse including nursing unit assignment, role on unit, gender, years of pediatric nursing experience, educational preparation, and race and ethnicity. No personally identifiable data were collected (see Appendix D).

#### *Patient/Family Satisfaction*

*NRC Picker satisfaction report.* NRC Picker is a fee for service health care consulting firm offering performance measurement and improvement services. NRC Picker determines the number of surveys needing to be mailed to patients in order to obtain a 30-34% response rate. This response rate is representative of the industry standard. The survey has 72 questions on 4 pages with a single comment section at the end. Item response choices vary depending on the type of question and there are two to five choices, again depending on the question. Four questions (34, 35, 36, and 37) are related to satisfaction with pain control (see Appendix E). Surveys are mailed to patients who are randomly selected from a discharge list provided each month by the hospital. The mailing includes the survey and a return postage paid, pre-addressed envelope. If the first mailing of surveys does not achieve the desired response rate a second mailing occurs.

*Press Ganey satisfaction report.* Press Ganey is another health care consulting firm focusing on performance measurement and offering improvement services. Press Ganey mails out enough surveys to obtain a 30% response rate which results in about 10% of the discharged patients receiving surveys. The survey is 54 questions on 4 pages with comment sections at the end of each grouping of questions. Items are rated on a 1-5 Likert scale with 1= very poor and 5= very good. A single question (see Appendix F) regarding satisfaction with pain control is near the end of the survey. Surveys are mailed to patients who are randomly selected from a discharge list provided weekly by the hospital. The mailing includes the survey and a return postage paid, pre-addressed envelope.

The monthly reports for both surveys provide a cumulative score for those surveys returned by families discharged from the PACC. There are no individual scores reported. Limitations of this data include having two different measures and different numbers of questions on each measure (four on NRC Picker versus one question on Press Ganey).

### *Data Collection Procedures*

#### *Baseline Data*

*Barriers survey.* After receiving Institutional Review Board (IRB) approval, permission was granted to access the RNs email list from the Nursing Division Director and unit nurse managers for Doernbecher. The baseline survey (April 2008) was then administered to all RNs working at DCH (N = 300) via an email which included the electronic link to a Zoomerang version of the survey items. Completion of the survey was voluntary and implied willingness to participate. A weekly email with the electronic link was sent to the same distribution list as a reminder to complete the survey if it had not already been done. The survey was available for four weeks and took approximately 25 minutes to complete. A quality management specialist experienced with using the Zoomerang system, transferred the data from Zoomerang to an Excel spreadsheet. From the Excel spreadsheet, the data was imported to SPSS for statistical analysis. At all times, access to the survey results, Excel spread sheet, and SPSS were stored on secure, password protected computers in locked offices. Baseline data will be those survey responses from respondents identifying their unit of work as the PACC.

*Satisfaction scores.* NRC Picker family satisfaction scores are reported monthly to Doernbecher administration by the consulting firm. The report from April 2008 will provide the baseline pain satisfaction scores from the four questions related to pain (see Appendix E). It must be noted, the relevance of these scores is marginal given the convenience sampling and small numbers of surveys returned.

### *Prospective Data*

*Barriers Survey.* For the purposes of this clinical inquiry project, after implementation of the PRN Program, the Barriers to Optimal Pain Management survey will only be distributed to PACC RNs. Permission to access the RNs email list has been granted by the Nursing Division Director and PACC nurse manager. An email with the electronic link to a Zoomerang version of the survey items will be sent. Completion of the survey is voluntary and implies willingness to participate.

A weekly email (with the electronic link) will be sent to the same distribution list as a reminder to complete the survey if it not already done (see Appendix G). The survey will be available for four weeks and takes approximately 25 minutes to complete. A quality management specialist experienced with using the Zoomerang system, will transfer the data from Zoomerang to an Excel spreadsheet. From the Excel spreadsheet, the data will be imported to SPSS for statistical analysis. At all times, access to the survey results, Excel spread sheet, and SPSS will be stored on secure, password protected computers in locked offices.

*Satisfactions Scores.* Each month Press Ganey family satisfaction scores are reported to Doernbecher administration by the consulting firm. Post-intervention family pain satisfaction scores will be those reported during the same month the PACC RNs are being surveyed regarding barriers. It must be noted, the relevance of these scores is marginal given the single survey question, the convenience sampling, and small numbers of surveys returned.

### *Data Collection Cost and Revenue Information*

No revenue will be generated from this data set. No direct costs have been identified. Indirect costs will include hours of time needed for a quality management specialist to create the Zoomerang survey and transfer results to Excel.

### *Analysis*



*Question One (Most Frequent Perceived Barriers)*

*Preliminary work.* Baseline survey data collected in April 2008 will be analyzed. Means with standard deviations will be reported for each survey item that did not load in the factor analysis (5 of 19 items). Means with standard deviations will also be reported for the three subscales of barriers identified from the factor analysis (Beliefs and Biases, 4 of 19 items; Institutional Commitment, 7 of 19 items; and Patient Barriers, 3 of 19 items). Pre and post program barrier percentages and frequency means and standard deviations will be displayed in tables.

*Question Two (Does PRN Program Decrease Barriers?)*

Question two will be answered by comparing data gathered at the baseline point (survey results) and data collected after implementation of the PRN Program. Analysis of question two will include reporting of the means and standard deviations for each of the three subscales. Comparisons between the baseline and post-program data will be done using a series of single-sample t-tests and reporting those results with the degrees of freedom and p value.

*Question Three (Does PRN Program Improve Satisfaction Scores?)*

Question three will be answered by comparing data gathered at the baseline point (satisfaction scores) and data collected after implementation of the PRN Program. Analysis of question three will be done using Chi-square because the pre- and post-program samples will not be the same and the dependent variable (satisfaction scores) will be categorical.

Demographic characteristics of the sample population will be described. This includes nursing unit assignment, role on unit, gender, years of pediatric nursing experience, educational preparation, race, and ethnicity.

### *Project Associated Costs and Revenue*

Direct costs of this program will include the initial 16 hours for training and materials for the seven PRN nurses, which are projected to be approximately \$5,000. Ongoing direct costs will be monthly support, training, and recognition of the PRN nurses. Indirect costs associated with the project will be related to the advanced practice nurse (APN) time to manage and support the PRN nurses. Decreasing barriers to pain management may result in cost savings from more efficient use of staff time, improved patient outcomes, improved patient throughput (patients who discharge more quickly will result in more open beds to accommodate admissions), and perhaps decreased pharmacy costs because of fewer medications used and fewer side effects needing to be treated. The full financial implications of this program will be more thoroughly evaluated in future, and therefore not presented in detail for this project.

### *Protection of Human Subjects*

This project has been reviewed by the Institutional Review Board and granted approval as an exempt quality improvement project. An amendment to the approved project will be filed as the original proposal was to resurvey all DCH RNs two years after the April 2008 survey and surveying the PACC RNs after implementation of the PRN program will occur at one year. No ethical conflict or concern has been identified for this clinical inquiry project.

### *Dissemination of Results to stakeholders*

A full clinical inquiry report will be presented in writing and an oral presentation to DCH nursing leadership at the completion of the project. Poster presentation of the project results will be done for the PACC staff as this has been determined by unit leadership as an efficient and effective method of communication with the RNs. Any additional requests for dissemination of the results will be addressed as and presentation format will be determined as appropriate to the audience.

*Project Timeline*

10/1	10/13	11/3	12/1	1/1	2/1	3/1	4/1	5/4
-Incentive Program -Establish criteria for PRN nurses	-eIRB (PRAF to existing project )	-Plan classes (check with BF, DG, MC) -CE Applic. -Identify PRN nurses	-Gather training materials	<b>PRN Program</b>	-PRN RN support and ongoing development	-Resurvey the PACC -PRN RN support and ongoing development	-Analyze Data -PRN RN support and ongoing development	-Final Due -PRN RN support and ongoing development

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## Appendix A

## Question 1 O

- O = observations

Question 2  $Y_b$ 

X Y

- $Y_b$  = Baseline barriers, Y = post barriers
- X = PRN Program

Question 3  $Y_b$ 

X Y

- $Y_b$  = Baseline satisfaction scores, Y = post
- X = PRN Program

*Figure 2. Clinical Inquiry Design Diagram*



<b>Variable</b>	<b>Independent or dependent</b>	<b>Measure</b>	<b>Level of measurement</b>
Barriers to Optimal Pain Management	Dependent	Barriers to Optimal Pain Management survey	Categorical, Chi-square—means and SD for each of the three dimensions and compare pre and post
Family Satisfaction Scores	Dependent	Press Ganey Report	Categorical, Chi-square—collapse into three groups (very poor/poor, fair, good/very good and look at the difference in the proportion in these collapsed groups
PRN Program	Independent		

*Figure 3. Clinical Inquiry Variables*

## Appendix B

**WANT TO MAKE A DIFFERENCE?**  
**Be a PACC Pain Relief Champion**

**Pain Resource Nurse (PRN) Program**

**Call for Applications**

**PROGRAM INCLUDES:**  
 16 hours of pain specific CE training  
 Monthly update and review meetings  
 1 year commitment

**Application Process: Due Nov 7**  
 In Email or writing (in 200 words or less) why you want to do this, what skills you would bring to the group, and why you think you are qualified.  
 Send to Helen Turner (turnerh@ohsu.edu)

**What's In It For You?**  
 Professional Development  
 Skills to Enhance Clinical Practice  
 Recognition as PRN  
 Paid meeting time including parking for meetings

**Selection Criteria:**

- ◆ At least 1 year pediatric experience
- ◆ Commit to attend monthly meeting with Peds Pain Team (time to be determined by PRNs)
- ◆ Commit to be a resource for 1 year

6 PRNs will be selected by Helen Turner. Selections will be announced on November 17

## Appendix C

**Doernbecher PACC Pain Resource Nurse Program Agenda**

<b>DAY ONE</b>	<b>JANUARY 12, 2009</b>		
8:00-8:30	Introduction to PRN Program	(Ruby Jason and Helen Turner)	30
8:30-9:30	Pain Anatomy and Physiology	(Jessica Miller, MD)	60
9:30-9:45	BREAK		
9:45-11:00	Psychosocial Implications	(Michael Harris, PhD)	75
11:00-12:00	Crucial Conversations	(Mary Pate, DNS, RN)	60
12:00-12:30	LUNCH		
12:30-13:30	Pain Assessment Case Studies	(Interactive)	60
13:30-14:45	Misconceptions and Barriers	(Helen Turner MSN, RN)	75
14:45-15:00	BREAK		
15:00-16:00	Pharmacological Treatment	(Marianne Krupika, PharmD)	60
16:00-16:30	Q and A, Wrap up, and Homework Review	(Helen Turner)	30
<b>DAY TWO</b>	<b>JANUARY 13, 2009</b>		
8:00-9:15	Empowering Change/Caring Relationships	(Helen Turner)	75
9:15-9:30	BREAK		
9:30-10:15	Ethics and Disparities	(Helen Turner)	45
10:15-11:15	NonPharmacological Treatment	(Kim Kuehnert , CCLS)	60
11:15-11:45	LUNCH		
11:45-12:45	Types of Pain	(Kirk Lalwani, MD)	45
12:45-14:15	Epidurals, PNB, PCA	(Angela Kendrick, MD)	90
14:15-14:30	BREAK		
14:30-16:00	Challenging Case Studies/Role Play	(Interactive)	90
16:00-16:30	Future Planning, Course Evaluation	(Interactive)	30

## Appendix D

**Barriers to Optimal Pain Management**

Doernbecher Children’s Hospital (DCH) has been looking at ways to improve pain management for our children. Sometimes, nurses are not able to provide optimal pain management for a variety of reasons. The Doernbecher Pain Coalition (DPC) is interested in hearing from you, what (if anything) gets in the way of you being able to provide optimal pain management to your patients.

You are being asked to complete this survey because you work with children who may experience pain. This is part of a research study being conducted by DPC. Your participation is voluntary. The results of these surveys will be used to drive improvement initiatives and will be repeated every other year. No information identifying any one nurse specifically will be collected or shared. We anticipate this taking approximately 10 minutes to complete. Please use the comment section for any additional comments and submit **by APRIL TBD, 2009.**

**Principal Investigator: Helen Turner**

**eIRB #4161**

**1. BRIEFLY, tell us what good or optimal pain management looks like to you?**

*This will be a free text space in the survey tool.*

Below are some barriers to optimal pain management that have been identified previously by other Health Care Professionals. In the past year, on a scale of 0 to 10, (0 being “Not a barrier” and 10 being “A major barrier”) please **select** the number that best rates how much your personal ability to provide optimal pain management has been effected by the following.

**2. My concern about children becoming addicted**

0      1      2      3      4      5      6      7      8      9      10

Not a barrier

A major barrier

**3. My concern about side effects of medications (other than addiction)**

0      1      2      3      4      5      6      7      8      9      10

Not a barrier

A major barrier

**4. My concern about children becoming tolerant to analgesics**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**5. Competing demands on my time**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**6. Limitations in my knowledge of pain management**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**7. Limitations in my ability to assess pain**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**8. Low priority given to pain management by medical staff**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**9. Low priority given to pain management by nursing staff**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**10. Low priority given to pain management by nursing management**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**11. Low priority given to pain management by me**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**12. Inadequate or insufficient physician medication orders**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**13. Timeliness/responsiveness from medical staff to your concern about pain management**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**14. Patients' reluctance to report/rate pain**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**15. Patients' reluctance to take pain medications**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**16. Parents' reluctance to have children receive medication**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**17. Insufficient time allowed to pre-medicate prior to procedures**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**18. Insufficient pre-medication orders prior to procedures**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**19. Current documentation format for documenting assessment/interventions/reassessments**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**20. Insufficient resources to provide guidance/expertise in managing patients' pain**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**21. In general, to what degree do you feel you are able to overcome barriers and ultimately provide quality pain management for your patients?**

0	1	2	3	4	5	6	7	8	9	10
Not at all able										Very able

22. How much of an impact would there be on your ability to provide quality pain management if the barriers you identified above were improved/alleviated?

0 1 2 3 4 5 6 7 8 9 10

None at all

A great impact

23. Overall, what impact does the involvement of the Pediatric Pain Service with your patients have in your ability to provide optimal pain management?

0 1 2 3 4 5 6 7 8 9 10

A Very **NEGATIVE**

Neutral

A very **POSITIVE**

Impact on patient care

impact on patient care

24. What other barriers to pain management at DCH are not included on this tool?

*This will be a free text space in the survey tool.*

Comments:



**Now, tell us a little bit about your nursing education and practice**

<b>Primary Unit/Department-choose only 1</b>	<b>Years of <u>Pediatric</u> Nursing Experience</b>		<b>Highest level of <u>NURSING</u> education completed</b>	<b>What is your role</b>
PACC <input type="radio"/>	0-<2	<input type="radio"/>	Associate degree <input type="radio"/>	Staff nurse <input type="radio"/>
PICU <input type="radio"/>	2-<5	<input type="radio"/>	Diploma <input type="radio"/>	Supervisor <input type="radio"/>
PMCU <input type="radio"/>	5-<10	<input type="radio"/>	Baccalaureate <input type="radio"/>	Manager <input type="radio"/>
10S <input type="radio"/>	10-<15	<input type="radio"/>	Masters <input type="radio"/>	APN <input type="radio"/>
Float Pool <input type="radio"/>	15-<20	<input type="radio"/>	Doctorate <input type="radio"/>	Administrator <input type="radio"/>
Panda <input type="radio"/>	≥20	<input type="radio"/>		Other: _____
Gen Peds Clinic <input type="radio"/>			Race:	
Spec. Peds Clinic <input type="radio"/>			<input type="radio"/> White	Gender:
Heme/Onc Clinic <input type="radio"/>			<input type="radio"/> Black or African American	<input type="radio"/> male
ED <input type="radio"/>			<input type="radio"/> Native Hawaiian or Pacific Islander	<input type="radio"/> female
PACU			<input type="radio"/> Asian	
Sedation Service			<input type="radio"/> American Indian or Alaska Native	
			Ethnicity:	
			<input type="radio"/> Hispanic or Latino	
			<input type="radio"/> Not Hispanic or Latino	

**The following questions are about your individual (personal) practice/experience.**

**What sources do you use most often to assist you in making pain management decisions?**

- \_\_\_\_ Assessment of infant/child
- \_\_\_\_ Nurses report from previous shift
- \_\_\_\_ Other nurses on your unit
- \_\_\_\_ Specialty Nurse or APN
- \_\_\_\_ Unit Based NPEC
- \_\_\_\_ Clinical resources page information, articles etc.
- \_\_\_\_ Other
- \_\_\_\_ Physician order
- \_\_\_\_ Child/family request
- \_\_\_\_ Clinical pharmacist
- \_\_\_\_ Pain Service
- \_\_\_\_ Child's physician
- \_\_\_\_ The patient's chart

**How did you learn about pain management?**

- \_\_\_\_ Nurses on the unit
- \_\_\_\_ Orientation at DCH
- \_\_\_\_ Professional conference
- \_\_\_\_ Unit Based NPEC
- \_\_\_\_ OHSU SON Online course
- \_\_\_\_ My personal experience, from the patients and families I care for
- \_\_\_\_ Nurse or physician mentor/expert
- \_\_\_\_ Nursing school
- \_\_\_\_ Staff education program after orientation
- \_\_\_\_ Journal articles
- \_\_\_\_ Pain Team APN
- \_\_\_\_ OSBN required CEU

**During a typical work week, how often do you encounter patients in pain?**

1 Almost Never	2 Rarely	3 Sometime	4 Frequently	5 Almost always
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**In general, how would you describe your pain management practices?**

1 Very Conservative	2	3 Neutral	4	5 Not At All Conservative
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**How would you rate the current level of pain management at Doernbecher Children's Hospital?**

1 Poor	2 Borderline	3 Satisfactory	4 Very Good	5 Excellent
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Thank you for your participation. Stay tuned for results as well as interventions aimed at improving the barriers you have identified. Please submit this survey by APRIL TBD, 2009

Appendix E

NRC Picker Survey Pain Specific Questions

**34. Was your child ever in any pain?**

Yes No (Go to #38)

**35. Was the pain your child experienced in the hospital more than what you were told it would be?**

Yes, definitely Yes, somewhat No I was not told

**36. Overall, how much pain medicine did your child get?**

Not enough Right amount Too much Did not need any pain medicine

**37. Did the hospital staff do everything they could to help control your child's pain?**

Yes, always Yes, sometimes

Appendix F

Press Ganey Survey Pain Specific Question

<b>I. PERSONAL ISSUES</b>	very				very
	poor	poor	fair	good	good
	1	2	3	4	5

2. How well your child's pain was controlled .....

Appendix G

From: Doernbecher Pain Coalition  
To: RN Name  
Subject: Pain Management Survey

Doernbecher Children's Hospital (DCH) is looking at ways to improve pain management for our children. In response to your concerns and questions about the management of pain, the Doernbecher Pain Coalition (DPC) is interested in hearing from you, what (if anything) gets in the way of you being able to provide optimal pain management to your patients. You are being asked to complete a survey because you work with children who may experience pain. This is part of a research study being conducted by DPC. Your participation is voluntary. The results of these surveys will be used to drive improvement initiatives. No information identifying any one nurse specifically will be collected or shared. We anticipate this taking approximately 10 minutes to complete. Please use the comment section for any additional comments and submit **by APRIL TBD, 2009**.

To begin the survey, click on the following link: Link will be added after IRB approval and survey available.

Running head: PEDIATRIC PAIN MANAGEMENT BARRIERS AND PRN PROGRAM

Evaluating the Effect of a Pain Resource Nurse Program on Barriers to Pediatric Pain  
Management

Helen N. Turner

Oregon Health & Science University

Executive Summary for Doernbecher Leadership: Pain Resource Nurse Program Evaluation  
Helen N. Turner, MS, RN-BC, PCNS-BC  
Clinical Nurse Specialist, Pediatric Pain Management Center  
Doctor of Nursing Practice Candidate, OHSU School of Nursing  
May 4, 2009

**Background and Problem:**

Untreated or poorly treated pain affects every system in the human body and can lead to poor healing, delayed recovery, developmental regression, longer hospital stays, reoccurrence of illness or injury, and in some cases, death.

Nurses providing direct care spend the most time and are in constant contact with the patients and are positioned to make the greatest impact on improving pain care. The Pain Resource Nurse (PRN) Program is a model that has been shown to be successful in improving pain care in other pediatric hospitals by training direct care nurses to be experts in assessing and treating pain.

Patient and family satisfaction with pain management has been suboptimal, and identified as an organizational quality improvement priority.

**Intervention and Assessment:**

Under the direction of a Doctor of Nursing Practice (DNP) student, a program evaluation pilot project was undertaken on the Pediatric Acute Care Center (PACC). Eight RNs attended 2 days of focused pain education. They were available to interact with staff and provide additional treatment/intervention options with support from the DNP student and Pediatric Pain Management Service.

Effectiveness of the PRN program was measured using a survey to identify the presence of perceived barriers to optimal pain management and patient satisfaction. Assessment of the behaviors the PRNs used to enact their role will be used to modify future classes and guide ongoing support for these local experts.

**Costs:**

Implementation cost was \$9,459.80 or \$1,182.50 per RN. Ongoing costs are paying for 1 hour monthly meetings totaling \$3523.20 annually. Support and further development of the PRNs by the DNP student is an expectation of this role within the organization and will not be an additional cost.

**Outcomes:**

Eight weeks after implementation of the PRN Program, RNs on the PACC were surveyed regarding perceived barriers to pain care. The results were compared to results of the same survey completed 9 months prior to implementation. Barriers related to nurses' beliefs and biases were significantly decreased; those related to physician orders and timeliness to pain concerns significantly increased. Patient satisfaction scores were trending in a positive direction and above the UHC peer group benchmark. Behaviors of role enactment demonstrated by the PRNs included being a resource, change agent, role model, and advocate.

**Feasibility:**

Cost and RN scheduling are the greatest constraints for implementation of the PRN Program. With advanced planning and budgeting these two factors can be appropriately addressed. The commitment of Doernbecher Children's Hospital Leadership to improving the quality of pain management offers additional support for this program.

**Summary:**

The primary tenets of this pilot project were to support and develop skills and accountability of all PACC RNs providing pain management, and determine feasibility of expansion to other DCH patient care units. This pilot project has demonstrated that by using an evidence-based approach to improving pain care, the PRN Program has the potential to improve the delivery of optimal (evidence-based, appropriate, safe, and effective) pain management, reduce barriers to optimal pain management, develop and empower RNs in clinical practice, and increase patient and family satisfaction.



### Background and Clinical Problem

Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain, 1994). When children are hospitalized, they are often faced with the experience of acute pain and pain related to procedures. They may also endure chronic or end-of-life pain. Among hospitalized children, the prevalence of clinically significant pain may be as high as 60% (Walker & Wagner, 2003). Hospitals admit thousands of children each year, and yet despite the American Pain Society (APS) and American Academy of Pain Medicine (AAPM) identifying children as being at risk for under treatment of pain (Ferrell et al., 2001), it is well documented that pain is not properly managed in this vulnerable population (Beyer, 2000; Ellis et al., 2002; Sheidler, McGuire, Grossman, & Gilbert, 1992; Sutters et al., 2004). Untreated or poorly treated pain affects every system in the human body and can lead to impaired healing, delayed recovery, prolonged hospitalization, exacerbation of illness or injury, and, in some cases, death (Pasero, Paice, & McCaffery, 1999; Schechter, Berde, & Yaster, 2003).

There are many barriers that contribute to the under-treatment of pain in children. These barriers are multi-factorial and include: knowledge and attitudes of nurses (Clarke et al., 1996; Ferrell, McGuire, & Donovan, 1993; Hamers, Abu-Saad, van den Hout, & Halfens, 1998; Hester, 1993; Manworren & Hayes, 2000); characteristics of nurses (Abu-Saad & Hamers, 1997; Clarke et al., 1996; Fuller, 1996; Griffin, Polit, & Byrne, 2007; Horbury, Henderson, & Bromley, 2005; Wilson, 2007); characteristics of the child (Hamers, Abu-Saad, Halfens, & Schumacher, 1994); amount of analgesia administered by nurses (Fuller, Neu, & Smith, 1999; Hall-Lord & Larsson, 2006; Hamers, Abu-Saad, Halfens et al., 1994; Horbury et al.; Vincent & Denyes,

2004); and other patient/family, health care providers, and health care delivery systems factors (American Medical Association [AMA], 2007; APS, 2006; Czarnecki et al, 2008; Gunnarsdottir, Donovan, & Ward, 2003; McCaffery, 1999; Vincent & Denyes, 2004).

Many strategies have been used to overcome barriers to pain management. One strategy is improving nurses' knowledge through the Pain Resource Nurse (PRN) Program, which develops staff nurses as pain management experts on their units. In 1992, Ferrell and colleagues at The City of Hope in Duarte, California (Ferrell, Grant, Ritchley, Ropchan, & Rivera, 1993) developed this educational program. This, or adapted versions of this program, have since been implemented in hospitals around the United States and have been reported to be effective (Ellis et al., 2007; McCleary, Ellis, & Rowley, 2004; Paice, Barnard, Creamer, & Omerod, 2006). The program consists of developing unit-based experts, via didactic training covering topics such as pain assessment, pharmacologic management, non-pharmacologic management, types of pain (acute, surgical, end of life, and special populations), psychosocial-spiritual aspects of pain, patient education, caring for the caregiver, and professional growth and development. Case study, skills application, and role play are used to develop clinical decision making and leadership skills. The Pain Resource Nurses (PRNs) also serve as role models, provide education and consultation, and act as change agents for improving pain management. Critical attributes of the PRNs are increased self efficacy, augmented pain knowledge, improved assessment and communication skills, leadership, and acting as change agents (Ellis et al.; McCleary et al.; Paice et al.).

Additional strategies used to decrease barriers to pain management include use of evidence based guidelines, state wide initiatives, institution wide pain committees, quality improvement projects, and patient education programs. Although experts espouse the value of

these efforts, they all agree that multiple strategies, including implementation of the PRN Program are ideal for measurable and sustained success. (Brockopp et al., 1998; Clarke et al., 1996; Dahl et al., 2003; Ellis et al., 2007; Gunnarsdottir et al., 2003; Pasero, Gordon, McCaffery, & Ferrell, 1999). Although I fully support the multiple strategy approach, my passion is developing direct care RNs to be empowered in the provision of evidence based pain management. This program evaluator believes the PRN Program is the most effective method of achieving this.

Overcoming barriers is a complicated and multidisciplinary challenge. Doernbecher Children's Hospital (DCH) has barriers similar to what are reported in the literature. Clinical experience, discussions with nursing staff, and family satisfaction reports indicate there are several barriers to the delivery of optimal pain management at DCH. This was confirmed by a survey of DCH registered nurses (RNs) regarding perceived barriers to pain management. As the pediatric pain management Clinical Nurse Specialist, I provide direct patient care; work with nurses and multidisciplinary providers; and guide institutional standards and policies. The PRN Program may be an influential program for improving practice and driving the change for an organizational commitment to value optimal pain management (Ellis et al., 2007; McCleary et al., 2004; Paice et al., 2006). As a Doctor of Nursing Practice (DNP) student with a leadership role and expertise in pain management, I am well prepared and positioned to champion the values inherent to relieving pain; to evaluate the evidence supporting clinical standards and guidelines, the safety and efficacy of pain management practices, and the effectiveness of nursing education programs; to begin removing barriers to the delivery of optimal pain management; and to empower the staff nurses to do many of these activities.

The purpose of this program evaluation was to determine the effectiveness of the PRN Program for reducing barriers to optimal pain management on DCH's Pediatric Acute Care Center (PACC) and improving patient satisfaction with pain management. This evaluation included describing the behaviors PRNs used to influence changes in practice as they enacted their role as pain experts on the PACC. In order to perform this program evaluation, the following questions were posed:

1) Does the PRN Program change nurses' perceptions of barriers to pain management on the PACC?

2) What behaviors do PRNs use to influence change in practice as they enact their role as pain experts on the PACC?

3) Does the PRN Program improve family pain satisfaction scores on the PACC?

#### Conceptual Framework

A conceptual framework was developed to guide this project (see Figure 1). This framework was used to identify barriers, evaluate interventions, and focus additional clinical inquiry. Although there are multiple complex barriers to providing optimal pain management, the concepts of interest for this clinical inquiry project were nurses' perceived barriers to pain management, nurses' abilities to overcome those barriers, and family satisfaction with pain management during hospitalization.

Optimal pain management is defined as the evidence-based, appropriate, safe, and effective treatment of pain (Czarnecki et al, 2008; Pasero, Paice, & McCaffery, 1999; Schechter, Berde, & Yaster, 2003; Vincent, 2005). Using barriers and family satisfaction scores as outcome measures, this program evaluation project assessed the effectiveness of the PRN Program in improving nurses' abilities to overcome perceived barriers.

Barriers are defined as any factor that diminishes or prevents the delivery of optimal pain management. There is extensive literature on such barriers, and they are generally grouped into three broad categories: barriers within the health care delivery system (hospital, local, regional, and national policy, standards, and laws), barriers related to health care professionals (knowledge, beliefs, and behaviors), and patient and family barriers (knowledge, communication, and disease process; AMA, 2007; APS, 2006; Czarnecki et al, 2008; Ferrell, Grant, et al., 1993; Gunnarsdottir et al., 2003; McCaffery, 1999; Polkki, Laukkala, Vahvilainen-Julkunen, & Pietila, 2003; Vincent & Denyes, 2004).

Family satisfaction with pain management can be assessed in many ways, both formal and informal. Nursing and administrative staff may have conversations with families who report dissatisfaction or satisfaction with pain management. These personal stories can be powerful, but they are not measureable. More formal pain satisfaction measures have been developed by nursing units, health care systems, professional organizations, and health care consulting businesses. For the purpose of this study, family pain satisfaction was defined as the mean scores reported by the hospital chosen performance measurement vendor (Press Ganey).

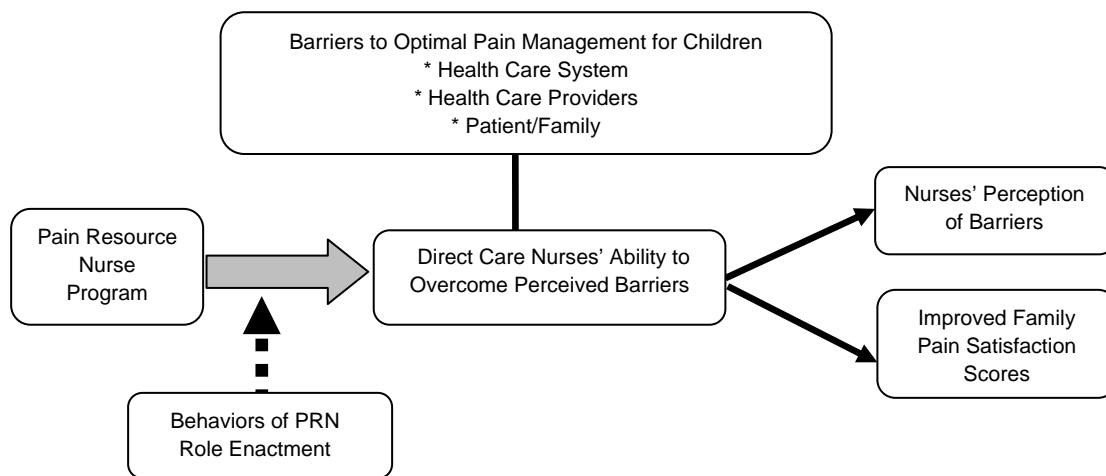


Figure 1. Evaluation of the Pain Resource Nurse Program

## Review of Literature

### *Under-Treatment of Pediatric Pain*

Despite significant advances in the field of pain management, pain in children continues to be under treated. In their review article, Walker and Wagner (2003) reported the prevalence of clinically significant pain in hospitalized children may be as high as 60%; only about 60% of pediatric hospitals ( $n=113$ ) have pain management standards; and of the 60%, only 15% indicate those standards are followed 80% or more of the time. Walker and Wagner said knowledge in the field of pediatric pain management has advanced greatly, yet the translation to clinical practice continues to lag.

Ellis et al. (2002) reported in their descriptive study that they found a “substantial number of children had unacceptably high levels of pain” (p. 267) and that “nurses are assessing pain accurately but not using the assessment information to take action” (p. 268). The limitations of this study are substantial. The pain measurements were done in single 8 hour (9:00 a.m. to 5:00 p.m.) period on week days, sample size varied because patients were unavailable at all measurement points (2 hour intervals), and pain intensity was measured by parent or health professional report, if the child did not self report. Self reporting of pain is the gold standard with proxy reporting being less desirable and accurate. The tool used by the children to measure intensity (color analog scale) is non-metric and not currently in common use due to concerns about validity and reliability. They concluded that their results were comparable to what was reported in the literature.

Acetaminophen with codeine is one of the most commonly used analgesics for mild to moderate postoperative pain in children. Sutters et al. (2004), in a randomized three group treatment ( $n=80$ ) study showed this standard treatment analgesic did not provide adequate relief

for children following tonsillectomy, whether the medication was given on a scheduled basis with routine post operative instructions, given on a scheduled basis with RN coaching, or given on an as needed basis. Limitations of this study include a single surgical population (tonsillectomy) was used, data were not recorded by the researchers but rather by using a parent completed home diary, and subjects were 6 to 15 years of age precluding the ability to generalize the results beyond this age group. Despite the limitations, it can be concluded continued use of suboptimal analgesics further contributes to the under treatment of pediatric pain.

Beyer (2000), using a small ( $n=21$ ) convenience sample reported 71% of the sample were in moderate to severe pain at the time of the study interview, which occurred during hospitalization for a veno-occlusive event related to sickle cell disease. Though this study may not be representative of the overall hospital experience for these patients, nor can it be generalized beyond the study institution, it indicates that pain was under treated in this sample.

Sheidler et al. (1992) used four clinical vignettes to examine nurses' decision-making skills related to analgesic administration. Of the 708 responses provided by 177 participants attending an oncology conference, only 26% were answered correctly. All four vignettes were answered incorrectly by 29% of the sample, and 44% of the sample answered only one vignette correctly. The vignettes covered changes in routes of analgesic administration, specific analgesic and doses administered, and a combination of route, analgesic, and dose. There was no statistically significant relationship between correct answers, type of work setting, academic preparation, number of patients cared for, years of nursing experience, or recent experience with the medications used in the vignettes. The findings may indicate patients in pain may not receive adequate analgesia. The ability to make generalizations from this study is limited, as the

vignettes were based in cancer care, not tested for clinical relevance and accuracy, and they were not specific to pediatric nurses.

In spite of limitations related to sample size, population specificity, pain assessment timing, and pain intensity measurement, these studies document the under treatment of pain in children. The available literature supports Walker's and Wagner's (2003) report that despite significant increases in knowledge of pediatric pain management, translation to clinical practices is lagging.

### *Barriers to Pain Management*

As an intervention follow-up, a survey was developed by Ferrell, Dean, and colleagues (1995) that included wording regarding barriers to improving pain management from the 1994 Agency for Health Care Policy and Research's (AHCPR) Management of Cancer Pain Guideline. There were 14 perceived barriers to pain management that fell into three categories: problems related to the health care system, problems related to health care professionals, and problems related to patients.

In a study designed to describe factors that promote or hinder nurses' use of nonpharmacological methods to relieve surgical pain, Polkki et al. (2003) identified five factors that promoted the use of nonpharmacological pain relieving methods and five factors that hindered their use by pediatric nurses. The factors that were seen as hindering were the nurse's insecurity, beliefs regarding the expression of pain, workload/time constraints, limited use of pain alleviation methods, and work model/patient turnover. This descriptive study was done in a pediatric hospital in Finland, had a 99% response rate to a Likert-type questionnaire and a final sample of 162. The factors identified have the familiar underpinnings of barriers related to health care systems, health care providers, and patients.



Vincent and Denyes (2004), drawing on the 1994 AHCPR guidelines and Ferrell's work, developed a 13-item instrument that focused on barriers to optimal pain management. The tool was used to quantify nurses' abilities to overcome barriers to optimal pain management in relation to knowledge, attitudes, characteristics (nurse and child), and the amount of analgesia administered. The four most frequently reported barriers in the Vincent study were "inadequate or insufficient physician medication orders," "children's reluctance to report pain," "parents' reluctance to have children receive medications," and "children's reluctance to take pain medications" (p. 181; Vincent, 2005). Limitations of this study included convenience sampling ( $n = 67$ ) of nurses, pain levels measured during a 6 hour block to match the nurse subject availability rather than pre- and post analgesic administration, and the majority (80%) of the child subjects were experiencing pain from surgery.

Building on the work by Vincent and Denyes (2004), Czarnecki et al. (2008) made slight modifications to the 13-item instrument and completed a survey of RN staff in their 250 bed pediatric teaching hospital. Respondents ( $n=272$ ) identified the following top five barriers: inadequate or insufficient physician orders, insufficient premedication orders prior to procedures, insufficient time allowed to pre-medicate prior to procedures, low priority given to pain management by medical staff, and parents' reluctance to have patients receive pain medications. The investigators then did a principal component factor analysis that highlighted the components of institutional commitment/systems barriers, nurses' biases and beliefs, and patient/parent barriers. These components follow the categories of barriers related to health care systems, health care providers, and patients identified by Ferrell et al. (1995).

Barriers to pain management have been systematically identified and described in the literature. The challenges of conducting research in busy clinical settings, did not overshadow

the affirmation of the presence of barriers in the health care systems, health care providers, and patient categories.

### *Nursing Knowledge and Attitudes as Barriers*

Knowledge deficits related to pain management persist despite a plethora of literature providing current and emerging information in the field. Changes to nursing education (basic and continuing) focusing on pain management have not appeared to yield significant changes in clinical practice.

Hester (1993), a pediatric pain expert, wrote that, “improving knowledge and clinical judgment skills of nurses regarding pain” (p. 131) would potentially alleviate the inadequacies of pain management in children. Ferrell et al., (1993b) were of the same opinion, and to facilitate quantifying nurses’ knowledge and attitudes, they developed the Survey of Knowledge and Beliefs Regarding Pain. This tool had 23 questions to measure knowledge, beliefs, and combined knowledge/beliefs scores. The scores discriminated in the direction predicted between the novice and expert nurses, with students having the lowest scores, and pain experts having the highest scores. Construct validity was verified by a panel of pain experts. Eighteen of the 23 items had  $\geq 90\%$  agreement in appropriate word and content. The other five questions ranged from 60 to 80% agreement and were revised based on feedback from the panel. Content was deemed to measure both knowledge and beliefs. The tool was then used in a survey of nursing faculty at 14 baccalaureate nursing schools in the US. Based on responses from 498 faculty members, Ferrell et al. (1993b) speculated that 1 in 10 faculty members were teaching outdated or inappropriate material on pain and pain management. This study is now more than 15 years old, and many advances have been made in the knowledge of pain and its treatment. New knowledge may not

be quickly integrated into nursing education making it difficult to determine if nursing education related to pain management has shown improvement.

In their 1997 review of the literature and comparison of the surveys used over the years 1988 to 1995, such as the Nurses' Knowledge and Attitude Survey (NKAS), McCaffery and Ferrell reported some areas of nurses' knowledge showed improvement (assessment, opioid dosing, and the likelihood of addiction) though deficits remained (importance of patient's self report of pain and opioid titration). They deemed the NKAS still to be a valid and reliable assessment tool but pointed out the limitation of survey methodology generally accessing on a single point in time. Additional limitations they identified are that surveys reviewed were those developed by the authors, surveys were modified over time, and there was potential for sample bias because the nurses completing the surveys were not likely representative of practicing nurses, as they were probably more motivated to learn about pain or care for populations known to experience significant pain (cancer and end of life).

Hamers et al. (1998), in their review of the literature reported nurses' knowledge and attitudes regarding pain relief methods contributed to the insufficient administration of analgesics. This review is limited in applicability, as the snowball methodology used to gather written materials may not have identified additional relevant publications.

Clarke et al. (1996) used the NKAS in a study evaluating the impact of RN education and characteristics on knowledge, attitudes, and clinical practice. The sample for this study was 120 RNs from nine units caring for clinically diverse populations at a large university affiliated teaching hospital with the highest response rate (94%) from the oncology unit. They discussed the appropriateness of this tool for nurses not caring for cancer patients. The oncology unit in their study had the highest mean score on the survey, and Clarke et al. pointed out that one third

of the questions on the survey are specific to cancer pain. They recommended modification to the survey that would allow it to be more applicable to pain management in general. They also described how nurses' characteristics (e.g., age, work experience, personal experience with pain) and education (basic and continuing) levels affected clinical practice, including documentation. Based on their findings, their recommendations included continued and repeated education regarding pain management principles, wide spread distribution and utilization of evidence-based guidelines, and implementation of programs such as the PRN Program. This study's results were consistent with findings previously reported in the literature.

None of the studies previously reviewed were specific to pediatric nurses. Manworren and Hayes (2000) modified the NKAS to reflect pediatric pain management standards. The modified tool was called the Pediatric Nurses' Knowledge and Attitudes Survey Regarding Pain (PKNAS) and contained 42 items. Content validity was established by a national nursing panel of pediatric pain experts. The original tool author (B. Ferrell) verified the consistency of concepts between the NKAS and PKNAS. Manworren and Hayes administered the survey, with responses from 247 staff, at large pediatric teaching hospital. After analysis of the descriptive data, they concluded the PKNAS is a valid tool for the identification of pain management knowledge deficits in pediatric nurses.

Although some variability is noted in all of these studies, it appears knowledge deficits related to pain management generally persist. Continued efforts must be made to address these deficits so nurses are practicing with accurate knowledge and information.

*Lack of nursing empowerment as a barrier.* Extensive literature exists documenting that education alone is not enough to change clinical practice (Brockopp et al., 1998; Ferris, von Gunten, & Emanuel, 2001; Max, 1990; Paice et al., 2006). The overarching principle of the PRN

Program is to improve nursing practice related to pain management, and I believe, as a program evaluator, that empowerment and effective communication techniques are critical to the ability of the PRN Program to positively influence practice. Manojlovich (2007) posited that nurses who have a sense of empowerment and expertise are more effective at influencing others (“expert power, p. 15”) resulting in improved patient outcomes. Maxfield, Grenny, McMillan, Patterson, and Switzler (2005) in their report *Silence Kills: The Seven Crucial Conversations for Healthcare* said their “study shows that healthcare workers who are confident in their ability to raise these crucial concerns observe better patient outcomes, work harder, are more satisfied, and are more committed to staying (p. 3).”

There is limited literature describing the role components and enactment behaviors PRNs use in this role. Identification of these role components and behaviors is essential to adapting the educational programs and ongoing supports for the PRNs, if they are to be empowered to change clinical practice. McCleary et al., (2004) reported the PRNs were to function as resources, coaches, mentors, role models, and champions. The PRNs in their study described seven components: communicator, coach and mentor, troubleshooter, champion, advocate, evaluator and monitor, and educators. Debra Gordon is nationally recognized as an expert on the PRN Program. Although she has not published her knowledge of the PRN role enactment, she indicates the following components are expectations of the role: resource, change agent, role model, educator, and leaders in hospital pain initiatives (D. B. Gordon, personal communications, March 19, 2009). Paice et al. (2006) reported that three competencies were developed to guide activities of the PRN role: role model and resource, staff development, active participation in quality management initiatives related to pain management.

There is significant literature regarding the effectiveness of nursing empowerment for positively influencing patient outcomes and nursing practices. The literature discussing the PRN Program and expected functions of PRNs describes characteristics similar to those used in the empowerment literature (change agent, role model, advocate, leader, champion). However, there is limited discussion of the importance of empowerment for PRNs to more effectively enact their role as local pain experts.

### *Health Systems Barriers*

There is a broad range of barriers reported under the health care system category, although few researchers have quantified the impact of these systems barriers. The barriers have been described to be as global as societal attitudes related to poverty, culture, addiction, and substance abuse; legal barriers, which include restrictive laws and regulations around controlled substances commonly used for pain management; or as focused as which medications are stocked based on hospital pharmacy formularies (Schechter et al., 2003). Failure of health care systems to make pain relief a priority and lack of accountability for pain management practices are major barriers (APS, 2006). Managed care processes may limit access to pain specialists, comprehensive pain management facilities, and certain medications (Ferrell, Novy et al., 2001). Because the focus of my project was barriers related to health care providers and specifically nursing knowledge, an extensive review of the literature on health care system barriers has not been included.

### *Patient and Family Barriers*

Patient/family barriers are multiple and complex. These barriers can include age, sex, socioeconomic status, and educational level. Significant disparities in pain management exist for women, the extremes of age (children and elderly), the poor, and those with lower education

levels (Green, et al., 2003; Green, Todd, Lebovits, & Francis, 2006; Sullivan & Egel, 2005). Race and ethnicity can influence where patients seek care and the quality of care received (Iwashyna, Curlin, Christakis, 2002; Kahn et al., 1994). Communication difficulties (cultural, language, cognitive, etc.) between patients/families and health care providers and concerns about risk of addiction, abuse, or diversion (Sullivan & Egel) may also act as barriers to receiving optimal pain management. The patient's disease process may present a barrier if it complicates appropriate assessment and management. Unresolved anxiety, grief, anger, misconceptions, concerns, biases, and beliefs are additional factors which can become barriers preventing patients from adequate pain management care.

#### *Guidelines for Pain Management*

The American Academy of Pediatrics (AAP) and the APS in their 2001 joint statement titled *The Assessment and Management of Acute Pain in Infants, Children, and Adolescents*, stated “most acute pain experienced in medical settings can be prevented or substantially relieved” (p. 793), and recommended the anticipation of predictable painful experiences, appropriate interventions, and monitoring effects and processes. Other guidelines available are more disease focused and specific; however this statement appears to have set the stage and tone for the nearly 200 guidelines found when electronically searching the National Guideline Clearinghouse using the term *pediatric pain*. The plethora of guidelines has not had the desired impact of improving pediatric pain management as indicated by the many current reports of continued under treatment in this population.

#### *Preliminary Work*

DCH was asked to participate in a multisite study assessing barriers to optimal pediatric pain management using the *Barriers to Optimal Pain Management* survey (Appendix A). The

purposes of this earlier study were to identify the most frequent barriers in each of the three participating institutions and to determine if the barriers were different between organizations. Identification of common barriers may support the development of shared strategies to overcome these barriers, and allow for the sharing of these strategies with other pediatric hospitals on a national level.

The survey was distributed via electronic mail (email) to 300 RNs at DCH from March 14 to April 11, 2008 (T1). Recruitment and data collection procedures are described in detail in the Methods section. A response rate of 41% was achieved with 123 responses. Of this sample 92.2% were Caucasian, 95.8% were female, 95.9% were staff RNs, and 60.7% reported having a baccalaureate degree. Years of experience working in pediatrics were as follows: < 5 years = 25% , 5 up to 15 years = 38%, and 15 years or more = 38%.

The five most frequent barriers identified were, in descending order: inadequate or insufficient physician medication orders, insufficient pre-medication orders prior to procedures, insufficient time allowed to pre-medicate prior to procedures, timeliness/responsiveness from medical staff to your concern about pain management, and low priority to pain management by medical staff. The five barriers all fall into the subscale of Institutional Commitment/Systems Barriers as describe by Czarnecki and colleagues (2008). The five least common barriers identified were, in ascending order: low priority given to pain management by me, my concern about children becoming addicted, low priority given to pain management by nursing management, limitations in my ability to assess pain, and low priority given to pain management by nursing staff.

Results of this study are being presented to DCH nurses and key members of DCH nursing and physician leadership to guide the establishment of priorities and development of



multidisciplinary strategies to decrease identified barriers to optimal pain management at DCH. Results from the PACC provided baseline data for the current program evaluation.

### *Summary of Existing Knowledge*

Much work has been done to improve the care of children in pain. Never-the-less, much of what is reported in the literature is descriptive in nature and lacking consideration of process or measurement of outcomes. There is a significant lag between new evidence and changing practice. In the current healthcare environment, demonstrating consistently improved outcomes in the form of decreased patient morbidity and mortality and increased cost effectiveness may more rapidly drive change. The next steps in this area involve rigorous evaluation of pediatric pain management programs and practices in relation to patient and health care system outcomes.

## Methods

### *Clinical Inquiry Design*

The following questions were asked to perform a program evaluation:

- 1) Does the PRN Program change nurses' perceptions of barriers to pain management on the PACC?
- 2) What behaviors do PRNs use to influence change in practice as they enact their role as pain experts on the PACC?
- 3) Does the PRN Program improve family pain satisfaction scores on the PACC?

The first question was answered using a pre-test post-test design. Qualitative content analysis of written reports from the PRNs was used to address the second question. The third question of this program evaluation was answered by monitoring monthly mean scores of patient satisfaction during the evaluation period for descriptive purposes. See Appendix B for the design (Figure B1) diagrams. These designs were chosen to determine if the program changed nurses'

perceived barriers to optimal pain management and improved patient satisfaction scores.

Dependent variables for this project were perceived barriers to pain management and family satisfaction scores. The independent variable was the PRN Program. See Table B1 in Appendix B for variable presentation. Data on the perceived barriers collected at T1 served as the baseline measure. Data collected March 15 to April 11, 2009 (T2) were compared to the baseline data. Convenience sampling was used for both the RN and family samples.

### *Setting*

DCH is a 150 bed, university based teaching hospital and clinic system providing tertiary care for children ages 0-18 on nursing units such as pediatric intensive care, intermediate care, neonatal intensive care, emergency care, hematology/oncology, medical/surgical, and a multitude of general and specialty care outpatient clinics. The setting for this project was the PACC. The PACC has 48 patient beds, is staffed by approximately 70 RNs who are supported by 12 certified nursing assistants and 5 health unit coordinators (secretarial/administrative support staff). This unit is budgeted for 12,300 patient days annually. Staffing patterns are consistent with national standards National Association of Children's Hospitals and Related Institutions (NACHRI) for similar University Healthcare Consortium (UHC) pediatric hospitals. Staffing patterns are four patients to one RN on the 7:00 a.m. to 3:00 p.m. and 3:00 p.m. to 11:00 p.m. shifts, and four to five patients per RN on the 11:00 p.m. to 7:00 a.m. shift. This is based on 10.13 hours of care per patient day (HPPD). The charge nurse does not take patients on the PACC. According to the PACC nurse manager, staff retention is high with a maximum turnover rate of 1.85% for fiscal year July 2007 through June 2008 which is the last data available (D. Lampa, personal communication April 13, 2009).

The PRN Program is congruent with the DCH mission, which highlights family-centered care, education, and training of healthcare professionals, and setting new standards of care for children in Oregon, the Pacific Northwest and worldwide. Implementation of the PRN Program was supported by DCH nursing administration and the PACC's Unit Based Nursing Practice Council (UBNPC), which is part of the hospital's shared governance model.

Challenges to overcome in the project setting included cost of the program implementation, scheduling conflicts, and recent major system technology changes. After the baseline data were collected, there was a multi-phased conversion from paper to electronic medical record requiring extensive training, as well as a major software conversion for email communication. These changes required a significant amount of flexibility and effort from the staff. Cost is significant for implementation of the PRN Program given its length (16 hours), the need to provide coverage for the RNs who are being trained, the cost of educational materials, and the promotional costs. These costs were covered by DCH, demonstrating organizational support and commitment.

#### *Sample and Data Sets*

The first sample of interest was the RN staff working on the PACC. This unit was chosen as the site for this project, as it is the largest unit, represents the broadest cross-section of patients and RNs at DCH, and because of the variety of patients, has the greatest number and variety of multidisciplinary and specialty health care teams. Convenience sampling of PACC RNs was used for purposes of the baseline (T1) and post-intervention (T2) surveys. Recruitment for the pre- and post-intervention surveys was identical. An email (See Appendix C), with an electronic link to the survey and weekly (total of 4 weeks) reminders, was sent to all PACC RNs (T1  $n=72$ , T2  $n=69$ ). The baseline response rate was 39% ( $n=28$ ). The post-intervention response rate was

35% ( $n=24$ ). There were no exclusion criteria. This investigator was on the PACC on a regular basis and had the support of DCH nursing leadership to evaluate the effectiveness of the PRN Program. Therefore, no major issues with access to the sample group were identified.

Eight RNs who completed the 2 day educational component of the PRN Program provided the material for addressing the second question through a content analysis. Each week, for eight weeks, the PRNs were asked to complete a series of program evaluator developed questions. These responses were electronically cut and pasted verbatim from the emails to pages organized by week for analysis.

The third data set of interest was the monthly means of family satisfaction scores reported by Press Ganey. Satisfaction scores were monitored from August 1, 2008 throughout the evaluation period for descriptive purposes. These satisfaction scores are available from the Press Ganey internet site.

### *Intervention*

The PRN Program was developed and first used by Ferrell and colleagues (1993) at The City of Hope in Duarte, California (Ferrell, Grant, et al., 1993). It is an educational program focused on creating pain experts at the patient bedside. This or closely adapted programs have since been implemented in hospitals around the United States (McCleary et al., 2004). The program consists of didactic training covering topics such as pain assessment, pharmacologic management, non-pharmacologic management, types of pain (acute, chronic, surgical, end of life, special populations), psychosocial-spiritual aspects of pain, patient education, case study and skills application, communication role play, and caring for the professional caregiver.

All staff nurses on the PACC received an email announcing the plan to offer the PRN Program and requesting those who were interested to submit a statement of interest and intent to

participate. Fliers were also posted on the PACC with the same information (Appendix D).

Seven RNs submitted statements and all were accepted into the Program. One additional RN (Nursing Education and Practice Coordinator for the PACC) also participated in the Program.

For this project, the program was similar to the content outlines used by Ferrell, Grant, et al. (1993) and McCleary et al. (2004). The course involved 15 hours of didactic education, case study and skills application, and role play delivered over two 8 hour days (Appendix E). The agenda was reviewed and supported by PRN Program experts Betty Ferrell and Debra Gordon (B. R. Ferrell and D. B. Gordon, personal communications, December 11, 2008). Local experts presented the content to participants in a classroom type setting. In addition to this content, sessions on empowerment, being change agents, and having difficult conversations were provided. A recently published guide to offering PRN courses (*Pain Resource Nurse Curriculum and Planning Guide*) developed by pain nursing experts with PRN program expertise, includes detailed planning information, content, evaluation, and references (Resource Center of the Alliance of State Pain Initiatives, 2009). The only notable difference between the DCH agenda and the *Pain Resource Nurse Curriculum and Planning Guide* suggested agendas is a session dedicated to pain management in patients with substance abuse. Substance abuse in the pediatric population is not a common occurrence. Therefore, content on substance abuse was not offered in a separate session in the DCH course, but it was covered briefly during case study discussions.

Continuing education credits were awarded to participants. On a monthly basis after completion of training, the participants meet for 1 hour with pain management experts to review patient care, discuss successes and challenges, and to discuss current evidence using a journal club format.

### *Measures*

#### *Barriers to Optimal Pain Management Survey*

Registered nurses completed a survey titled *Barriers to Optimal Pain Management*, which had been adapted with permission from the designer (Czarnecki et al., 2008). The original measure was developed by Vincent and Denyes (2004) and included 13 items (barriers) designed to assess how much each barrier interfered with nurses' ability to provide optimal pain management. Each item is rated on a 10-point Likert scale with 0 = *not a barrier* and 10 = *a major barrier*. Content validity of the barriers measures was addressed by the developer, an instrument development scholar, and two pediatric nursing experts (Vincent & Denyes). The development process included extensive literature review, item construction, and pilot testing with an internal consistency alpha of 0.86 (Vincent and Denyes).

Adaptations by Czarnecki et al. (2008) included the addition of one barrier item related to nursing documentation format as well as a free text space to allow nurses to describe what optimal pain management would look like, to list any barriers not specifically identified, and make any other comments. A principal component factor analysis of the 18 barrier items by Czarnecki et al., resulted in three subscales with Eigen values above 1 and factor loadings above 0.5. The three subscales identified were titled Institutional Commitment/Systems Barriers (7 items), Beliefs and Biases (4 items), and Patient/Parent Barriers (3 items; See Table 1).

Table 1

*Items in Factor Analysis Subscales (Czarnecki et al., 2008)*

	Institutional Commitment/Systems Barriers $\alpha = .77$	Beliefs and Biases $\alpha = .81$	Patient/Parent Barriers $\alpha = .71$
Items	Low priority given to pain management by medical staff	Concern about child becoming addicted	Patient's reluctance to report pain
	Low priority given to pain management by nursing staff	Concern about side effects of medications	Patient's reluctance to take medications
	Low priority given to pain management by nursing management	Concern about children becoming tolerant to analgesics	Parent's reluctance to have child receive medications
	Inadequate medication orders	Limitation in nurse's knowledge of pain management	
	Insufficient time allowed to pre-medicate prior to procedures		
	Insufficient pre-medication orders prior to procedures		
	Insufficient resources to provide guidance/expertise in managing patient's pain		

Four items did not load onto a subscale but were still considered important barriers to providing optimal pain management (competing demands for time, limited ability to assess pain, pain as a low priority for me, and documentation format). The survey was further modified by Czarnecki et al. (2008) to include one additional barrier measure regarding timeliness/responsiveness from medical staff to the RNs' concern about pain management. Reliability of the modified survey (19 items) was established (Cronbach's Alpha = .85) by Czarnecki (M. Czarnecki, personal communication, April 27, 2009). Scores were constructed as the mean for the items. High scores indicate the barrier is more important. The survey also

gathers demographic characteristics of the nurse including nursing unit assignment, role on unit, gender, years of pediatric nursing experience, educational preparation, and race and ethnicity. No personally identifiable data were collected (see Appendix A).

#### *PRN Role Implementation Behaviors Content Analysis*

Following methodology outlined by Klaus Krippendorff, (1980) a latent content analysis was performed on written responses provided by the PRNs over an 8 week period. The investigator-developed questions were designed to gather information regarding the experiences of the PRNs as they enacted their role (see Appendix F). The questions were distributed weekly to the PRNs via email. Responses were transcribed verbatim each week and reviewed multiple times to identify commonalities and themes specific to PRN role enactment. Using the actions, behaviors, and competencies described as components of the PRN role by D. Gordon (personal communication, March 19, 2009), McCleary et al. (2004), and Paice et al. (2006), critical attributes were defined. Four role components (resource, change agent, role model and advocate) and enactment behaviors used to operationalize the role were identified. The transcripts were read several more times to determine if additional themes were noted. See Table 2 for descriptions of each component's enactment behaviors.



Table 2

*Examples of Enactment Behaviors in Role Enactment Components*

	Resource	Change Agent	Role Model	Advocate
Enactment Behaviors	Disseminate information	Organize	Put knowledge into practice	Champion
	Assists peers	Perform need assessments	Communicate	Collaborate
	Teach for families, peers, and MDs	Develop policy and procedure	Be proactive	Advocate
	Make recommendations	Evaluate/monitor	Use correct terminology	Persist
	Consult	Promote quality	Precept other RNs	Encourage

This process was repeated for challenges and successes as reported by the PRNs. Eight themes emerged as challenges and six as successes (See Table 3).

Table 3

*Themes of Challenges and Successes*

	Challenges	Successes
Themes	Conflict with physicians	Appreciative feedback
	Undesirable clinical practice	Patient/family
	Time (lack of)	Peers/others
	Stigma/attitudes/beliefs	Interdisciplinary collaboration
	Knowledge	Acceptable pain care
	Patient/parent	Effective pain relief
	Lack of awareness of role	Positive changes in clinical practice
	Lack of clinical hours	Changes in clinical environment
		Maturation in PRN role
		Role awareness

Mutually exclusive numeric codes were assigned to the four concepts of role enactment behaviors, challenges, and successes (see Appendix G). Intra-rater reliability was achieved by having the program evaluator read the transcripts multiple times until no codes were changed or additional comments coded for three consecutive readings. Inter-rater reliability was established by having a doctorally prepared nurse advisor independently code a subset of the transcripts, which were then compared to the program evaluator's coding. Where differences were identified, discussion occurred until agreement for a single code was established. A focus group with the PRNs was held 3 weeks after the evaluation period to verify and validate the themes used for the content analysis. See Appendix H for focus group questions. The PRNs concurred with role enactment components (resource, change agent, role model, and advocate), and the themes identified in challenges and successes. No new concepts were identified from the focus group.

#### *Patient and Family Satisfaction Scores*

Press Ganey is a health care consulting firm focused on performance measurement and offering improvement services. Press Ganey mails surveys to discharged DCH patients randomly selected from a discharge list provided weekly by the hospital. Mailings are done until a 30% response rate is achieved, which results in about 10% of the discharged patients receiving surveys. The mailings include the survey and a return postage paid, pre-addressed envelope. The survey is 54 questions on 4 pages with comment sections at the end of each grouping of questions. Items are rated on a 1-5 Likert-type scale with 1= *very poor* and 5= *very good*. A single question regarding satisfaction with pain control ("how well your child's pain was controlled") is near the end of the survey (see Appendix I).

The monthly reports for the survey provide a mean score with standard deviation, the number of surveys returned by families discharged from the PACC, and benchmarking data for

all hospitals using Press Ganey and peer group hospitals from the University HealthSystem Consortium (UHC). UHC represents nearly 90% of the United States' non-profit academic medical centers as a coalition of 103 academic medical centers and their affiliated hospitals (University HealthSystem Consortium, n.d.). As an organization, DCH strives to rank in the top quartile of Press Ganey scores. However, the number of surveys returned each month is quite small, which makes robust interpretation difficult. For the purposes of this project, the UHC peer group benchmark was used with the goal being a consistent upward trend each month for the pain score.

### *Data Collection Procedures*

#### *Baseline Data*

*Barriers survey.* After receiving Institutional Review Board (IRB) approval, permission was granted to access the RN email lists from the Nursing Division Director and unit managers for DCH. The *Barriers to Optimal Pain Management Survey* was sent from March 14 to April 11, 2008, to all RNs working at DCH ( $N = 300$ ) via an email that included the electronic link to a Zoomerang version of the survey items. Completion of the survey was voluntary and implied willingness to participate. A weekly email with the same electronic link was sent to the same distribution list as a reminder to complete the survey if it had not already been done. The survey took approximately 25 minutes to complete. A quality management specialist experienced with using the Zoomerang system, transferred the data from Zoomerang to an Excel spreadsheet. From the Excel spreadsheet, the data was imported to SPSS 15.0 software for statistical analysis. At all times, access to the survey results, Excel spread sheet, and SPSS were stored on secure, password protected computers in locked offices. Baseline data for this project were those survey responses from PACC respondents ( $n = 28$ ).

*Satisfaction scores.* Press Ganey family satisfaction scores are reported monthly to DCH administration by the consulting firm. August 2008 was the first month these reports were available. Satisfaction data prior to that time was provided by a different vendor. The monthly reports provide satisfaction scores from the single question related to pain (see Appendix I).

#### *Outcome Data*

*Barriers Survey.* For the purposes of this clinical inquiry project, after implementation of the PRN Program, the *Barriers to Optimal Pain Management* survey was distributed to PACC RNs only after an IRB approved protocol modification. Using the same data collection procedure as that used for the baseline data, the post-intervention survey occurred March 15 to April 11, 2009 (T2).

*Satisfaction Scores.* Post-intervention family pain satisfaction scores are those reported by Press Ganey. Monthly reports were monitored to provide descriptive post-intervention pain satisfaction scores from the single question related to pain (see Appendix I).

*Content analysis.* For each of the first 8 weeks after implementation of the PRN Program, the eight PRNs were asked to respond to a series of questions via email. Responses to the emails were then transcribed verbatim for latent content analysis.

#### *Data Collection Cost and Revenue Information*

No revenue was generated from this data set. No direct costs were identified. Indirect costs include the time needed for the RNs to complete the survey and a quality management specialist's time to create the Zoomerang survey.

### *Analysis Methods*

The samples for question one were characterized using descriptive statistics.

Demographic information includes sex, race, ethnicity, role on unit, years of pediatric nursing experience, and educational preparation.

*Question One: Does the PRN Program change nurses' perceptions of barriers to pain management on the PACC?* Comparisons between the pre- (T1) and post- (T2) program data were done using single-sample *t*-tests ( $\alpha = .05$ ). Baseline survey data collected at T1 served as the test value. Analysis of question one included the means and standard deviations for each of the three subscales of barriers identified from the Czarnecki (2008) factor. Reliability testing of the three subscales was carried out for both T1 and T2 (See Table 4). All scales demonstrated adequate internal consistency.

Table 4

#### *Barrier Subscale Reliability Results*

Barriers Subscales (number of items)	Example items	T1 Cronbach's $\alpha$	T2 Cronbach's $\alpha$
Beliefs and Biases (4)	Concern about child becoming addicted	.68	.62
	Concern about children becoming tolerant to analgesics		
Institutional Commitment/Systems Barriers (7)	Low priority given to pain management by medical staff	.74	.82
	Inadequate medication orders Insufficient pre-medication orders prior to procedures		
Patient /Parent Barriers (3)	Patient's reluctance to report pain	.83	.74
	Parent's reluctance to have child receive medications		

*Question Two: What behaviors do PRNs use to influence change in practice as they enact their role as pain experts on the PACC?* Following Krippendorff's (1980) methodology, performance of a latent content analysis on text obtained from written reports from the PRNs regarding their experience, identified commonalities and patterns representative of role enactment behaviors. The results were described using frequencies of theme occurrences and examples of text narrative.

*Question Three: Does the PRN Program improve family pain satisfaction scores on the PACC?* Question three was answered descriptively by trending patient satisfaction scores reported monthly (Press Ganey) prior to and after implementation of the PRN Program.

#### *Project Associated Costs and Revenue*

##### *Direct Costs*

Direct costs of this program included the initial 16 hours for education and materials for the seven PRN nurses, which were estimated to be approximately \$9,500 or \$1200.00 per RN. Ongoing direct costs are monthly meetings, training materials, and recognition of the PRN nurses.

##### *Indirect Costs*

Indirect costs associated with the project are related to the advanced practice nurse (APN) time to manage and support the PRN nurses. Decreasing barriers to pain management may result in cost savings from more efficient use of staff time, improved patient outcomes, improved patient throughput (patients who have good pain management may be discharged more quickly resulting in more open beds to accommodate admissions), and perhaps decreased pharmacy costs because PRNs' recommendations result in fewer medications being tried and fewer medications

needed to treat side effects. However, if it is demonstrated pain is being under treated, pharmacy costs may increase if medication use is increased.

*Protection of Human Subjects*

This project was reviewed by the Institutional Review Board and granted approval as an exempt quality improvement project. An amendment to the approved project was filed as the original proposal was to resurvey all DCH RNs 2 years after the T1 survey and surveying the PACC RNs after implementation of the PRN program occurred at one year. A second amendment was filed to allow the focus group for content analysis validation. No ethical conflicts or concerns were identified for this clinical inquiry project.

*Dissemination of Results to Stakeholders*

A full clinical inquiry report will be presented in writing and orally to DCH nursing leadership and Quality Committee at the completion of the project. Poster presentation of the project results will be done for the PACC staff, as this has been determined by unit leadership to be an efficient and effective method of communication with the RNs. Additional requests for dissemination of the results and presentation format will be determined as appropriate to the audience. Manuscript publication and presentation of findings will occur at a national level.

10/1/08	10/13/08	11/3/08	12/1/08	1/1/09	2/1/09	3/15/09	4/15/09	5/4/09
-Incentive Program -Establish criteria for PRN nurses	-eIRB (PRAF to existing project )	-Plan classes (check with BF, DG, LM) -CE Applic. -Identify PRN nurses	-Gather training materials	<b>PRN Program</b>	-PRN RN support and ongoing development	-Resurvey the PACC -PRN RN support and ongoing development	-Analyze Data -PRN RN support and ongoing development	-PRN RN support and ongoing development

Figure 2. Project timeline

## Results

*Sample and Data Sets*

*PACC RNs.* Convenience sampling was used such that all PACC RNs (T1  $n=72$ , T2  $n=69$ ) received the *Barriers to Optimal Pain Management* survey. The two groups were homogeneous in gender, race, ethnicity, role on unit. Demographic characteristics of the samples are displayed in Table 5. Respondents at T1 and T2 were not significantly different in years of pediatric experience (Pearson Chi-Square value 6.44,  $p = .27$ , see Figure 3) or years of nursing education (Pearson Chi-Square value 2.95,  $p = .40$ , see Figure 4).

Table 5

*Demographic Characteristics of Respondents*

Survey Time	T1( $n=28$ )	T2 ( $n=24$ )
Response rate %	39	35
Gender %	$F=100$	$F=91.6, M=4.2, \text{Unknown} =4.2$
Race %	Caucasian=78.6 Asian=14.3 Unknown=7.1	Caucasian=87.5 Asian=8.3 Unknown=4.2
Ethnicity %	Not Hispanic or Latino=100	Not Hispanic or Latino=100
Role %	Staff nurse=100	Staff nurse=100



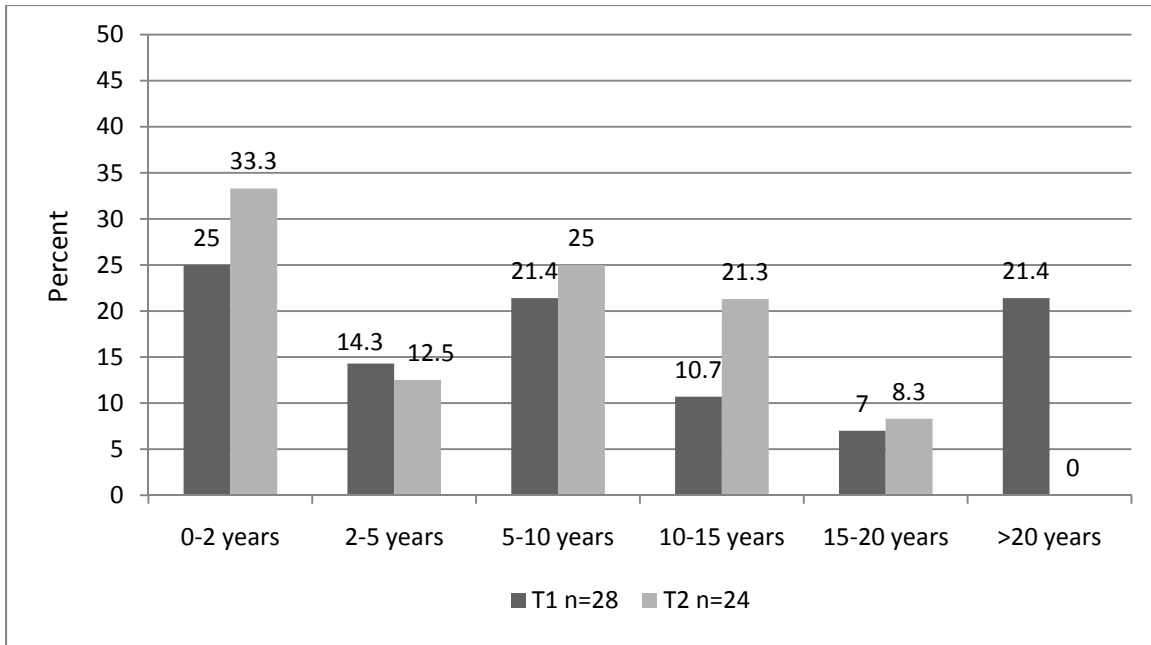


Figure 3. Years of pediatric nursing experience

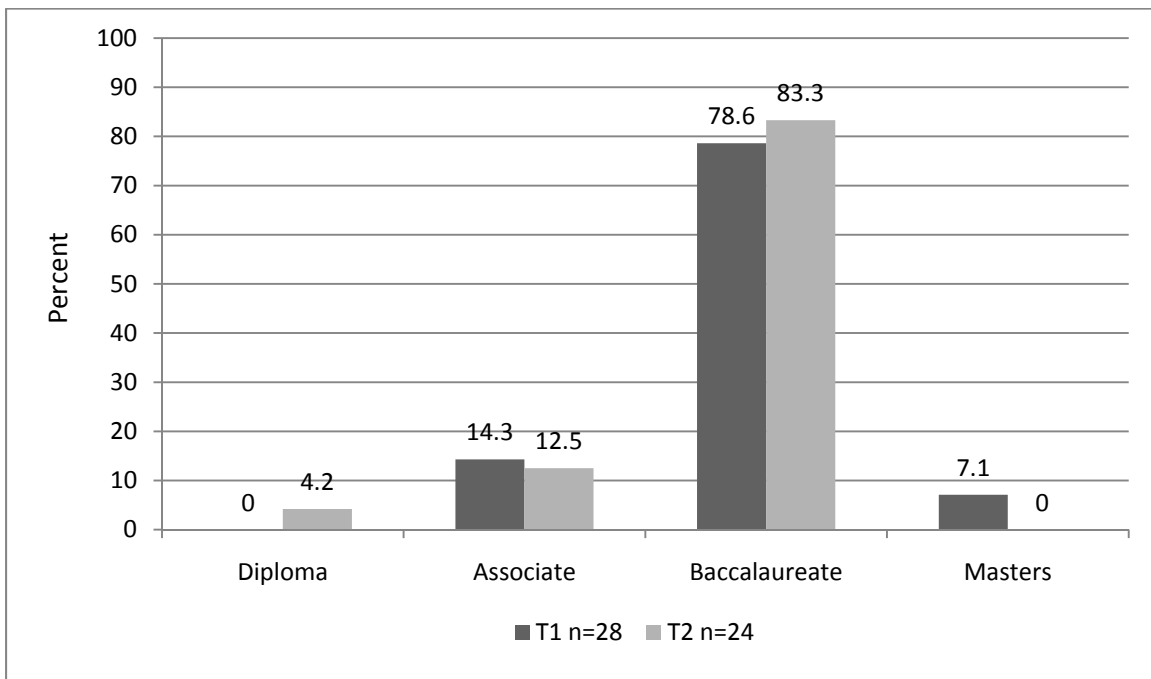


Figure 4. Level of nursing education

*Content analysis.* Over the 8 week period, a total of 38 email responses were received from the 8 PRNs. These emails, when cut and pasted verbatim into weekly summaries, resulted in a total of 42 pages with 209 text comments coded for content analysis.

*Press Ganey scores.* Press Ganey patient pain satisfaction mean scores were obtained for the nine months from August 2008 through April 2009.

### *Findings*

*Question One: Does the PRN Program change nurses' perceptions of barriers to pain management on the PACC?* The most common 5 barriers were the same at T1 and T2; however, the rank order was different. The mean scores, as shown in Table 6, were significantly higher at T2 for all perceived barriers except the item related to pain management being a low priority for physicians.

Table 6

#### *Rank Order of Most Common Perceived Barriers*

Perceived Barrier	T1, <i>n</i> =28 M (SD)	T2, <i>n</i> =24 M (SD)	One Sample <i>t</i>	<i>p</i>
Q8. Low priority to pain management by physicians	4.86 (2.61)	5.25 (2.45)	.779	n.s.
Q12. Inadequate physician orders	5.25 (2.14)	6.13 (1.96)	2.18	.04
Q13. Timeliness/responsiveness to pain concerns	4.64 (2.28)	6.00 (1.91)	3.49	.002
Q17. Not enough time for medications to work prior to procedure	4.86 (2.26)	6.25 (2.07)	3.29	.003
Q18. No pre-procedure medication orders	5.18 (2.36)	6.38 (1.95)	2.99	.006

Comparisons between the pre- (T1) and post- (T2) program barrier subscales were done using one-sample *t*-tests ( $\alpha = .05$ ). The test values were the T1 means for each subscale (See Table 7). The mean for Beliefs and Biases was significantly lower at T2 (2.39) than T1 (2.89;  $p = .013$ ). The Institutional Commitment mean was significantly higher at T2 (4.54) when compared

to T1 (3.94;  $p=.021$ ). There was no significant difference in the T1 (3.94) and T2 (4.26;  $p=.38$ ) means for Patient Barriers.

Table 7

*Perceived Barrier Subscale Means*

	T1, n=28		T2, n=24		One Sample <i>t</i> <i>df</i> = 23	p
	<i>M</i> ( <i>SD</i> )	[actual range]	<i>M</i> ( <i>SD</i> )	[actual range]		
Beliefs and Biases	2.89 (1.15)	[1.00 - 5.25]	2.39 (.92)	[1.25 - 4.50]	-2.68	.013
Systems Barriers	3.94 (1.35)	[1.43 – 6.29]	4.54 (1.18)	[2.29 – 6.71]	2.49	.021
Patient/Parent Barriers	3.94 (1.69)	[1.00 - 7.00]	4.26 (1.78)	[1.67 - 7.33]	.89	n.s.

There was no significant relationship between level of nurses’ education or experience and any of the subscales (See Table 8).

Table 8

*Correlation between Education, Experience, and Subscales*

	Level of Nursing Education	Years of Pediatric Experience
	Spearman’s rho ( <i>p</i> )	Spearman’s rho ( <i>p</i> )
Beliefs and Biases	-.15 (.28)	-.21 (.14)
Institutional Commitment	-.03 (.85)	-.06 (.65)
Patient Barriers	-.05 (.71)	-.17 (.22)

*Question Two: What behaviors do PRNs use to influence change in practice as they enact their role as pain experts on the PACC?* The number of email responses received ranged from a low of 3 in week 5 to a high of 7 in week 2. The 8 PRNs worked all three shifts (7:00 a.m. to 3:00 p.m., 3:00 p.m. to 11:00 p.m., and 11:00 p.m. to 7:00 a.m.) for a total of 848 hours over the 8 weeks. Two PRNs also worked as charge nurses and were in that role 144 (17% of the total)

hours. The number of PRN hours worked each week did not influence the number of coded comments obtained (See Appendix J, Figure J1). Neither did the number of hours worked influence the numbers of times the PRNs were specifically asked pain management questions or offered pain care advice proactively without being directly questioned (See Appendix J, Figure J2). PRNs consulted on both surgical and medical patients. The PRNs were asked to track the number of contacts with patients and families, peers, or physicians they had in their PRN role. The number of contacts with peers was relatively uniform across the evaluation period. The number of contacts with physicians increased in the second half of the evaluation period (See Appendix K, Figure K1).

Of the 209 coded comments, 37% (78 comments) were coded as the role enactment behaviors (resource, change agent, role model, and advocate). The greatest number of coded role behaviors was in week 3 (25) and least was in week 8 (3) with an average of 9.75 behaviors coded per week over the 8 week evaluation period (See Appendix L, Table L1 and Figure L1). Of the 78 comments 49% were coded as resource behaviors (e.g. “I had to explain to the surgeon that we could change Tylenol to q4 instead of q6” and “It was so perfect to...and teach about the mechanisms of NSAIDs and opioids”), 3% as change agent behaviors (e.g., “Reinforce change of practice with post-op Tylenol ATC”), 28% as role model behaviors (e.g., “I encouraged other RNs to continue our pain regimen” and “I significantly increased the interventions that the nursing staff had been prophylactically doing”), and 20% were coded as advocate behaviors (e.g., “I immediately paged” and “I tried to be persistent”; See Figure 5).

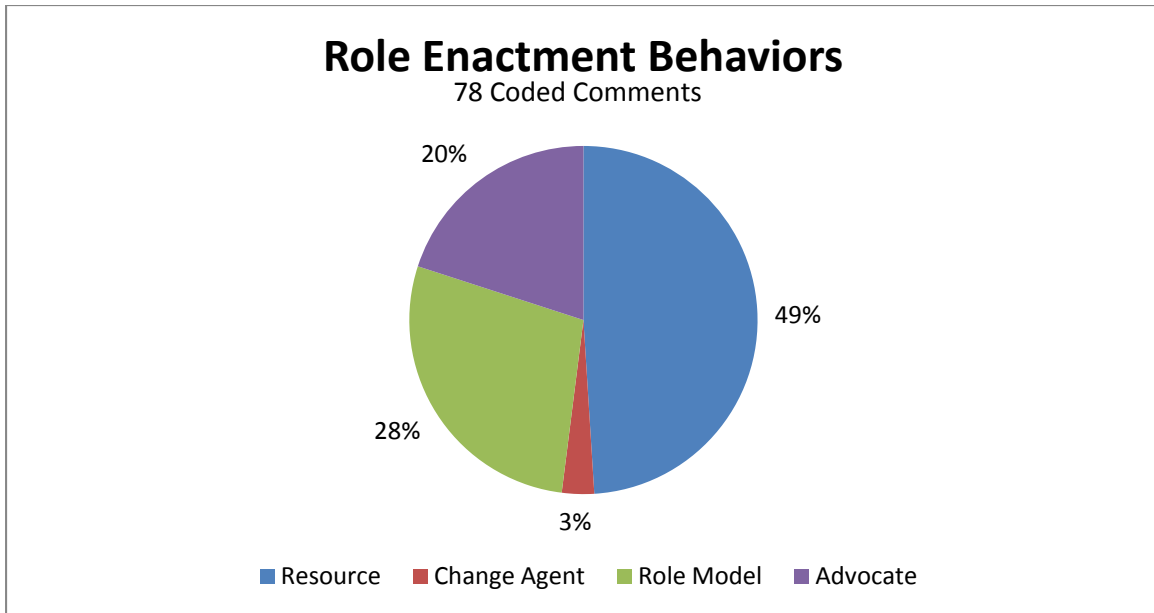


Figure 5. Percent of coded comments by role behavior

Coded comments regarding challenges and success accounted for 63% (131) of the 209 total comments. Of these comments, 53% were coded as challenges and 47% were coded as successes Figure 6 shows the weekly frequency comparison of challenges and successes.

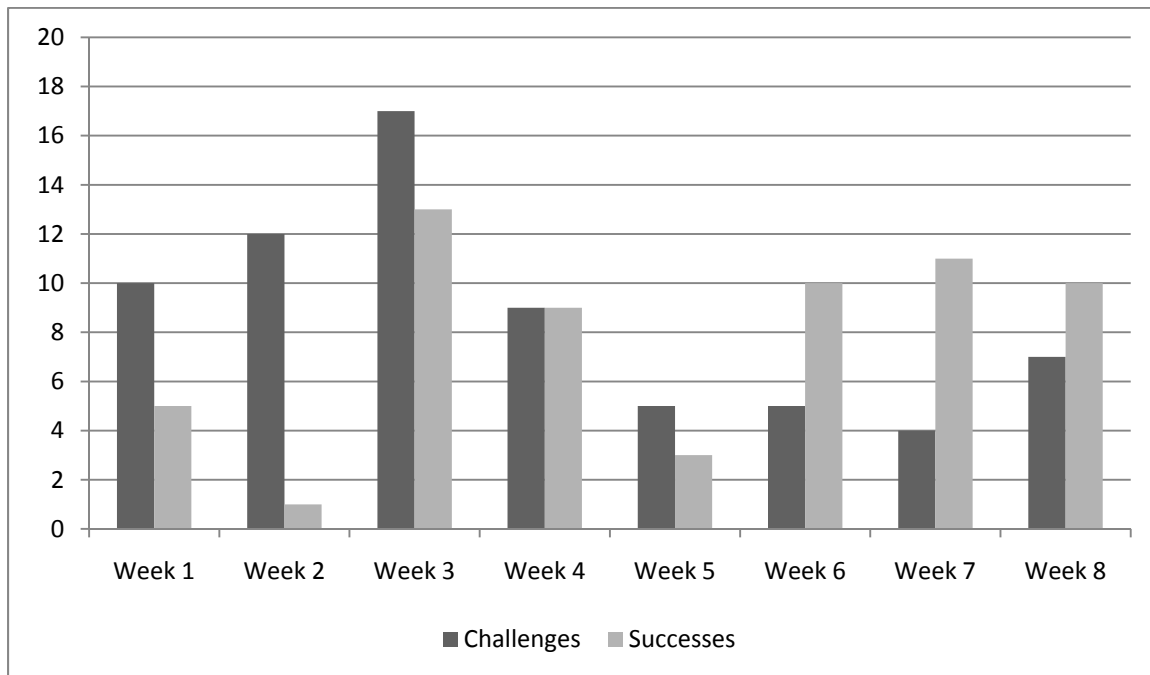


Figure 6. Comparison of coded challenges and successes each week

The frequencies of codes specific to challenges are reported in Appendix M, Table M1 and Figure M1. In the early weeks of the evaluation period most challenges were related to conflict with physicians and staff not being aware of the PRNs and their role. Overall the number of challenges decreased the longer the PRNs were in their role. See Figure 7 for narrative examples of coded challenges.

**5A = Conflict with physicians:** “difficulty with surgeons listening to us”  
**5B = Undesirable clinical practice:** “night nurse let him go all night without medicating”  
**5C= Time:** “I wish we had more time to discuss our experiences”  
**5D = Stigma/attitudes/beliefs:** “She’s going to hurt...She just had surgery.”  
**5E = Knowledge:** “I walked away having more questions”  
**5F= Patient/parent:** Parents who “would have not given anything at home for fear of addiction”  
**G= Lack of awareness of role:** “they don’t know we exist”  
**5H= Lack of clinical hours:** “get more shifts to work”

*Figure 7. Examples of comments coded as challenges*

The number of challenges exceeded successes early in the evaluation period. However, during the last 3 weeks successes were more commonly reported than challenges. The frequencies of codes specific to successes are reported in Appendix N, Table N1 and Figure N1. The frequency of successes tended to be greater in the second half of the evaluation period with the exception of week 5. Most coded successes were related to appreciative feedback and acceptable or effective pain care. See Figure 8 for narrative examples of coded successes.

**6A = Appreciative feedback****6Ai = Patient/family**

“they were amazingly receptive and appreciative of my teaching” “The parents were very pleased.”

**6Aii = Peers/others**

“the doc was very appreciative of my knowledge and took me really seriously”

**6B = Interdisciplinary collaboration**

“process went well. Drs. were in pretty fast and gave prn orders then quickly ordered pca”

**6C = Acceptable pain care**

“I managed to keep her comfortable for the night”

**6Ci = Effective pain relief**

“the patient finally seemed comfortable” “I checked on him, about 30 min later, he was sound asleep”

**6D = Positive changes in clinical practice**

“I used pharm and non-pharm tactics to get him up out of bed”

**6Di = Changes in clinical environment**

“everyone noticed the procedure rooms being clean”

**6E = Maturation in PRN role**

“my suggestion was to get the pain level down with the dilaudid, and then continue with the oxycodone q 3-4 hours”

**6F = Role awareness**

“people are becoming more aware of who we are on the unit and utilizing us more”

*Figure 8. Examples of comments coded as successes*

Key findings for question two include: 8 PRNs worked all shifts and covered 63% of the eight week evaluation period hours; the patient mix was evenly distributed between surgical and medical patients; the number of hours worked did not influence the number or characteristics of coded comments obtained; PRN role enactment behaviors used most frequently were resource and role model while the least frequently used was change agent; and slightly more comments were coded as challenges than successes. Notable changes from the beginning to the end of the evaluation period included more offering of advice versus waiting to be asked regarding pain care, number of MD contacts increased, and the number of comments coded as successes exceeded the number of contacts coded as challenges.

*Question Three: Does the PRN Program improve family pain satisfaction scores on the PACCC?* Mean patient satisfaction scores for pain control were monitored for 9 months. The means ranged from 77.3 (October 2008) to 90.6 (January 2009) on a 100 point scale, and were at

or below the UHC quarterly benchmark mean of 85.1 five of nine months. There is no evidence that the PRN program improved patient satisfaction with pain management (see Figure 9).

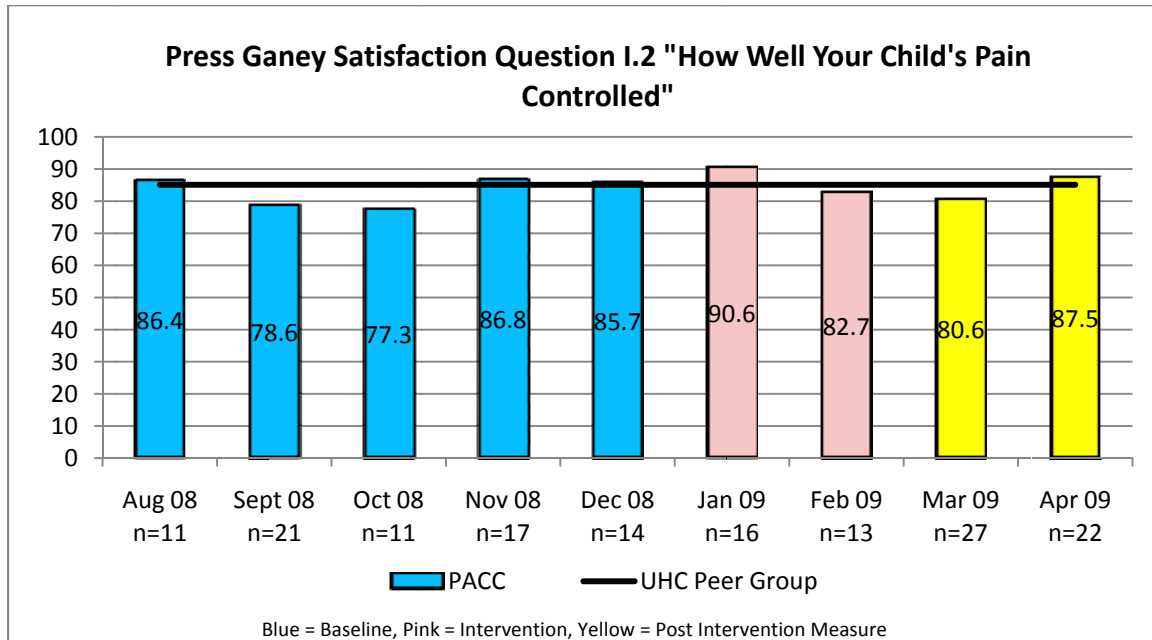


Figure 9. Press Ganey Monthly Satisfaction Score Means

*Financial Considerations*

Cost is a major consideration for implementing the PRN Program given its length (16 hours), the need to provide coverage for the RNs who are being trained, the cost of educational materials, and the promotional costs. When calculating the costs for this type of program, staffing patterns and restrictions must be considered. For budget purposes, it was assumed approximately half of the group would be paid at regular salary rates, approximately half of the group would be attending classes on overtime rates, and additional RNs would need to be paid to work the nursing unit to allow the nurses to attend the class. Calculations for the cost of the two day class were done as follows: 4 nurses paid regular average salary for 16 hours at \$36.70 per hour = \$2,348.80; 4 nurses paid at overtime for 16 hours at \$55.05 per hour = \$3,523.20; and it was estimated 4 additional nurses would be necessary to work the 16 hours on the nursing units to free up the nurses to attend class at \$36.70 per hour = \$2,348.80. This resulted in a total cost



of \$8,219.80 for class time. Additional costs totaling \$1,000.00 were budgeted for educational materials (copies of relevant journal articles, reference books, handouts from each presenter, and fees for continuing education credits). These costs do not include salary support for the program coordinator and other presenters. Vests with a Pain Resource Nurse designation were provided for each of the eight RNs at a cost of \$30.00 each. The proposed budget for initiating the program was \$10,500 or \$1,312.50 per RN. Actual cost was \$9,459.80 or \$1,182.50 per RN. Ongoing costs are paying the PRNs for 1 hour monthly meetings at the average pay rate of \$36.70 per hour. Annually, this is an additional \$3,523.20 cost to support the program. These financial data will provide critical information for proposals seeking expansion of the program to other units throughout the organization. These data will also be useful when sharing results of the program with other organizations who may be considering implementation and for future cost effectiveness study.

#### *Situation Analysis*

The proposal for and implementation of the PRN Program was well received and supported. In October 2008, after gaining approval to do this program evaluation as a pilot project on the PACC, recruitment and selection of the PRNs occurred. Timing of the 2 day education course was delayed until January due to new processes and work flow issues related to the ongoing electronic medical record conversion. During the interim weeks, curriculum development, securing speakers, and completion of the process to grant continuing education credits occurred. The PRN classes were held January 12 and 13, 2009. RNs who attended the classes appear to be engaged in the effort to improve pain management through the PRN Program, and have identified several areas of clinical practice on which to focus their efforts. Monthly meetings are used to discuss clinical care, review journal articles, and for presentations

of additional information related to pain management. As a result of this program evaluation, three notable changes will be made for future expansion classes. In order to better evaluate the effectiveness of the PRN classes, a knowledge assessment before and after will be done in accordance with the *Pain Resource Nurse Curriculum and Planning Guide* (Resource Center of the Alliance of State Pain Initiatives, 2009). A possible explanation for the limited change agent behaviors exhibited by the PRNs is the need to provide additional content and guidance toward influencing practice across the organization. Finally, more content and discussion is necessary regarding patient and family barriers as these perceived barriers did not change after implementation of the PRN Program and are in the higher ranges of mean scores indicating they are important barriers to optimal pain care to be addressed at DCH.

Being the leader of this project has been very rewarding. As a DNP student, it was necessary for me to have a well planned and documented implementation process. This will be invaluable information for expansion of this program throughout the organization, and I can refer to this when presenting the implementation process to other hospitals. After a national presentation on the multi-site barrier study, I was asked to be a resource to two hospitals considering implementation. Curriculum development will be much less onerous due to a recently published course planning guide and curriculum (Resource Center of the Alliance of State Pain Initiatives, 2009). The energy and enthusiasm of the PRNs has provided additional motivation for me to pursue expansion, and the PRNs will be integral to teaching the next classes. However, it will also be imperative to involve physicians, given the perceptions of them as barriers. This will include making them aware of the findings of the barrier survey and providing education related to the importance of and ways to decrease those barriers specific to

their practices in collaboration with the RN staff. Positive feedback and reception from other RNs, nursing leadership, and physicians has affirmed the worthiness of this program.

### *Outcomes*

Outcomes measured in this program evaluation included perceived barriers to pain management, identification of PRN role enactment behaviors, and patient/family satisfaction with pain management. Barriers related to RNs' beliefs and biases were significantly decreased while those related to institutional commitment and systems issues were significantly increased. Role enactment behaviors demonstrated by the PRNs were consistent with those reported in the literature and patient/family satisfaction was trending in a positive direction.

Based on observations of and discussions with the PRNs and other clinicians, the PRNs, even in a brief time period, had an impact on pain management practices on the PACC. This impact was reflected in the decreased perception of barriers related to beliefs and biases, and in the positive reactions to PRN's suggestions for clinical practice. In an unsolicited email from a PACC RN she commented, "I just wanted to pass along how much I appreciate your pain team already. (PRN) was such an amazing resource to me today when I worked with a very painful person." The PRNs also reported increased confidence and demonstrated maturation in the role as illustrated by the following comments provided in the last 3 weeks of the evaluation period, "just feeling more confident and keeping pain at the front of my mind," "people had some validation about my expertise," and "putting my PRN knowledge into practice!!" Future assessments will be necessary to determine if this effect is sustained and if other barriers are similarly impacted.

Since the course in January, the PRNs have been actively educating families, peers, and colleagues through unit posters, newsletters, and one-on-one interactions as demonstrated by the

coded weekly reports, investigator observations, and peer feedback. They have been involved with the redesign of the procedure rooms so those environments are more child friendly, and they have worked with a Child Life Specialist to develop Comfort Kits to facilitate the use of non-pharmacological pain management techniques. The PRNs have also indicated a strong desire to be involved with expansion to other DCH units.

The PRN Program offers several potential ways to change barriers to pain management. An educational outcome of the 2 days of didactic content was increased awareness of personal barriers to providing optimal pain care. It is posited by this program evaluator that having an increased awareness of barriers allows for increased personal control. Therefore, with increased self awareness and control (empowerment) of personal barriers the institutional and system barriers become more apparent and frustrating to the RNs. Increased awareness of barriers related to patients and families can help PRNs focus and modify information provided to patients and families.

### Discussion

In even a short time, the PRN Program had an impact on barriers to optimal pain management. The decrease in the barriers related to the nurses' beliefs and biases was more significant than had been anticipated. This may be a result of improving knowledge and information through the PRN Program and role modeling of appropriate attitudes by the PRNs. The significant increase in Institutional Commitment/Systems barriers was also not anticipated. Presence of the PRNs and increased awareness of pain care, including those related to physician ordering and commitment may have resulted in this increase. The lack of significant change in barriers related to patients and families was not unexpected. What was of note however, was the

ranges of mean scores for these barriers was in the higher range, indicative of this as another important area of focus in the efforts to decrease barriers to optimal pain management at DCH.

PACC PRNs' role enactment behaviors were consistent with those reported in the literature (D. Gordon, personal communication, March 19, 2009; McCleary et al., 2004; & Paice et al., 2006). Being a resource was the most common role component in this evaluation, followed by role modeling. Advocacy was demonstrated slightly (20% vs 28%) less than role modeling. The role enactment behavior used the least was change agent. These results may be influenced by the short period of evaluation, and the initial focus of this group has been to improve nursing practice at the unit level rather than at an organizational level. Many of the change agent behaviors described in the literature are more in line with organizational level change (Gordon; McCleary et al., & Paice et al.). Role enactment behaviors showed maturation over the period of evaluation. Early in the evaluation, many of the resource comments were regarding utilization of scheduled acetaminophen for the first 24 hours postoperatively. By the end of the evaluation period, comments were reflective of more sophisticated and broader thinking such as suggesting alternative medication use (nalbuphine for opioid induced itching, considering an anxiolytic when a child was demonstrated clinically significant anxiety) and involvement of other specialists (psychologist). Although every effort was made to code role enactment behaviors in a mutually exclusive manner, there was some overlap in the critical role attributes. An example of this overlap is if the PRN was advocating for his/her patient while being observed by peers, is this also role modeling? Role modeling and advocate behaviors also matured to include discussing plans of care with peers, using correct terminology ("It was so perfect to say "opioid" instead of "narcotic"), being more "persistent" in securing appropriate orders and "being more vocal about being a PRN." A concept of interest in the background of this program evaluation

related to PRN role enactment was the influence of empowerment of nurses in improving pain care. When asked during the focus group, “do you feel you have enough preparation and support (empowerment) to maintain this program?” The response was a unanimous and resounding “yes.” This was supported and illustrated by the shift from challenges being more prevalent early in the evaluation period to successes being more prevalent as the PRNs matured in their role.

### *Limitations*

Convenience sampling was used for both the RN sample and patient satisfaction data. Though other influences may have been present, the PRN Program was the only variable controlled for in this program evaluation. Evaluation of the effectiveness of the PRN Program would ideally have occurred at three months post implementation to allow the PRNs more time to effect change. The short time from intervention to outcome measurement was a limitation of this evaluation. However, this initial analysis provides information for comparison with subsequent evaluations. A repeat of the *Barriers to Optimal Pain Management* survey is planned for April 2010 which will be approximately one year post implementation. Time and workload permitting, a repeat survey may be done at 6 months post implementation. Using patient satisfaction scores as an outcome measure was also a limitation, as the monthly samples are small and patient satisfaction with pain may be influenced by factors unrelated to pain management such as memory recall when completing the survey and overall satisfaction with the hospital experience (Paice et al., 2006). An additional limitation of the Press Ganey measure was that it was a single question related to satisfaction with pain management.

Potential confounding influences for the evaluation include implementation during a time of major organizational change (electronic medical record conversion and work force restructuring including reductions). Efforts to address these limitations and influences involve

rigorous evaluation of the program and outcomes through appropriate statistical analysis, and acknowledgement of those factors which could not be controlled for, such as timing of outcome measurement following intervention and implementation during major organizational changes. Biases that had potential to influence the evaluation were the evaluator's preference for the PRN Program and enthusiastic support from nursing leadership. Potential biases were acknowledged, and every effort was made to maintain objectivity for the duration of the pilot project. This was done by developing rigorous and reproducible processes for planning, implementing, evaluating, and reporting findings of the project.

### *Conclusions*

Literature exists reporting the benefits of the PRN Program (Ellis et al., 2007; McCleary et al., 2004; Paice et al., 2006) and the presence of barriers to pain management ((Abu-Saad & Hamers, 1997; AMA, 2007; APS, 2006; Clarke et al., 1996; Czarnecki et al, 2008; Ferrell, McGuire et al., 1993; Fuller, 1996; Fuller et al., 1999; Griffin et al., 2007; Gunnarsdottir et al., 2003; Hall-Lord et al., 2006; Hamers, Abu-Saad, Halfens et al., 1994; Hamers, Abu-Saad, van den Hout et al., 1998; Hester, 1993; Horbury et al., 2005; Manworren & Hayes, 2000; McCaffery, 1999; Vincent & Denyes, 2004; Wilson, 2007). However, there are no reports of the effectiveness of the PRN Program for reducing barriers. This is the first study that examined the changes in the perception of barriers in response to the PRN Program.

In a limited period of time the PRN Program decreased the nurses' perceptions of barriers related to their own beliefs and biases. Although this is an important improvement, maintaining this achievement will require ongoing vigilance and effort.

Perceived barriers that increased post intervention were mainly related to physician orders and responsiveness. This indicates there is a need to garner improved multidisciplinary collaboration and organizational support. It may be that the PRN Program increased pain

management awareness among nursing staff which resulted in a heightened perception of these Institutional Commitment/Systems barriers.

Barriers related to patient and family factors showed no change. However, the means for are at levels similar to the Institutional Commitment/Systems barriers. These higher means indicate Patient/Family barriers are important to monitor and deserving of efforts to decrease them at DCH.

### *Implications for Future*

The 8 PRNs worked all shifts and covered 63% of the 8 week evaluation period hours. However, of the 8 weeks in the evaluation period, during only 2 (weeks 1 and 7) did all 8 PRNs work at least 4 hours. The other weeks were impacted by sick time, vacation, or lack of clinical hours. It will be necessary to be thoughtful of the impact of PRN availability on the success of the Program. This will be critical not only for maintaining the program, but also when planning for expansion to other units.

Future work relative to this project will include continued monitoring of patient satisfaction, repeating the *Barriers to Optimal Pain Management* survey, ongoing observation and evaluation of role enactment behaviors with modifications to course content to support effective behaviors, expansion to other DCH units, and a cost effectiveness analysis.

Just as barriers to optimal pain management are multi-factorial so too must be the approach to decreasing those perceived barriers. Providing optimal pain management is a multi-faceted process. Improving nursing knowledge through the PRN Program is one strategy. Though there are reports in the literature regarding the influence of the PRN Program for improving pain care, there are no published reports regarding its impact on perceived barriers. Identification of role enactment behaviors provides a foundation for tailoring education and



support for the PRNs to be more effective in their role. Rigorous evaluation of PRN role enactment behaviors will allow for enhanced professional development and support of these local experts as they grow and mature in their roles. Empowering the PRNs to be local resources, change agents, role models and advocates for pain management will improve the delivery of pain care and be instrumental in the professional development of those nurses who participate in the program.

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Appendix A

*Barriers to Optimal Pain Management Survey*

**Barriers to Optimal Pain Management**

Doernbecher Children’s Hospital (DCH) has been looking at ways to improve pain management for our children. Sometimes, nurses are not able to provide optimal pain management for a variety of reasons. The Doernbecher Pain Coalition (DPC) is interested in hearing from you, what (if anything) gets in the way of you being able to provide optimal pain management to your patients.

You are being asked to complete this survey because you work with children who may experience pain. This is part of a research study being conducted by DPC. Your participation is voluntary. The results of these surveys will be used to drive improvement initiatives and will be repeated every other year. No information identifying any one nurse specifically will be collected or shared. We anticipate this taking approximately 10 minutes to complete. Please use the comment section for any additional comments and submit **by APRIL 11, 2008** (April 11, 2009 for post-implementation survey)

**Principal Investigator: Helen Turner**

**eIRB #4161**

**1. BRIEFLY, tell us what good or optimal pain management looks like to you?**

*This will be a free text space in the survey tool.*

Below are some barriers to optimal pain management that have been identified previously by other Health Care Professionals. In the past year, on a scale of 0 to 10, (0 being “Not a barrier” and 10 being “A major barrier”) please **select** the number that best rates how much your personal ability to provide optimal pain management has been effected by the following.

**2. My concern about children becoming addicted**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**3. My concern about side effects of medications (other than addiction)**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier



**4. My concern about children becoming tolerant to analgesics**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**5. Competing demands on my time**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**6. Limitations in my knowledge of pain management**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**7. Limitations in my ability to assess pain**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**8. Low priority given to pain management by medical staff**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**9. Low priority given to pain management by nursing staff**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**10. Low priority given to pain management by nursing management**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**11. Low priority given to pain management by me**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**12. Inadequate or insufficient physician medication orders**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**13. Timeliness/responsiveness from medical staff to your concern about pain management**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**14. Patients' reluctance to report/rate pain**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**15. Patients' reluctance to take pain medications**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**16. Parents' reluctance to have children receive medication**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**17. Insufficient time allowed to pre-medicate prior to procedures**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**18. Insufficient pre-medication orders prior to procedures**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**19. Current documentation format for documenting assessment/interventions/reassessments**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**20. Insufficient resources to provide guidance/expertise in managing patients' pain**

0	1	2	3	4	5	6	7	8	9	10
Not a barrier										A major barrier

**21. In general, to what degree do you feel you are able to overcome barriers and ultimately provide quality pain management for your patients?**

0	1	2	3	4	5	6	7	8	9	10
Not at all able										Very able

22. How much of an impact would there be on your ability to provide quality pain management if the barriers you identified above were improved/alleviated?

0 1 2 3 4 5 6 7 8 9 10  
None at all A great impact

23. Overall, what impact does the involvement of the Pediatric Pain Service with your patients have in your ability to provide optimal pain management?

0 1 2 3 4 5 6 7 8 9 10  
A Very **NEGATIVE** Neutral A very **POSITIVE**  
Impact on patient care impact on patient care

24. What other barriers to pain management at DCH are not included on this tool?

*This will be a free text space in the survey tool.*

Comments:

**Now, tell us a little bit about your nursing education and practice**

<b>Primary Unit/Department-choose only 1</b>	<b>Years of <u>Pediatric</u> Nursing Experience</b>		<b>Highest level of <u>NURSING</u> education completed</b>	<b>What is your role</b>
PACC <input type="radio"/>	0-<2	<input type="radio"/>	Associate degree <input type="radio"/>	Staff nurse <input type="radio"/>
PICU <input type="radio"/>	2-<5	<input type="radio"/>	Diploma <input type="radio"/>	Supervisor <input type="radio"/>
PMCU <input type="radio"/>	5-<10	<input type="radio"/>	Baccalaureate <input type="radio"/>	Manager <input type="radio"/>
10S <input type="radio"/>	10-<15	<input type="radio"/>	Masters <input type="radio"/>	APN <input type="radio"/>
Float Pool <input type="radio"/>	15-<20	<input type="radio"/>	Doctorate <input type="radio"/>	Administrator <input type="radio"/>
Panda <input type="radio"/>	≥20	<input type="radio"/>		Other: _____
Gen Peds Clinic <input type="radio"/>			Race:	
Spec. Peds Clinic <input type="radio"/>			<input type="radio"/> White	Gender:
Heme/Onc Clinic <input type="radio"/>			<input type="radio"/> Black or African American	<input type="radio"/> male
ED <input type="radio"/>			<input type="radio"/> Native Hawaiian or Pacific Islander	<input type="radio"/> female
PACU			<input type="radio"/> Asian	
Sedation Service			<input type="radio"/> American Indian or Alaska Native	
			Ethnicity:	
			<input type="radio"/> Hispanic or Latino	
			<input type="radio"/> Not Hispanic or Latino	

**The following questions are about your individual (personal) practice/experience.**

**What sources do you use most often to assist you in making pain management decisions?**

- Assessment of infant/child
- Nurses report from previous shift
- Other nurses on your unit
- Specialty Nurse or APN
- Unit Based NPEC
- Clinical resources page information, articles etc.
- Other
- Physician order
- Child/family request
- Clinical pharmacist
- Pain Service
- Child's physician
- The patient's chart

**How did you learn about pain management?**

- Nurses on the unit
- Orientation at DCH
- Professional conference
- Unit Based NPEC
- OHSU SON Online course
- My personal experience, from the patients and families I care for
- Nurse or physician mentor/expert
- Nursing school
- Staff education program after orientation
- Journal articles
- Pain Team APN
- OSBN required CEU

**During a typical work week, how often do you encounter patients in pain?**

1 Almost Never	2 Rarely	3 Sometime	4 Frequently	5 Almost always
-------------------	-------------	---------------	-----------------	--------------------

**In general, how would you describe your pain management practices?**

1 Very Conservative	2	3 Neutral	4	5 Not At All Conservative
------------------------	---	--------------	---	---------------------------------

**How would you rate the current level of pain management at Doernbecher Children's Hospital?**

1 Poor	2 Borderline	3 Satisfactory	4 Very Good	5 Excellent
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Thank you for your participation. Stay tuned for results as well as interventions aimed at improving the barriers you have identified. Please submit this survey by APRIL TBD, 2009

Appendix B

Research Design and Variables

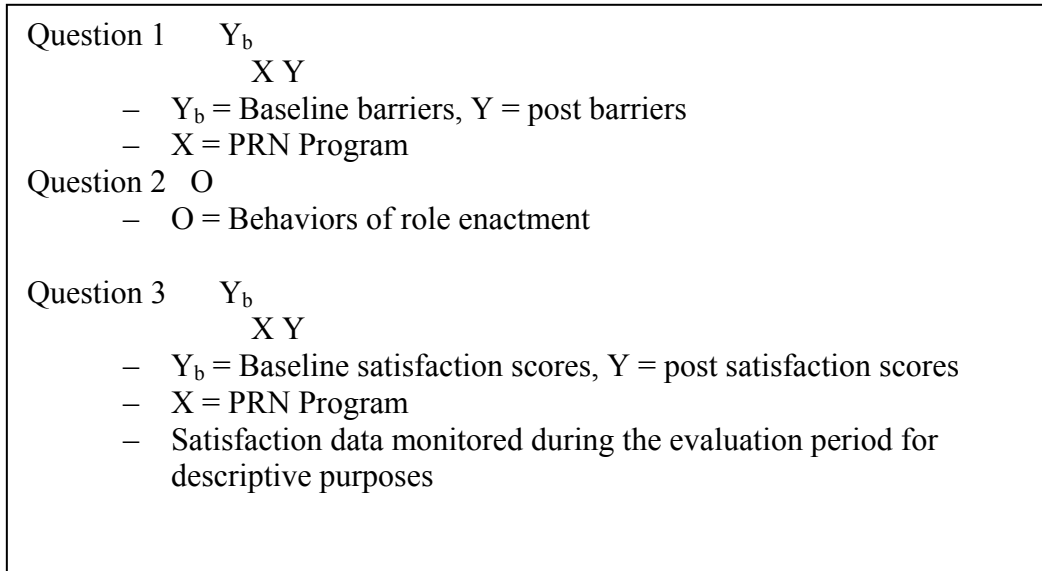


Figure B1. Clinical inquiry design diagram

Table B1

*Clinical Inquiry Variables*

Variable	Variable Type	Measure	Level of Measurement
Barriers to Optimal Pain Management	Dependent	<i>Barriers to Optimal Pain Management Survey</i>	Ordinal, One-sample t-test—means and SD for each of the three dimensions and compare pre and post
PRN Program	Independent		
Family Satisfaction Scores	Dependent	Press Ganey Report	Ordinal, means and describe



## Appendix C

## Survey Recruitment Email

From: Doernbecher Pain Coalition  
To: RN Name  
Subject: Pain Management Survey

Doernbecher Children's Hospital (DCH) is looking at ways to improve pain management for our children. In response to your concerns and questions about the management of pain, the Doernbecher Pain Coalition (DPC) is interested in hearing from you, what (if anything) gets in the way of you being able to provide optimal pain management to your patients.

You are being asked to complete a survey because you work with children who may experience pain. This is part of a research study being conducted by DPC. Your participation is voluntary. The results of these surveys will be used to drive improvement initiatives. No information identifying any one nurse specifically will be collected or shared. We anticipate this taking approximately 10 minutes to complete. Please use the comment section for any additional comments and submit **by APRIL 11, 2008** (April 11, 2009 for post-implementation survey)

To begin the survey, click on the following link: Link will be added after IRB approval and survey available.

Appendix D

Call for PRN Applications Poster

**WANT TO MAKE A DIFFERENCE?**  
**Be a PACC Pain Relief Champion**

**Pain Resource Nurse (PRN) Program**



**Call for Applications**

**PROGRAM INCLUDES:**  
16 hours of pain specific CE training  
Monthly update and review meetings  
1 year commitment

**What's In It For You?**  
Professional Development  
Skills to Enhance Clinical Practice  
Recognition as PRN  
Paid meeting time including parking for meetings

**Application Process: Due Nov 7**  
In Email or writing (in 200 words or less) why you want to do this, what skills you would bring to the group, and why you think you are qualified.  
Send to Helen Turner (turnerh@ohsu.edu)

**Selection Criteria:**  
♦ At least 1 year pediatric experience  
♦ Commit to attend monthly meeting with Peds Pain Team (time to be determined by PRNs)  
♦ Commit to be a resource for 1 year

6 PRNs will be selected by Helen Turner. Selections will be announced on November 17

## Appendix E

## Doernbecher PACC Pain Resource Nurse Program Agenda

<b>DAY ONE</b>	<b>JANUARY 12, 2009</b>	
8:00-8:30	Introduction to Pain Resource Nurse Program	Ruby Jason & Helen Turner
8:30-9:30	Anatomy and Physiology of Pain	Jessica Miller, MD
9:30-9:45	BREAK	
9:45-11:00	Psychosocial Factors in Pediatric Pain	Michael Harris, PhD
11:00-12:00	Crucial Conversations Skills for PRN Nurses	Debbie Buchwach, BSN, RN
12:00-12:30	LUNCH	
12:30-13:30	Pain Assessment Case Studies	Group—Interactive
13:30-14:45	Misconceptions and Barriers in Pediatric Pain Management	Helen Turner MSN, RN
14:45-15:00	BREAK	
15:00-16:00	Pharmacological Treatment of Pain	Marianne Krupika, PharmD
16:00-16:30	Q and A, Wrap up, and Homework Review	Helen Turner with Group
<b>DAY TWO</b>	<b>JANUARY 13, 2009</b>	
8:00-9:15	Empowering Change and Relationship Centered Care	Helen Turner MSN, RN
9:15-9:30	BREAK	
9:30-10:15	Ethics and Disparities in Pain Management	Helen Turner, MSN, RN
10:15-11:15	Non What? Nonpharmacological Coping Techniques for Children and Their Families	Kim Kuehnert, MA, CCLS
11:15-11:45	LUNCH	
11:45-12:45	Types of Pain—The Differences Are Important	Kirk Lalwani, MD
12:45-14:15	Epidural Analgesia; Patient Controlled Analgesia; Peripheral Nerve Blocks	Angela Kendrick, MD
14:15-14:30	BREAK	
14:30-16:00	Challenging Case Studies and Role Play	Group—Interactive
16:00-16:30	Future Planning, Course Evaluation	Helen Turner with Group

Appendix F

PRN Weekly Email Report

Number of hours worked:

Which shift(s) worked—days, evenings, nights?

Role on shift—staff nurse or charge nurse

Did you float? If so where and would you have been comfortable making pain recommendations there?

Number and types of pain questions/"consults" you had:

How many times were you able to provide information before being asked?

Who requested the information—Peers, MDs, Family, other?

What were your challenges?

What were your successes?

How stressful were your interactions and why?

New thoughts, ideas, or problems identified:

## Appendix G

### Codes for Content Analysis

1 = Resource

2 = Change Agent

3 = Role Model

4 = Advocate

5 = Challenges

5A = Conflict with physicians

5B = Undesirable clinical practice

5C= Time

5D = Stigma/attitudes/beliefs

5E = Knowledge

5F= Patient/parent

5G= Lack of awareness of role

5H= Lack of clinical hours

6 = Successes

6A = Appreciative feedback

6Ai = Patient/family

6Aii = Peers/others

6B = Interdisciplinary collaboration

6C = Acceptable pain care

6Ci = Effective pain relief

6D = Positive changes in clinical practice

6Di = Changes in clinical environment

6E= Maturation in PRN role

6F = Role awareness

## Appendix H

### Focus Group Questions

Four Components of PRN Role have been identified.

Resource

Change Agent

Role Model

Advocate

**WHAT BEHAVIORS/ACTIVITIES HAVE YOU USED, AND TO WHICH COMPONENT DO YOU THINK THESE ACTIVITIES BELONG?**

Challenges encountered appear to group into 4 themes.

Conflict with providers

Slow pace of clinical practice

Undesirable clinical practice

Lack of time

**HOW PROBLEMATIC WAS EACH OF THESE FOR YOU?**

Successes experienced appear to group into 4 themes.

Appreciative feedback (peer/colleagues and patient/family)

Interdisciplinary collaboration

Acceptable pain care

Positive changes to clinical practice

**ARE THERE OTHER INDICATORS OF SUCCESS YOU EXPERIENCED?**

**DO YOU FEEL YOU HAVE ENOUGH PREPARATION AND SUPPORT (EMPOWERMENT) TO MAINTAIN THIS PROGRAM? IF NOT WHAT WOULD BE HELPFUL?**

Appendix I

Press Ganey Survey Pain Specific Question

<b>I. PERSONAL ISSUES</b>	very				very
	poor	poor	fair	good	good
	1	2	3	4	5

2. How well your child's pain was controlled .....

Appendix J

PRN Hours Comparisons

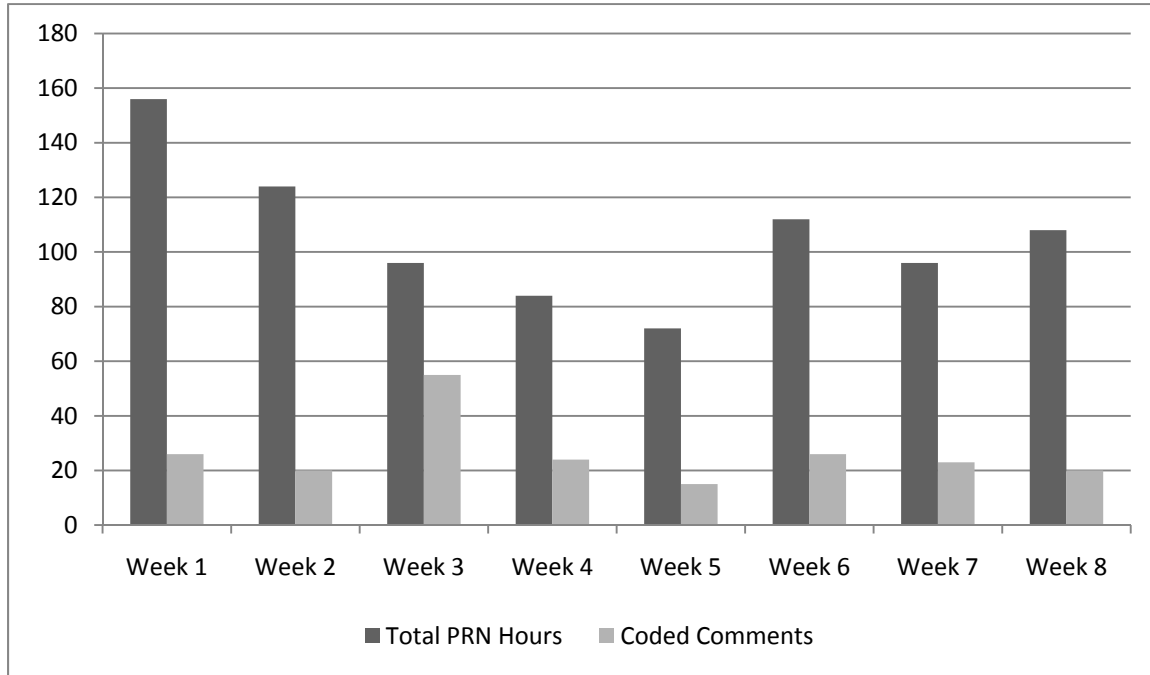


Figure J1. Comparison of hours and number of coded comments per week

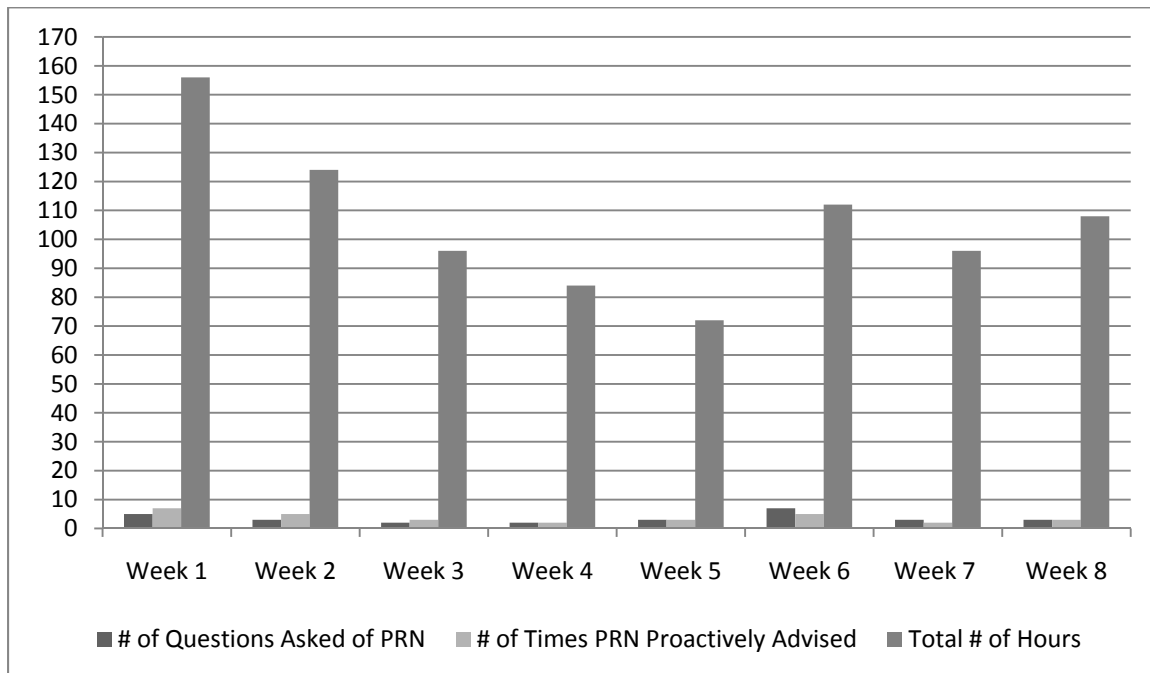


Figure J2. Number of questions or advisements compared to hours worked



Appendix K

PRN Weekly Contacts

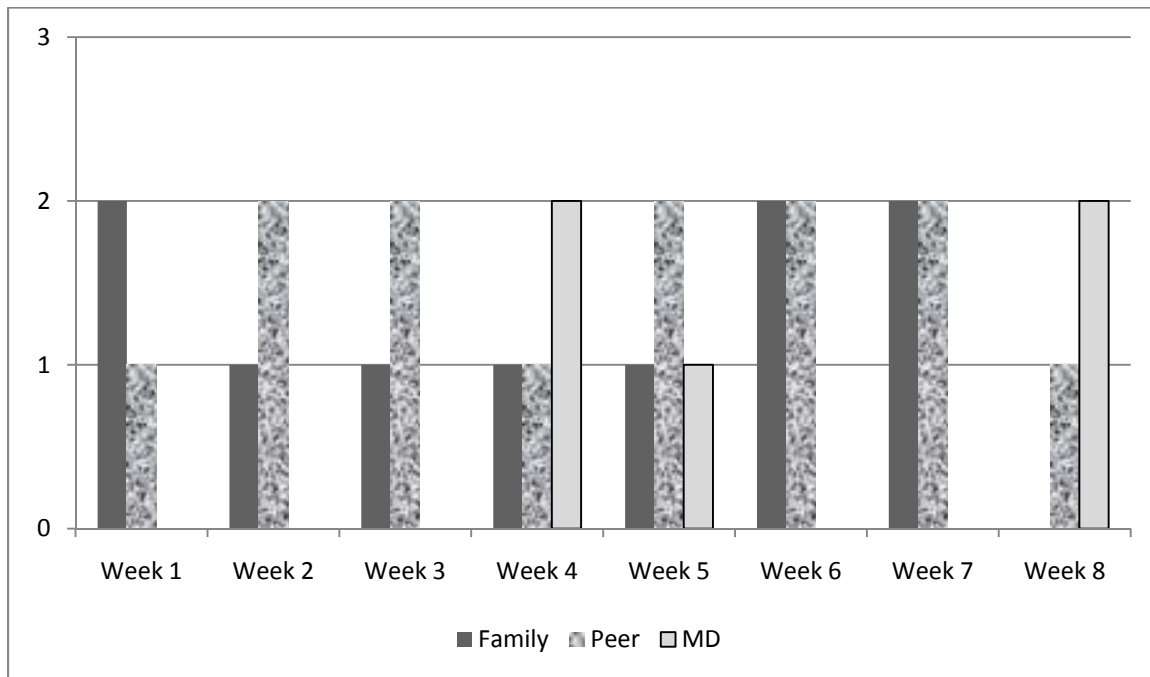


Figure K1. Average number of family, peer, or M.D. contacts per week

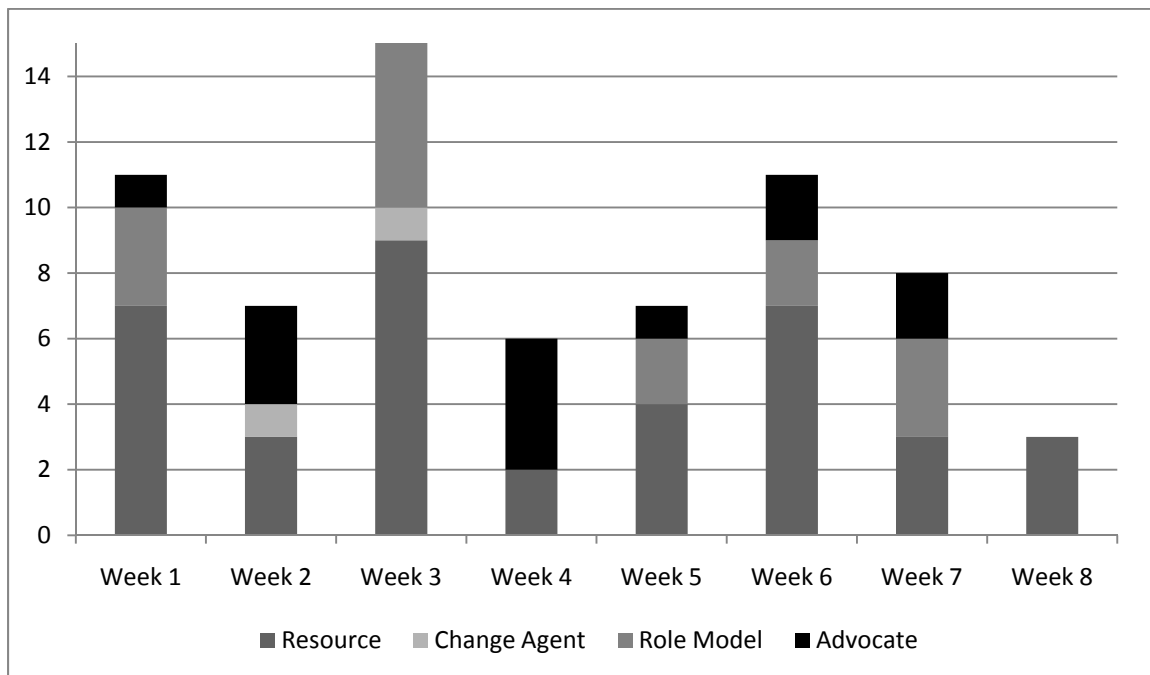
Appendix L

Coded Comments Frequencies

Table L1

*Number of Coded Comments by Major Category*

	Resource	Change Agent	Role Model	Advocate	Challenges	Successes	Totals
Week 1	7	0	3	1	10	5	26
Week 2	3	1	0	3	12	1	20
Week 3	9	1	12	3	17	13	55
Week 4	2	0	0	4	9	9	24
Week 5	4	0	2	1	5	3	15
Week 6	7	0	2	2	5	10	26
Week 7	3	0	3	2	4	11	23
Week 8	3	0	0	0	7	10	20
Totals	38	2	22	16	69	62	209



*Figure L1.* Frequency of coded comments by behavior each week

Appendix M

Coded Challenges Frequencies

Table M1

*Number of Coded Challenges Comments by Week*

	5A	5B	5C	5D	5E	5F	5G	5H	Totals
Week 1	1	1	0	0	0	3	4	1	10
Week 2	8	2	0	1	1	0	0	0	12
Week 3	6	2	0	1	5	1	2	0	17
Week 4	2	0	0	0	2	4	0	1	9
Week 5	1	1	1	0	2	0	0	0	5
Week 6	0	1	0	0	1	1	0	2	5
Week 7	2	0	0	0	0	1	0	1	4
Week 8	0	4	1	0	0	0	1	1	7
Totals	20	11	2	2	11	10	7	6	69

5A = Conflict with physicians; 5B = Undesirable clinical practice; 5C= Time; 5D = Stigma/attitudes/beliefs; 5E = Knowledge; 5F= Patient/parent; 5G= Lack of awareness of role; 5H= Lack of clinical hours

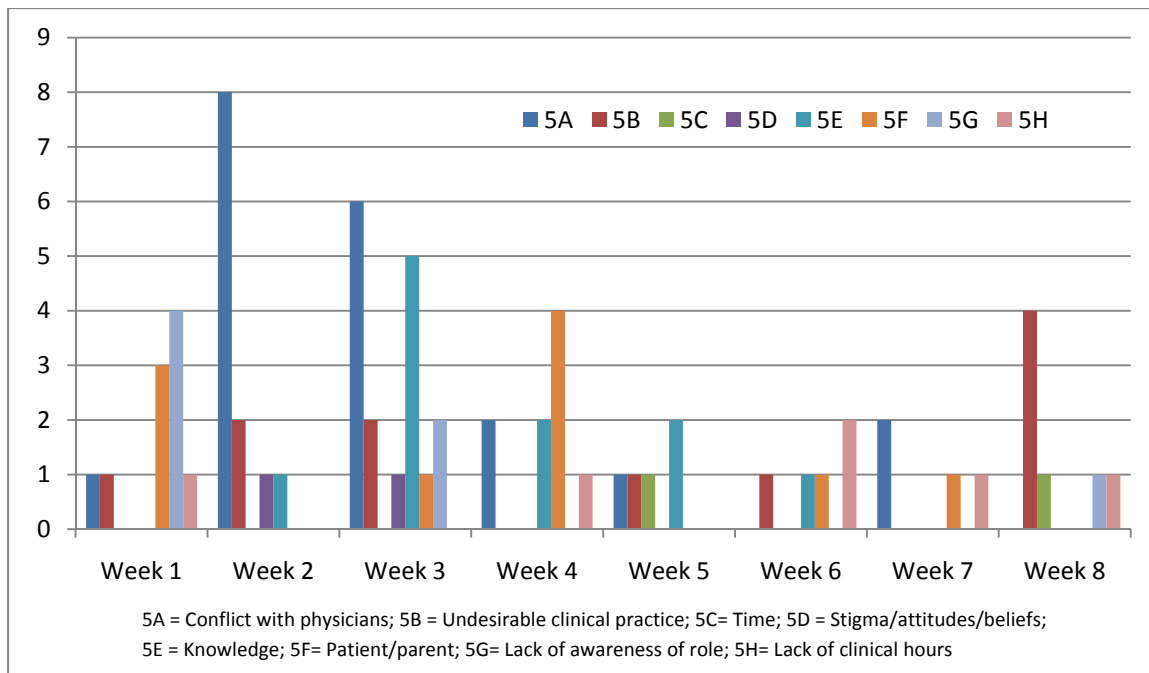


Figure M1. Number of coded challenges comments by week

Appendix N

Coded Successes Frequencies

Table N1

Number of Coded Successes Comments by Week

	6Ai	6Aii	6B	6C	6Ci	6D	6Di	6E	6F	Totals
Week 1	1	0	0	4	0	0	0	0	0	5
Week 2	0	0	0	0	1	0	0	0	0	1
Week 3	3	0	0	2	4	1	1	1	1	13
Week 4	1	0	2	2	2	0	1	1	0	9
Week 5	0	0	0	0	0	1	1	1	0	3
Week 6	2	2	0	0	1	0	3	0	2	10
Week 7	4	0	0	1	3	2	0	1	0	11
Week 8	2	2	0	2	0	0	0	2	2	10
Totals	14	4	2	11	11	4	6	6	5	62

6A = Appreciative feedback; 6Ai = Patient/family; 6Aii = Peers/others; 6B = Interdisciplinary collaboration; 6C = Acceptable pain care; 6Ci = Effective pain relief; 6D = Positive changes in clinical practice; 6Di = Changes in clinical environment; 6E= Maturation in PRN role; 6F = Role awareness

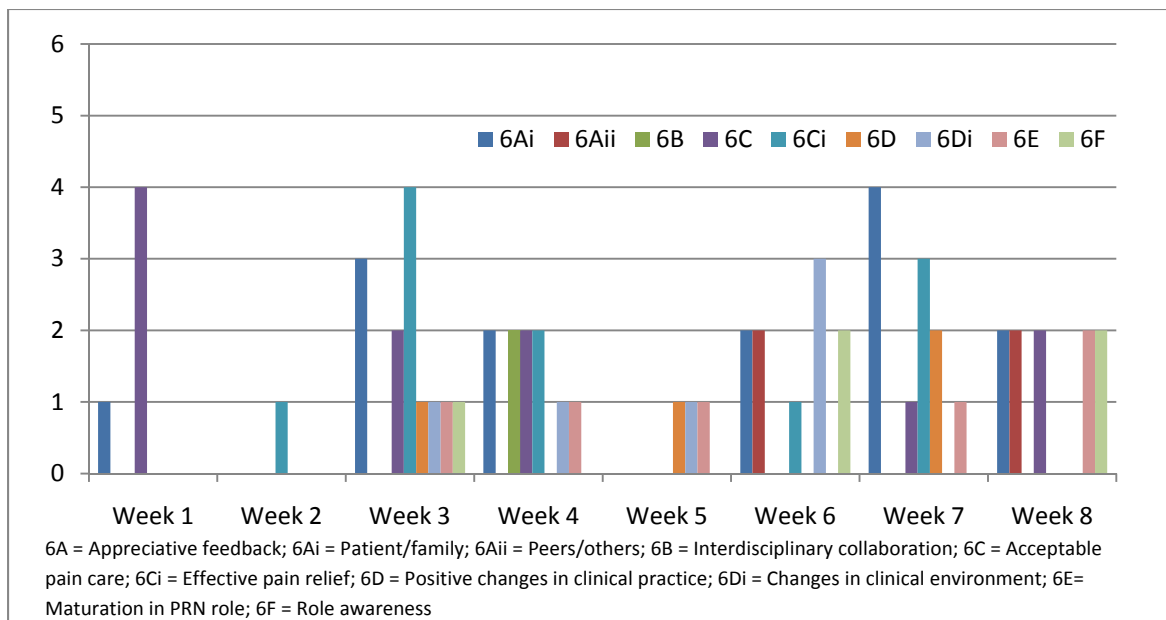


Figure N1. Number of coded successes comments by week

## Figure Captions

*Figure 1.* Evaluation of the Pain Resource Nurse Program

*Figure B1.* Clinical inquiry design diagram

*Figure 2.* Project timeline

*Figure 3.* Years of pediatric nursing experience

*Figure 4.* Level of nursing education

*Figure J1.* Comparison of hours and number of coded comments per week

*Figure J2.* Number of questions or advisements compared to hours worked

*Figure K1.* Average number of family, peer, or M.D. contacts per week

*Figure L1.* Frequency of coded comments by behavior each week

*Figure 5.* Percent of coded comments by role behavior

*Figure 6.* Comparison of coded challenges and successes each week

*Figure M1.* Number of coded challenges comments by week

Figure 7. Examples of comments coded as challenges

*Figure N1.* Number of coded successes comments by week

Figure 8. Examples of comments coded as successes

*Figure 9.* Press Ganey monthly satisfaction score means

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HEALTH  
& SCIENCE  
UNIVERSITY



# Evaluating the Effect of a Pain Resource Nurse Program on Barriers to Pediatric Pain Management

Helen N. Turner, MS, RN-BC, PCNS-BC  
Doctor of Nursing Practice Candidate

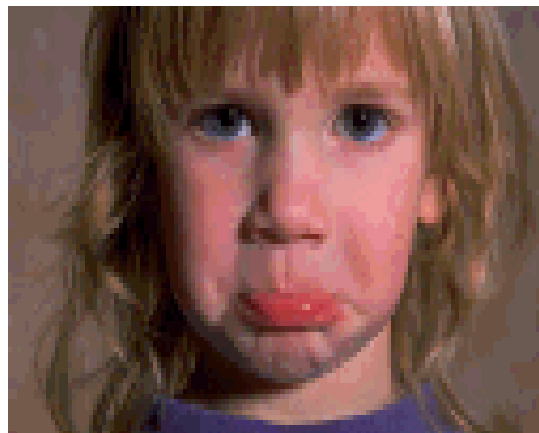
# Why A Doctor of Nursing Practice?

- Broaden, enhance, and advance my clinical leadership skills.
- Challenged to look at clinical situations more critically and methodically.
- Make a valuable contribution to the practice of nursing and knowledge related to pediatric pain management.

# Significance

- Thousands of children are hospitalized each year and experience pain
- Prevalence of clinically significant pain in children may be as high as 60%

Walker and Wagner, 2003





# Significance

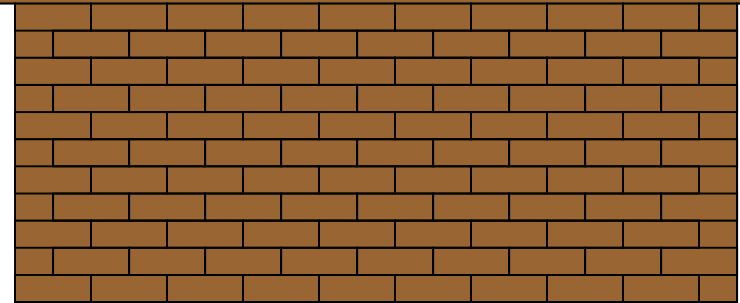
- Children are identified as a vulnerable population at risk for under treatment of pain
- Untreated or poorly treated pain impacts every body system and can lead to:
  - Impaired healing
  - Delayed recovery
  - Prolonged hospitalization
  - Exacerbation of illness or injury
  - Death

AAP & APS, 2001; Ferrell et al., 2001

# Barriers to Pain Management

- Patients
  - Knowledge
  - Experience
- Health Care Providers
  - Knowledge
  - Attitudes
- Health Care Systems
  - Patient care unit level to global laws/attitudes/values

## Barriers to Pain Management



# Clinical Inquiry Purpose

- The purpose of this program evaluation was to determine the effectiveness of the Pain Resource Nurse (PRN) Program for reducing barriers to optimal pain management on Doernbecher Children's Hospital's (DCH) Pediatric Acute Care Center (PACC) and to describe what behaviors PRNs use to influence changes in practice as they enact their role as local pain experts on the PACC.

# Questions of Interest

- 1) Does the PRN Program decrease nurses' perceptions of barriers to pain management on the PACCC?
- 2) What behaviors do PRNs use to influence change in practice as they enact their role as pain experts on the PACCC?
- 3) Does the PRN Program improve family pain satisfaction scores on the PACCC?

# Program Evaluation Setting

- Doernbecher Children's Hospital
  - 150 bed, university based pediatric teaching hospital and clinic system providing tertiary care
- Pediatric Acute Care Center
  - 48 medical/surgical patient beds
  - 70 direct care nurses (RNs)
  - Budgeted for 12,300 patient days annually

# Measures

- *Barriers to Optimal Pain Management* survey
  - 18 items (Cronbach's  $\alpha = .85$ )
  - Factor analysis
    - Institutional Commitment/Systems Barriers
    - Beliefs and Biases
    - Patient/Parent Barriers
- Press Ganey pain satisfaction question
  - “How well your child's pain was controlled”

# Intervention

- Implementation of PRN Program
  - 2 days of pain education (January 2009)
    - Types of pain, anatomy and physiology of pain
    - Assessment
    - Pharmacological management
    - Non-pharmacological treatment options
    - Psychosocial impact of pain
    - Ethics and disparities in pain management
    - Empowerment, change behavior
    - Crucial conversations

# Intervention

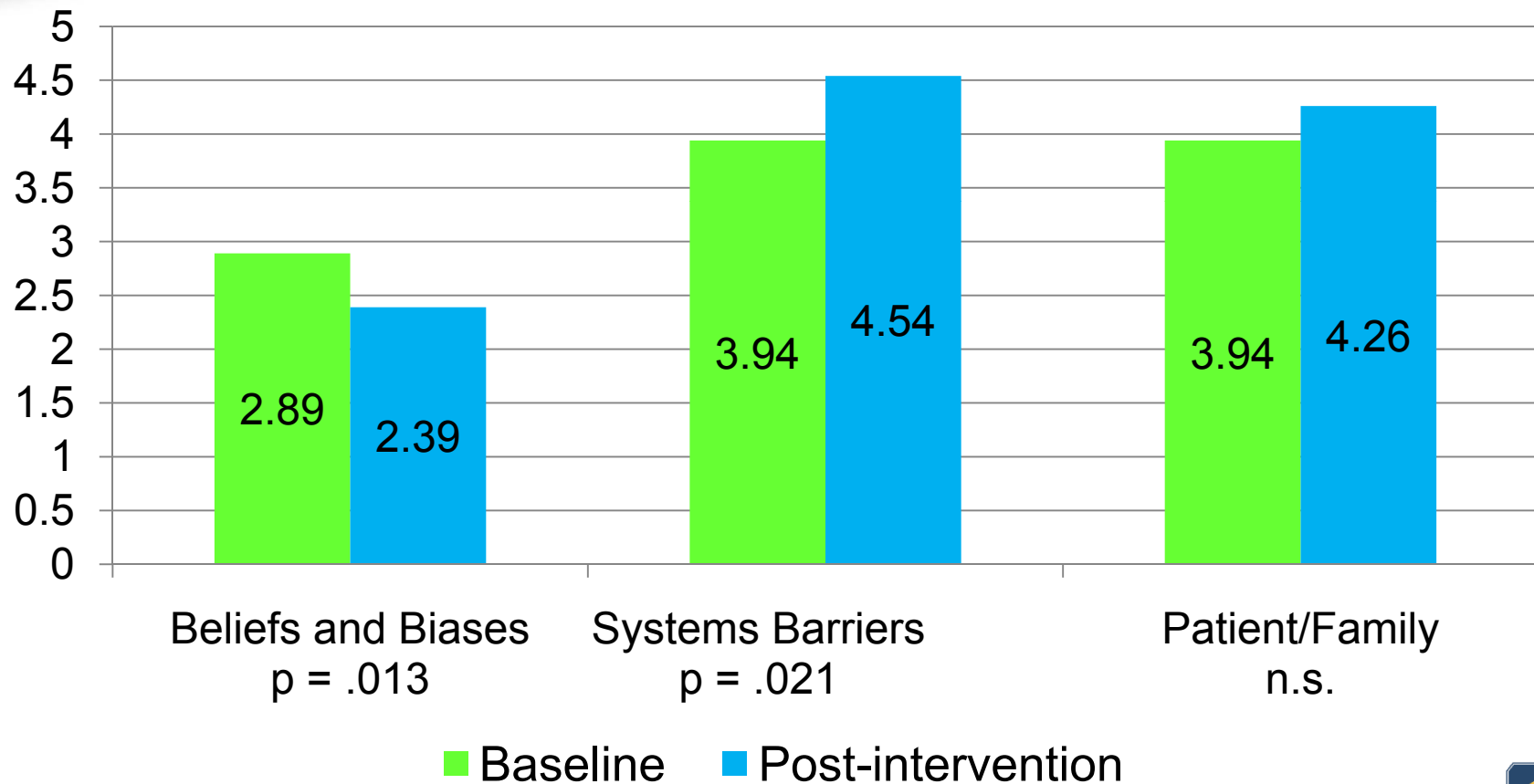
- Supporting implementation
  - Frequent face to face contact with PRNs
  - Email communication
  - Monthly meetings
  - Journal articles for discussion
  - Ongoing educational offerings/support
  - Encouraging certification



# Evaluation

- Comparison of perceived barriers pre- and post-intervention (single sample t-tests)
- Content analysis of weekly PRN reports
- Trending patient pain satisfaction scores
- 8 week evaluation period

# Reducing Nurses' Perceptions of Barriers to Pain Management (Q1)



# Latent Content Analysis (Krippendorff, 1980)

- 209 coded text comments
  - 78 were role enactment behaviors
  - 69 were challenges
  - 62 were successes

# PRNs Role Enactment Behaviors (Q2)

- Resource (49%)
  - Teaching
  - Helping
  - Recommending
  - Explaining
- Change Agent (3%)
  - Change minds
  - Reinforce change of practice
- Role Model (28%)
  - Review
  - Discuss
  - Anticipating pain
  - Being proactive
- Advocate (20%)
  - Working for optimal orders
  - Being persistent
  - Advocated
  - More vocal
  - Encouraged use

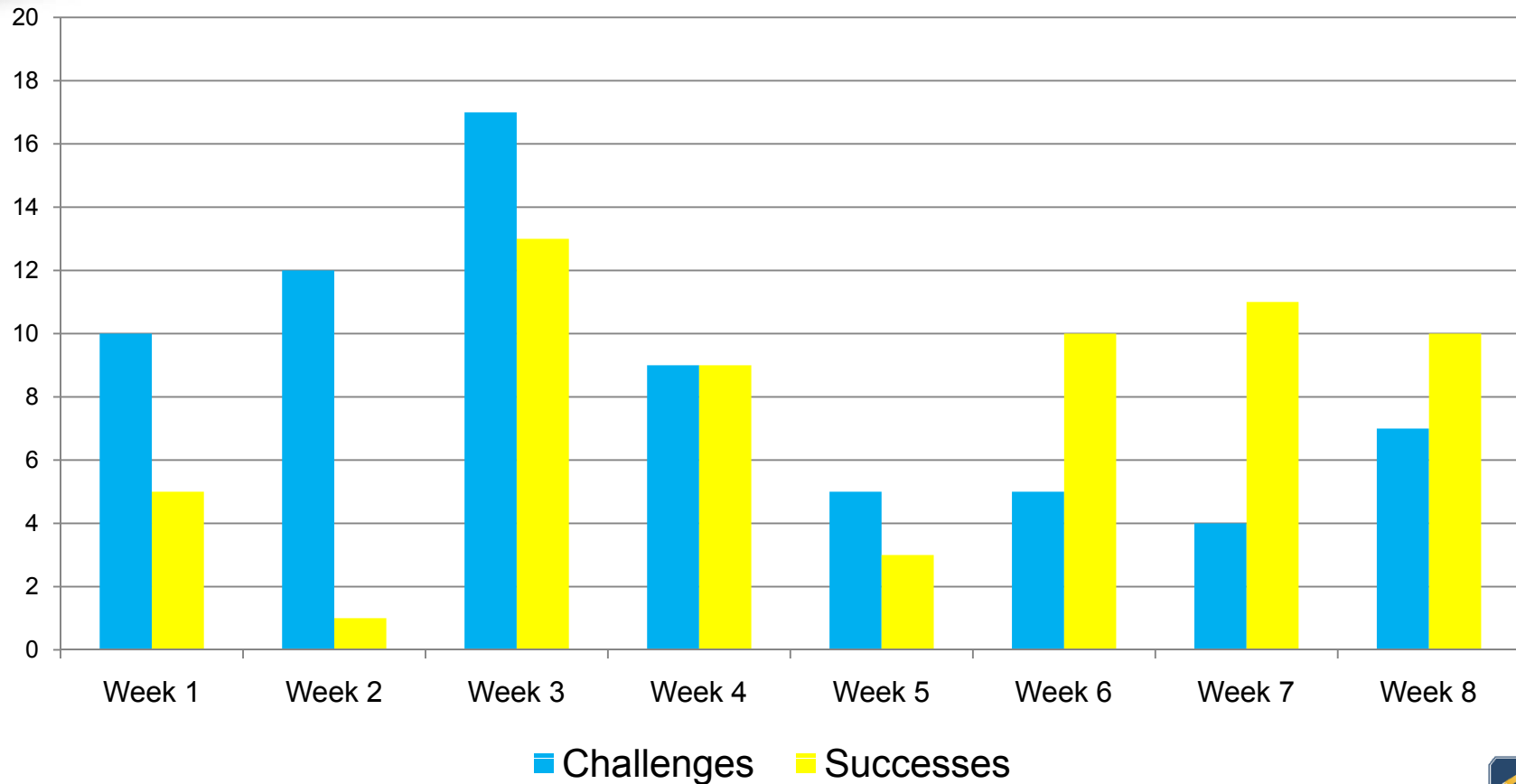
# Challenges Faced

- Conflict with physicians
- Undesirable clinical practice
- Lack of time
- Stigma/attitudes/beliefs
- Knowledge
- Patient/parent
- Lack of awareness of role
- Lack of clinical hours

# Successes Experienced

- Appreciative feedback
  - Patient/family
  - Peers/others
- Interdisciplinary collaboration
- Acceptable pain care
  - Effective pain relief
- Positive changes in clinical practice
  - Changes in clinical environment
- Maturation in PRN role
- Role awareness

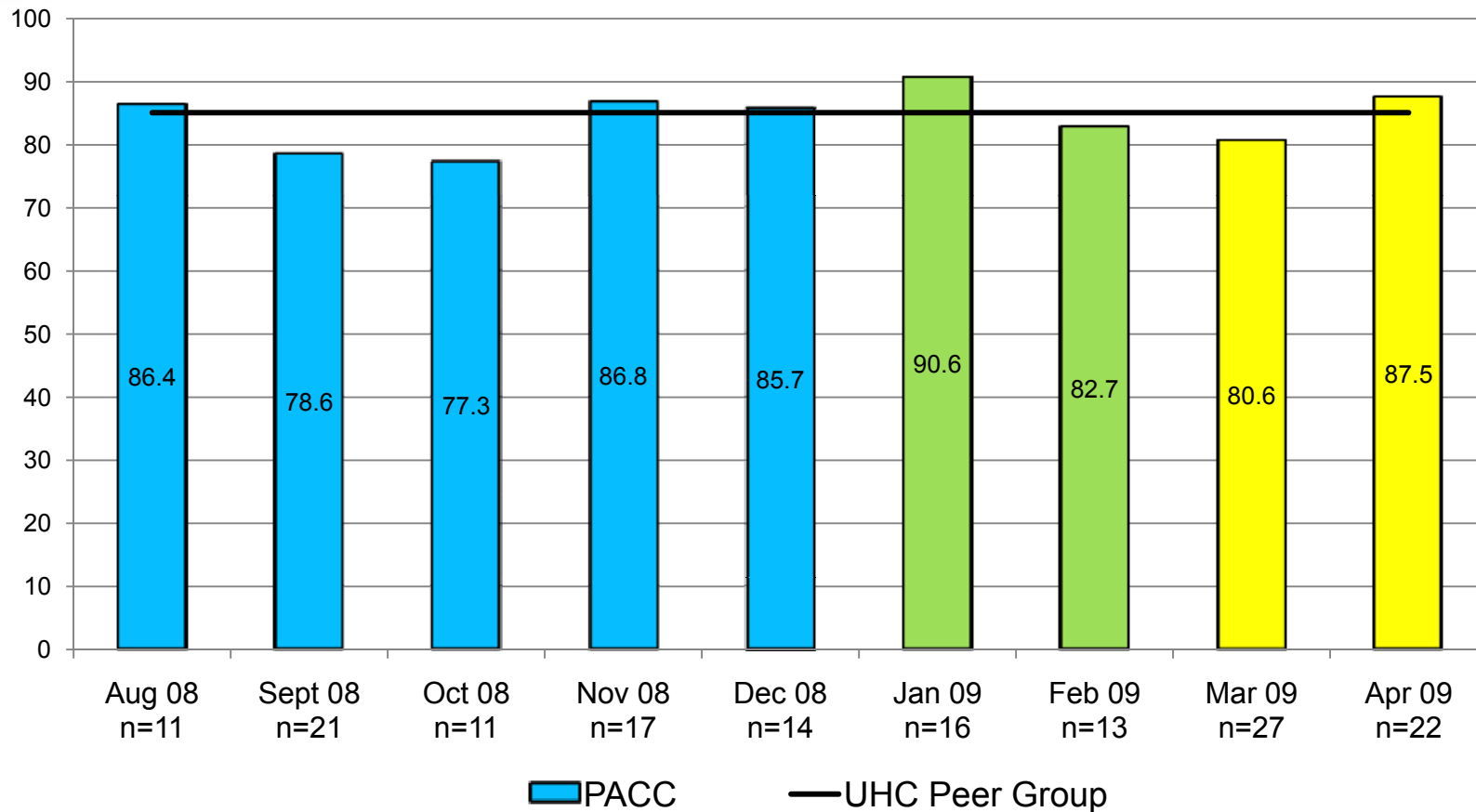
# Weekly Challenges and Successes



Successes exceed challenges as the PRNs matured in role

# Effect on Patient Experience of Pain Management (Q3)

Press Ganey Satisfaction Question: "How Well Your Child's Pain Controlled"



Blue = Baseline, Green = Intervention, Yellow = Post Intervention Measure



# Summary of Findings (Q1)

- PRN Program decreased some barriers while others increased or did not change.
  - ↓ Beliefs and Biases
  - ↑ Institutional Commitment/Systems Barriers
  - No Change in Patient/Family Barriers

## Summary of Findings (Q2)

- PRNs used role enactment behaviors similar to those reported in the literature.
  - Resource, Change Agent, Role Model, Advocate
- Role maturation occurred over time.
  - More offering advice Vs waiting to be asked
  - Increased MD contacts
  - More successes than challenges!

## Summary of Findings (Q3)

- PRN Program did not improve patient satisfaction with pain management.
  - Trend is in a positive direction however

# Feasibility

- Initial Cost = \$9,459.80 (\$1,182.50 per RN)
  - 2 days of class time (\$8,219.80)
  - Training materials (\$1,000.00)
  - PRN vests—for easy recognition (\$240.00)
- Ongoing Cost = \$3,523.20 annually
  - Monthly 1 hour meetings
- 8 PRNs worked 63% of hours in 8 week period on all shifts

# Limitations

- Convenience sampling
- Small sample sizes
- Short time from intervention to outcome measurement
- Patient satisfaction as outcome
- Single question for pain satisfaction outcome
- Did not control other potential variables

# Implications for the Future

- Clinical practice
  - Maintaining and improving gains
  - Expansion of the program to other units
  - Physician engagement and education

# Implications for the Future

- Research
  - Regular monitoring of barriers and satisfaction
  - Cost effectiveness analysis

# Conclusions

- PRN Program decreased nurses' perceptions of barriers related to their own beliefs and biases.
- Physician engagement will be necessary to decrease Institutional Commitment/Systems barriers.
- Efforts must be made to decrease patient and family barriers.



# Competency Achieved and Plans for Future Growth

- **Advanced Clinical Skills**
  - Increased knowledge regarding substance abuse disorders
  - Improved understanding of assessment and treatment of pediatric patients with pain
- Continue to develop clinical expertise in pediatric pain management as an advanced practice nurse.

# Competency Achieved and Plans for Future Growth

- Clinical Inquiry
  - PRN Program Evaluation
  - Policy Evaluation
  - Systems and Organizational Change Assessment
- Evaluate clinical practice more thoroughly and with an appreciation of system and policy influences and factors.

# Competency Achieved and Plans for Future Growth

- Leadership
  - Implementation of PRN Program
  - Promote pain management improvements across the organization
  - Develop common strategies for providing care to children needing chronic opioid therapy
- Plan, develop and lead interventions that are evidence-based, ethical, and measurable.

# ACKNOWLEDGEMENTS

- Scott, Abby, and Aiden Turner & Sydney too!
- The 8 PRNs involved in this pilot project
- Ruby Jason, MSN, RN, CNAA-BC  
Division Director for Women and Children
- Doctoral Committee:
  - Dr. Deborah Eldredge, PhD, RN (Chair)
  - Dr. Judith Baggs, PhD, RN, FAAN
  - Dr. Susan O’Conner-Von, DNSc, RNC
- Lisa Piper, RN & colleagues in the PPMC



Questions ? ? ?

Running Head: CONTROLLED SUBSTANCE ELECTRONIC PRESCRIBING  
POLICY ANALYSIS

Electronic Transmission of Controlled Substance Prescriptions: An Analysis of Code of

Federal Regulation 21, Section 1306

Helen N. Turner

Oregon Health & Science University

Writing and processing a medication prescription is not a simple matter and is even more complicated with the push for electronic prescribing and medical record keeping. Federal law dictates the elements of a prescription and as well, how the prescription is communicated to a dispensing pharmacist. The majority of rules related to prescriptions are contained in the Title 21 Code of Federal Regulation (21 CFR) (2001) Controlled Substance Act (CSA) which is Title II of the Comprehensive Drug Abuse Prevention and Control Act of 1970 (Comprehensive Drug Abuse Prevention and Control Act of 1970, 1970). These rules and regulations are necessary to protect the patient, the prescribing provider, the dispensing pharmacist, and the general public.

### Context

To facilitate patient access to medications and to not slow treatment initiation, verbal prescriptions have been allowed whereby a provider or provider's agent can relay (generally by phone) the required elements of the prescription to the pharmacist. With the advent of facsimile technology many providers were able to make prescription writing more efficient and the movement toward automation began. As healthcare systems in the United States (US) have transitioned to electronic health record (EHR) systems, further automation, increased safety, and efficiency related to prescriptions have been touted as major benefits of the EHR by both healthcare professionals and vendors of these systems. However, technology advanced more rapidly than regulations guiding prescription medication ordering and dispensing could be followed and maintained or amended.

Within 21CFR, Section (§) 1306.21 defines the requirements of prescriptions written for medications classified as controlled substances which fall under the jurisdiction of the Drug Enforcement Administration (DEA). The DEA recently

announced its intent to fully enforce 21CFR § 1306.21 language in relation to electronic transmission of prescriptions resulting in much furor and consternation in the world of prescribing. Collins' (2005) eight step framework of policy analysis will be used to analyze the DEA's policy in relation to electronic transmission of prescriptions for Schedule III-V medications. Because Schedule II medications require a hard copy printed and signed prescription, electronic transmission of these medications is not under debate at this time or within this document.

#### *Situational Factors*

Financial implications of the development and maintenance of a Homeland Security effort, defense spending to support military presence and activity around the world, and a nationally stagnant economic status have distracted from the support of a single EHR and other technologically sophisticated components of healthcare (including the transmission of prescriptions) by high level government agencies and political parties. However, healthcare reform which includes EHR and health information technology (HIT) is on the political platforms of hopeful candidates for this year's presidential election.

#### *Structural Factors*

The conservative nature of the current US administration has encouraged and supported the DEA in its efforts to cut down on prescription drug diversion. The war on drugs has been a political platform agenda item for years, with the influence and power of the DEA waxing and waning with the changes in political parties and majorities.

The writing, processing, and dispensing of medication prescriptions is highly regulated by the DEA, Boards of Pharmacy, and federal, state, and local regulations. The



major role for the DEA is monitoring and enforcement of these regulations. Since early in the 20<sup>th</sup> century there have been efforts to control substances presumed to be detrimental to society (alcohol, drugs, and illegal substances). The DEA's roots can be traced back to the 1915-1927 Bureau of Internal Revenue in the Department of Treasury; these roots grew for the next three years in the Bureau of Prohibition, and then moved into the Bureau of Narcotics until 1968. In 1966, the Bureau of Drug Abuse Control in the Department of Health, Education, and Welfare's Food and Drug Administration was created. From 1968 to today, the Department of Justice has had oversight of the DEA which was created in 1973 during the Nixon administration. Though drug use had not reached its peak use, the increased tolerance for drug use in the 1960's was blamed for increased crime rates. The general population was agitated by the increased crime rates and welcomed Nixon's new approach to the war on drugs. The DEA is generally perceived in healthcare as the pit bull of law enforcement when it comes to medications.

Drug trafficking and diversion (illicit and prescription) is reflective of the economic disparity in the US. As the gap between the wealthy and poor has widened, some of those living in poverty look for ways to supplement their income by involvement in black market drug sales. In a hearing before the Senate Judiciary Committee, Joseph Rannazzisi (2007) stated controlled substances fetch five to ten times their retail value on the black market and profits like these are strong incentive for diversion. Unscrupulous healthcare providers have found the market for psychotherapeutic drugs very lucrative. Additionally, those who are wealthy, but have limited scruples can feed the drug market by supplying diverted drugs, reaping the financial payout, and either laundering the money or feeding their own addictions, keeping the cycle in motion.

The most recent data available show about 7 million persons 12 years or older reported having used prescription-type psychotherapeutic (pain relievers, tranquilizers, stimulants, and sedatives) drugs nonmedically in the previous month. Of these 7 million, 5.2 million report using pain relievers which is an increase from 4.7 in 2005. Sources of these drugs are reported as a friend or family member at no cost (55.7%), purchased from a friend or family member (9.3%), a single doctor (19.1%), drug dealer or stranger (3.9%), and the Internet (0.1%) (National Survey on Drug Use and Health [NSDUH], 2006).

The pharmaceutical industry has a monumental interest in prescribed medications and enjoys a significant relationship with and influence on officials at the federal level. Direct and aggressive marketing of medications (including controlled substances) has resulted in patients asking providers for medications by name. Just over 3.25 billion prescriptions were written in the one year period from March 1, 2004 to February 28, 2005 (Sarasohn-Kahn and Holt, 2006). This \$221 billion in retail pharmacy spending represents 10% of national health spending and doesn't include prescriptions in the inpatient setting, long-term care setting, or medications dispensed by physicians such as infusible chemotherapy (Smith, 2004).

Forces pushing for automation of medical records and prescriptions include retail domination by mega pharmacy chains, central automation of medication wholesalers, increasing numbers of Americans with third-party drug benefits, greater use of pharmacy benefits managers to contain costs (formularies), and automation of financial adjudication between pharmacies and payers. Those processed by chain drug stores and mail order pharmacies make up 50% of all prescriptions. Small independent pharmacies are quietly

fading away, and their demise has likely been additionally impacted by the cost of technology to keep up with electronic prescribing (Sarasohn-Kahn and Holt, 2006)

A final structural contextual issue is the rapidly aging population in the US with multiple chronic health conditions. According to He, Sengupta, Velkoff, and DeBarros (2005), nearly 80 % of those over 65 years of age have at least one chronic health condition and 50 % have at least two which greatly increase the number of medications (many of which are controlled substances) required to maintain a sense of health and/or wellness.

### *Cultural Factors*

Drugs are the downfall of the civilized world is a common mantra of proponents of restricted access to both legal and illegal drugs. There is significant stigma and ostracism directed at people with addictions or addictive tendencies by the vast majority of Americans and this holds true in the healthcare professions as well. Mass media has targeted all ages, but specifically children regarding the effects of drugs. Anti-drug slogans and campaigns permeate the school systems and encourage the stereotyping and avoidance of those using drugs illicitly.

In the specific context of Schedule II-V medications there are also cultural implications regarding pain and illness and how to appropriately treat them. Many patients who suffer from pain and illnesses are often labeled as drug seeking, and often are inappropriately stereotyped as hypochondriacs or manipulative and undeserving of respectful treatment.

*Environmental Factors*

The number and variety of groups interested in electronic prescription transmission is staggering. These groups cover local, regional, national, international, and global venues especially in relation to controlled substances. The functions of these organizations range from grass roots efforts to impact prescribing policy such as the e-Prescribing Controlled Substances Coalition to global organizations such as the National Association of Boards of Pharmacy (NABP), the Single Convention on Narcotic Drugs, the World Health Organization (WHO), and the United Nations Commission on Narcotic Drugs which strive for world wide consistency in drug production, supplies, and regulation. On a national level the number and functions of organizations involved in the regulation of medications is equally complex and includes groups such as the National Committee on Vital and Health Statistics (NCVHS), the DEA, the Department of Justice (DOJ), the Department of Health and Human Services (DHHS), and the Food and Drug Administration (FDA). A significant environmental factor impacting this issue is the rapidly growing and ever expanding field of HIT and the challenges of its implementation some of which are identified by the then Executive Vice President of the American Medical Association Michael Maves in his letter to DHHS Inspector General Daniel Levinson regarding the Medicare and State Health Care Programs: Fraud and Abuse; Safe Harbor for Certain Electronic Prescribing Arrangements Under the Anti-Kickback Statute (2005).

**Problem Statement**

Enforcing the 21CFR § 1306.21 will cause undue burden to the healthcare systems and providers who have embraced technology and implemented electronic

prescription practices. Requiring providers to enter a prescription in the electronic system then either phone or fax the prescription for controlled substances to the patient's pharmacy or hand the prescription to the patient (see Figure 1) results in a duplicative work process.

While enforcement of 21CFR § 1306.21 is within the legal purview of the DEA it has created conflict between the proponents of electronic record keeping and prescribing and the enforcement agencies. This conflict is based mainly in the debate about the security of electronic transmission of prescriptions (especially those for controlled substances); however with current HIT capabilities a reasonable solution is attainable.

#### Evidence

According to McCraig and Ly (2002), when a clinician sees a patient, at two out of three visits at least one medication prescription will be written. A Kaiser Family Foundation (2007) report indicates the number of prescriptions bought for the ten year period 1994 to 2005, increased from 2.1 billion to 3.6 billion, a whopping 71% increase compared to only a 9% increase in growth of the US population. This likely is a reflection of our rapidly expanding older population that has multiple health care needs (He, et al., 2005).

The number of prescriptions for controlled substances is a small portion (15%) of the overall total, but based on the above figures, the number of prescriptions for controlled substances ranges between 360 and 400 million (Rannazzisi, 2007; Cohn, 2005). The National Association of Chain Drug Stores estimated in 2003 that 4 billion new and 2 billion refills and renewals would be processed (National Association of Chain Drug Stores [NACDS], 2004). With an increasing number of prescriptions being written

during visits in which clinicians are pressured to keep shorter and more efficient (see more patients in less time) prescription automation and efficient record keeping is paramount.

Title II of the Comprehensive Drug Abuse Prevention and Control Act of 1970, the Controlled Substances Act (CSA) is the legal foundation for the government's efforts against drug abuse. All drugs and substances that are under federal regulation have been placed into one of five schedules which are based on the medicinal worth, safety risk, and potential for abuse and addiction. Schedule I drugs have no recognized medical use, are considered the most dangerous, and are illegal. Marijuana (including that deemed as medically appropriate by some states) falls into this schedule and has resulted in significant conflict between federal and state regulators and enforcers. Schedule II substances are considered highly addictive and therefore the most regulated of legal substances. While Schedule III, IV, and V drugs are controlled, they are less regulated and considered progressively less dangerous. Schedule II medications can only be dispensed by a pharmacist after receipt of the original prescription with a handwritten ("wet") signature. Prescriptions for Schedule III – V medications may be given in writing, verbally (generally phoned), or faxed to a pharmacy for dispensing to the patient (21CFR, § 1306, 2001; Cohn, 2005).

What has changed, and why the conflict and wide spread attention? What does this mean for patients for whom these prescriptions are being written? There has been a rapid growth of technology (hardware and software) that can support and streamline health care, documentation, and reimbursement processing, and there is significant

pressure from the public, healthcare providers, third party payers, and government administrations for increased patient safety.

Prescription processing involves: 1. the patient, 2. the clinician, 3. the retail pharmacy, 4. the pharmacy benefits manager, 5. pharmaceutical manufacturers, 6. pharmaceutical wholesalers, 7. insurance plan/payer sponsor, and 8. the information technology (IT) vendors (Sarasohn-Kahn and Holt, 2006). Having this many interested parties in a single, though complex, process makes it ripe for conflict and challenges related to standardization and conformity. The DEA acknowledges the importance of prescribing controlled substance as a critical part of medical care. At the same time, the DEA claims to be concerned about and vigilant of the pressures being placed on providers by various public and private groups which are attempting to instill technologic advances as a means to streamline care and decrease costs (Rannazzisi, 2007).

As healthcare in the US has increasingly embraced technology, prescription processing has not been able to keep pace. Transactions between providers and pharmacies lag in comparison to other processes in the move toward electronic health information automation (Sarasohn-Kahn and Holt, 2006). The Medicare Modernization Act of 2003 has been a driving force in the reshaping of the prescribing process by including language requiring electronic transactions for Medicare funded prescriptions. Other forces supporting utilization of electronic prescribing are the many faceted pay for performance efforts, large pharmacy retail chains which have developed the infrastructure to support electronic prescribing, and information technology vendors who are pushing the advantages of technology innovations and embracing open information

systems which allow interface between the providers, pharmacies and payers (Johnston, Pan, and Walker, 2003).

Patient safety has been another driver of the push for electronic health information and prescribing systems and processes. The prevalence of medication errors was highlighted by in the Institute of Medicine's (IOM) (2000) *To Err is Human*. One suggested and reasonable solution to illegible handwriting, inconsistent shorthand characters and abbreviations, and the similarity of many drug names was electronic prescription processes. In their 2005 report titled *Building A Better Delivery System: A New Engineering/Health Care Partnership*, the National Academy of Engineering and Institute of Medicine recommended that all prescriptions be written and received electronically by the year 2010. According to S. P. Cohn (2005), the Center for Information Technology Leadership (CITL) estimated that approximately 2 billion dollars were spent on hospitalizations and provider visits as a result of adverse drug events (ADEs) which resulted from medication related errors that could have been prevented with electronic prescribing. It should be expected these numbers will increase given the rapidly aging population, increasing numbers of medications available and used, and complex care issues being dealt with in the healthcare systems across the country.

Those organizations and providers that have adopted the electronic prescribing technology as a means to increase patient safety and streamline prescription processing are now being forced to return to the old practices of phoning or faxing a prescription for Schedule III-V medications. This duplication of process has ameliorated much of the efficiency hoped to be gained by using electronic prescribing.



The country can no longer afford to have a two-tiered prescribing system. It is time for the e-prescribing and law enforcement communities to work together to harness all of the attendant benefits that health information technology can provide to the nation's health care system and the consumers it serves (*e-Prescribing Controlled Substances Coalition*, personal communication, November 27, 2007).

### Policy Alternatives

The writing and processing of prescriptions are critical factors in patient quality of care, safety, and health outcomes, and it is paramount the focus remains on the patient (Showstack, Lurie, Larson, Anderson Rothman, and Hassmiller, 2003) who should have reliable, quick, and easy access to prescribed medications.

As with any situation in which there are options or alternatives, one option to address this policy is to do nothing and leave all as is. This means prescribers and healthcare systems that have put significant financial resources into HIT and implemented EHR will be forced to continue with the inefficient and duplicative process of printing an electronically entered prescription and then either calling or faxing it to the patient's pharmacy.

A second alternative would be for the DEA to "look the other way" in relation to the electronic prescribing of controlled substances and accept the current transmission and verification processes as acceptable. This softer approach to enforcement of the policy would allow electronic prescribing already in place and not deter those who are considering or in the midst of implementing HIT for electronic prescribing. Current HIT has been deemed adequately secure to meet the Health Information Privacy and

Protection Act (HIPPA) requirements which should offer reassurance to the DEA regarding the security of electronic record keeping and prescription transmission.

Another policy alternative is one that would allow state Boards of Pharmacy, in collaboration with prescribers and healthcare systems using electronic prescribing, to provide a statement of verification to the DEA to attest to the security of their transmission system. Individual state Boards of Pharmacy are by statute required to determine who is qualified to write prescriptions and how these prescriptions are written and processed. The DEA only has authority over the prescribing and dispensing of controlled substances. “Through state statutes, dispensers have the ultimate authority and responsibility to assess the validity of a prescription” (Cohn, 2005).

A fourth alternative involves an immediate and collaborative resolution between the State Boards of Pharmacy, the DEA, CMS, pharmacy industry representatives, and IT vendors. It is critical that the technology and standards to be included in such a resolution provide adequate security incorporating authentication, nonrepudiation, and integrity in the recordkeeping process. Authentication refers to the ability of a pharmacy to provide evidence to a third party of positive identification of the prescriber. Nonrepudiation involves the ability of a third party to verify the origin of the prescription as well as preventing a prescriber from denying the signing of a prescription. Integrity is demonstrated when the pharmacy or a third party can accurately detect if a prescription has been altered. These three security-related elements are necessary to ensure that DEA can fulfill its obligations under the CSA (Rannazzisi, 2007).

Through the use of a Public Key Infrastructure (PKI), biometrics, digital signatures, and other authentication and security measures all safety and regulatory

requirements and concerns could be addressed. PKI is an International Standards Organization authentication framework that uses public key cryptography and the X.509 standard protocol to enable authentication to happen across different networks and the Internet (Bell and Friedman, 2005, Chadwick and Mundy, 2004, National Association of Boards of Pharmacy [NABP], 2007). Biometric methods uniquely recognize humans based upon one or more intrinsic physical or behavioral traits and can be used to link an event to a particular individual. They accurate (positive authentication and integrity), can provide an audit trail (nonrepudiation and integrity), and are becoming socially acceptable and cost effective (Intro to biometrics, 2008). Digital signature security can be addressed in either PKI or biometric processes.

#### Outcomes and Evaluative Criteria

In the following section outcomes of each of the four above alternatives will be identified and then evaluated according to the five criteria of Rosalia Rodriguez-Garcia as described by Collins (2005). These criteria are relevance—contribution to health needs and consistency with policies and priorities; progress—compare actual results with those projected or scheduled; efficiency—best use of resources; effectiveness—intervention meets its objective; and impact—overall effect on health and society.

##### *Alternative One*

*Outcome.* In the situation of the first alternative identified, the option of doing nothing will perpetuate the inefficiencies of the existing duplicative process of printing an electronically entered prescription and then calling or faxing it to a pharmacy.

*Evaluative criteria.* Continuing with this redundancy would not be progressive nor would it make any relevant contribution to the health needs of the American people.

Organizations and providers that have embraced technology and are using electronic prescribing have likely removed fax machines and perhaps have been able to decrease staff. However, those efficiencies will be obliterated and the costs for replacements will not be insignificant. If prescriptions are phoned in, there is increased risk of error (either through what is said or what is heard) with a resulting increased risk to patient safety.

The DEA claims the main intent of these regulations is to decrease diversion and abuse of controlled substances, but this duplicative process has actually opened a significant loophole for diversion and abuse. When a provider prints a prescription it is signed and faxed to pharmacy A. The provider is then left with a signed prescription that could be filled at pharmacy B thereby allowing a medication to be dispensed twice from a single prescription. The system is at the mercy of the provider or the provider's agent to destroy the prescription after it has been faxed.

#### *Alternative Two*

*Outcome.* A second alternative would be for the DEA to deem the current electronic prescription transmission and verification processes acceptable. Current IT security is adequate for the HIPPA as well as the financial world (electronic purchase/payment option, electronic transfer of funds between banks). Financial institutions would not accept a security risk that allowed anything more than a negligible risk for diversion of financial materials and potential destruction/demise of our economic structures.

*Evaluative criteria.* Modified enforcement by the DEA of this process would be relevant because providers would not be discouraged or impeded from using HIT for record keeping, prescribing, and reimbursement in the health care arena. The efficiency,

effectiveness, and safety of electronic prescribing would be supported and encouraged, and there would be little impact to the healthcare system or change in the incidence of diversion.

*Alternative Three*

*Outcome.* Allowing state Boards of Pharmacy to verify and attest to the security of electronic prescribing systems and transmissions would be consistent with current statute which requires them to determine who is qualified to write prescriptions and how they are processed. An amendment to DEA regulations could be to accept verification from each state Board of Pharmacy regarding the security of electronic prescribing of controlled substances which addresses the DEA's concerns about authentication, nonrepudiation, and record integrity.

*Evaluative criteria.* This alternative seems highly relevant in that state Boards of Pharmacy are already responsible for and have authority to validate prescriptions for non-controlled medications. Progress toward use of HIT would not be impaired. It would be efficient in that the DEA would only need to scrutinize documentation from each state rather than individual practices and pharmacies. State Board of Pharmacy verification would be effective in meeting the DEA's objectives of authentication, nonrepudiation, and record integrity; support HIT adoption by healthcare providers; improve reimbursement processes; and provide for patient safety. Impact of this alternative would be immediate and significantly supportive of electronic prescribing and controlling the risk of diversion.

*Alternative Four*

*Outcome.* The fourth alternative requiring a rapid and collaborative resolution between the State Boards of Pharmacy, the DEA, CMS, pharmacy industry representatives, and IT vendors is also consistent with current statute. It would be the ultimate solution to multiple problems highlighted by electronic prescribing including security (of the prescriptions), safety (of the patients), documentation (benefits of EHR), prescription processing, and reimbursement.

*Evaluative criteria.* An alternative such as this is highly relevant in that it would address the root of the problem—too many layers of too many regulations with too many interested parties. This alternative would support significant progress in cooperation, efficiency, and effectiveness between these organizations. Increased efficiency would be achieved by decreasing redundancies in cooperative or shared programs and procedures. This is perhaps the alternative that is the most effective and with the most impact, but it is the most complicated and challenging due to the number of stakeholders involved.

#### Weighing the Outcomes

The first potential alternative of doing nothing increases inefficiencies in the current process of printing a prescription that has been electronically generated and then calling or faxing it to a pharmacy. According to CITL (2003), “our findings reveal that widespread adoption of ACPOE can prevent millions of medication errors and save billions of dollars.” Due to increased replacement costs required to be compliant, increased risks for medication errors, and appreciably increased risk potential of diversion, the impact of doing nothing in this case will be significant in terms of

efficiency, cost, patient safety, and increased risk of diversion. The outcomes of this alternative are not ideal, and the least desirable of the four alternatives presented.

Having the DEA deem the current transmission and verification processes for electronic prescribing as acceptable is a second alternative. This outcome would essentially maintain the status quo, has no cost associated with it, would not positively or negatively influence the acceptance of electronic record keeping and prescribing, and would not change current prescribing practice. It would however require a major philosophical and practice change for the DEA which would meet with significant resistance if not outright refusal. Maintaining the status quo is an acceptable though not completely desirable alternative outcome and would put it just above the first option as an alternative policy solution.

Outcomes of the third alternative (allowing state Boards of Pharmacy to verify and attest to the security of electronic prescribing systems and transmissions) include a timely resolution, consistency with current statute, and shifting the burden of enforcement from the federal level to the state level. This could be done with an emergency amendment to DEA regulations. These outcomes would incur some costs to the state Boards of Pharmacy who might need added resources to verify and attest to the electronic systems used, but these costs would likely be minimal in comparison to those resulting from medication errors as described in the first alternative.

The fourth and final alternative requiring a rapid and collaborative resolution between the State Boards of Pharmacy, the DEA, CMS, pharmacy industry representatives, and HIT vendors offers the ultimate solution with multiple outcomes. These include safe and efficient prescribing resulting in significant cost savings for

patients, providers, pharmacies, and payers like CMS; security of prescriptions; potentially decreasing the risk for diversion (at the least not adding to the risk); and more rapid integration of EHR and prescribing systems across the nation resulting in even more costs savings in patient safety, efficiency of distribution, and reimbursement. The down side of this alternative is these outcomes will be slow in realization due to the complexity, variety, and different agendas on the parts of essential stakeholders.

### Decision

The final step in health policy analysis according to Collins (2005) is to make the decision about which policy option to support and pursue. The problem identified in this analysis is the undue burden placed on healthcare systems and providers who have embraced technology and implemented electronic prescription practices when the DEA strictly enforces 21CFR § 1306.21 language in regard to controlled substance prescriptions.

The specific issues and context regarding this problem have been presented, four options to address the problem have been described and evaluated, and it has become clear the third alternative presented is, at this time, the best option. By allowing state Boards of Pharmacy to verify and attest to the security of electronic prescribing systems and transmissions there can be a timely resolution, consistency and maintenance of current statute, and minimal cost incurred by shifting the burden of verification and monitoring from the federal to state level.

In cooperation with the DEA, CMS, and HIT vendors, the state Boards of Pharmacy could develop a rigorous and standardized process for verifying and attesting to the security of transmissions and the electronic prescribing systems used within each



state. Because of this cooperation, the DEA could be assured the processes would meet its objectives of authentication, nonrepudiation, and record integrity for controlled substance prescriptions. The CMS's requirement for electronic transactions for Medicare funded prescriptions would be met as dictated by the Medicare Modernization Act of 2003. Some of this process has already begun according to the Liaison and Policy Section Chief of the Office of Diversion Control Mark Caverly in a letter to Gary Schnabel, Executive Director of the Oregon Board of Pharmacy. Caverly writes, as a result of a meeting between the DEA and DHHS in July of 2006 the DEA is drafting a notice of Proposed Rule Making which would change the current regulations to address the use of electronic prescriptions for controlled substances (Caverly, 2007).

As Blankenau (2001) describes J. W. Kingdon's multiple stream theory of policy feasibility, the time may be right for this policy alternative. Nineteen US senators including Barack Obama (D-IL), Sheldon Whitehouse (D-RI), Sherrod Brown (D-OH), Richard Burr (R-NC), Maria Cantwell (D-WA), Tom Coburn (R-OK), Susan Collins (R-ME), Dick Durbin (D-IL), Lindsey Graham (R-SC), Edward Kennedy (D-MA), John Kerry (D-MA), Herb Kohl (D-WI), Tim Johnson (D-SD), Bob Menendez (D-NJ), Jack Reed (D-RI), Arlen Specter (R-PA), Debbie Stabenow (D-MI), John Thune (R-SD), and Ron Wyden (D-OR) signed a letter to Attorney General Michael Mukasey asking him to review the issue of electronic prescribing and to encourage the DEA to change rules related to this quickly (Whitehouse and Obama, 2007). This support and a possible change in administration may provide the change Blankenau describes as Kingdon's third stream (political variables) when added to the first (problem existing within the

government's purview) and second (solution) streams will be the catalyst and opportunity for implementation of this necessary policy change related to electronic prescribing.

Removing the burden placed on healthcare systems and providers who have embraced technology and implemented electronic prescription practices when the DEA strictly enforces 21CFR § 1306.21 language in regard to controlled substance prescriptions will support the critical factors of patient quality of care, safety, and health outcomes, while maintaining the focus on the patient who should have reliable, quick, and easy access to prescribed medications.

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## Figure Captions

*Figure 1.* Printed electronic health record prescribing system alert captured January 21, 2008

Due to Drug Enforcement Agency restrictions on e-prescribing, your prescriptions for controlled substances cannot be faxed via Epic - they require a manual signature.

If you have selected an order class of Fax for these drugs, you will receive an alert warning you that the prescription cannot be faxed.

Upon signing the order, EpicCare will route these prescriptions to your department's prescription printer for your signature.

Once signed, the following methods for processing a prescription are acceptable:

(During an office visit) handing the prescription to the patient to bring to his/her pharmacy;

(Outside of an office visit) manually faxing the prescription via your departments fax machine\*, phoning the prescription into the pharmacy (Schedule III-V only), or asking the patient to pick-up the prescription from your practice.

\*Note that Schedule II drugs may be manually faxed only for hospice patients after your manual signature is applied to the prescription.

Running head: PARENTAL PREFERENCE OR CHILD WELLBEING

Parental Preference or Child Wellbeing: An Ethics Case Study

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Do parental preferences override the right of a child to receive appropriate care in medical foster care? A case study will be used to illustrate the challenges presented by caring for a child when there is ethical conflict between the parents and healthcare team.

### Case Presentation

Ting (not her real name) is a 12 year old Chinese female with significant developmental delay and limited mobility confining her to a wheelchair. Her medical diagnoses include Proteus Syndrome (a rare, progressive, congenital condition of soft tissue overgrowth/nonmalignant tumors resulting in swelling with nerve, vessel, and organ compression, and skeletal distortion throughout the body), weight loss, chronic aspiration, recurrent pneumonia, gastric bleeding, chronic mastoiditis requiring surgical debridement, and chronic pain. Ting requires complete care and has gotten big enough neither of her parents alone can lift her.

One year ago, the parents made a decision to voluntarily place Ting in medical foster care due to their inability to care for her. Ting thrived in foster care. She gained fifteen pounds after a gastrostomy feeding tube was placed, and with minimal need for oral intake she had fewer episodes of aspiration and pneumonia. With consistent physical therapy her mobility improved significantly. Her mood changed from self injury (head banging, scratching, banging her hands and arms on things until they were bloodied) grimacing, whining, and almost constant agitation to calm, quiet vocalizations, laughter, and hours of water play with her hands. Her sleep improved dramatically from two or three hours to a full ten hours at night with an occasional afternoon nap. Because of consistent administration of analgesic medications her pain seemed well controlled, but in reality her pain was probably most decreased by her physical therapy and the use of



proper lifting equipment so she didn't need to be dragged by her arms across the floor to the toilet or her bed.

Ting's level of agitation increases significantly when her mother and sisters are present. The little girls have been known to taunt, pinch, and shove Ting. Her mother speaks very loudly (nearly shouting) when trying to calm Ting. She also constantly pats Ting's head, face or arms when Ting cries out or is restless and this further agitates Ting. In the care of her foster parents, Ting learned to calm herself and started smiling, demonstrated understanding of simple words and phrases, and was beginning to use consistent sounds to communicate her needs, i.e., "waa" for water.

During a hospitalization three months ago, the medical team thought it was important to review Ting's disease progression and prognosis with her parents. The course/progression of Proteus Syndrome is essentially unknown. Recent CT and MRI images indicated most of Ting's tumors had been stable over the past two years; however she has a very large intrathoracic tumor involving her spine and lungs which has continued to slowly grow. This particular tumor and one in her brain also have significant and increasing vascular malformations. Using a Mandarin interpreter, a care conference was held. Ting's mother informed the healthcare team they decided to take her home so they could care for her. She stated it was their duty to care for Ting if she was dying. In Chinese culture, according to filial duty it is a moral obligation to care for sick family members and this cannot be done by someone else (Wong & Pang, 2000). The medical team had not indicated Ting's demise was imminent, and in fact her life expectancy was unknown. It could be a few weeks or several years (with diligent care).

As an incompetent minor Ting's care decisions reside with her parents, however they are not capable of caring for her, and by returning to their care her quality of life is diminished. The ethical dilemma in this case is: Do parental preferences override the right of this child to receive appropriate care in medical foster care? Using a paradigm for making ethical decisions promoted by Jonsen, Siegler, and Winslade (2006) this case will be presented. This paradigm is based on four topics of importance in ethical dilemmas which are medical indications, patient preference, quality of life and contextual features.

#### Medical Indications

Ting's medical diagnoses are Proteus Syndrome, weight loss, chronic aspiration, recurrent pneumonia, gastric bleeding, chronic mastoiditis requiring surgical debridement, and chronic pain.

Proteus syndrome appears to be very rare with only 100-200 individuals worldwide. Asymmetric growth occurs of the head, face, and digits. It is this asymmetric growth with soft tissue overgrowth that results in the more significant complications. Spinal deformities (scoliosis or kyphoscoliosis) can be progressive and severe enough to lead to respiratory compromise. The respiratory system is further compromised by cystic malformations in the lungs and intrathoracic and/or intra-abdominal masses. Abnormal skeletal and muscle development contribute to functional abnormalities. Soft tissue masses (lipomas, connective tissue nevi, epidermal nevi, and vascular malformations) may cause vascular, nerve, and/or organ compression and contribute significantly to morbidity in these patients. Mental retardation is present in a subset of patients with Proteus Syndrome. Central nervous system malformations and seizures may be present as

well (Pletcher, 2006; Mahlberg, 2007). Tumor progression is unpredictable and vacillates between rapid tumor growth and periods of quiescence and stability.

There are no data on long-term survival however disease progression and complications likely contribute to premature death. It is now thought that Joseph Merrick (known as the Elephant Man) had Proteus Syndrome rather than neurofibromatosis, as was initially suggested (Proteus Syndrome Foundation, 2007).

Ting's other diagnoses are resultant of the Proteus Syndrome. She has had weight loss due to her inability to consume adequate calories by mouth, her constant state of agitation, and chronic pain. Because of soft tissue compression, Ting cannot consistently protect her airway, and frequently aspirates food and her own secretions with pneumonia a recurrent result. Her parents had agreed to placement of a gastrostomy feeding tube to supply her with adequate nutrition. However, her mother insists on continuing to provide her food by mouth which is likely culturally significant and related to the importance of dying with full stomach (Hsiung & Ferrans, 2007). The frequency of clinically significant aspirations is somewhat less, but still concerning.

Gastric bleeding has twice been contributed to the use of nonsteroidal anti-inflammatory analgesics which seem to offer her good pain control. Her parents believe she has headaches, and all those who care for Ting recognize the pain she experiences related to immobility and her many skeletal deformities. Pain relief without intolerable side effects is a primary goal in Ting's care. Low dose long acting opioids offer good pain relief but Ting has difficulty to control constipation as a side effect. Anticonvulsants are used to treat the presumed neuropathic pain she experiences from nerve compression.

The chronic mastoiditis was finally controlled after an extensive surgical debridement and extended course of antibiotics just prior to her placement in foster care. She is at increased risk for a reoccurrence of the mastoiditis.

The goal of medical treatment for patients with Proteus Syndrome is to minimize complications. Identifying potential problems and prompt attention to complications may significantly reduce morbidity and mortality for these patients. Given the complexity of this condition a multidisciplinary approach is necessary.

#### Patient Preferences

Ting has significant cognitive impairment, but it has not been determined to what extent. Her cognitive function showed improvement in the six months she was in foster care. Ting did show evidence of decreased agitation, happiness, and physical healing while in foster care. Her old behaviors returned when she was in the presence of her mother and sisters.

Ting is unable to cooperate with medical treatment because of her level of cognitive and physical impairment. Her parents are willing, but unable to provide the level of care Ting requires due to her size, their physical limits, and their current understanding of disease, treatments, and day to day care requirements.

Her parents act as her surrogate decision makers, but their understanding of her disease and prognosis is unclear. Ting's parents repeatedly say it is their duty as parents to have Ting in their home and provide her end of life care.

#### Quality Of Life

Ting never has nor ever will lead a normal life. Despite treatment her physical, mental, and social deficits will increase, but at an unknown rate or intensity. In the future

she will likely become so impaired and have such medical complications as to make continuation of her life medically futile. She has not reached that point. Nor can it be predicted when she might. Her health care team has presented information to Ting's parents about the inevitability of forgoing treatment due to the continued growth of the complex lesions in her brain and chest. The parents indicate their desire for Ting to be comfortable. The focus of care seems to be shifting from supportive/palliative care to comfort care.

#### Contextual Features

Family knowledge/understanding is a huge influence on treatment decisions. Cultural expression may be a factor in this, but their level of understanding or comprehension is not clear to the healthcare team. Ting's life may end prematurely due to the parents' lack of understanding, ability to identify potential problems, and seek prompt medical attention. Communication barriers may get in the way of aggressive treatment which could prolong Ting's life without significantly impacting her quality. Utilizing professional interpreters adds to the challenge of building a relationship with her parents and coordinating care for Ting.

Ting and her parents moved to the United States from China when she was two years old. The family has minimal financial resources with no extended family available. Her father works at a minimum wage job to support his wife, Ting, and two younger (healthy) daughters, ages 3 and 5. Both parents speak very little English. They live in a small apartment (so small Ting's wheelchair does not fit through the bathroom or bedroom doors). Communication has made it difficult to assess the importance of culture and religion in this situation.

The Oregon Health Plan covers Ting's healthcare costs, and she utilizes many resources because of poor communication/understanding when in the care of her parents. It is nearly impossible (even with the use of interpreter services) to have a phone conversation with Ting's mother, making teaching, follow-up care, or treatment adjustments impractical resulting in frequent and unnecessary visits to the emergency department (ED) and clinic. Her visits to the ED and clinic were less frequent during her time in medical foster care.

No laws are being broken by allowing Ting's parents to care for her. They are not abusive or neglectful. She is 12 years old so she is not old enough (if she were cognitively normal) to consent for her care. She would however be able to provide assent. She is unable to perform even basic self care (feeding, toileting) though she is able to remove articles of clothing. No Advanced Directives or Physician Orders for Life Sustaining Treatment (POLST) forms have been completed.

#### Analysis

The ethical dilemma of parental preference versus child wellbeing can be argued strongly for each side. Some will favor parental preference and choice as the premise that must be supported in this situation, as according to Jonsen, Siegler, and Winslade (2006), "parents or guardians have the moral and legal responsibility to act in the child's best interest" (p. 24), while others will say because this child is vulnerable (diminished autonomy) she must be protected (National Commission for the Protection of Human Subjects: Belmont Report, 1978). While it is important to consider the four widely accepted principles of bioethics; respect for autonomy, beneficence, nonmaleficence, and justice as described by Beauchamp and Childress (2001), in this situation these principles

must be viewed using the cultural filter as presented by this Chinese family. According to Tsai (2005) these four principles and their moral values can be identified in the ancient Confucian ethical philosophy of the Chinese culture, but they are viewed within the context of Confucius' moral philosophy.

According to Hsiung et al. (2007), Chinese Americans generally acculturate into one of four broad categories: (1) elderly immigrants who remain traditional and the least acculturated, (2) less acculturated working class immigrants, (3) professionals equally comfortable in both cultures, and (4) Chinese Americans who are born in the United States and are the most acculturated. Ting's family seems to be in the second category.

Important cultural components of which to be thoughtful of in this situation include the importance of family which is the center of Chinese culture and respect must be given to the wishes of the family (Yam, Rossiter, & Cheung, 2001); male paternalism; physician paternalism; and the importance of hard work, privacy and a good death (Barnes, Davis, Moran, Portillo, Koenig, 1998; Hsiung et al., 2007).

Though it seems there has been the beginning of a transition from supportive/palliative care toward comfort care and Ting's quality of life may be restricted, it has not yet become minimal. Therefore, it will be important to have many extensive conversations with this family to address supporting their need to care for her, resource utilization, and planning for Ting's eventual death.

Most discussions regarding Ting's care occur (using an interpreter) with her mother, as the father is unable or unwilling to take time off from work. This does not respect the importance of hard work to this man, nor does it facilitate decision making as well as if discussions could be planned at a time when he could comfortably be present

given his role as decision maker in this traditional Chinese family. It is critical he have the information first hand rather than through two translations (an interpreter and his wife).

The healthcare team needs to understand the impact of this family's culture on the family's ability to freely discuss their concerns regarding Ting and her care. Privacy and lack of sharing of emotions and concerns are cultural norms that may be interpreted as lack of understanding and knowledge. The healthcare team may have concerns regarding the family's ability to care for Ting because of this perceived lack of understanding. The family may be uncomfortable asking questions because that would be unacceptable given their culturally based respect for physicians and acceptance of physician paternalism. It is important to be sensitive to the cultural collision course this family is traveling between Chinese and American cultures as well as between the cultures of medicine and lay people (Kleinman & Benson, 2006).

My recommendation for this case would be to allow the family to take Ting home. The healthcare team should then work diligently and proactively with them to develop a relationship that will allow discussion of their needs to be able to care for her, and support them in their care of her. This will also provide ongoing opportunities for discussions about whether or not more surgeries will be performed, whether or not she will be readmitted to the hospital, how to continue nutritional support and pain management, completing Advance Directives and Physician Ordered Life Supporting Treatment (POLST) forms, and what it will mean for them to have Ting die a good death.



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Running head: CARE GUIDELINES THROUGH ORGANIZATIONAL CHANGE

Implementing Medication Weaning Guidelines through an Organizational Change

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## Background

Children experiencing critical injury, surgery, and/or illness are cared for in the Pediatric Intensive Care Unit (PICU). Clinical experience in this area indicates approximately one fourth of the patients who receive prolonged or high dose opioids and benzodiazepines (greater than 10 days) experience withdrawal.

The implications of opioid and benzodiazepine withdrawal are well described in the literature by Anand and Arnold (1994), Cunliffe, McArthur, and Dooley (2004), Dunajcik (1999), Siddappa et al. (2003), Turner (2005). While opioid withdrawal is miserable to experience, withdrawal from benzodiazepines can be life threatening (Dunajcik, 1999).

The implications of opioid and benzodiazepine withdrawal are well described in the literature by Anand and Arnold (1994), Cunliffe, McArthur, and Dooley (2004), Dunajcik (1999), Siddappa et al. (2003), and Turner (2005). While opioid withdrawal is miserable to experience it is not life threatening unlike benzodiazepine withdrawal which can be life threatening (Dunajcik, 1999). Mild withdrawal behaviors and symptoms have minimal effect on a child's recovery; however, if the symptoms become severe the physiologic impact can be profound and affect vital physiologic processes thereby prolonging critical care and hospital stays (Siddappa et al., 2003; Tobias, 2000).

Additionally, clinicians without expertise or guidelines related to opioid and benzodiazepine management may order too high of doses resulting in oversedation with inability to tolerate removal of ventilatory support and prolonged hospital stays or too low of doses resulting in uncontrolled pain and agitation (Gammaitoni, Fine, Alvarez, McPherson, & Bergmark, 2003).

The intent of this change effort (implementing weaning guidelines) was to decrease the amount of withdrawal (and/or over-medication) using a more consistent approach to weaning from and transition to long acting medications in the same pharmacologic class. To this end, local experts developed clinical guidelines to direct the management of patients receiving prolonged opioids or benzodiazepines. Focused toward the PICU physicians, nurses, and pharmacists, the Analgesic and Sedative Weaning (Pediatric and Neonatal Patients) Practice Standards (Weaning Guidelines) contain a significant amount of information which was believed would address an apparent knowledge deficit. It was thought increasing knowledge, having some PICU physician support, and guidance of the experts (the Pediatric Pain Service) would be the motivation necessary to promote a change toward utilization of the guidelines. The primary goal of this change effort was for clinicians to use the Weaning Guidelines with every patient which would thereby decrease the incidence of avoidable withdrawal to less than 5% of the patients. The approach to implement the change effort (described later in this paper) was very passive, and none of these strategies dealt with the root causes of the failure of the implementation which is a knowledge deficit regarding pharmacologic management of pain and sedation in the PICU.

### Analysis of the Problem

#### *Systems-level Analysis*

*Ecological environmental perspective.* The analysis of this change effort was begun using an adaptation of Bronfenbrenner's model of the Ecology of Development (1979) to determine which global and organizational model systems might be involved. In the global model, influencing factors identified were in the macrosystem and included attitudes and beliefs around pain, pain medications, knowledge of or experience with withdrawal, and the hierarchy of staff roles.

The majority of factors influencing this problem are found in the microsystem, mesosystem, exosystem and macrosystem of the organizational model as it is pulled out of the global mesosystem which is the PICU at Doernbecher Children's Hospital. In the microsystem: RNs, intensivists, Pediatric Pain Service, and pharmacists; in the mesosystem: Unit Based Nursing Practice Council, Medication Safety Committee, and QI Monitoring; in the exosystem: QI Committee, Standards of Care, knowledge assessment and development, Pediatric Nursing Practice Council, and Medical Leadership; in the macrosystem: culture and attitudes about pain and sedation, consistent and evidence based clinical practice, and accountability for consistent practice were identified as principle influencing factors.

*Systems-level inputs, outputs, facilitators, barriers.* According to Cusins (1994), systems theory or systems thinking "is merely a way of thinking about, or understanding any dynamic process." In his description of inputs and outputs in relation to systems thinking Cusins describes, operational system inputs as more specific to the system, tangible, physical, and observable. In the PICU these would include but are not limited to: critically ill children, medications, physician orders, clinicians, expert resources, and practice guidelines. Managerial system inputs are more conceptual, general and across multiple systems. Managerial inputs would include: availability of expert resources, development and approval of practice guidelines, and processes related to physician orders and implementation of those orders. Cusins describes system outputs as transformed/processed inputs to that system. System outputs include: recovering children, desired physiologic responses to medications, completed physician orders based on expert knowledge, and care delivered in accordance with practice guidelines. Inputs and outputs move between systems and what is an output of one system is an input to another and vice versa.

Facilitators of this change effort were those clinician champions who identified the problem and worked toward a solution. Evidence in the literature can also be used to facilitate and support the need for thoughtful management of these patients.

Barriers to the change effort were physician resistance, cumbersome and inconsistent processes for development and implementation of practice standards/guidelines, lack of accountability for clinicians to follow the guidelines, and lack of user friendly access to intranet posted guidelines.

### *Root Cause Analysis*

A root cause analysis using the five why's approach revealed two main causes for the failure of this change effort. The first question asked was: why are these patients experiencing withdrawal? The answer was patients are weaned too rapidly or received unusually high or prolonged doses of opioids or benzodiazepines. The next question was: why do they get weaned too rapidly or get to such high doses or prolonged therapy? The answer was a knowledge deficit related to withdrawal management despite development and availability of the Weaning Guidelines. The third question asked was: why is there a knowledge deficit related to withdrawal management? The answer to this question was two-fold with the first being there is no accountability to use available resources/expertise (Weaning Guidelines and Pediatric Pain Service), and the second being poor awareness of the guidelines. Asking why there was no accountability to use available resources resulted in the following answer, there is no system wide mechanism to hold practitioners accountable to follow practice guidelines. The fifth question related to this was: why is there no mechanism of accountability? The answer was again two-fold. In the ecological environmental model's' global exosystem, there is a lack of national standards related to weaning of opioids and benzodiazepines, and in the model's organizational

macrosystem, there is no system wide interest in standardizing practice—the individual is valued. Asking why there was poor awareness of the Weaning Guidelines resulted in the fifth and final answers which were the lack of marketing and ongoing awareness of the guidelines for key providers, and the guidelines are buried in institution's intranet making them difficult to access.

### *Organizational Readiness to Change*

Development and implementation of the Weaning Guidelines was the result of a handful of providers being frustrated by the number of patients experiencing withdrawal. A summation of interviews with key stakeholders (two intensivists, a hospitalist, a Pediatric Pain Service physician, and a PICU RN) regarding their perceptions of the underlying causes leading to the writing of the Weaning Guidelines includes agreement that the guidelines were developed to help physicians/RNs appropriately wean opioids and benzodiazepines to prevent withdrawal. Each stakeholder stated withdrawal has significant impact on the patient's recovery and the patient's/family's satisfaction with care and, withdrawal is generally preventable. The pain service physician felt the guidelines were necessary from a safety perspective; to prevent dosing errors (specifically with methadone) that may occur which can have significant ramifications (extended length of stay and/or death). The hospitalist identified lack of consistent intravenous to oral dosing conversions which often resulted in children being over-sedated or in withdrawal; as well as overly aggressive weaning regimens. This illustrates how the lack of knowledge was a driving force behind this change effort.

A group of clinicians met to discuss the significance of withdrawal and options for decreasing its incidence. After this discussion, the authors of the guidelines (a pain physician and I) did an extensive review of the literature to look for guidelines and when no consistency was



found, to provide the best evidence for developing guidelines. We wrote drafts of the proposed guidelines and distributed them via email (with a reminder email) to all attending physicians from the PICU and Pediatric Pain Service for feedback and input. Minimal feedback was received, but it was decided to proceed toward a final version which in retrospect was not an effective approach. To implement the guidelines the following methods were used: a lecture presentation (Pediatric Grand Rounds), a poster announcing the Weaning Guidelines (directed toward the nurses), one to one communications with staff members (mainly physicians) in the PICU, and posting to Practice Standards section of the internal web site. The guidelines were to be initiated in the PICU; however, there was resistance from key physicians (a key factor in readiness to change).

Factors influencing readiness to change were clearly identified by the stakeholders in response to the following question, “what is your perspective/assessment of why implementation/sustainability of the guidelines was less than optimally successful.” The pain service physician felt despite a high profile kick off (presentation at Pediatric Grand Rounds), there were several obstacles: all of the PICU intensivists didn’t support the guidelines, so individual practice variance remained; the other pediatric pain physicians also use their individual preferences for medications and weaning schedules; withdrawal is not seen as an important enough problem for physicians to give up their autonomy; and the guidelines are on the website so not readily available in a preprinted format when needed. One of the intensivists stated, “I don’t think any of them (other intensivists) read the guidelines at all and furthermore, I think some of them already had erroneous preconceived treatment plans and thought that the Pain group was a waste of time consult.” This physician attitude barrier was confirmed by the hospitalist as she stated, “Some PICU attendings disagree with pain management’s weaning

approach.” Systems issues were identified by the hospitalist and the PICU RN. The hospitalist believes there is significant ‘just another form’ mentality and providers don’t see any personal benefit, and the PICU nurse (who was not employed at Doernbecher when the guidelines were developed) said she was not aware of them until many months after her orientation and because there was no sustained effort to support the implementation people basically forgot the guidelines exist.

Prochaska, Prochaska, and Levesque (2001) describe the use of the Transtheoretical Model in assessing organizational readiness for change. There are five stages of change according to this model: a. precontemplation, b. contemplation, c. preparation, d. action, and e. maintenance. They further describe ten covert and overt processes to facilitate change. These are consciousness raising, dramatic relief, emotional arousal, self-reevaluation, self-liberation, environmental reevaluation, reinforcement management, counter-conditioning, helping relationships, stimulus control, and social liberation.

The PICU was the targeted organization, and the majority of the staff was in the contemplation stage—they were thinking about it and there was a sense that something needed to happen to decrease the incidence of avoidable withdrawal. There was awareness of the problem and thinking about how to resolve it, but there was no commitment to take action. A few folks were in the precontemplation stage and were either unaware of the problem or unwilling to change. Even fewer were in the preparation stage with intention to take action and none were in the action or maintenance stages.

### Conclusions

The development and implementation of the Weaning Guidelines was not an effective change effort because it was poorly organized, did not completely address the root cause of the

problem (knowledge deficit regarding pharmacologic management of pain and sedation), and there was a lack of fit between the change effort and the PICU staff's readiness for change. Adding to the poor organization, incomplete transfer of knowledge, and minimal readiness for change were a lack of system wide accountability to follow care guidelines and very limited awareness of the Weaning Guidelines. A significant amount of clinical information was included in the guidelines, but there was no systematic method to inform providers about the guidelines. Expectations to follow the guidelines were never established, and there was no mechanism for ongoing review and knowledge dissemination. This approach was much too passive to ensure success.

### Discussion

In this situation, three factors contributed to the change effort failure. These factors are inadequate knowledge, poor communication, and lack of accountability. In regards to inadequate knowledge, information/knowledge was provided in the Weaning Guidelines and was meant to address the knowledge deficit. However, the majority of clinicians did not know to look there, and the information was a summary of key points with references but likely not enough to facilitate practice changes. It is well recognized that education or knowledge alone do not result in changes to practice, but there are basic knowledge requirements for safely managing prolonged use of opioids and benzodiazepines. There was also inadequate knowledge regarding the existence of the Weaning Guidelines due to passive implementation strategies.

Communication was poor during the development of the Weaning Guidelines as much of the work was done via email rather than face to face due to scheduling conflicts of key stakeholders. Minimal feedback was obtained via email and because of time constraints was not aggressively

sought. There is no system wide expectation to follow the Weaning Guidelines or even the recommendations of the expert clinicians, in this case the Pediatric Pain Service.

While the majority of factors contributing to the failure of this change effort are organizational issues that can be changed with minimal effort, some factors (clinician individuality highly valued, no requirement to use available expertise and resources, no mechanism to systematically evaluate clinical concerns) are steeped in organizational culture which is much more challenging to change. To offset the negative force of these cultural factors, it will be imperative for the organizational issues to be addressed thoughtfully and meticulously. This is best summarized by Gammaitoni et al. (2003), “Therefore, in the face of what is at best an inexact science, a blend of empirical reasoning, and disciplined application of clinical principles, all coupled with artful practice and close follow-up, is requisite” (p. 296).

#### Recommendations

This is an important change effort and despite an unsuccessful initial implementation, another more thoughtful effort is planned. As suggested by the PICU RN interviewed, first data will be collected to demonstrate the extent of the problem. Staff is more likely to support a change in light of a clearly identified and quantified problem. Face to face meetings rather than email communication with all of the PICU, Hospitalists, and Pediatric Pain Service physicians will facilitate consensus, likely reveal any underlying agendas/disagreements that may foil the attempt to reimplement the Weaning Guidelines, and identify any additional reasons for the initial implementation failure.

Many of the processes to facilitate change described by Prochaska, et al. (2001) such as consciousness raising, dramatic relief, self-reevaluation, self-liberations, counter conditioning, helping relationships, and social liberation will be used to encourage movement from the

precontemplation and contemplation stages to the preparation and action stages. Also, increasing the PICU's awareness of its function as a reliable microsystem is an important part of the change process. According to Mohr and Batalden (2002), the key characteristics of a reliable microsystem are: preoccupation with failure; reluctance to simplify interpretations; sensitivity to system operations; commitment to resilience; and deference to expertise of the frontline staff and others.

Though education alone is not effective in changing practice, this renewed change effort will include extensive education of providers, because a knowledge deficit was determined to be part of the reason patients were experiencing avoidable withdrawal. Using a variety of the training knowledge and strategies related to assessing and enhancing readiness to learn as described by Lehman, Greener, & Simpson (2002), Narayan, Steele-Johnson, Delgado, & Cole (2007), and Simpson & Flynn (2007) will also be helpful.

The knowledge deficit was not remedied by the Weaning Guidelines in part because of a lack of awareness of their existence, so in addition to clinically relevant teaching, emphasis will be placed on accessing the Weaning Guidelines on the intranet. Sustaining awareness and continued education can be done during monthly multidisciplinary (PICU staff, Pain Service staff, Pharmacy staff) reviews of all patients receiving prolonged opioids and benzodiazepines. At this time, trying to make access to the Practice Standards (where the Weaning Guidelines are posted) easier to access and more user friendly will be difficult as the organization is actively moving to an electronic health record and hospital leadership has placed a moratorium on changing policies, procedures, and practice standards until it can be decided how these documents will be connected to the electronic system. One option might be to place a bright

colored sticker at each computer workstation with a reminder to use the Guidelines and the electronic link to them on the intranet.

Establishing accountability to accept and follow standardized practice guidelines (Weaning Guidelines) will involve ongoing conversations and efforts to develop system wide expectations and processes which foster this accountability. Because accountability and standardized practice cross into organizational culture, small systems level changes will be needed to slowly move the culture along so there is acceptance of standardized practice without devaluing the individual clinician's knowledge and practice. These small changes will include working with the pharmacy to develop an automatic alert to clinicians when a child has been on opioids and benzodiazepines for 10 days or more or at high doses. This will be a reminder to the clinician to request a Pediatric Pain Service consult and/or to implement the Weaning Guidelines. Finally, review of sentinel events and medication errors related to opioids and benzodiazepines presented to the institutional Pharmacy and Therapeutics and Medication Safety committees would likely leverage support for accountability to follow the recommendations of the Pediatric Pain Service and the Weaning Guidelines.

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Running head: PICU RN DECISION MAKING RELATED TO PAIN AND SEDATION

Factors Influencing Pediatric Intensive Care Unit RN Decision Making Regarding Pain and  
Sedation Management

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### Introduction to Clinical Problem

Children experiencing critical injury, surgery, and/or illness are cared for in the Pediatric Intensive Care Unit (PICU). According to Cheung, van Dijk, Green, Tibboel, and Anand (2006), 35-57% of critically ill children experience opioid tolerance and withdrawal. Anecdotal clinical experiences in this PICU indicate approximately one fourth of the patients (ages 0 to 18 years) who receive prolonged opioids and benzodiazepines (greater than 10 days) experience withdrawal. This is compounded and confounded by the high doses of opioids and benzodiazepines patients receive.

The implications of opioid and benzodiazepine withdrawal are well described in the literature by Anand and Arnold (1994), Berens et al. (2006), Cunliffe, McArthur, and Dooley (2004), Dunajcik (1999), Siddappa et al. (2003), and Turner (2005). While opioid withdrawal is miserable to experience it is not life threatening; unlike benzodiazepine withdrawal which can be life threatening (Dunajcik, 1999). Mild withdrawal behaviors and symptoms have minimal effect on a child's recovery; however, if the symptoms become severe the physiologic impact can be profound and affect vital physiologic processes thereby prolonging critical care and hospital stays (Cheung et al., 2006; Siddappa et al., 2003; Tobias, 2000).

Over-medication refers to clinical situations in which unusually high doses of opioids, benzodiazepines, or both are administered; resulting in decreased respiratory function, prolonged need for mechanical ventilation, severe nausea and constipation, toxicity, and increased length of stay. An additional complication is the need for prolonged weaning of these medications once the child is recovering. The actual incidence of withdrawal and over-medication in the PICU is unknown, and will be a descriptive part of a future clinical inquiry project. Though discussions

with clinicians in other PICUs suggest this is a complex, multidisciplinary, and nearly universal phenomenon, there is a dearth of published literature.

Organizational knowledge of the scope of this problem is variable. Nursing leadership (chief nurse executive, unit manager, quality improvement specialist, pain management clinical nurse specialist) is acutely aware and actively supporting change. Unit based pharmacists acknowledge the problem, but due to workload have made minimal efforts toward change, and the intensivists each have different perspectives and levels of interest in the problem. Some PICU staff are concerned and would like to take action, but many seem unaware or unconcerned.

As the advanced practice nurse (APN) who is consulted to manage these patients, it is clear a clinical problem exists that needs to be quantified, critically evaluated, and managed in an evidence based and consistent manner. This is a complex and multidisciplinary problem that will require a significant change in practice. As a Doctor of Nursing Practice (DNP) student with my leadership role and expertise in pain management, I am well equipped and positioned to improve patient outcomes by facilitating evidence based RN decision making related to pain and sedation management in the PICU.

Clinical decision making related to the management of pain and sedation appears to be influenced by individual beliefs and life experiences, knowledge, work experience, and characteristics of the patient situation. However, evidence based clinical decision making can likely be improved and result in the following patient outcomes: more appropriate doses of opioids and benzodiazepines; decreased side effects, withdrawal, over-medication, and length of stay; evidence based practice using standards of care and/or weaning guidelines; and increased parent, RN, and hospital administration satisfaction (Abu-Saad and Hamers, 1997; Horbury,

Henderson, and Bromley, 2005; Manworrn, 2001; Van Hulle Vincent and Denyes, 2004; Wilson, 2007).

The purpose of this practice improvement project is to describe the prevalence of withdrawal and over-medication and the nursing practices that may lead to these, and to assess the influence of beliefs and attitudes, knowledge, experience, and patient situation characteristics on RN decision making (nursing practice). Specific questions to be answered are: (a) what is the incidence of withdrawal in the PICU, (b) what is the incidence of over-medication in the PICU, (c) what are the beliefs and attitudes, knowledge levels, work experience, and patient characteristics that influence RN decision making, and (d) is there a relationship between the influences of RN decision making and the incidences of withdrawal and over-medication?

### Conceptual Framework

A conceptual framework was developed to guide the assessment of the situation, interventions to improve patient care, and the measurement of outcomes. While it is recognized other factor can influence RN decision making, for the purposes of this project, the concepts of interest are factors specific to RNs affecting decision making, safe and effective pain and sedation management, and how the two interact to ultimately influence patient outcomes. See Figure 1.

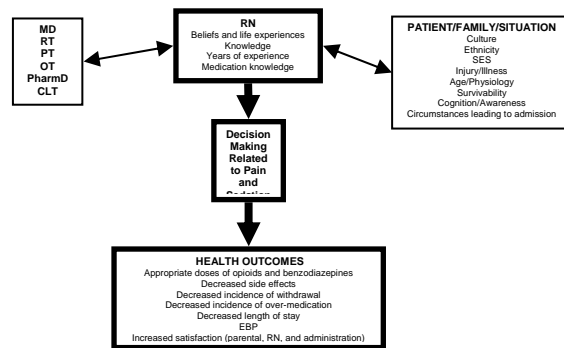


Figure 1. Factors Affecting RNs Decision Making Related to Pain and Sedation in PICU

*Definitions*

“Pain is whatever the experiencing person says it is, existing whenever he says it does” (McCaffery, 1968). Operationally pain is described as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. (International Association for the Study of Pain [IASP], 1994). In the PICU, RNs use previously validated tools: the Neonatal Pain and Sedation Scale, the FLACC scale, the Faces Pain Scale Revised, and the Numeric Scale (Herr, et al., 2006). Scores on these scales range from 0-10 with 0 being no pain and 10 being the worst possible pain.

Sedation is defined as a drug induced mental and physical state of calm and relaxation. The American Society of Anesthesiologists (ASA) (2004) operationalizes the concept of sedation on a continuum beginning with minimal sedation, followed by moderate sedation and deep sedation, and ending with the deepest level of sedation which is general anesthesia. In the PICU, the Ramsay Sedation Scale is used to quantify sedation on a 1-6 scale, with 1 being anxious, agitated and restless and 6 being no response (Ramsey, 2000).

Nurses’ clinical decision making is broadly defined as any decision made in the clinical setting. Operationally, clinical decisions related to pain and sedation management should be guided by knowledge, experience, and patient situation. Knowledge will be measured as the highest level of nursing education completed and hours of pain and sedation related continuing education completed since January 1, 2004. Experience includes personal as well as professional experience. Professional experience will be measured in years as an RN and in years as a PICU RN. The Pediatric Nurses’ Knowledge and Attitude Survey (Manworren, 2001) will be used to categorize personal and life experiences and attitudes.

### *Concept Relationships*

The relationship between pain and sedation management and factors influencing RN decision making is complex, multidimensional, and not well described in the literature. Because of the influence of individuals' beliefs and life experiences there is significant variability in how individual RNs manage pain and sedation. This variability is confounded by differences in knowledge and years of experience as an RN and as a PICU RN.

Nurses' clinical decision making using evidence based pain and sedation management standards and guidelines should result in improved health outcomes such as: appropriate doses of opioids and benzodiazepines; decreased side effects, incidences of withdrawal and over-medication; decreased length of stay; evidence based decision making and nursing practice; and increased satisfaction (parental, RN, and hospital administration).

### Review of Literature

#### *Introduction*

A multitude of publications can be found on the many clinical aspects of pain and sedation. Unfortunately, in this plethora of publications, sorely few are well designed clinical studies. In fact, most are written to describe institutional practices, as literature reviews, or expert opinions on specific components (dosing, weaning, assessment, monitoring, and the like) of pain and sedation management. Additionally much has been written about various influences on nurses' clinical decision making related to pain assessment and treatment. However the bulk of this literature is quite dated and very little was specific to pediatric nurses let alone PICU nurses. There were no publications identified that related specifically to decision making around sedation. The concept of sedation is often folded into pain management, especially in the critical care population.

*Summary of Relevant Literature*

*Pain, sedation, over-medication, and withdrawal.* By far, the majority of the literature is descriptive and opinion based. The citations by McCaffery (1968), IASP (1994), and ASA (2004) provide widely accepted definitions of pain and sedation. Herr et al. (2006) and Ramsey (2000) describe ways to measure (quantify) pain and sedation. The position statement on pain assessment of the non-verbal patient by Herr et al. is a combination of literature review and expert opinion. Ramsey describes how to use the Ramsey Sedation Scale; however there were no articles found addressing the validity or reliability of this specific tool. This is an example of a measurement tool that is widely used in practice yet has had limited sound testing.

Articles by Anand and Arnold (1994), Cunliffe, McArthur, and Dooley (2004), Dunajcik (1999), and Turner (2005) clearly describe the problems related to withdrawal, but again are expert opinion. Tobias (2000) offers a review of the published English literature, based on a MEDLINE search using several pain and sedation terms. However, he gives no indication of the number or types of publications reviewed. Siddappa et al. (2003) reported, as part of a quality improvement initiative, on a retrospective chart review (n=30) to evaluate methadone dosing as a risk factor for withdrawal and to assess methadone dosing and efficacy for preventing opioid withdrawal. Berens et al. (2006) reported findings of a prospective, randomized, double blind comparison of the effectiveness of weaning pediatric opioid dependent patients with enteral methadone in five days and ten days. Both Siddappa et al. and Berens et al. had small samples and limited applicability outside their settings; and both evaluated opioids only and did not control for or include sedatives. Cheung et al. (2006) reported their attempt to prevent opioid tolerance and withdrawal with infusions of low-dose naloxone. They report a case control study of retrospective chart review, assessing the use of naloxone to decrease opioid requirements.

Opioid requirements were not decreased during the naloxone infusion but did tend to be less after the infusion. Kress, Pohlman, O'Connor, and Hall (2000) indicated daily interruptions of sedative infusions in adult critically ill patients decreased the length of time patients required mechanical ventilation and length of stay in the intensive care unit. Dominguez, Lomako, Katz, and Kelly (2003) report findings from their prospective interventional cohort study to determine the occurrence of and risk factors for withdrawal after receiving continuous infusions of fentanyl in critically ill neonates. All three of these studies have small numbers, have design flaws, and lack applicability to broader populations in different settings.

Literature based on strong clinical evidence is lacking in this area. This may be due to a limited and inconsistent knowledge base to support well designed research studies; a patient population which has significant physiologic variability; multiple causes of illness and injury; and comorbidities not commonly seen in adult patients i.e., life limiting progressive neuromuscular diseases. This compounded by inconsistent and variable practices that do not lend themselves to even informal consensus.

*RN decision making.* Concepts of RN decision making are well described by Abu-Saad and Hamers (1997) in their review article. They point out some of the challenges of using this literature are the confusion around and inconsistent use of terminology, multiplicity of paradigms and theories, and the lack of scholarly work. This literature is also dated. The article itself is ten years old and the majority of the references are more than fifteen years old. Horbury, Henderson, and Bromley (2005), set out to identify nurses' beliefs and intentions to treat pain. Their findings reported the nurses' knowledge related to pain management was more often inaccurate, resulting in treatment decisions that did not address patients' pain, than influenced by their (RNs) beliefs. Wilson (2007) set out to assess if continuing education and clinical experience influence nurses'



pain knowledge. Her findings indicate there is a positive correlation between increased knowledge scores and years of experience. She posits that nurses' work environments may have significant influence on their utilization of clinical knowledge. Horbury et al. and Wilson studied nurses who cared for adult patients. In a prospective cohort study, Curley et al. (1992) described patient behaviors the PICU nurses considered when administering analgesics and or sedatives. Findings show more patients were medicated for agitation alone than pain alone and 28% of the patients were medicated for both. Van Hulle Vincent and Denyes (2004) asked if nurses' knowledge, attitudes, and ability to overcome barriers to pain management effected the amount of analgesia given; if the amount of available analgesia given effected children's pain levels; if nurses' knowledge, attitudes, and ability to overcome barriers to pain management effected children's pain levels; were there nurse characteristics that effected the amount of analgesics given; were there any relationships between child characteristics, amounts of analgesia given, and the children's pain levels; and how amounts of analgesics ordered and amounts administered compared to 1992 Agency for Health Care Policy and Research (AHCPR) guidelines. Findings indicated positive relationships between nurses' analgesic administration and nurses' years of pediatric experience and ability to overcome barriers. Manwarron (2001) reported on validity and reliability testing on modifications made to a tool for assessing nurses' attitudes and beliefs. Her modifications were to make the vignettes pediatric based so the survey could be used with pediatric nurses. See Appendix for a collective evidence table.

### *Guidelines*

There are no nationally recognized guidelines or protocols in the area of pain and sedation management in pediatric critical care. Protocols reported in the literature for pain and sedation management are not standardized, tend to be institution specific, and have inconsistent

results. However, Curley (2008) has received grant funding to evaluate a protocol driven approach to management of sedation in pediatric patients with acute respiratory failure.

### Summary

The existing literature supports the influences of nurses' knowledge, beliefs and personal experiences, and years of work experience. While the PICU nurses may have received education and training regarding pharmacologic management of pain and sedation, their clinical decision making and nursing practice may not reflect this knowledge. It will be important to assess the importance of beliefs and personal experiences and years of work experience on decision making. Identifying the characteristics of nurses who demonstrate evidence based clinical decision making regarding pain and sedation management will be important as efforts to improve clinical decision making and nursing practice are undertaken. Through identification of factors that influence RN decision making, strategies can be identified to enhance evidence based decision making by nurses providing pain and sedation management in the PICU, thereby improving patient outcomes.

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## Appendix

Collective Evidence Table

Clinical Inquiry Questions: 1. What are the beliefs/attitudes, knowledge levels, work experience, and patient characteristics that influence RN decision making? 2. Is there a relationship between the influences and incidences of withdrawal/over-medication?

SYNOPSIS			FINDINGS		CLINICAL APPLICABILITY
Citation	Clinical Question	Design	Credibility	Significance	Applicability
Author & Year	Hypothesis, Variables under study	Design Sample Population Would you change anything?	Rigor in data collection & analysis	Statistical & clinical significance Level of Evidence	To whom and under what situations could findings apply? Can these be applied to your inquiry?
Abu-Saad & Hamers (1997)	Decision making in pediatric pain	Review of pediatric literature	No review methodology Peer reviewed journal	GRADE D evidence	Review article Personal agenda Dated materials reviewed
Anand & Arnold (1994)	Definitions of tolerance and dependence Assess methods of withdrawal assessment Treatment suggestions	Expert opinion	Peer reviewed journal	GRADE D evidence	Older article
Cunliffe et al. (2004)	Process suggestions to prevent withdrawal	Pediatric institutional process report	Peer reviewed journal	GRADE D evidence	Didn't they have data for comparison of effectiveness?  Not generalizable

Horbury et al. (2005)	To study nurses intent to treat pain in different patients	Convenience sample of RNs (n=221) in adult hospital with <25% response rate Questionnaire Descriptive	Modification of a validated tool without revalidation Peer reviewed journal	GRADE D evidence "Findings support existing literature"	Not generalizable Australian study
Manwarron (2001)	Establish content validity of a modified survey for use with pediatric RNs	Convenience sample of pediatric nurses in children's hospital (n=247) and pediatric specialty organization (n=88)	Investigator modified highly reliable survey tool. Utilized national experts for validation and reliability testing Peer Reviewed journal	GRADE D evidence Test-retest reliability of the tool: $r = 0.67$ , indicating acceptable level of stability.  Cronbach's alpha was 0.72 (n = 247) and 0.77 (n=88), indicating acceptable level of internal consistency	Samples were from a single hospital and pediatric specialty organization Limited generalizability
Siddappa et al. (2003)	Evaluate methadone dosing as risk factor for withdrawal To determine dose and efficacy of methadone for withdrawal prevention	Clinical retrospective chart review (n=30) Descriptive QI initiative	Peer reviewed journal	GRADE D evidence  Used ROC (explained in article!) to calculate odds ratio	Small sample Minimally generalizable Didn't account for benzos
Cheung et al. (2007)	Did low-dose naloxone infusions decrease the amount of opioid required and development of tolerance	n= 26 Pilot study Retrospective matched case control	Peer reviewed journal	GRADE C evidence	Look at references from this article to determine if the literature supports the use of opioid antagonists to minimize the development of opioid tolerance

Dominguez et al. (2003)	Does continuous infusion of fentanyl increase the risk of withdrawal in critically ill neonates	N=19 Prospective interventional cohort	Peer reviewed journals	GRADE C evidence	Neonate physiology is different than older infants and children--?effect
Kress et al. (2000)	Hypothesis was that daily interruption of the sedative infusion would decrease drug accumulation and reduce delays in improvement of mental status. Variables: - duration of mechanical ventilation - LOS in ICU - LOS in hospital -total dose of midazolam and morphine -total dose of propofol and morphine	n=128 Adults receiving mechanical ventilation and continuous infusions of sedative drugs Randomized, controlled	Peer reviewed journal Limited blinding	GRADE C evidence	Not generalizable to pediatric patients Did not discuss tolerance, but may in theory support the notion of “drug holidays” which have been suggested to decrease tolerance
Tobias (2000)	Describe consequences of prolonged opioid and sedative use in PICU	Review of literature	No review methodology Peer reviewed journal	GRADE D evidence	Review article Dated materials cited
Van Hulle Vincent & Denyes (2004)	Examine relationships between RN knowledge, abilities to overcome barriers, analgesic practices, and pain levels	Descriptive RNs (n= 67) and patients (n=132) Complicated “messy” analysis	Peer reviewed journal	GRADE D evidence  Internal consistency on small pilot of modified tool was 0.64  Zero-order correlation then hierarchical regression	Limited by study tool design  Appears to confirm earlier work about RNs not using as much opioid as available when indicated



Wilson (2007)	Determine if CE and experience influence pain knowledge	Convenience sample (n=72) Questionnaire Descriptive	Peer reviewed journal	GRADE D evidence  Descriptive and inferential stats  Revised tool--? validity/reliability	Specialist RNs had more knowledge and it wasn't based on experience
McCaffery (1968)				GRADE D evidence  Unable to obtain actual document	Masters Thesis "universally excepted definition of pain"
IASP (1994)				GRADE D evidence	Definition
ASA (2004)	Sedation definitions and monitoring needs			GRADE D evidence	Guidelines by professional organization
Ramsey (2000)			Internet post	GRADE D evidence  Difficult to find clean validity/reliability info	Instruction for use of tool
Herr et al. (2006)				GRADE D evidence	Position paper with clinical practice recommendations by professional organization
Dunajcik (1999)		Expert Opinion	Edited book	GRADE D evidence	Book Chapter Dated material
Turner (2005)		Case reports	Peer reviewed journal	GRADE D evidence	Review article

Berens et al. (2006)	Comparing effectiveness of weaning opioid dependent patients with methadone in 5 days or 10 days	Prospective, randomized, double blind comparison < 18 years old (n-37)	Peer reviewed journal X2 test Fisher's exact test Student unpaired T pValue ,0.05 was statistical significant	GRADE D evidence	No control for sedatives
Curley (2008)	Will patients managed with a sedation protocol have fewer complications, decreased LOS, and increased QOL	Cluster randomized Organizational change effort	NIIH funded grant	Unavailable at this time	Our PICU will be a study cite
Curley et al. (1992)	Described factors PICU nurses consider when giving opioids or sedatives	Prospective cohort	Published abstract only Descriptive report		

Running head: DISPARITIES AND PAIN

Disparities in Pain Management

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Though my clinical area of expertise is pediatric pain management, I was asked to write a book chapter because of my special interest in disparities in health care and specifically disparities in pain management. Pages five through fifteen of this manuscript are adapted from a chapter in Section II (Pain Management and Social Policy) of *Core Curriculum for Pain Management Nursing*, 2<sup>nd</sup> edition, (Turner, in press). It has been written to describe disparities in pain management care and ways to decrease them. Disparities are defined in Section I of the chapter. Unequal care related to pain management is compounded by factors that result in overall health care disparities (female sex, minorities, extremes of age, socioeconomic disadvantage, lower education, location, chemical dependency, etc.). In effect, people with pain are at a significantly increased risk for disparate care.

#### Prevalence and Contextual Factors

It has been reported extensively that the most common reason Americans seek health care services is for pain relief. With more than 75 million people suffering from pain, an estimated 60 to 100 billion dollars are associated to pain in the form of health care expenses, lost income, and lost productivity (American Pain Society, 2008; Kirsch & Passik, 2008).

Inequality in health care seems to mirror those populations who, historically, have experienced discrimination—women, children, racial minorities, the poor, the less educated, and those who the majority deems unfit or undeserving. Section II reviews examples of health disparities in general. As time has passed some discrimination, such as slavery, women not being allowed to vote, and other inequities, have been outlawed but there remain historical, societal, and cultural undercurrents perpetuating attitudes and behaviors of discrimination.

Pain is often viewed as a weakness, and because patients are afraid to be labeled and/or providers do not believe the patients' reports, it goes under treated. Though Richard Nixon's

“war on drugs” was supposedly directed at illicit substances, all controlled substances (including pain medications) became suspect. This resulted in further stigmatization of people who required opioids for pain management and increased the challenge for these people to receive unbiased health care. Sadly, many biases persist today and disparities related to pain management are described in Section III.

### Interventions and Implications for Nursing

As a Doctor of Nursing Practice (DNP) student, it is my duty to provide role modeling and leadership in providing unbiased and individualized care to every patient regardless of race, gender, socioeconomic status, or education level. It is imperative as a nursing leader that I advocate for equality within my health care system, state, and nation. Advocacy will include continually striving to remove barriers to adequate pain management (described in Section IV); raise public and health care provider awareness of the impact of unequal and unethical pain management practices; and develop and support policy and legislation designed to remove the disparities of care in our current health care system. Interdisciplinary health care education curriculum development to increase cultural competence, social justice, and communication between health care providers and patients is another area of potential reform, and within the role of the DNP. Additional interventions are described in Section VIII.

The implications of unequal care for those experiencing pain are significant. Their pain will likely be under treated, resulting in the physiological, psychological, and sociological, and spiritual sequella of poorly treated pain. Untreated or poorly treated pain impacts every system in the human body and can lead to impaired healing, delayed recovery, prolonged hospitalization, exacerbation of illness or injury, and in some cases death (Pasero, Paice, & McCaffery, 1999; Schechter, Berde, & Yaster, 2003).

### Self Reflection

Writing this paper/chapter has been a growth experience on many fronts. In my naiveté, I was continuously amazed and frustrated that discrimination and inequalities persist on any level in the modern world. Through this learning process I have gained a better understanding of why disparities persist and potential strategies to decrease them. At the beginning of this process, I did not appreciate how insidious and ubiquitous discrimination is, especially in health care. Nor did I appreciate how inequalities are perpetuated by our current health care system. Early and basic education of health care providers (doctors, nurses, physical therapist, etc.), has limited content on disparities and its impact on our patients. Increasing awareness of disparities through publication, lecturing, and role modeling is the first step to removing them.

There continues to be a dearth of minority and culturally diverse students in the health care education pipeline. Without their lived experience and knowledge, bringing culturally competent care and social justice to the health care arena will be impossible. Increased efforts to encourage minority students to consider health care as a career, improved recruiting by health education programs, and increased funding for minority students are ways to increase the numbers of minority providers who can positively influence the culture of health education and delivery of culturally appropriate care.

Constant vigilance is required on my part to be aware of my attitudes and how they might be perceived by others (other providers or patients). As a professional and leader in my clinical setting, I must be above reproach in role modeling unbiased attitudes and practice. When I become complacent or languid, I am at a higher risk of having biases seep into my attitudes and clinical practice. In an effort to prevent this, I plan to implement a scheduled appointment with myself each week to review and critique my thoughts and behaviors.

## Disparities in Pain Management

Helen N. Turner, MSN, RN-BC, PCNS-BC

### Objectives

After studying this chapter, the reader should be able to:

1. Explain at least five causes of health disparities impacting pain management
2. Identify patient populations at high risk for inadequate pain care secondary disparities
3. Describe at least five personal and professional activities to decrease disparities in pain management

#### I. DEFINITIONS

Disparities are defined as the following:

- A. Healthy People 2010: “population-specific differences in the presence of disease, health outcomes, or access to health care” and “unequal burden in disease morbidity and mortality rates experienced by ethnic/racial groups as compared to the dominant group.” (USDHHS, 2000)
- B. Institute of Medicine (IOM): “differences in the quality of health care that are not due to access-related factors or clinical needs, preferences or appropriateness of intervention.” (Smedley, Stith, & Nelson, 2003)

#### II. DISPARITIES IN HEALTH CARE

##### A. Major Causes

1. IOM delineates two sources of disparities: health care systems including legal and regulatory climate, and discrimination (biases, stereotyping, clinical communication and decision making) (Smedley, et al., 2003)
2. Disparities are caused by treatment decisions, differences in income, differences in education, sociocultural factors, failure by the medical profession (Lebovits, 2005)

##### B. Prevalence

1. Fourteen percent of United States (US) population is without health insurance and health insurance facilitates access to health care systems

2. Sixty eight percent of US population live in medically underserved areas (Sullivan & Egel, 2005)

### **C. Results of Disparity in Health Care**

1. Those who suffer disparity in general have poorer health, get diagnosed later, are sicker when hospitalized, and die earlier (USDHHS, 2008)
2. African Americans and Asians have higher risk of death than Caucasians after injury (Arthur, Hedges, Newgard, Diggs, & Mullins, 2008)
3. Patients who are Asian, older, female, or married tend to get less aggressive cardiac care (Blomkalns, et al., 2005; Diercks & Miller, 2008; Gnani, Migliardi, Demaria, Petrelli, Caprioglio, & Costa, 2007) and African Americans, Hispanic, and Asians less likely to receive invasive cardiovascular procedures (Kressin & Petersen, 2001)
4. African Americans and Hispanics get less surgery for liver cancer (Sloan, Chen, & Howell, 2006; Sonnenday, Dimick, Schulick, & Choti, 2007)
5. African Americans have greater numbers of emergency department visits for acute asthma (Ginde, Espinola, & Camargo, 2008)
6. African Americans more often diagnosed with schizophrenia than Caucasians; contributing factors may include higher rates of substance abuse, cultural mistrust being interpreted as paranoia, misdiagnosis, methods used for diagnosis, provider influence or bias, and care setting (DeCoux Hampton, 2007)
7. Women of color less likely to have access to reproductive health care (Webb, 2004)
8. African Americans with severe sepsis less likely to receive ICU care than Caucasians (Barnato, Alexander, Linde-Zwirble, & Angus, 2008)
9. Uninsured and African American females less likely to be hospitalized for traumatic brain injury (Selassie, Pickelsimer, Frazier, Ferguson, 2004)
10. Less educated (below ninth grade) and African American patients have lower rates of cardiac catheterizations (Schechter et al, 1996)
11. Global issue not just in the US
  - a. Sweden—men received more treatment than women for dermatologic conditions (Nyberg, Osika, & Evengard, 2008)



- b. Jerusalem, Israel—Jewish residents receive better diabetes care than Arab patients (Tirosh, Calderon-Margalit, Mazar, & Stern, 2008)
- c. Torino, Italy—Statins prescribed less based on age (older) and sex (female) for secondary prevention of ischemic heart disease (Gnavi, et al., 2007)
- d. Canada—Females and Asians receive less aggressive cardiac treatment (Diercks & Miller, 2008)
- e. South Africa—Racial differences account for infant mortality rates (Burgard & Treiman, 2006)
- f. Glasgow, Scotland—Women less often prescribed statins and ACE inhibitors after stroke (McInnes, McAlpine, & Walters, 2007)

### III. DISPARITIES IN PAIN MANAGEMENT

#### A. Population Segments

1. Pain management differs among population segments. Those at particular risk are children, the elderly, people with history of chemical dependency, the mentally ill, women, racial and ethnic minorities, and those with socioeconomic disadvantage, language barriers, geographic remoteness, poor health literacy, specific types of pain related conditions (acute, chronic nonmalignant, cancer, and experimental), and specific co-morbidities (Green, Anderson, Baker, Campbell, Decker, Fillingim, et al., 2003; Green, Todd, Lebovits, & Francis, 2006; Sullivan & Egel, 2005)

#### B. Sociodemographics

1. Gender—female
  - a. Women are more likely to receive less opioids and more often sedatives rather than analgesics (Green & Wheeler, 2003, Paulson, Dekker, & Aguilar-Gaxiola, 2007)
2. Race and Ethnicity (Ezenwa, Ameringer, Ward, & Serlin, 2006; Green, Anderson, et al., 2003; Green, Todd, et al., 2006, Paulson, et al., 2007)
  - a. Hispanics with long-bone fractures twice as likely as non-Hispanics to **not** receive pain medication in a large, urban, Level 1 trauma center, and if they did the doses were generally lower (Todd, Samaroo, & Hoffman, 1993), and African Americans with long-bone fractures less likely to receive analgesics in ED than Caucasian, and risk of receiving no

analgesics was 66% higher for African Americans than Caucasian (Todd, Deaton, D'Adamo, & Goe, 2000)

- b. African Americans and other people of color in Medicaid managed care plans had one third less odds of receiving a COX-2 prescription than Caucasians (Shaya & Blume, 2005)
  - c. Hispanic ethnicity predicts limited access to care for chronic pain (Nguyen, Ugarte, Fuller, Haas, Portenoy, 2005)
3. Age—the extremes
    - a. Children are under treated due to the challenges of assessing and communicating pain (Yaffa Zisk, 2003; Yaffa Zisk, Grey, MacLaren, & Kain, 2007)
    - b. Regardless of setting, older patients are more likely to die in moderate to severe pain (SUPPORT Principle Investigators, 1995)
  4. Socioeconomic Disadvantage (Bernheim, Ross, Krumholz, & Bradley, 2008; Poleshuck & Green, 2008)
    - a. Includes factors of neighborhood socioeconomic status, education, income, and socioeconomic disadvantage is consistently associated with increased risk for pain (Poleshuck & Green, 2008)
  5. Patient/Family Education Level (Poleshuck & Green, 2008)
    - a. Lower education generally associated with lower income, decreased access to care, and possibly decreased quality of care (Bernheim, et al., 2008; Field, 2008)
    - b. Education has a greater association with health than income (Poleshuck & Green, 2008)

### **C. Location**

1. Rural Vs Urban—those in rural areas have less access to care and specialty care (Baicker, Chandra, & Skinner, 2005; Green, Todd, et al., 2006; Nelson Bolin, Phillips, & Hawes, 2006; Tollefson & Usher, 2006)
2. Distance from Knowledgeable Providers—limits access to specialists, especially pain specialists who tend to practice in urban areas (Green, Todd, et al., 2006)
3. Neighborhoods—generally people from lower income neighborhoods have less access to health care in general and pain care specifically

- a. Pharmacies in low income areas not stocking adequate opioids (Green, Ndao-Brumblay, West, & Washington, 2005; Morrison, Wallenstein, Natale, Senzel, & Huang, 2000)
  - c. Pharmacies in the state of Washington had adequate opioids supplies regardless of location and economic status (Mayer, Kirlin, Rehm, and Loeser, 2008)
4. Homeless (Kushel & Miaskowski, 2006)
- a. Limited access to basic health care and care is often poorly coordinated with inconsistent providers
5. Health Care Setting—impacts quality and consistency of pain management
- a. Emergency Department: Delivery of analgesia is often delayed and/or ineffective based on race, ethnicity, and gender (Arendts & Fry, 2006; Epps, Jowers Ware, & Packard, 2008; Heins, Heins, Grammas, Costello, Huang, & Mishra, 2006; Pletcher, Kertesz, Kohn, & Gonzales, 2008; Quazi, Eberhart, Jacoby, & Heller, 2008; Rupp & Delaney, 2004; Todd, et al., 1993)
  - b. Nursing Home Residence: Nursing home residents experience significant amounts of moderate to severe pain (Nelson Bolin, et al., 2006; Cadogan, 2004; Green, Anderson, et al., 2003)
  - c. End of Life Care: Despite improvements many patients receive inadequate analgesia at the end of life (Brunnhuber, Nash, Meier, Weissman, & Woodcock, 2008; Harris, 2007; Rabow & Dibble, 2005)

#### **D. Special Populations**

- 1. Chronic Pain: unclear if under treatment in this population is solely based on under treatment or confounded by differences in coping and psychological responses (Green, Anderson, et al., 2003; Watkins, Wollan, Melton, & Yawn, 2006)
- 2. Cognitive Impairment: tend to be undertreated because of assessment and communication challenges (Cadogan, 2004; Jowers Ware, Epps, Herr, & Packard, 2006)
- 3. Mental Illness: pain involves both physical and psychological elements and is confounded by mental illness often resulting in under treatment (Gureje et al., 2008; Hughes, Nosek and Robinson-Whelen, 2007; Ohayon, 2006)

- a. Mental illness often complicates history taking, assessment, treatment, compliance, and follow through (Broyles, Colbert, Tate, Swigart, & Happ, 2008; Fishbain, 2005)
4. Chemical Dependency: often poorly treated due to inadequate provider knowledge related to pain and addiction treatment, as well as providers fears of repercussions from authorities and regulators, and their own personal biases (American Society for Pain Management Nursing, 2002; Fosnocht, Swanson, & Barton, 2005; Morgan, 2006; Paulson, et al., 2007; Rupp & Delaney, 2004; Sullivan & Eigel, 2005)
5. Immigrants/Culture: difficulty in assessment and history taking, delays or lack of treatment seeking, cultural norms dictating pain response, providers lacking knowledge of cultural variability in pain response (Sobralnske & Katz, 2005)
6. Incarcerated: prison medical care is often substandard (Moore & Elkavich, 2008)
  - a. Barriers to pain management identified by health care providers included concern for misuse diversion and patient credibility (Lin & Mathew, 2005)
  - b. Similar to non-incarcerated minorities there is a high incidence of uncontrolled cancer pain and severe chronic pain (Lin & Mathew, 2005)
  - c. Prison policies prohibiting inmates from carrying medications (Lin & Mathew, 2005)
  - d. There is a higher percentage of minorities in prisons (Bonney, Clarke, Simmons, Rose, & Rich, 2008)
7. Workers' Compensation (Chibnall, Tait, Andresen, & Hadler, 2005; Scherzer, Rugulies, & Krause, 2005; Tait & Chibnall, 2001)
  - a. Inadequate treatment (Chibnall, Tait, Andresen, & Hadler, 2005)
  - b. Negative provider attitudes or outright refusal to accept Workers' Compensation cases (Chibnall, Tait, Andresen, & Hadler, 2005; Scherzer, Rugulies, & Krause, 2005)
  - c. Those in low wage jobs experience higher burden of illness, injury, and disability, and falls on workers who are multiply disadvantaged in society (female and minorities) (Scherzer, Rugulies, & Krause, 2005)
  - d. Under reporting of work related injuries due to punitive attitudes of managers, inadequate compensated time off, inadequate treatment, and failure to address workplace hazards (Scherzer, Rugulies, & Krause, 2005)

- e. Adversarial nature of Workers' Compensation process (Chibnall, Tait, Andresen, & Hadler, 2005)

#### IV. BARRIERS CONTRIBUTING TO DISPARITIES IN PAIN MANAGEMENT

##### **A. Patient/Family**

1. Age, sex, socioeconomic status, educational level
2. Race and ethnicity can influence where patients seek care and the quality of care received (Iwashyna, Curlin, Christakis, 2002; Kahn, et al., 1994)
3. Communication between patients and health care providers, and concerns about risk of addiction, abuse, or diversion (Sullivan & Egel, 2005)
4. Disease process
5. Anxiety, grief, anger
6. Misconceptions, concerns, biases, and beliefs

##### **B. Health Care Providers**

1. Attitudes and Beliefs
  - a. Physicians underestimate pain in African American patients (Staton, et al., 2007)
  - b. Physicians' and nurses' ethnic, cultural, and gender biases and knowledge influence treatment (Berger, 2008; Clarke, French, Bilodeau, Capasso, Edwards, & Empoliti, 1996; Ferrell, McGuire, Donovan, 1993; Fosnocht, et al., 2005; Hamers, Abu-Saad, van den Hout, & Halfens, 1998; Layman Young, Horton, & Davidhizar, 2006; Manworren, & Hayes, 2000; McCaffery, & Ferrell, 1997; Tamayo-Sarver, et al., 2003; Weisse, Sorum, & Dominguez, 2003)
  - c. Clinical management decisions are influenced by patients' socioeconomic status (Bernheim, et al., 2008)
2. Providers' who had personal experience with pain tend to be more empathetic in the management of pain (Abu-Saad, & Hamers, 1997; Banja, 2006; Fuller, 1996; Griffin, Polit, & Byrne, 2007; Horbury, Henderson, & Bromley, 2005; Wilson, 2007)
3. Lack of training in pain medicine or addiction medicine (Fosnocht, et al., 2005; Paulson, et al., 2007; Sullivan & Egel, 2005)
4. Lack of priority given to pain care

5. Lack of accountability to provide pain management
6. Time restrictions placed on providers in clinical settings

### **C. Healthcare Systems**

1. Access (Green, Todd, et al., 2006; Kahn, et al., 1994)
  - a. Pharmacies not stocking sufficient medications to treat severe pain adequately (Green, Ndao-Brumblay, West, & Washington, 2005; Morrison, Wallenstein, Natale, Senzel, & Huang, 2000)
  - b. Medication decisions may be based on potential for abuse rather than effectiveness (Flugsrud-Breckenridge, Gervitz, Paul, & Gould, 2007)
2. Society—the war on drugs, diversion prevention (Joranson, Elliott, & Lipman, 2003)

## **V. ETHICAL IMPLICATIONS**

Pain relief declared a basic human right by World Health Organization (Green, Todd, et al., 2006)

American Nurses Association (ANA) and American Medical Association (AMA) Codes of Ethics (AMA, 2002; ANA, 2001) outline ethical practice including pain care.

### **A. Autonomy**

1. Self-determination is respecting the choices and wishes of persons who have the capacity to decide and protecting those who don't have the capacity

### **B. Nonmaleficence**

1. Do no harm
2. We know untreated pain results in harm

### **C. Beneficence**

1. Care should benefit patients and protect their interests

### **D. Justice**

1. Justice (“fair, equitable, and appropriate distribution in society of a privilege, benefit, or service” (Lebovits, 2005, p. 3)

## VI. LEGISLATION/POLICIES ADDRESSING DISPARITIES IN PAIN MANAGEMENT

### A. Health Care Reform (American Pain Foundation, 2008)

1. National Pain Care Policy Act of 2008 (HR 2994) calls for a Congressional finding for improved pain care research, education, access, and care. These are national health care priorities requiring appropriate funding.
2. Veterans Pain Care Act is part of the Veterans Health Care Policy Enhancement Act of 2008 (HR 6445) and addresses assessment and management of pain (acute and chronic), standardization of pain care, pain research, pain education of health care providers and patients, and performance accountability for veterans' pain care.
3. Military Pain Care Act of 2008 is part of the FY09 National Defense Authorization Act and directs the Secretary of Defense to plan a pain care initiative in all health care facilities of the military.

### B. Advocacy Groups

1. Pain & Policy Studies Group University of Wisconsin Paul P. Carbone Comprehensive Cancer Center World Health Organization Collaborating Center for Policy and Communications in Cancer Care <http://www.painpolicy.wisc.edu/>
  - a. Through research, education, and communication the focus is on identifying and addressing barriers to appropriate use of opioids especially in chronic pain and palliative care
    - i. State report cards on pain policy
    - ii. Collaboration with DEA
  - b. Mission includes balancing international, national, and state policies to assure access to pain medications while minimizing diversion and abuse, and to support communication around the globe to improve access to information about pain relief, palliative care, and policy
2. Center for Practical Bioethics Balancing Pain Policy <http://www.practicalbioethics.org/cpb.aspx?pgID=978>
  - a. Works with pain policy groups, state medical boards, and attorney generals to educate, advocate, and influence pain policy on a national basis

## VII. PAIN MANAGEMENT DISPARITIES IN CURRENT LITERATURE AND MEDIA

- A. There is a need for increased coverage of disparities in the popular media (television, internet, and printed press) to increase public awareness
- B. Research activities may result in low socioeconomic status participants to be missed in traditional pain studies that recruit by phone or in a medical setting
- C. Pain management organizations (not a complete list) who address education, advocacy, and disparities in pain care
  - 1. American Society for Pain Management Nursing
  - 2. American Pain Society
  - 3. American Pain Foundation
  - 4. American Academy of Pain Medicine
  - 5. International Association for the Study of Pain
  - 6. Alliance of State Pain Initiatives
  - 7. American Chronic Pain Association
  - 8. The Pain Relief Foundation
  - 9. Mayday Fund
  - 10. National Foundation for the Treatment of Pain
- D. Governmental organizations addressing disparities
  - 1. Agency for Healthcare Research and Quality (AHRQ)
  - 2. National Guideline Clearinghouse
  - 3. National Institutes of Health
  - 4. National Library of Medicine
  - 5. United States Drug Enforcement Administration (US DEA)
  - 6. United States Food and Drug Administration (US FDA)
  - 7. VHA Office of Quality and Performance, Clinical Practice Guidelines



## VIII. WHAT WE CAN DO?

- A. Increase awareness of disparities and populations at greatest risk (Green, Tait, & Gallagher, 2005; Paulson, et al., 2007; Sullivan & Egel, 2005)
- B. Ongoing research and monitoring of pain management disparities (American Pain Society (APS), 2004; Green, Todd, et al., 2006; Sullivan & Egel, 2005)
- C. Address disparities through healthcare education, continuing education (Green, Todd, et al., 2006; Paulson, et al., 2007)
- D. Promote cultural competence and social justice (Green, Todd, et al., 2006)
- E. Encourage and inspire minority students to pursue careers in pain management (Green, Todd, et al., 2006)
- F. Develop and advocate for policy and legislation directed at removing barriers to pain management (APS, 2004; Green, Tait, et al., 2005; Green, Todd, et al., 2006; Taylor, Gostin, & Pagonis, 2008). This will include education to address prescribing fears and (Passik, 2006; Rich, 2006; Rowe, 2006), making access to appropriate pain care and medications easier (Lin, Crawford, & Salmon, 2005, von Gunten, 2006).
- G. Work with third party payers and pharmacy organizations to improve access to care and treatment (Paulson, et al., 2007)
- H. Improve communication between patients and providers (Carcaise-Edinboro & Bradley, 2008; Kalauokalani, Franks, Wright Oliver, Meyers, Kravitz, 2007)
- I. Advocate for patient and family involvement in pain management care (Walker, Signal, Russell, Smiler, & Tuhiwai-Ruru, 2008)
- J. Advocate for comprehensive multidisciplinary pain management at hospital, local, state and national levels (APS, 2004; Paulson, et al., 2007) including developing close working relationships with addiction specialists (Paulson, et al., 2007)
- K. “ Still, an insightful clinician will always need to avoid ethnic or racial stereotypes, eschew the notion of cultural uniformity, and assess and manage each patient as an individual” (Rollman, 2005, p. 4)
- L. “Our greatest opportunities for reducing health disparities are in empowering individuals to make informed health care decisions and in promoting communitywide safety, education, and access to health care.” (USDHHS, 2000, p. 16)

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Running head: ENVIRONMENTAL IMPACT ON PAIN IN OBESE ADOLESCENTS

Environmental Influences on Physical Activity and the Impact on Adolescent Obesity and  
Chronic Pain

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### Clinical Case Selection, Description, and Focus

A significant number of patients in my practice are overweight teenage females with some form of chronic pain. Anecdotally, these patients are challenging to manage, and my success rate for decreasing their pain and increasing their functionality is about one third that of my normal weight female patients. Obesity is a well recognized factor contributing to back, joint, and myofascial pain. In addition to physical therapy for strengthening of core muscles, losing weight through diet modification and increased physical exercise are the foundation of the pain treatment plan.

Childhood obesity is a multi-factorial epidemic which has potential to overwhelm our health care system. Because childhood obesity has reached epidemic proportions, much has been written about it, its causes, and its effect on children's health. The majority of the literature focuses on endocrine and cardiovascular complications of childhood obesity. I will explore what I believe to be environmental factors affecting obesity especially when compounded with a chronic pain condition, but will focus on lack of access to consistent, safe, and low cost exercise options.

Environmental risks for childhood obesity and chronic pain syndromes are influenced by and have ramifications in cultural, economic, and political dimensions. Many of the cultural, economic, and political factors overlap and will be discussed in more depth later in this paper, but briefly, these factors include: the availability of technology which encourages sedentary behaviors (video games, computers, cellular phones, wireless connectivity, etc); mass media representations and the general public attitudes toward obesity and eating disorders; the desire for quick fixes; socioeconomic status; food and beverage marketing directed at children; access to inexpensive and reliable transportation; and cuts to school physical education programs

(Fitzgibbon & Stolley, 2006; Dowda, Ainsworth, Addy, Saunders, & Riner, 2001; Koplan, Liverman, & Kraak, 2005).

A case study will be used to illustrate how the lack of access to safe walking areas or exercise facilities is an environmental health risk factor for overweight female teenagers with chronic pain.

The case is a 15 year old female (XZ) with back pain. She is 5'10" tall and weighs 288.2 pounds giving her a body mass index (BMI) of 41.4 which is greater than the 99<sup>th</sup> percentile for females of her age. By report she has always been a "big girl." Both her parents and younger brother are overweight. She was referred to the pediatric chronic pain clinic by her pediatrician after extensive work-ups by an orthopedist and neurologist.

### Review of Literature

#### *Epidemiology*

*Weight related data.* Nationally, 16% of children aged 12-19 years are overweight. This is more than 50% higher than it was ten years ago and three times higher than twenty years ago (Oregon Physical Activity and Nutrition Program [OPANP], 2007).

For the purpose of this paper the term obese is used to describe adolescents at or above the 95<sup>th</sup> percentile for BMI by sex and age. The term overweight is used for those adolescents between the 85<sup>th</sup> and 94<sup>th</sup> percentile. Oregon has no population-based system to assess BMI in children below 8th grade, though it is recognized the risks for obesity are present at conception.

According to the Office of Disease Prevention and Epidemiology, Physical Activity and Nutrition Program (Ngo & Leman, 2007) report to the Oregon Health Policy Commission:

- the proportion of 8<sup>th</sup> and 11<sup>th</sup> graders who were overweight or obese in 2005 was 1 in 4 (11,600 8<sup>th</sup> and 11<sup>th</sup> graders were overweight and 8,500 were obese),
- the percentage of 11<sup>th</sup> graders who were obese has increased 63% since 2001,

- males tend to be heavier—15.8% of 8th grade males are overweight and 12.2% are obese, compared to 13.3% of overweight females and 7.5% obese females,
- 14.2% of 11<sup>th</sup> grade males are overweight compared to 12.0% of the females, and nearly twice as many 11<sup>th</sup> grade males (14.4%) are obese compared their same age females (7.3%),
- teens in the Portland Metro Tri-County region have lower percentages of being overweight (8<sup>th</sup> graders-13.6% overweight and 8.4% obese; 11<sup>th</sup> graders-11.2% overweight and 9.9% obese) compared to the state totals (8<sup>th</sup> graders-14.6% overweight and 9.9% obese; 11<sup>th</sup> graders-13.1% overweight and 10.9% obese),
- Eastern/Central Oregon region percentages (8<sup>th</sup> graders-15.7% overweight and 10.6% obese; 11<sup>th</sup> graders-15.1% overweight and 11.3% obese) are higher than state total which is reflective of the urban versus rural dichotomy.

*Exercise/activity related data.* The Surgeon General recommends at least 60 minutes of physical activity most days of the week and ideally daily for adolescents. Oregon teens did poorly in meeting the previous more modest recommendation of 30 minutes of moderate physical activity at least five days a week. Nearly 20% of 8<sup>th</sup> graders and over 25% of 11<sup>th</sup> graders did not meet the old recommendations (Ngo & Leman, 2007). Under the new recommendations, 42% of 8<sup>th</sup> graders and nearly 51% of 11<sup>th</sup> graders do not meet target (Ngo & Leman, 2007).

Lack of access to consistent, safe, and low cost exercise options is a result of several environmental factors. Though walking requires no additional equipment or costs, it may not be a feasible exercise option due to concerns about neighborhood safety or lack of reasonable walking paths or parks. Bicycle riding faces the same environmental challenges. Swimming

pools and exercise gyms tend to be located more centrally in urban areas and often have a membership or use fee associated to them. According to The California Endowment (2007a) communities with safe local parks (these promote physical activity) and practical opportunities to walk, run, and/or bicycle have protective environmental and infrastructure factors which contribute to healthy people and neighborhoods. Additionally, having convenient access to reliable transportation allows people to get to exercise facilities, jobs, and school.

Environmental and temporal factors making outside activities less desirable include inclement weather (rain, snow, extreme heat or cold), seasonal challenges (weather, early evening or late morning darkness), and geographic location. In a study by Singh, Kogan, and van Dyck (2008), the prevalence of childhood obesity varied across geographic areas of the US. They reported children in the South-central region of the US had the highest prevalence ( $\geq 18\%$ ) while the Mountain region had the lowest (11.4%), and children in West Virginia, Kentucky, Texas, Tennessee, and North Carolina had greater than twice the odds of being obese than children in Utah. Singh et al. concluded “although individual and area level socioeconomic factors are important predictors, substantial geographic disparities in childhood and adolescent obesity remain (p.90).”

Although decreased school budgets and physical education classes are thought to contribute to the decreased amount of activity, there are no well designed correlational studies. Oregon has limited ability to systematically track the conditions in communities that promote or discourage physical activity and healthy eating (OPANP, 2007).

### Case Analysis and Discussion

Despite consistent physical therapy sessions, trials of several medications, and encouragement to lose weight, XZ continued to report significant back pain and inability to regularly exercise at home. She attended two sessions in the Pediatric Coping Clinic where she was to learn cognitive behavioral therapy

(CBT) techniques to improve her function both emotionally and physically. XZ was uncooperative with this approach which she deemed “useless.” Without her engagement in this treatment modality, there was little hope for successful integration of CBT skills. Throughout her treatment, XZ and her mother often stated they thought there had to be something wrong and we just couldn’t find it. XZ and her mother refused to acknowledge that her weight and diminished physical conditioning were likely significant contributing factors to her back pain. At one point the mother asked if I would not make reference to XZ’s weight because it “bothered” her.

### *Ramifications, Interventions, and Prevention Strategies*

*Social/cultural.* In the Executive Summary of the Institute of Medicine (IOM) report, Preventing Childhood Obesity: Health in the Balance, Koplan et al. (2005) write, the society in which our children live has changed dramatically in the last three decades. The authors go on to say having both parents work outside the home and working longer hours; changes in school lunch programs; more meals eaten outside the home; community designs that effect what and how much children eat and their levels of physical activity; increased technology that encourages less activity (television, computers, video games, cellular telephones); and aggressive and focused food marketing are some of the changes noted. These characteristics have been accepted as a normal way of life even though they are contributing to increased levels of childhood obesity.

Like most other health conditions in the United States (US), obesity has significant racial-ethnic disparities with Mexican-American, African-American, and Native American children being disproportionately affected (Dietz, Lee, Wechsler, Malepati, & Sherry, 2007). While about 1 in 6 US children are overweight, a prevalence of almost twice that (nearly 1 in 4) exists for non-Hispanic black girls ages 6 to 19 (Anderson & Butcher, 2006). In an analysis of Mexican-American adolescents, 40.9% of the adolescents were overweight and 22.9% were obese (Forrest & Leeds, 2007). Prevalence rates of overweight and obesity in Northern Plains American Indians

exceeded those for all US children at almost every age (Zephier, Himes, Story, & Zhou, 2006). African-American women have a greater prevalence of obesity when compared to white women—49% versus 31% (Latner, Stunkard, & Wilson, 2005).

It is well recognized that obesity is more prevalent in communities of lower socioeconomic status (SES) (Isaacs & Schroeder, 2004; Vieweg, Johnston, Lanier, Fernandez, & Pandurangi, 2007; The California Endowment, 2007b). Many neighborhood factors have been identified and include increased number of fast food restaurants, decreased availability of fresh produce, higher crime rates, and fewer safe public parks and walking/biking trails.

Despite vast amounts of data showing pediatric obesity is a significant and growing health care concern; there is also a large amount of evidence indicating it is not perceived as clinically important by health care providers, patients, or their families (Baur, 2005). There are those subgroups of adolescents in whom a large size is an advantage such as football players. According to Malina, et al. (2007), youth football players may be at risk for being overweight and obese later in life given that childhood and adolescent weight conditions carry into adulthood for many individuals. While on one hand our society is appalled by obesity, on the other it is supported and even supported.

*Economic.* Overall spending associated with adult obesity in 2000 was \$117 billion, half of which was publicly funded through Medicare or Medicaid (Dietz et al., 2007). In 2003, the estimated medical costs related to obesity among adults in Oregon were \$781 million which represents nearly 6% of Oregon's total health care bill. Obesity-attributable medical costs to Medicare were estimated at \$145million (6% of Medicare costs) and \$180 million was financed by Medicaid (8.8% of Medicaid costs in Oregon) (Ngo & Leman, 2007).

*Ethical.* Even though obesity is multi-factorial, there is an ethical imperative to actively support prevention of those factors which can be influenced such as availability of healthier foods, increased activity, and improved environments in which increased activity is encouraged.

Obesity also carries a powerful stigmatization which can result in unethical treatment such as discrimination in education, employment, and health care settings, not to mention the impact of diminished self-esteem and negative body image (Latner, Stunkard, & Wilson, 2005).

*Political/legal.* At this time, most of the political and legal ramifications of obesity are related to cost of care. There is a small, but hopefully increasing interest by insurance companies to partner with providers in the medical setting to influence practices directed at preventing and treating childhood obesity. Insurance companies can also influence policy and local environments through partnerships with departments of health, schools, employers, and community organizations (Dietz et al., 2007)

Reilly (2006) cites a systematic review indicating pediatric obesity is a health burden that follows from childhood and adolescence into adulthood. The adverse effects of childhood and adolescence obesity include psychological ill health, cardiovascular risk factors, asthma, chronic inflammation, diabetes (Type 1 and 2), orthopedic abnormalities, and liver disease, and those for adults include persistence of obesity, cardiovascular risk factors, adverse socioeconomic outcomes, and premature mortality (Reilly, 2006). Even without dollar values assigned, the economic and societal impact of this health burden is obviously profound.

### Recommendations and DNP Involvement

Though recommendations have been made to standardize the definitions and language surrounding childhood obesity, these are inconsistently followed (Chinn, 2006) and some authors believe it is necessary to avoid stigmatizing terminology (Ngo & Leman, 2007) which may

further add to inconsistencies and confusion. The Doctor of Nursing Practice (DNP) should be a change agent in this situation by role modeling consistent use of terminology, correcting inaccurate information, publish reports using accurate terms and definitions, and continually reminding other professional about the importance of consistent definitions and language.

On a national level, obesity should be designated a national health priority with appropriation of funds and policies to support treatment and prevention strategies. Healthy marketing and media representation (including nutrition labeling and public relation campaigns) would also offer positive influences. Community programs and designs promoting physical activity and preventative health care would further support reducing the risk for obesity. School programs should be designed to increase student education regarding the importance of diet, exercise, and healthy life styles. Singh et al., (2008) suggest state policy measures that include: health promotion campaigns to increase physical activity by adding/improving trails, playgrounds, and recreational facilities; improving access to healthy foods and fresh produce in poor neighborhoods through grants, loans, and tax benefits; sponsoring educational/media campaigns that encourage limitations to TV watching, computer use, and video games; and designation of resources for surveillance, monitoring, prevention, and intervention research on obesity. Advanced practice nurses educated at the doctoral level are poised to make an impact concerning this recommendation by being involved in advocacy and policy development at the local, regional, and national levels to offer expert opinion about the impacts of marketing, physical activity, and education on childhood obesity and health.

Recommendations for land use planning and transportation from the Oregon Physical Activity and Nutrition Program (2007) report to the Oregon Health Policy Commission includes such strategies as creating incentives for local government to increase access to healthy food in



underserved areas; requiring “Health Impact Assessments” in municipal planning; requiring land use planning that promotes physical activity and healthy eating; including school costs in the System Development fees paid by land developers; ensuring school locations facilitate walking and biking to and from school; doubling the percentage of state highway funds dedicated to bicycle and pedestrian trails; and providing grants to community organizations in an effort to increase participation in outdoor physical activity through parks and recreation facilities.

The family lives in a fairly rural area of a small metropolitan area. XZ stated she was willing to walk as a form of exercise, but her parents would not allow her off their property for fear of her safety. XZ enjoyed swimming and had been on a swim team between the ages of nine and twelve, but she had to drop that activity when the family moved further out of the city. XZ’s parents did not have the financial resources for a gym membership and even if they had, transportation would again have been a problem as the gym was several miles away and both her parents worked and weren’t available to drive her. XZ took the bus to and from school. This was a forty minute ride and she was picked up and dropped off at the gate to the family property.

Involving the family in the treatment of this chronic, complex and multi-factorial disease is paramount. Beginning in early childhood, more innovative and effective interventions will likely result in improved and long-term results. Because weight management issues are so challenging, interventions should involve the family and actively engage the child and parent in adopting healthy eating and physical activity habits (St Jeor, Perumean-Chaney, Sigman-Grant, Williams, & Foreyt, 2002). Fernandez Rodriguez and Gonzalez Fernandez (2008) suggest “these interventions should be perceived by young people as pleasant to perform and attractive in outcome (p. 358).” Behavioral interventions targeting weight reduction and physical activity have been shown to improve the natural course of diabetes which is a major consequence of obesity (Jeffery & Sherwood, 2008).

Bariatric surgery has been offered as an acceptable weight loss option for some extremely obese teenagers (Kalra, Inge, Garcia, Daniels, Lawson, Curti, et al. (2005). However, this is a highly invasive procedure not without significant risks and potential complications.

For the vast majority of my patients, moving to better neighborhoods, securing gym memberships, and/or quickly losing weight are not reasonable expectations. It seems to me the best approach would be to involve the family in many of the physical and behavioral strategies that have been shown effective—self -monitoring, stimulus control, eating management, contingency management/rewards and cognitive behavioral techniques (St. Jeor, et al., 2002). For my patient XZ, involving her parents and brother in interventions of increased physical activity would be beneficial for each of them. Healthy meal planning and preparation could become a family function which encourages healthy eating as well as increasing family interaction time which seems to have a positive influence on family relationships as well as health status. Unfortunately, this patient and family pursued surgical interventions which had multiple complications and she was lost to follow up from our clinic.

### Self Reflection

Until writing this paper, I had given very little thought to the impact of the environment in which we live on obesity. My attitude has generally been ‘everyone can at least walk,’ but after reviewing the literature I understand the issue is much more complicated and I was being myopic. Writing this paper has given me a new appreciation for the complexity of childhood obesity and affirmed the importance of the DNP practitioner in impacting change.

I plan to incorporate an environmental assessment during the initial assessment of my patients in my clinical setting, and to develop a list of suggestions for options for exercise. Increasing awareness of the impact of environmental factors is necessary as well and can be done

through publishing, lecturing, and role modeling for other providers. Active involvement in community design and development is another opportunity for a nurse at the Doctor of Nursing Practice level. Political involvement to testify and support the need for healthy community development; increased infrastructure (walking paths, biking paths, parks, etc.) which encourages health activities; and funding support to subsidize fees for gyms and swimming pools also is within the scope and role of the DNP.

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Running head: TEENAGER WITH CHRONIC PAIN AND ADDICTION

Teenager with Chronic Pain and Addiction Disorder: A Case Study

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## Case Selection and Presentation

### *Co-existing Addiction and Chronic Pain*

As a Clinical Nurse Specialist (CNS) practicing in pediatric pain management, a significant part of my clinical work involves teenagers with chronic pain. The majority of these patients are willing and able to follow and benefit from the multidisciplinary treatment plan offered. The key components of treatment include physical therapy (PT) and counseling including cognitive behavioral therapy (CBT). Medications (especially opioids) are used only as needed to allow the patient to actively participate in PT and CBT. However, a number of teens I see present with or develop substance use disorders (SUDs) or addiction. These patients, though few in number, are very challenging and consume vast amounts of time. I am not trained to assess and treat co-existing SUDs which results in frustration and concern for these patients. The lack of understanding the behaviors exhibited and what feels like inappropriate use of my time are frustrating. I am concerned that I may be contributing to their SUDs because of my limited knowledge. I have selected a case to review that was particularly challenging and has been a major motivator behind my efforts to learn and understand more about addiction. What I learn in preparing this report will be a foundation for developing the knowledge and skill set I need to care for these patients.

### *Case Presentation*

Lulu (not her real name) was 16 years old when she was referred to the Pediatric Pain Management Clinic by her orthopedic surgeon. She had been involved in a motor vehicle accident ten months earlier, continued to report significant pain, and was requesting and being prescribed regular and consistent opioids. The referral note from her surgeon focused on Lulu's "prolonged need for narcotics."



At her first clinic evaluation, Lulu and her mother completed questionnaires designed to help the pain management team understand the patient's and family's perceptions of the pain problem, therapies that have been used in the past, and expectations of treatment. This initial visit also included evaluations by a clinical psychologist and a physical therapist.

Her medical and social history were notable for abdominal migraines; sexual abuse; alcohol, marijuana and cigarette use; one suicide attempt; school absenteeism; being sexually active; and a right hip fracture, right pneumothorax, and liver laceration received in the car accident ten months earlier. Lulu's family history was positive for depression and chronic pain in her mother and alcoholism in her biological father. She lived at home with her mother, stepfather who had been in her life since she was age 4, and six siblings. She also had a grown brother who was living on his own. Lulu had been evaluated by a psychiatrist 14 months earlier for mood swings, self injury behaviors, and insomnia. Recommendations from that evaluation included a referral to a post traumatic stress disorder (PTSD) clinic and regular psychotherapy sessions. These recommendations were not followed.

Her physical exam was remarkable only for healed scar over her right iliac crest, healed scar over site of right chest tube insertion, and her thin appearance. She reported having lost 20 pounds since the accident. Her hip x-rays were reviewed and showed a healed iliac fracture with three fixation screws and no other deformities. No laboratory tests were obtained.

Approximately six weeks prior to coming to the pediatric pain clinic, Lulu had been prescribed sustained release oxycodone (Oxycontin) 20 milligrams (mg) every 8 hours and immediate release oxycodone 5mg every 4 to 6 hours as needed for pain by her orthopedic team. Our initial treatment plan included increasing her Oxycontin to 30 mg every 8 hours, regular PT, and CBT and counseling in our affiliated Coping Clinic. As is standard with our prescribing of

opioids, we discussed our expectations regarding these medications which are: we are the only prescribers, no adjusting doses without our approval, call for refills during normal business hours only, and allowing two to three days to process refills. Lulu and her mother indicated they understood the plan and expectations and were motivated to improve Lulu's functioning (including returning to school) and decreasing her need for opioids.

Over the next 4 months, Lulu's Oxycontin dose was titrated to 80 mg every 8 hours in an attempt to provide her acceptable pain relief and minimize her use of immediate release oxycodone. Her attendance at PT and Coping Clinic appointments was sporadic with multiple excuses for missed appointments. There had been one early refill request after "about 30 pills were dropped in the sink and down the drain." Approximately one week after the dose increase to 80 mg, Lulu was seen in the orthopedic clinic where it was noted "she was over narcotized or using other drugs." One week later a request for an early refill was placed by Lulu's stepfather as she had "been vomiting so she had used extra pills." Several desperate calls over the next few days, including one from Lulu's grown brother saying "she can't live like this" and one from Lulu saying her "stepfather must be taking my pills," resulted in Lulu and her family seen urgently in clinic to develop a new treatment plan. The decision was made to switch her to methadone. However this was unsuccessful as Lulu vomited with every dose of methadone and she was put back on Oxycontin. A care conference was held with Lulu, her mother, one of the pain physicians, the psychologist familiar with her case, and me. The main point of discussion was our concerns for opioid misuse. It was agreed prescriptions would be limited to two week supplies, we would mail them on schedule, there would be no early refills, Lulu and her mother needed to identify three possible sources of counseling in their local community, and Lulu was asked to read and sign an opioid agreement.

Over the next 10 weeks there were fewer calls from Lulu's family, but her attendance at PT and Coping Clinic remained inconsistent. Requirements of her insurance company were making it difficult to secure local counseling. The family seemed more focused on their lawsuit against Lulu's friend who was driving the car in which Lulu was riding when the accident occurred.

When drug paraphernalia was found in a purse she left in the clinic, it was determined Lulu was either using illicit drugs or misusing her Oxycontin. Lulu and her mother were confronted with the paraphernalia at her next appointment. Lulu denied knowing anything about it and her mother didn't seem overly concerned. The decision was made by the pediatric pain team to wean Lulu off Oxycontin. This was done at over the next four months. Lulu was lost to follow up two months after her final prescription was sent after having been in our care for about 15 months.

### *Review of Literature*

Terms such as addiction, dependence, tolerance, and substance use and abuse are used inconsistently and even incorrectly among different health care services, whether they are primary care, addiction, mental health, or pain specialists. Inconsistent use of terminology creates significant confusion among clinicians and patients, and this confusion adds to the complexity of caring for patients with chronic pain conditions receiving opioids therapy.

In a 2001 consensus statement issued by the American Academy of Pain Medicine (AAPM), the American Pain Society (APS), and the American Society of Addiction Medicine (ASAM), addiction is defined as:

a primary, chronic, neurobiologic disease with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is

characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm and craving.

(p. 2)

In the same consensus statement, dependence is defined as: “adaptation that is manifested by a drug class specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist (p. 2),” and tolerance is defined as: “a state of adaptation in which exposure to a drug induces changes that result in a diminution of one or more of the drug’s effects over time (p. 2).”

According to the American Psychiatric Association’s (1994) *Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition (DSM-IV)*, substance dependence can be diagnosed when a person continues to repeatedly use a substance despite problems associated with the use of the substance. This pattern of use may result in withdrawal if the substance is stopped or reduced and tolerance to the effects of the substance. Substance abuse is a maladaptive pattern of substance use leading to clinically significant impairment or distress (e.g., failure to attend to work, school, or home responsibilities), use when physically hazardous (e.g., driving or operating machinery), use resulting in legal problems (e.g., arrests for disorderly conduct or illegal possession or distribution), continued use despite repeated social or interpersonal problems resulting from use of the substance, and the symptoms have not met criteria for substance dependence (DSM-IV). Substance dependence is generally more regular and consistent use whereas substance abuse may be inconsistent but interferes with usual life responsibilities. Substance abuse and substance dependence are considered SUDs according to the DSM-IV.

Addiction is characterized by cravings and preoccupation with obtaining the substance; using more than necessary for the intoxicating effects; and experiencing tolerance, withdrawal, having decreased drive for ordinary daily activities and responsibilities (DSM-IV, 1994).

Pseudoaddiction is an iatrogenic syndrome caused by the under treatment of pain and is frequently misidentified by clinicians as inappropriate drug-seeking behaviors (Weissman & Haddox, 1989). These behaviors which resolve when the pain is adequately treated can include clock watching, anger, and asking for specific or more medications. Pseudoaddiction is not a diagnosis but rather a description of a clinical interaction, and clinicians often erroneously label it as addiction.

The latest data from the Substance Abuse and Mental Health Services Administration (SAMHSA); (2008) indicate approximately 8 percent of Americans, aged 12 years or older, are current users of illicit drugs. Illicit drugs are categorized as marijuana, nonmedical use of psychotherapeutic medications, inhalants, hallucinogens, and cocaine. Pain relievers, tranquilizers, stimulants (including methamphetamine), and sedatives are considered psychotherapeutics. In persons 12 years and older, 2.8 percent (6.9 million) used psychotherapeutics nonmedically and of those 5.2 million used pain relievers. According to the 2007 National Survey on Drug Use and Health (NSDUH), 9.5 percent of youth aged 12 to 17 years used illicit drugs, which is a decline from the 11.6 percent reported for 2002 (SAMHSA).

Of the youth 12 to 17 years of age reporting illicit drug use in the 2007 NSDUH, 3.3 percent used prescription psychotherapeutics for nonmedical reasons which is down from 4 percent in 2002, but this was a 212% increase from 1992 (Ford & Arrastia, 2008; SAMHSA, 2008). The 2007 NSDUH reports 2.5 percent of females and 2.8 percent of males aged 12 to 17 use pain relievers for nonmedical reasons and from 2002 to 2007, nonmedical use of pain

relievers declined from 3.2 to 2.7 percent (SAMHSA). Other data from the NSDUH indicate males have about two times the illicit drug use rate as females except in the 12 to 17 year old age group where the rates are nearly the same; Asians have the lowest rate (4.2%), followed by Hispanics (6.6%), whites (8.2%), Blacks (9.5%), persons of mixed races (11.8%); and the highest rates are among American Indians or Alaska Natives at 12.6% (SAMHSA).

Addiction is very rare (less than 1 percent) in patients receiving opioid therapy for severe, acute, and cancer pain (Portney & Foley, 1986; Porter & Jick, 1980). According to Ballantyne (2006), the risk for iatrogenic addiction (addiction surfacing during opioid treatment of pain) is likely somewhere between 5 and 19 percent. These numbers are based on adult data and problematic because, even in adults, iatrogenic addiction is not well defined or understood. The prevalence of SUDs and addiction in teenagers receiving opioids for chronic pain is essentially unknown. Tools for addiction risk assessment have been developed for adult chronic pain patients or those teens with primary substance abuse disorders, but none are specific to teenagers receiving opioid therapy for chronic pain. This paucity of evidence adds further the challenge of caring for this multifaceted population.

#### Substance Use Disorder in Pediatric Pain Management

The goals of treatment for patients coming to the Pediatric Pain Management Clinic include decreasing pain with a minimum of medications, obtaining restorative sleep, developing effective coping strategies, increasing function (physical and psychosocial), developing a treatment plan for pain exacerbations, and having appropriate goals for the future. These treatment goals are reached with variable levels of success, as each patient situation is unique and treatment must be individualized. When co-existing conditions are identified every effort is made to facilitate referral to appropriate specialists.

*Critical Decision Points and Interventions*

The decisions to increase Lulu's Oxycontin doses were done to provide pain relief, decrease the use of immediate release oxycodone, and to overcome the potential development of opioid tolerance. Even though I see these patients as a licensed independent provider, I constantly review them with the physicians and psychologists in our group especially during periods of dose escalation or when dosing becomes unusually high as was the case with Lulu. It was frequently discussed that despite increasing doses we were seeing little benefit for Lulu, and we considered other possibilities such as pseudoaddiction, opioid induced hyperalgesia, and SUDs.

Another critical decision point came when Lulu was noted to be over sedated followed by a series of intense phone calls. Though none of us has expertise in addiction, discussion with other pediatric pain team members affirmed my concerns about SUDs. The decision to try methadone was based on it being a less desirable drug for misuse; it may offer improved analgesia in certain pain conditions; and because of its formulation it is easier to titrate. When this was unsuccessful, a very specific and controlled Oxycontin regimen was developed. I attempted to find adolescent addiction specialists who we could refer Lulu to or consult with for advice.

The final critical decision came with the discovery of the drug paraphernalia. It was clear to the team that Lulu had a SUD our clinic was ill equipped to deal with her disease; and I had not been able to identify any local experts. Additionally, as prescribers, we have an obligation to protect the public from controlled substance misuse. It seemed prudent to discontinue her access to opioids unless she was under the care of an addiction specialist.

None of the decisions made during Lulu's care were done without careful consideration and discussion. However, without specific training in SUDs, clinical decisions were based on intuition, professional reading, and experience. This case became the impetus for my decision to gain more knowledgeable of SUDs and their treatment.

#### *Evaluation of Care and Implications for Specialty*

The outcomes of this case were not desirable given Lulu did not experience increased function nor decreased pain, continued to demonstrate behaviors consistent with addiction, and was lost to follow up. Reviewing this case has allowed me to more objectively evaluate the treatment decisions. I am confident in the decisions made throughout Lulu's care given my existing knowledge and experience with SUDs. I have also become aware of many of the risks associated with SUDs including PTSD, school absenteeism, minimal parental involvement or disapproval of drug use, early substance use, sexual activity, and multiple substance use including cigarettes and alcohol (Becker & Curry, 2008; Ford & Arrastia, 2008; SAMHSA, 2008).

As a future Doctor of Nursing Practice (DNP), I must find and implement the best evidence based practice guidelines, risk assessment tools, and treatment recommendations. Doing this will require me to obtain additional education focused on SUDs and networking with SUD experts in the specialty of pain management and adolescent SUD experts. To this end I have attended a three day conference on addiction free pain management and identified several distance learning or online continuing education programs. I will assure complete knowledge on the correct use of terminology among health care providers and others with which I interact. Searching the literature for applicable studies and evidence must be a routine and ongoing part of my clinical practice and professional development. Because there is an obvious lack of literature



in this area, publishing relevant articles will make a contribution to nursing knowledge. I must advocate within my practice, community, state, and the nation for more and more accessible services for teens with substance abuse disorders. The 2007 NSDUH indicates less than 10 percent of adolescents in the community who meet criteria for SUDs receive treatment (SAMHSA, 2008).

### Self Reflection

As a person whose career focus is to relieve pain and suffering, the most difficult message to deliver to my patients and their families is that the child may have pain for the rest of his or her life. The next most difficult is to tell them the current level of pain may have to be accepted and we need to focus on improving functionality. My experience has been that these two concepts are universally unacceptable to and resisted by patients with substance abuse disorders.

The 15 months of caring for Lulu was similar to a roller coaster ride in that there were highs, lows, unexpected curves, and some level times. Some of this wild ride was driven by Lulu's and her family's behaviors, but much of it was driven by my lack of knowledge and understanding of SUDs. My professional and personal obligation to gain more knowledge and skills has been driven by my experience with Lulu. I have cared for several similar patients since Lulu and with each one I have been able to use my growing knowledge and skill set resulting in improved care for my patients. I am able to more quickly recognize aberrant behaviors, set boundaries, or if necessary discharge the patient from my care. I fully recognize I am a neophyte in this area of clinical practice, but I embrace the opportunity to continue to learn, grow, and become a resource for other providers caring for patients with substance use disorders. It has

become even more clear to me as I have prepared this case report, that I often don't even know what I don't know.

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Running head: PEDIATRIC PATIENTS AND OPIOID INDUCED HYPERALGESIA

Opioid Induced Hyperalgesia in Pediatric Patients

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## Case Selection and Presentation

### *Opioid Induced Hyperalgesia*

Hyperalgesia is an increased pain response to a noxious stimulus. Opioids are medications commonly used to produce analgesia (pain relief). Why then is there such a condition as opioid-induced hyperalgesia (OIH) in which the treatment may make the condition worse? As a Clinical Nurse Specialist (CNS) practicing in pediatric pain management, I see patients with various painful conditions. I am often consulted to help when the pain seems out of proportion to the condition or when the usual treatment is ineffective. After a thorough medical history, review of current clinical situation, and a physical exam; I routinely consider four possible causes of inadequate analgesia. The first possibility is the patient may have developed pharmacological opioid tolerance. Secondly, the child may have developed behavioral responses that are dramatic and unusual. A third possibility is inappropriate medication use, and finally the patient may be experiencing OIH which is the focus of this case report. Distinguishing between OIH and tolerance requires direct assessment of pain sensitivity. This is not practical in day to day clinical practice, and is complicated by many medical factors and conditions. Because I did not have a definitive diagnosis in any one case, I have chosen three cases to illustrate this phenomenon.

### *Case Presentations*

Lulu (not her real name) was referred to the Pediatric Pain Management Clinic by her orthopedic surgeon. She was 16 years old, had been involved in a motor vehicle accident ten months earlier, continued to report significant pain, and was requesting and being prescribed regular and consistent opioids. Her medical and social histories were reviewed, and her physical exam was remarkable only for healed scar over her right iliac crest, healed scar over site of right

chest tube insertion, and her thin appearance. Her hip x-rays were reviewed and showed a healed iliac fracture with three fixation screws and no other deformities. No laboratory tests were obtained. Over four months, Lulu's Oxycontin dose was increased from 20 mg every 12 hours (BID) to 80 mg every 8 hours (Q8H) in an attempt to provide her acceptable pain relief and minimize her use of immediate release oxycodone.

Bebe (fictitious name) was an 8 month old admitted to the Pediatric Intensive Care Unit (PICU) with meningococemia sepsis resulting in massive tissue necrosis. Her medical history and current treatment were reviewed. Her physical exam was remarkable for complete necrosis of both legs below the knees and three fingers to the second joints; wound vacuum applied to poorly healing abdominal wound secondary to abdominal compartment syndrome; multiple areas of skin breakdown of various depths (some to the bone) requiring frequent dressing changes; intubation and ventilator support due to respiratory failure; and crying and wincing with any movement. I was consulted to assess her inadequate sedation and analgesia when she had been on continuous high dose opioid and benzodiazepine infusions for 37 days.

Tom (alias) was an 18 year old in remission from acute lymphocytic leukemia after a matched unrelated bone marrow transplant complicated by inadequate analgesia and severe graft versus host disease (GVHD) requiring high dose steroids. Tom had developed avascular necrosis (AVN) in both hips and both shoulders as a result of the steroid treatment. I was involved in Tom's pain management both during hospitalization and outpatient treatment. His physical exam was unremarkable except for pain limited range of motion of his hips and shoulders. Over the course of a year Tom had four joint replacement surgeries (both hips and both shoulders), and his Oxycontin doses increased from 40 mg BID to 120 mg Q8H.

## Review of Literature

Opioids are used to treat pain and provide analgesia. When opioid tolerance develops analgesia decreases. A common clinical approach to improve analgesia and overcome tolerance is to increase the opioid dose. OIH is a paradoxical response to opioids being administered to provide analgesia, and may be an alternative explanation for opioid tolerance.

Hyperalgesia has been observed during opioid withdrawal (Chang, Chen, & Mao, 2007; Compton, Athanasos, & Elashoff, 2003; Mao, 2008). Clinicians have noted hyperalgesia in patients with opioid addiction for many years (Chang, Chen, & Mao, 2007; Compton, Athanasos, & Elashoff, 2003; Compton, Charuvastra, & Ling, 2001; Doverty et al., 2001; Koppert, 2007; Nackley, Diatchenko, & Maixer, 2006). Studies in recent years suggest hyperalgesia may occur during opioid administration, rapid dose escalation, and increased dosing (Angst & Clark, 2006; Compton, Athanasos & Elashoff, 2003; Mao, 2008; Mercandante & Arcuri, 2005). A relatively recent shift toward more aggressive pain management and increased use of opioids has resulted in increased adverse effects such as allodynia, myoclonus, seizures, and OIH (Mercandante & Arcuri).

The mechanisms of OIH are still not clearly understood, but appear complex, multifaceted, and perhaps genetically influenced (Mao, 2008; Nackley, Diatchenko, & Maixer, 2006). Data suggest involvement of the peripheral, spinal cord, and higher central nervous system structures in OIH (Angst & Clark, 2006). There is some evidence demonstrating neuroplastic changes with prolonged opioid exposures, and these changes result in enhanced neuropeptide activity and release which manifests as increased pain and antinociceptive tolerance (Chang, Chen, & Mao, 2007; Mao, 2002; Pud, Cohen, Lawental, & Eisenberg, 2006; Xu, Colpaert, & Wiesenfeld-Hallin, 2003). Various neuroreceptors appear to play a role in the

development of OIH and may be influenced by genetic and/or neurobiologic factors (Nackley, Diatchenko, & Maixer, 2006). Nackley and colleagues discuss the significance of increased expression of  $\beta_2$ -adrenergic receptors and opioid receptor stimulation inducing hyperalgesia.

Distinguishing between increasing pain, opioid tolerance, and OIH is challenging. In his summary of the clinical implications of OIH, Mao (2008) describes two approaches. The first is to differentiate the quality, location, and distribution of the pain. OIH tends to be generalized pain while pre-existing and neuropathic pain tend to have distinct anatomic distributions. The second differentiation comes with opioid dosing. OIH will increase with opioid dose escalation and decrease with dose tapering, whereas, pre-existing pain and tolerance will decrease with increased opioid dosing.

The obvious treatment for OIH would be prevention; however, because of the unpredictability of its occurrence this is difficult. Avoiding OIH may be easier with careful opioid dose escalation and the addition of adjuvant therapies such as *N*-methyl-D-aspartate (NMDA) agonists such as ketamine,  $\alpha_2$  agonists such as clonidine, or non-steroidal anti-inflammatory drugs (NSAIDs; Koppert, 2007; Mercandante & Arcuri, 2005; Simonnet, 2005). Using mixed opioid agonist antagonist medications, such as buprenorphine, or adding a low dose opioid antagonist, such as nalaxone, have also been shown to decrease OIH (Simonnet & Rivat, 2003). Mercandante and Arucuri also describe the potential benefit of opioid rotation. Stimulation of the 5-hydroxytryptamine<sub>1A</sub> (5-HT<sub>1A</sub>) or serotonin receptors may also be beneficial (Xu, Colpaert, & Wiesenfeld-Hallin, 2003).

There is strong evidence in both the animal and human studies supporting the existence of OIH. Scientists and clinicians agree this is a complex and still poorly understood



phenomenon. However, clinicians must consider the possibility of OIH when assessing and treating patients receiving opioids who are reporting inadequate analgesia or increasing pain.

#### Critical Decision Points and Interventions

In none of the three cases was there a clear and definitive diagnosis of opioid induced hyperalgesia as each case had confounding factors. However, it was very high on the list of differential diagnoses being considered.

At the time of Lulu's first evaluation in our clinic, I felt her inadequate analgesia was likely due to opioid tolerance, which is treated by increasing the opioid dose or opioid rotation. I opted to increase her dose which seemed to offer relief for a few weeks, but then she reported the pain wasn't better and maybe even a bit worse. At that time I was concerned that she might be experiencing OIH. I discussed her case with other members of the team and they concurred it was certainly possible. Distinguishing between tolerance, increasing pre-existing pain, and OIH can be challenging. By my assessment, Lulu was not showing clinical evidence of increased pain in her hip. She now described more generalized body pains which I attributed to deconditioning and muscle atrophy. Opioid tolerance seemed more likely given she reported decreased pain after the previous dose escalation. The easiest way to make a clinical assessment of OIH is to carefully decrease the opioid dose. If the patient reports less pain, it can be assumed OIH is present. I was hesitant to decrease her opioid dose because she lived 2 hours away and transportation was a challenge. I didn't feel this was appropriate care unless I could see her daily and be able to make dose adjustments quickly if she got into a pain crisis. With each dose escalation, the team considered the possibility of OIH, but it quickly became apparent Lulu had a substance use disorder (SUD) and was weaned from her opioids for that reason. Her pain levels

remained consistently inconsistent throughout the weaning so we were not able to use that as a clinical indicator of OIH, and in review her pain reports were likely distorted by her SUD.

When I was consulted on Bebe, I had three differential diagnoses in mind. She was receiving extremely high doses of opioids which may have resulted in opioid toxicity or OIH, or she may have had opioid tolerance. This infant was still critically ill with significant sources of pain and agitation. As per my routine practice with challenging cases, I discussed her care with other members of the pain team. We all had the same concerns, and my decision to drastically reduce her opioid dose was based on intuition. The critical decision involved how much to decrease her opioid infusion. Initially I thought about a 50% reduction, but I had never made that severe of a reduction before, and given this was based on intuition I made a more conservative reduction of 30% which was still viewed with concern by the PICU physicians. Bebe tolerated the decrease well and we reduced her opioid infusion another 20% the following day. She was less agitated and gave no indication of increased pain. However, in this infant it was impossible to know if she was experiencing opioid toxicity, OIH, or both.

Decisions around Tom's care were influenced by my experience with his difficult to control pain during previous hospitalizations for severe GVHD and AVN. He had inadequate analgesia with several opioids, but was finally able to have some relief with significant doses of intravenous hydromorphone which I thought to be indicative of opioid tolerance. So when, as an outpatient, he had inadequate analgesia, I did not hesitate to increase his Oxycontin. Initially he reported that most of his pain was in his hips. He had minimal pain in his right hip after it was surgically replaced, but then his left hip was problematic and I increased his dose further. My intervention was based on his apparent tolerance, and it is not unusual for patients to become aware of different but pre-existing pain when the worst source of pain is treated. After the left

hip was replaced, his shoulders became the focus. At this point he was receiving Oxycontin 100 mg Q8H, which was well above the dose where dose reduction or opioid reduction should be considered (Ballantyne, 2006). Another discussion with pain team members resulted in my decision to increase him to 120 mg Q8H with the understanding we would increase no more and start to wean as soon as he was recovered from his shoulder replacements. Again, I cannot definitively say Tom had OIH rather than tolerance. His weaning was slow and he did not report feeling better with each wean. If he had pure OIH, I would expect him to feel better with each dose decrease. A definitive diagnosis in Tom's case is further complicated by the length of time he has been receiving opioids and the level of dependence (both physiologic and emotional) he has developed to the opioids. The literature on OIH is either based on animal models, experimental pain models, or clinical reports in adults making it difficult to translate to the care of children receiving opioids. Therefore, many of my decisions and interventions were based on intuition and other clinical experiences. However, what I have found in the literature will be shared and discussed with my colleagues as a basis for future discussions and decisions regarding patients who may have developed OIH.

#### Evaluation of Care and Implications for Specialty

Each of these cases has had a different outcome and in none of them was I confident that what I was dealing with was OIH, though it was forefront in my clinical decision making. In reviewing these cases, I don't think I would have changed any of my treatment decisions, but what I have learned will help me have a more thoughtful assessment and treatment plan when I encounter what might be OIH in the future. A subset of the population I care for that is at particular risk for OIH are those critically ill children in the PICU. These children often receive high doses of opioids and rapid dose escalations.

As a future Doctor of Nursing Practice (DNP), I cannot focus my professional reading solely on the pediatric population. The vast majority of research (animal and human) is reported in the adult journals and I need to expand my reading in these areas. Having a dual specialty (pediatrics and pain) has been difficult, but throughout this program it has become clearer to me that I need to redirect more of my focus toward the pain literature. I have begun to share relevant articles with my physician colleagues and will continue to do so as I expand my reading. One of my constant struggles is finding time to do the reading. I have been much better about spending at least two hours a week reviewing my professional journals and choosing one or two articles to read in depth. I am considering scheduling an appointment with myself to make this even more consistent as it is an important to my ongoing learning and keeping abreast of advances in pain management.

OIH is a relatively newly recognized phenomenon and given the lag time between the discovery of specialty knowledge and application at the bedside, it will be necessary for me to provide information regarding OIH to the providers and nurses I come in contact with. This will be an ongoing and informal but important activity in my efforts to optimize pain management while being vigilant for potential complications and adverse effects.

I will use this new knowledge to develop, with other members of the pain team, a more systematic approach to OIH. This may eventually include a practice guideline regarding maximum opioid dosing, opioid rotation, use of adjuvant agents, and how to assess for OIH in the pediatric patient. Given the lack of pediatric literature, it would behoove me to publish and present on this topic as well.

### Self Reflection

This case report has given me an opportunity to reflect on several patients I have encountered over my years of practice in pediatric pain management. This reflection also resulted in evaluating my strengths and areas of potential growth. When I started in this practice over 8 years ago, my focus was to relieve pain and suffering at all costs. I have come to realize pain management is much more complex and occasionally my treatment can add to the pain and suffering. The field of pain management is literally exploding with new information and there is so much to learn. As with the fairly recent recognition of OIH, I believe there is still so much we don't know.

Caring for children is even more challenging as we are often borrowing from the experiences of adult providers and researchers and making modifications with little scientific basis for the pediatric patient. I have been blessed with excellent intuition, but I am well aware of the inherent risks of intuition based decision making and believe evidence based care is more consistent, provides for more rational decision making, and allows us to better measure our successes and failures. Though much of my focus in clinical practice is to relieve pain and suffering, I no longer approach it without careful consideration of the many potential consequences of my recommended treatments. My mantra is no longer "just give more!"

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Running head: PARENTING BEHAVIORS OF TEENS WITH CHRONIC PAIN

Difficult Conversations about Unhealthy Parenting Behaviors for Teens with Chronic Pain

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### Case Selection and Presentation

Seeing a child in pain is difficult for any parent. How the parent reacts and responds to the child in pain, and how the child responds and reacts to the parent are dependent on factors such as cultural background, social context, temperament, relevance of pain, previous pain experience, and the perception of control (Claar, Simons, & Logan, 2008; Logan & Scharff, 2005; Peterson & Palermo, 2004). Being the parent of an adolescent with chronic pain is fraught with additional challenges such as feeling incompetence in being an effective parent, uncertainty about the future, and a feeling that he/she is parenting a younger child (Jordan, Eccelston, & Crombez, 2008).

Many of the parents of the adolescents with chronic pain seen in the Pediatric Pain Management Center demonstrate significant distress related to parenting their child. In my experience these parents struggle with several issues. While wanting their teen to be pain free, these parents are frustrated by the often lack of diagnosis or cause for the pain, the amount of time spent in pain related healthcare appointments, and difficulty understanding the teen's pain behaviors.

The multidisciplinary approach we use to treat pediatric pain management includes decreasing pain with a minimum of medications, obtaining restorative sleep, developing effective coping strategies, increasing function (physical and psychosocial), developing a treatment plan for pain exacerbations, and having appropriate goals for the future. In order to progress toward improved functionality, the patient must be actively engaged and participate in the treatment plan. The parents are asked to be supportive of their child, and also to follow the treatment plan. When parenting styles or behaviors perpetuate the teen's pain behaviors progress

through the treatment plan may be impeded. Many health care providers find it difficult to have conversations with parents identifying these behaviors and their impact on the teenager.

### *Case Presentation*

Bob was a 16 year old with chronic abdominal pain. I first met Bob when he was in the hospital and I was consulted to help manage his pain. He was undergoing an extensive work up to determine the cause of his pain. The family had transferred care to Doernbecher because of their dissatisfaction with care received at another hospital. According to his mother Jo, Bob had suffered a massive gastrointestinal (GI) bleed requiring transfusions six months prior to our meeting. He had then undergone extensive testing at the other hospital and been given the diagnoses of Crohn's disease and mesenteric artery infarction. Jo reported Bob's GI bleed had been precipitated by the significant doses of non-steroidal anti-inflammatory drugs (NSAIDs) he had been taking to treat headaches and some diffuse joint pains.

Other than his GI issues, Bob's medical and surgical histories were negative. He reported morphine as an allergy, however his reaction was itching which is a side effect rather than an allergy. His immunizations were up to date. He maintained A's and B's in school and had lots of friends, including a steady girlfriend. He lived at home with his parents and younger brother. Family history was significant only for mother's diagnosis of fibromyalgia and depression, and his brother's diagnosis of autism. His father worked as a heavy equipment mechanic and his mother owned her own medical transcription business.

During the initial hospitalization, Bob was receiving intravenous (IV) hydromorphone via a patient controlled analgesia (PCA) pump which was only minimally effective at relieving his pain and the impetus for my consultation. My initial encounter with Bob and Jo was notable in that Jo did all of the talking even when questions were directed at Bob, and her demeanor was

defensive, angry, and distrustful. Unfortunately Jo's manner was offensive to many clinicians and interactions with her were avoided if possible. Over the course of the next two and a half months, Bob had four more admissions and our team was involved immediately each time. As an outpatient Bob was taking oxycodone or hydromorphone along with lorazepam. Jo had initially been resistant to our recommendations for amitriptyline and gabapentin, and during the third hospitalization had me paged to inform me she was "firing the Pain Service" because of an interaction with one of the psychologists during the first admission and because "we weren't making Bob's pain better." We had a long conversation resulting in Jo changing her mind and being willing to "give the Pain Service a second chance." After this conversation, Jo seemed less angry and distrustful.

The pain treatment plan for Bob included weaning him off the oxycodone, hydromorphone, and lorazepam; starting gabapentin and amitriptyline; physical therapy for strengthening and conditioning; and Coping Clinic to learn non-pharmacological methods of relaxation and coping with his pain. Over the next three months, Jo called often as Bob's pain seemed poorly controlled and the medications were less effective. At one clinic visit, Bob reported his pain as being fairly well controlled, but he was overly sedated and had not been attending school due to the sedation. Approximately three weeks after that visit, Jo called to request a refill of Bob's hydromorphone and to report his pain was again poorly controlled. I reviewed his refill records and determined he had used nearly 1,600 milligrams (mg) of oral hydromorphone in a two week period. At that point, I discussed Bob's case with other members of the Pain Service. It was agreed Bob needed to be changed to a long acting opioid. I chose to use methadone. When I returned Jo's call, we had a long and emotional conversation which

became a turning point in Bob's recovery. It is this conversation that I will use as a basis for the remainder of this paper.

### Review of Literature

As an undergraduate nursing student, my only exposure to communication theory was in a speech communication class. My nursing faculty talked about the use of "therapeutic communication" when working with our patients, but there was almost no content on how to deal with conflict or have difficult conversations with patients. I have had many occasions over the years to wish I had better training and skills in this aspect of patient care.

Searching the health care literature overwhelmingly results in publications about "delivering bad news" such as poor prognosis or outcome, confronting colleagues about unacceptable behaviors, or how to communicate more effectively in time limited encounters with patients. An internet search using the Google search engine and the phrase "difficult conversations" resulted in over 1.5 million hits. Scanning the first 150 hits resulted in less than ten related to healthcare and most of them were books following the aforementioned themes. The vast majority of references were based in the human resources and corporate management arenas. A plethora of literature regarding communication styles and strategies exist, but none was specific to communicating with patients and families about relationships and behaviors that interfere with health and recovery.

Patton (1999) describes a difficult conversation as "any conversation that you dread and perhaps seek to avoid, if possible" (p. 1). He goes on to write there are three inherent challenges that make these conversations difficult. These are that there is more than one way to understand the situation, the situation is highly emotional, and the situation is psychologically threatening to one of the parties. Lasley (2006) describes the "Authentic Communication" method for difficult

conversations which is based on the work of Marshall Rosenberg who believes everything we do or say is an endeavor to meet a need. The core philosophy of Authentic Communication involves identifying the need, empathizing with the need, and then developing strategies to meet the need. Lasley states “in a fast-paced work place, we often tell ourselves that we don’t have time for feelings. But ignoring them, and by extension ignoring our needs, may actually sabotage our productivity” (p. 2). The literature supports that intense emotions and feelings during difficult conversations compound the challenge of providing content that may already be intensely emotional.

Mauksch, Dugdale, Dodson, and Epstein (2008) identified three domains for physicians to improve communication and relationship quality while remaining time efficient during patient encounters. These domains are rapport building, up-front agenda setting, and acknowledgement of the patients’ social and emotional clues. In reporting the results of the Kalamazoo Consensus Statement, Makoul’s (2001) summary implies efforts to improve communication can increase the effectiveness of physician-patient communication, augment satisfaction for both the physician and patient, and improve health outcomes. Oates and Paasche-Orlow (2009) write that patients with the greatest disease burdens often are the least able to understand and utilize health information in part due to poor clinician communication. While these reports describe the attributes of more effective communication, there is no discussion of how to communicate with parents when their behaviors are interfering with their child’s care.

Sumner and Fisher (2008) in their description of the theory of the Moral Construct of Caring in Nursing as Communicative Action, describe the nurse-patient interaction as “an interactive, collaborative, covenantal, social contract, related to providing solace for the human condition, and which requires reciprocal accountability and answerability” (p. E22). They also

describe the bidirectional nature of communication between nurses and patients and when communication is ideal it can meet the needs of both. When accountability and answerability are reciprocal, communication is improved because it is bidirectional and meets the needs of both parties.

There is a growing body of research on the impact of parent/teen interactions, parenting styles, and the impacts these have on a child's pain response and coping style. Additionally, there is an abundance of literature on improving communication and having difficult conversations, but there is scarce literature about having the difficult conversation with parents when parenting behaviors have a negative influence on an adolescent's ability to be successful in a pain management treatment plan.

#### Critical Decision Points and Interventions

More than once, I heard clinicians discuss how challenged and frustrated they were by Jo. They complained that she was angry, wouldn't let Bob speak for himself, was resistant to many of the treatments offered, and was fixated on finding the cause for Bob's pain before making treatment decisions. Nursing staff voiced similar comments and feelings of ineffectiveness in caring for Bob. When the Pediatric Pain Service is involved in the care of patients with complicated family-health care team dynamics, there seems to be a belief among the other providers that the psychosocial aspect of care defaults to the Pain Service. Perhaps this belief is based on the concept that the pain experience is heavily influenced by psychosocial factors, but in reality most clinicians are ill prepared by the biomedical model of health care to effectively deal with this aspect of patient care. While I have no better training than most, I found Jo responded well to being "listened to" and being given time to make decisions. During the conversation when she was planning to "fire the Pain Service," I did not try to dissuade her.

Rather, I acknowledged her frustrations (not having a diagnosis for Bob's pain, receiving conflicting information from members of the health care team, and her lack of trust in the health care system in general), I let her know it was her right to not have us involved in Bob's care, and I offered some suggestions for her as she looked for other providers.

I believe my willingness to listen without becoming defensive and not trying to change her mind but instead give her options was critical for her to begin to trust me and be able to work as a member of the team caring for her son. I am a direct and honest communicator, and I believe it is essential to use language that the family is able to understand. I make every effort to put myself in the parent's place so I can be more empathetic, and I take responsibility for my misunderstandings or mistakes. The establishment of a respectful and trusting relationship makes having difficult conversations easier for both parties. Taking the time to establish a trusting relationship is difficult for busy clinicians. However, this investment early on can result in significant time saving as the relationship continues. I have also found it is important to provide a consistent message repeatedly as most information is not processed or processed completely until it has been heard several times.

I knew, from our many conversations that Jo was conflicted about having Bob on opioids. Jo's conflict was seeing her son in pain and her fear of him becoming addicted. We had discussed using long acting opioids several times, but the goals of the treatment plan didn't warrant the switch and was fostered by Jo's reluctance to use long acting opioids. When I made the decision to switch Bob to methadone, I was prepared for what I believed would be a difficult conversation when I returned Jo's call. I told her given the amount of hydromorphone he was using, I was no longer comfortable from a clinical standpoint using a short acting opioid, and in my clinical judgment, the best option for Bob would be methadone. Like many people, Jo's only

knowledge of methadone was in association with heroin treatment clinics. She stated she didn't want her son to have pain, so if this was necessary she would agree. I reviewed with her (as many times before) that we may never know the cause of his pain, and Bob may never be pain free. At this point she started crying and said, "Oh, don't tell me that." I believe she had finally processed that piece of information. This provided a solid platform for the remainder of the message which was the importance of using non-pharmacological strategies for pain management in addition to medications. Jo's tone was one of defeat and acceptance. At this point, I offered that she and I could meet and talk about the challenges of parenting a teen with chronic pain while Bob was meeting with the psychologist in Coping Clinic. She responded positively to this and quickly made arrangements to pick up the methadone prescription.

Considering the inherent challenges of difficult conversations as described by Patton (1999) this situation had all three. It could be understood more than one way—Jo was focused on finding a cause while I was focused on increasing Bob's functionality. The situation was highly emotional—Jo was angry and frustrated while I struggled to not be defensive and impatient. Finally the situation was psychologically threatening—Jo felt she was not being a good parent because she wasn't able to give her son a reason for his pain and make it go away while my clinical expertise was being challenged.

#### Evaluation of Care and Implications for Specialty

Bob has done well with the switch and is making significant strides in non-pharmacological management of his pain and anxiety. Jo and I have talked about the need for her to have Bob be responsible for his pain and its management. I have identified for her behaviors she does that encourage Bob's pain behavior including asking about his pain, reminding him when it is time to take more medication, and talking for him. Having positive patient outcomes



after difficult conversations provides reinforcement for using the communication strategies that were successful, and reflection on those that were not.

As clinicians, we need to be less afraid of having difficult conversations with our patients and families. In order for clinicians to be less afraid, they need to have a better appreciation for the importance and value of effective communication and then be equipped with the necessary tools. When caring for children, it is not just the child being cared for—the parents are included as well. While our focus is on the child, there are times when treatment will be unsuccessful until the parents are treated as well. In their 2005 study, Robins, Smith, Glutting, and Bishop showed children with chronic abdominal pain had decreased pain and disability when they received a cognitive-behavioral therapy including parent modeling of adaptive coping. Claar and colleagues (2008) showed children with higher pain related emotional distress may benefit most from parent training interventions. As pediatric providers we cannot assume care of the adults, but we can assess and manage parenting behaviors that are detrimental. However, I believe this aspect of pediatric care is often overlooked.

Nurses practicing at the level of a Doctor of Nursing Practice (DNP) are role models for all clinicians regarding professional communication. It is important for me to offer constructive feedback and support when I see other clinicians struggle with difficult conversations. I will share strategies that I have found to be successful and offer to provide appropriate reference materials on this topic. The literature is lacking on this specific topic and it would behoove me to research and publish in this area.

#### Self Reflection

This was a rewarding and fulfilling experience, not only from a personal perspective but also professionally. I feel good about how the conversation went—I didn't allow it to be

emotional or threatening and this young man and his mother are making great improvements clinically. Bob's pain is much less debilitating for him, and Jo has become more comfortable setting limits (with herself and with Bob) and much less focused on the cause of Bob's pain. I am, however, not naïve enough to think I will be successful every time I am confronted with a difficult conversation.

Though the focus of this paper has been on difficult conversations with patients and families, I believe even more frequently difficult conversations occur between physicians and nurses. I believe this is an area ripe for growth and have been talking with one of the pediatric hospitalists about developing a program for resident physicians focusing on communication and collaboration between physicians and nurses. Because of this interest I will continue to read about and practice effective communication strategies. I am also planning to attend a Crucial Conversations program.

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Running head: KETAMINE: ANESTHETIC, ANALGESIC, OR SEDATIVE

Ketamine: Anesthetic, Analgesic, or Sedative in Pediatrics

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### Presentation of Cases

In pediatrics, the use of ketamine has been almost exclusively restricted to operating rooms. Although it is gaining popularity in emergency departments and procedural or diagnostic settings, as it provides effective anesthesia, analgesia, and sedation without respiratory depression. In the adult population, ketamine has generally been restricted to pre-hospital procedures until recently (Lois & De Kock, 2008).

A review of three cases from my clinical practice in which ketamine was administered is illustrative of the effectiveness of this medication in pediatric pain management. In all three cases, its use was effective in providing analgesia with manageable side effects.

Jack was an 18 year old with a history of acute myelogenous leukemia. He had received a matched, unrelated donor bone marrow transplant. Three years later he was found to have relapsed with widespread metastases and pulmonary nodules for which he underwent a right thoracotomy and middle lobe lung resection. Routine pain management care for a patient undergoing thoracotomy involves placement of an epidural catheter. Because of an infected leukemic abscess on Jack's leg, he was not a candidate for an epidural. Initial pain management efforts included aggressive use of intravenous opioids via patient controlled analgesia (PCA). This modality was ineffective and limited by oversedation. After consultation with the Pediatric Pain Management service, a ketamine infusion was started. The infusion was started at 5 milligrams (mg) per (/) hour with moderate pain relief, and was increased to 10mg/hour after 4 hours. He remained on this dose for 3 days and was then tapered off over a 36 hour period. Based on his weight of 80 kilograms (kg), Jack's ketamine dosing ranged from 1-2 mcg/kg/minute.

Donald was a 16 year old with a history of neurofibromatosis, type 2, pilocytic astrocytoma of the lumbar spine, and Schwannoma of multiple nerve roots. He was admitted for surgical laminectomies of thoracic vertebrae 12 through lumbar vertebrae 2. Postoperatively Donald's pain was severe and poorly controlled with intravenous (IV) morphine. Recommendations were given by the Pediatric Pain Management service to begin a ketamine infusion at 10 mg/hour. Donald quickly obtained pain relief. He remained on this dose for 3 days and was tapered off over a 12 hour period. Based on his weight of 52 kg, Donald's ketamine dosing was 3 mcg/kg/minute.

Anabelle was a 6 year old with a history of repaired complex congenital heart disease, significant cognitive impairment secondary to anoxic brain injury, and severe scoliosis. She was hospitalized for surgical placement of a vertical expanding prosthetic titanium rib (VEPTR) to correct her scoliosis. Her surgery occurred at an affiliated hospital with a planned admission to the Pediatric Intensive Care Unit (PICU). The anesthesiologist who cared for Anabelle during her surgery started a ketamine infusion at 0.1mg/h which based on her weight of 22 kg, was a dose of 2 mcg/kg/minute. Anabelle appeared to have adequate analgesia and sedation, remained on this dose for 4 days, and was tapered off over 24 hours.

The use of ketamine was effective in these three cases. Dosing was within the ranges discussed for use by our practice (1-3 mcg/kg/minute). According to Micromedex (n.d.), sedation doses range from 5-20 mcg/kg/minute as compared to anesthetic dosing recommendations of 500mcg/kg/minute. The concomitant administration of other sedatives and analgesics precludes declaring ketamine as the single cause of improved pain control. However, its effectiveness in these cases has resulted in it more frequently being considered as a treatment option. Dosing in these cases was based on clinical effect and side effects experienced, but the Pediatric Pain

Management service does not have a standardized practice related to dosing, titration, or tapering of ketamine.

### *Review of Literature*

Ketamine was developed as a surgical anesthetic after World War II. It is a derivative of phenylcyclohexylpiperidine, also known as PCP. It was hoped to be the ideal anesthetic and became popular during the Vietnam War as battlefield anesthetic (Lois et al., 2008). It is a dissociative medication with potent psychoactive properties. It is the dissociative mechanism that made it useful as an anesthetic. By blocking signals to the conscious mind from the rest of the brain, the sensation of pain is not perceived. The potent psychoactive properties (disorientation, hallucinations, mania, and delirium) have been the limiting factors for the medicinal use of ketamine and make it a popular recreational drug.

Efforts to improve adult postoperative pain management have been increased with the recognition that up to 11% of patients having surgery will go on to develop chronic pain (Perkins & Kehlet, 2000). Ketamine is a N-methyl-D-aspartic (NMDA) antagonist that decreases the excitatory neurotransmitters which can lead to postoperative hyperalgesia. Ketamine also reduces the production of proinflammatory cytokines to support a more balanced inflammatory response—one that is conducive to healing rather than a hindrance. (Buyukkocak, et al., 2005; Zeyneloglu, Donmez, Bilezikci, & Mercan, 2005). Because of these properties ketamine is routinely used in adult care as part of balanced, pre-emptive operative analgesia.

There is considerable literature related to the use of ketamine as a pediatric anesthetic and agent to decrease opioid tolerance (Anand, 2007; Angheliescu & Oakes, 2005). its safety and efficacy; and the appropriateness of its use outside the operating room. Despite limited research in the literature regarding the analgesic benefits of ketamine in the pediatric population outside



the procedural or operating room setting, it is a common topic of discussion in our practice. My clinical experience with using ketamine in pediatric pain management has also been limited, and most often done as last choice.

#### Analysis and Interventions

Because of the effectiveness of the addition of ketamine in each of the three cases, there was a limited need for critical decisions related to individual patient care. The decisions were essentially determining dosing, length of therapy, and tapering method.

What was an unexpected and greater need was education and support of the nurses caring for these patients. Several years ago the administration of low dose ketamine was approved for use outside of the operating and intensive care settings. The approval process, per the Medication Safety Committee, involved the development of pre-printed orders used under the direction of the Pediatric Pain Management service only unless the patient was in intensive care. Education was provided on each unit for the RN staff. Since that time the use of ketamine has been limited and sporadic. Of note with these three cases is that they occurred in a relatively short time period, the duration of therapy was longer (previous cases had been only 24 to 48 hours), and the patients were on three different nursing units.

Providing information and support to the RNs was simplified by my increased knowledge and understanding of the use of ketamine. Because I did not have to focus as much on my clinical understanding and practice, I was able to better identify learning needs and themes of concerns from the RNs. This allowed me to tailor my education and support of the nurses caring for the patients. I was also able to more thoroughly evaluate system and practice issues related to the use of ketamine.

One system issue identified was related to transferring patients from the intensive care unit (where the pain service is more peripherally involved) to the intermediate care unit. There was no policy regarding the required level of involvement of the pain service for patients on the intermediate care unit. I am advocating that our team be directly involved, but what has been identified as a challenge to this are transfers that happen during nights and weekends when a pain service provider may not be immediately available. Discussions between the Pediatric Pain Management service, nursing, the intensivists, and the pediatricians involved are ongoing regarding the level of involvement required of the Pediatric Pain Management service for patients receiving ketamine on the intermediate care unit.

Another system issue was related to the electronic version of the physician order set. When the conversion to computer physician order entry (CPOE) was made from the paper pre-printed order set, information specific to pediatric patients was not included. The electronic order set has since been corrected based on my input.

Issues related to practice are associated with inconsistencies among providers on the Pediatric Pain Management service. As a group we have no clinical criteria for the consideration of the use of ketamine. Nor do we have a consistent approach to dosing or tapering at the end of therapy. While it is important to individualize treatment, it is critical to have an evidence based approach to treatment. As the most consistently available clinician on our service, the development of practice guidelines has fallen to me. As a group we have not had written guidelines and it has become clearer to me that they are necessary.

#### Evaluation of Care and Implications for Practice

The use of ketamine in the cases presented was effective and did not have any unfavorable outcomes. Analgesia was enhanced with the addition of ketamine, and each of the patients made

full recoveries without developing a chronic pain syndrome. There is no way of knowing any of the three would have developed chronic pain without the addition of ketamine postoperatively, but monitoring for this will provide valuable clinical information. Doctoral preparation has given me increased credibility with my peers and this has perpetuated my quest for knowledge. This will be useful not only in clinical practice, but also as I prepare for a national presentation on the use of ketamine in pediatric patients. As a member of the Pediatric Pain Management service, my expertise is recognized and sought by others requiring me to be current and well versed in the latest science and knowledge relative to my practice.

#### Self Reflection

As I have progressed through the DNP program and completed each of these case studies, I have honed my skills in critically reviewing the literature. In the past and often after the fact, I would make a mental note to check the literature regarding a clinical situation. I am now going to the literature as soon as possible, and looking at multiple articles rather than just one or two. My clinical practice is often very busy, making it difficult to find time to review the literature. However, I have grown to appreciate the benefits of having this knowledge immediately available. My colleagues also welcome the information, and as a team we are having more discussions based on the literature and have become more attentive to our treatment decisions. I have also become more efficient in my searching and reviewing of the literature which has decreased its burden on my time. To maintain this practice, I have blocked two hours of my schedule every week specifically for searching and reviewing the current literature.

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Running head: CLINICAL LEADERSHIP OF PAIN RESOURCE NURSE PROGRAM

Clinical Leadership for Implementation of the Pain Resource Nurse Program

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### Leadership in Clinical Practice

Over the last eight years, I have been involved in several multidisciplinary efforts directed at improving pain management practices across the organization. Both the adult and pediatric hospitals have dedicated acute pain services that offer consultation and recommendations for pain management to the primary providers. While these services have improved pain care for some patients, the consistent delivery of appropriate and safe pain management has continued to be a clinical challenge for the organization. I am the only Clinical Nurse Specialist (CNS) in the Oregon Health & Science University (OHSU) health care system dedicated full time to pain management.

One of the first organization wide efforts was in 2001 with a multidisciplinary group of clinical leaders who saw a need to address issues such as clinician knowledge and best practice. A physician from the adult pain service had trained at a hospital that had a Pain Resource Nurse (PRN) Program, and he believed it would make a significant difference for OHSU as well. This program provides additional education related to various aspects of pain management to direct care nurses at the unit level. These “local experts” are consistently and easily accessible, and able to provide accurate information related to pain management. I spent time learning about the PRN Program, talking with nursing leaders from around the country who developed and implemented the program, and agreed it would be beneficial to our organization. However, according to administrative leadership budget constraints made this program not feasible. This group dissolved after 3 years due to lack of support from organizational leadership and member burnout. Over the next 5 years, four task forces or performance improvement groups were convened to address continued concerns regarding pain management such as unfavorable patient outcomes, or in response to vocal frustrated physicians.

A consistent theme throughout these projects and initiatives has been a lack of reliable, easily accessible, and accurate knowledge related to pain management. The challenge of providing pain education to the myriad of physicians in this large academic setting has been another theme. Suggestions are regularly made about the need for the PRN Program.

One performance improvement group completed root cause analyses on 8 patient situations that had been identified as critical events. The major recommendation from this group was implementation of the PRN Program. I was asked to develop a proposal for the program development, implementation, and maintenance which was presented to the administrative leadership team and professional board. For three months, my salary support was shifted such that I had limited clinical responsibilities and was dedicated to the proposal development. This proposal was presented to the Quality Executive Council in February of 2007. No action was taken, until a year later when the Division Director (RJ) for Pediatric Services indicated interest in the program and asked me to determine the cost of and process for implementation of the PRN Program in Doernbecher Children's Hospital.

#### Process and Decisions

Nearly 20 years ago the PRN Program was developed by Betty Ferrell and colleagues (Ferrell, Grant, Ritchley, Ropchan, & Rivera, 1993), and it, or similar programs, have been implemented in several hospitals around the country. This program has been found to be an effective strategy for improving pain management (Paice, Barnard, Creamer, & Omerod, 2006; Pasero, Gordon, McCaffery, & Ferrell, 1999). With the effectiveness of the program established and support from RJ, the next step in the process was to determine the cost.

Discussions between RJ and I led to a decision to base the cost analysis on a 16 hour program (offered over two days) provided for 24 RNs. The major expense in the cost analysis

was to cover RN salaries for those who attended the classes and those who would work to cover for the RNs attending class. This amount was approximately \$42,000.00. Ongoing education (quarterly 2 hours classes) of the 24 Pain Resource Nurses (PRNs) would be an additional \$15,900.00 per year. There were insufficient funds to train 24 RNs. With this information, RJ asked me to propose a pilot project for one of the Doernbecher nursing units.

For the pilot project, I considered which nursing unit had the broadest cross-section of patients and RNs at DCH; and which had the greatest number and variety of multidisciplinary and specialty health care teams. I also considered which unit had nurses who demonstrated the most interest in pain management. I wanted to maximize the success potential for the pilot project. This would be critical to the possibility of expanding to other units in Doernbecher, and perhaps to the rest of OHSU. To measure the success of the program, I chose to compare RN perceived barriers to pain management pre- and post-implementation of the PRN Program. RJ asked that I also compare patient satisfaction scores before and after the implementation. I presented my proposal for the pilot project to RJ. I felt the unit most appropriate for the pilot was the Pediatric Acute Care Center (PACC), a 48 bed medical-surgical unit with an RN staff of 70. I recommended training 6 RNs. The cost would be approximately \$10,500.00. RJ agreed to fund the pilot.

In October 2008, I developed the criteria for applicants as well as the application process. Posters were made advertising the opportunity and posted in various locations on the unit. Seven RNs volunteered. RJ authorized me to proceed with the seven who had volunteered plus the PACC nursing educator and Nursing Practice and Education Coordinator (NPEC).

The next decision to be made was the timing of the class. Doernbecher was in the process of converting to an electronic health record system. All of nursing documentation had just



converted, with the final conversion for physician order entry scheduled for December 2008. Though the conversion had been done in phases, it had significant impact on workflow and stress levels for the RN staff. The decision was made to delay the PRN class until January 2009.

During the next few weeks, I spent time reviewing curriculum from other PRN Programs, speaking with the national experts most familiar with the program, developing the curriculum for the Doernbecher class, identifying speakers, obtaining continuing education credit, and preparing content for several lectures. I was contacted by an RN from the OHSU Quality Management office asking if she could also attend the class. She intended to advocate for the program throughout OHSU.

The PRN classes were held January 12 and 13, 2009. Participant evaluations of the classes were positive. This group appeared to be engaged in the effort to improve pain management through the PRN Program, and identified several areas of clinical practice on which to focus their efforts. We meet monthly to discuss clinical care, review journal articles, and for the presentations of additional information related to pain management.

#### Outcomes and Implications

The survey *Barriers to Optimal Pain Management* was completed March 14 to April 11, 2008 and served as the pre-implementation measure for perceived barriers to pain management. The survey was repeated two months after implementation of the PRN program, and the results were compared to the pre-implementation results. Barriers related to nurses' beliefs and biases decreased, those related to institutional commitment and systems issues increased, and those related to patients and family were unchanged.

Patient satisfaction is tracked using the Press Ganey survey. Mean scores of survey items are provided each month. There is one question specific to satisfaction with pain management.

The monthly means for this question have been tracked since August 2008. As an organization, OHSU strives to be in the top quartile. Doernbecher has not maintained that rank, but has met or exceeded the University HealthSystems Consortium (UHC) peer group benchmark 5 of the 9 months, and is trending upward in patient and family satisfaction with pain management.

Content analysis of verbal and written feedback from the PRNs was supportive of improved clinical decisions and role modeling by the PRNs. Feedback from other PACC RNs has been positive and appreciative. These findings are consistent with the published literature regarding the PRN Program (Ellis et al., 2007; McCleary, Ellis, & Rowley, 2004; Paice, Barnard, Creamer, & Omerod, 2006).

I was asked to provide an overview of the PRN Program at a monthly meeting of the Collaborative (Doernbecher/OHSU nursing leadership). I described the need for the program, the implementation process, and also featured two of the PRNs. The presentation was very well received, and afterward, three nursing leaders asked about the feasibility of this program on their units. I will be contacting these leaders to provide guidance and support should they proceed with implementation.

The effects of the PRN Program will continue to be monitored using the *Barriers to Optimal Pain Management* survey. It is scheduled (with IRB approval) to be repeated in April 2010 and every two years thereafter. Patient satisfaction scores will also be monitored as another measure of effect.

There appears to be a desire for change within the organization, however a specific change model to facilitate this process has not been used. I believe appreciative inquiry (AI), an organizational change model developed by David Cooperrider in the late 1980s, will be useful for the facilitation of changing clinical practice related to pain management. As described by

Sullivan Havens, Wood, and Leeman (2006) AI attempts to capture what an organization does well by identifying what has been successful and utilizing this knowledge and positive energy to invite and leverage change. The performance improvement groups dealing with pain management have focused on what is wrong with the delivery of care. The AI model with a focus on the positive aspects of care, can serve to generate creative solutions to improve pain management by engaging the nursing staff.

I will begin with the existing group of PRNs and lead them through a SOAR (strengths, opportunities, aspirations, and results) analysis of the PRN Program implementation. The SOAR analysis will serve to focus the strengths and values of the group. From here we will move into the 4-D cycle of AI. This cycle involves the iterative phases of discovery, dream, design, and deliver/destiny. Taking the PRNs through the AI process will prepare them to do the same with their peers and facilitate the integration of pain management as a value. The PRNs will also then be available to lead the process throughout the rest of the organization.

I struggle to define my leadership style. At times I question if I really am a leader. Being a leader is a huge responsibility and I often feel ill equipped for such responsibility. Some would say a leader is born. Others would say a leader is created. I believe truly transformational leaders are born and developed as they mature. I have tended to be a leader most of my life, but what I have lacked is the disciplined guidance and knowledge necessary to establish an identifiable and effective leadership style. My strengths include problem identification, creative thinking when looking for solutions, a direct communication style, a high level of energy, and an intense desire to provide the best care possible for my patients. Some weaknesses of which I am aware include inconsistent responses to conflict, being easily frustrated by a lack of action, and being able to quickly and objectively articulate my thoughts.

While I am recognized as a clinical expert throughout Doernbecher, I believe being a Doctor of Nursing Practice (DNP) will provide me additional credibility and influence throughout OHSU. Course work with the ensuing discussions and reflections have provided me additional insight, and highlighted areas of my potential growth as a leader. A doctoral degree is a testament to attainment of the highest level of education which generally results in greater respect from colleagues, particularly physicians. Credibility and respect are critical attributes of a successful leader and change agent within an organization.

### Self Reflection

The American Association of Critical-Care Nurses (AACN) Framework for Governance Leadership Positions (AACN, 2006) will be used as a model for self-reflection and evaluation of my clinical leadership role in this project. This framework is used to describe five competencies essential to the organization's leadership positions. The competencies are self-leadership, global thinking, visioning, consensus building, and delivering effective messages.

#### *Self-Leadership*

Self-leadership is described by AACN (2006) as “the ability to assess, manage and develop oneself in order to preserve and optimize relationships and add value to the outcomes of one's organization.” I am recognized as a clinical expert, who advocates for the best care for my patient population. At the same time, I often advocate for other special populations and how to best meet these needs while also supporting and advocating for the organization. Experience has taught me one of the best ways to grow and develop professionally is to actively seek feedback and to reflect on what I do well and on what I need to further develop and refine. I welcome having my thoughts and ideas challenged as this provides opportunities for me to consider alternatives and be clear in my communications. Because providing optimal pain management is

my professional passion, I must constantly be aware that my priorities may not always align with organizational initiatives.

### *Global Thinking*

“The ability to think beyond one's current role and practice and apply new perspectives that will improve and optimize one's role and practice” is used by AACN (2006) to describe global thinking. Though my clinical practice is in Doernbecher, I am valued for and able to use my advanced practice knowledge, my understanding of policy and organizational systems, and my leadership role to influence change across the entire organization. I am frequently called upon by various leaders in the organization to provide information regarding national trends, standards, and new information related to pain management. Though I am not a regular member of many of the leadership committees, I am consulted to offer suggestions for the integration of new standards applicable to the organization.

### *Visioning*

According to the AACN (2006) Framework for Governance Leadership, visioning is “the ability to create a clear view of the preferred future resulting from global analysis in order to lead other people and the organization to this preferred future.” Visioning is an area of leadership, which for me, is somewhat limited because I am not employed as a member of the Patient Care Services Division. I feel that I don't have the necessary amount of interface with nursing to clearly articulate a vision to a large enough audience to effectively influence change.

### *Consensus Building*

As I have matured in my role as a CNS and clinical leader, the one area in which I believe I have grown the most has been in helping build consensus. Consensus is about negotiation and compromise. I believe building consensus also helps a group identify priorities.

In the AACN (2006) Framework for Governance Leadership, consensus building is characterized as “the ability to achieve practical consensus within groups to promote strong teamwork and garner commitment and participation of others to achieve solutions and effect positive change.” Consensus building requires establishment of a safe venue for dialogue where others’ thoughts and ideas are welcomed, where conflict is identified and resolved, personal biases and judgments are suspended for the benefit of the group. I have also learned the power of supporting a group decision as this often comes back in my favor in future situations.

#### *Delivering Effective Messages*

My communication style is clear and direct. I make every effort to “deliver effective messages in order to motivate others to thought and action” (AACN, 2006), and to do so with a positive attitude, and when appropriate with a sense of humor. I have developed the ability to translate concepts and terminology into understandable information for my patients and families and use the same skills when discussing complex issues with colleagues. I make every effort to be objective in my communication, though at times my passion and emotions are apparent.

#### Future Leadership

As the leader of this project, my role has been one of support, encouragement, and clinical practice role modeling. I have had the good fortune to lead a group of committed and motivated individuals, making this a particularly rewarding experience. Feedback I have received from RJ, the PRNs, and other clinicians has been positive and supportive. As I reflect on areas of potential growth, I recognize that I have had to make a conscious effort to let others “do the work.” I am learning that I don’t have to be involved in every part of the process. Delegation of responsibilities and tasks is not something I have done very well, but I am accepting it as a necessary skill to be an effective leader. When I don’t delegate and try to do

most of the work myself, I become bored and frustrated with the process, often losing my motivation for completing the project. While I appreciate people's confidence in me as a leader, I am often uncertain of my effectiveness and seek reassurance and affirmation. I believe this lack of confidence stems from not having an identified leadership model and mentor, which has meant my leadership development has been self directed, inconsistent, and unstructured. With the attainment of a DNP comes the responsibility of leadership—a challenge I am ready to accept.

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Article Type: Clinical Article

Keywords: pediatric palliative care; ethical dilemma; culture; Chinese; Proteus Syndrome

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Abstract: An ethical dilemma that is not uncommon to encounter when caring for children occurs when parental preference does not appear to be in the child's best interest. Challenges facing the health care team are further amplified when the family's cultural background does not match that of the team. A case study will be used to illustrate the challenges of a pediatric palliative care ethical dilemma further complicated by cultural diversity. Review of the child's medical condition, patient/parent preferences, quality of life, and contextual features will be followed by an analysis and recommendation for resolution of this challenging situation.

April 16, 2009

Dear Dr. MacPhee,

I am resubmitting my revised manuscript per your suggestion. I have addressed the comments and feedback of the reviewers, and reviewed the manuscript for grammar and spelling.

Thank you for your time and consideration.

Sincerely,

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Running head: PARENTAL PREFERENCE OR CHILD WELLBEING

Parental Preference or Child Wellbeing: An Ethical Dilemma

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**Abstract**

~~A not uncommon~~An ethical dilemma ~~that is not uncommon to encountered~~  
~~when encounter when~~ caring for children occurs when parental preference does not appear to be in the child's best interest. Challenges facing the health care team are further amplified when the family's cultural background does not match that of the team. A case study will be used to illustrate the challenges of a pediatric palliative care ethical dilemma further complicated by cultural diversity. Review of the child's medical condition, patient/parent preferences, quality of life, and contextual features will be followed by an analysis and recommendations for resolution of this challenging situation.

**Key words.** pediatric palliative care; ethical dilemma; culture; Chinese; Proteus syndrome

**Case Presentation**

Ting (not her real name) was a 12 year old nonverbal Chinese female with profound developmental delay and limited mobility confining her to a wheelchair. She had the medical diagnosis of Proteus syndrome, a rare congenital and progressive condition of soft tissue overgrowth/nonmalignant tumors resulting in swelling with nerve, vessel, and organ compression, and skeletal distortion throughout the body. Ting required complete care and was big enough neither of her parents could easily lift her.

**Disease review.** Proteus syndrome appears to be very rare with less than 200 individuals [affected](#) worldwide (Satter, 2007). Asymmetric growth occurs of the head, face, and digits. It is this asymmetric growth with soft tissue overgrowth that results in the more significant complications (Biesecker, 2006). Spinal deformities (scoliosis or kyphoscoliosis) can be progressive and severe enough to lead to respiratory compromise. The respiratory system is further compromised by cystic malformations in the lungs and intra-thoracic and/or intra-abdominal masses. Abnormal skeletal and muscle development contribute to functional abnormalities. Soft tissue masses (lipomas, connective tissue nevi, epidermal nevi, and vascular malformations) may cause vascular, nerve, and/or organ compression and contribute significantly to morbidity in these patients (Satter). Mental retardation is present in a subset of patients with Proteus syndrome. Central nervous system malformations and seizures may be present as well (Pletcher, 2006; Mahlberg, 2007). During some periods there seems to be fairly rapid tumor growth followed by periods of quiescence, stability, and occasionally functional recovery.

There are no data on long-term survival; however disease progression and complications likely contribute to premature death (Biesecker, 2007; Satter, 2007). It is now thought that

Joseph Merrick (known as the Elephant Man) had Proteus syndrome rather than neurofibromatosis, as was initially suggested (Proteus Syndrome Foundation, 2007).

**Medical history.** Shortly after moving to the United States, Ting (age 6) and her family established care at our facility. At the time of her birth in China, several bony and soft tissue deformities were noted (leg length discrepancy, abdominal mass, hypertrophic hands). Ting's medical history included a brain infection at age two that left her with seizures, no immunizations, and developmental delay. No cause/diagnosis had been determined for her musculoskeletal deformities. An extensive work up resulted in the diagnosis of Proteus syndrome at age eight. When Ting was 10 she stopped walking and was unable to bear weight on her legs due to spinal cord compression at the T11-12 level. The family was reluctant to agree to surgery on her spine. By the time they agreed to see the neurosurgeon, it was felt Ting would not regain function of her lower extremities so surgical resection was not attempted. However, over the course of six years Ting underwent several other procedures and surgeries. Many were directly related to her Proteus syndrome including lung and chest wall biopsy, open surgical debridement of mastoid bone due to chronic infection in malformed bone, resection of ovarian cystadenoma, and placement of a gastrostomy feeding tube due to failure to thrive and chronic aspiration because of multiple soft tissue masses in her neck and chest. Others surgeries not directly related to her Proteus syndrome included pilonidal cyst resection and tonsillectomy. Ting had seven hospitalizations between ages 10 and 12. Two admissions for GI bleeding secondary to nonsteroidal anti-inflammatory medications and an H. pylori infection were not directly related to her Proteus syndrome. However, four admissions for aspiration pneumonia secondary to severe reflux and dysphagia and one for abdominal pain likely due constipation,

feeding difficulties, gastrostomy tube irritation, and compression of nerves, soft tissues, and organs were results of the soft tissue masses common with Proteus syndrome.

**Developmental and behavioral history.** When Ting established care at our facility she was attending special education classes at the local elementary school. Her father reported Ting played, was able to perform simple hygiene tasks (washing her hands), and fed herself with minimal assistance. Ting's parents reported she was nonverbal and would hit when frustrated. The Pediatric Pain Management Clinical Nurse Specialist (CNS) was consulted for recommendations related to agitation, abdominal pain, headaches, and musculoskeletal pain when Ting was 10 years old. At that time it was noted she was frequently self injurious (head banging, scratching, banging her hands and arms on things until they were bloodied) and often needed physical restraints as sedatives were minimally effective. Her parents reported this behavior was consistent at home and the only way to calm Ting was for her father to carry her piggy-back style and walk (sometimes for hours). During her hospitalizations, it was noted Ting's level of agitation increased significantly when her mother and sisters visited. The sisters were seen taunting, pinching, and shoving her. Her mother spoke very loudly (nearly shouting) when trying to calm Ting. She also constantly patted Ting's head, face, or arms when Ting cried out or was restless which seemed to increase the agitation. Ting's sleep pattern typically consisted of two to three hours at a time throughout the day and night.

**Social and family history.** The family had minimal financial resources with no extended family available. Her father worked at a minimum wage job to support his wife, Ting, and two younger (healthy) daughters, ages 3 and 5. Both parents spoke very little English and by report were healthy. They lived in a small apartment (so small that Ting's wheelchair didn't fit through the bathroom or bedroom doors) which meant her parents had to drag her by her arms across the

floor to the toilet or her bed. At age 12, Ting's parents, with community Social Services support, (but minimal input from her primary care provider) made the decision to voluntarily place Ting in medical foster care due to their inability to care for her extensive physical needs.

Ting began to thrive in foster care. She was initially placed in a foster home that was three hours away so visitation was very difficult for Ting's family. Her mother would often call on the phone and the foster mother reported that Ting would cry when hearing her mother's voice which was distressing to her mother. After five months, Ting was moved to a foster home closer, and her family was able to visit often. In the care of her new foster parents, Ting learned to calm herself, started smiling, demonstrated understanding of simple words and phrases, and began to use consistent sounds to communicate her needs, i.e., "waa" for water. Her mood changed from self injury to calm, quiet vocalizations, laughter, and hours of water play with her hands. Ting's sleep pattern improved to a full ten hours at night with an occasional afternoon nap. With consistent physical therapy provided by her foster parents Ting's mobility improved significantly.

Ting's pain was well managed with small doses of twice daily methadone and gabapentin. She required a vigorous bowel regimen due to her chronic constipation which was exacerbated with the addition of opioids. Ting was also much less agitated which may have been a result of improved pain control. She gained weight after placement of a gastric feeding tube, and with minimal need for oral intake she had fewer episodes of aspiration and pneumonia.

#### **Ethical Decision Making Process.**

During one of her last hospitalizations, Ting's primary medical team felt it was appropriate to request a palliative care consult as her hospitalizations were becoming more frequent and her condition seemed to be deteriorating. The course/progression of Proteus



syndrome is essentially unknown. CT and MRI images obtained during several of her hospital admissions indicated most of Ting's tumors had been stable over the previous two years; however there was a very large intrathoracic tumor involving her spine and lungs which showed continued slow growth. This particular tumor and one in her brain also showed significant and increasing vascular malformations. Using a Mandarin interpreter, a care conference was held with her parents, primary medical team, members of the palliative care service, and the pain management CNS to review Ting's disease progression and prognosis, and develop a plan of care.

After the care conference, Ting's parents informed the healthcare team they had decided to take her home so they could care for her. They stated it was their duty to care for Ting if she was dying. In Chinese culture, according to filial duty it is a moral obligation to care for sick family members and this cannot be done by someone else (Wong & Pang, 2000).

**Ethical dilemma.** As an incompetent minor Ting's care decisions resided with her parents, however they had not been able to adequately care for her. Ting had shown significant physical and emotional improvement in foster care, and several members of the health care team believed it would not be in Ting's best interest to return her to the parents' home and her that quality of life would be severely diminished. The ethical dilemma for members of the healthcare team was: Do parental preferences override the right of a child to receive appropriate care in medical foster care?

A meeting was held with members of the health care team and facilitated by an ethics consultant. An in depth analysis of the situation was done using the ethical decision making model described by Jonsen, Siegler, and Winslade (2006) in their book *Clinical Ethics*. This method uses four major categories for clarifying facts related to the case and facilitating

discussion about the priorities of one category over another. This model is sometimes referred to as the “four box” or “four quadrant” method of clinical ethical decision making. The four categories are medical indications, patient preferences, quality of life, and contextual features. These categories and examples of information considered in each category are shown in the following illustration.

<p style="text-align: center;"><b>Medical Indications</b></p> <p>Medical history Diagnosis Prognosis Treatment</p>	<p style="text-align: center;"><b>Patient Preferences for Treatment and Right to Choose</b></p>
<p style="text-align: center;"><b>Quality of Life</b></p> <p>Prospects with or without treatment</p>	<p style="text-align: center;"><b>Contextual Features</b></p> <p>Family issues Religion Culture</p>

**Comment [HNT1]:** Moved to separate document as requested..

**Medical indications.** Ting’s medical diagnoses included Proteus syndrome, seizure disorder, failure to thrive (g-tube dependent), scoliosis, leg length discrepancy, neurogenic bladder, chronic constipation, and chronic pain. She was at risk for aspiration, pneumonia, gastric bleeding, and recurrence of H. pylori infection and mastoiditis.

Several of Ting’s diagnoses were secondary effects of the Proteus syndrome. She had weight loss due to her inability to consume adequate calories by mouth, her constant state of agitation, and chronic pain. Because of soft tissue compression, Ting could not consistently protect her airway and frequently aspirated food and her own secretions often resulting in pneumonia. Her parents agreed to placement of a gastrostomy feeding tube to supply her with adequate nutrition. However, her mother insisted on continuing to provide her food by mouth which is likely culturally significant and related to the importance of dying with full stomach (Hsiung & Ferrans, 2007). The frequency of clinically significant aspirations decreased, but was still concerning.

Gastric bleeding was twice contributed to the use of nonsteroidal anti-inflammatory analgesics which seemed to offer her good pain control. Her parents believed she had headaches (she would hit her head), and all those who have cared for Ting recognized the pain she experienced related to immobility and her many skeletal deformities. Pain relief without intolerable side effects was a primary goal in Ting's care. Low dose long acting opioids offered good pain relief but Ting had difficulty to control constipation as a side effect. Anticonvulsants were used to treat the presumed neuropathic pain caused by nerve compression.

The chronic mastoiditis was finally controlled after an extensive surgical debridement and an extended course of antibiotics just prior to her placement in foster care. However the risk for a reoccurrence of the mastoiditis remained.

The goal of medical treatment for patients with Proteus syndrome is to minimize complications. Identifying potential problems and prompt attention to complications significantly reduces morbidity and mortality for these patients. Given the complexity of this condition, a multidisciplinary approach is necessary.

**Patient preferences.** Ting demonstrated limited cognitive ability, but the extent of her disability was unknown. Her cognitive function showed improvement in the eight months she was in foster care. Ting did show evidence of decreased agitation, happiness, and physical healing while in foster care. Her old behaviors of head banging, scratching, and banging her hands and arms on things until they were bloodied returned when she was in the presence of her mother and sisters.

Ting was unable to cooperate with medical treatment because of her level of cognitive and physical impairment. Her parents were willing, but unable to provide the level of care Ting

requires due to her size, their physical limits, and their understanding of the disease, treatments, and day to day care requirements.

Ting's parents act as surrogate decision makers, but their understanding of her disease and prognosis was unclear to the healthcare team. Ting's parents repeatedly said it was their duty as parents to have Ting in their home and provide her end of life care.

**Quality of life.** Ting never has nor ever will lead a normal life. Despite treatment her physical, mental, and social deficits will increase, but at an unknown rate or intensity. In the future she will likely become so impaired and have such medical complications as to make continuation of her life medically futile. She has not reached that point. ~~No~~ or can it be predicted when she might. Her health care team presented information to Ting's parents about the inevitability of forgoing treatment due to the continued growth of the complex lesions in her brain and chest. The parents indicated their desire for Ting to be comfortable. Some members of the healthcare team believed the focus of care should be shifted from supportive/palliative care to comfort care measures only. Other team members however, felt because Ting's condition seemed relatively stable and her improvement in foster care, it was premature to move to comfort care. It was thought by several that her quality of life was significantly improved in foster care and would rapidly diminish if returned to her parents.

**Contextual features.** Family knowledge/understanding has a huge influence on treatment decisions. Cultural expression may be a factor in this, but the level of parental understanding or comprehension was not clear to the health care team. Ting's life may end prematurely due to the parents' lack of understanding, ability to identify potential problems, and not seeking prompt medical attention. Communication barriers may get in the way of aggressive treatment which could prolong Ting's life without significantly impacting her quality of life. The

team did not overtly indicate that Ting was dying however referral to the palliative care team could easily be perceived to the contrary. Utilizing professional interpreters added to the challenge of building a relationship with her parents and coordinating care for Ting.

The state administered health plan (Medicaid) was responsible for Ting's healthcare costs, and resources were wasted because of poor communication/understanding when in the care of her parents. It was nearly impossible (even with the use of interpreter services) to have a phone conversation with Ting's parents; making teaching, follow-up care, or treatment adjustments impractical. This resulted in frequent and unnecessary visits to the emergency department (ED) and clinic. Her visits to the ED and clinic were less frequent when she was in medical foster care.

No laws were being broken by allowing Ting's parents to care for her. They were not abusive or neglectful. She was 12 years old, an age when children can assent to care. Her cognitive status, however, precluded her ability to assent. so she was not old enough (if she were cognitively normal) to consent for her care. She would however be able to provide assent. She was unable to perform even basic self care (feeding, toileting) though she was able to remove articles of clothing. The language barrier and a poor understanding of cultural influences resulted in a lack of knowledge (on the part of the health care team) regarding the parents' desires so no Advanced Directives or Physician Orders for Life Sustaining Treatment (POLST) forms had been completed.

### **Analysis and Recommendations**

The ethical dilemma of parental preference versus child wellbeing can be argued strongly for each side. Some will favor parental preference and choice as the premise that must be supported in this situation, as according to Jonsen, Siegler, and Winslade (2006), "parents or

guardians have the moral and legal responsibility to act in the child's best interest" (p. 24), while others will say because this child is vulnerable (diminished autonomy) she must be protected (National Commission for the Protection of Human Subjects: Belmont Report, 1978). It is important to consider the four widely accepted principles of bioethics; respect for autonomy, beneficence, nonmaleficence, and justice as described by Beauchamp and Childress (2001), but in this situation these principles must be viewed using the cultural filter as presented by this Chinese family. According to Tsai (2005) these four bioethical principles and their moral values can be identified in the context of ancient Confucian ethical and moral philosophies of Chinese culture.

There are several important cultural components of which to be thoughtful in this situation. These include the importance of family which is the center of Chinese culture and respect must be given to the wishes of the family (Yam, Rossiter, & Cheung, 2001); male paternalism; physician paternalism; and the importance of hard work, privacy and a good death (Barnes, Davis, Moran, Portillo, Koenig, 1998; Hsiung et al., 2007).

According to Hsiung et al. (2007), Chinese Americans generally acculturate into one of four broad categories: (1) elderly immigrants who remain traditional and the least acculturated, (2) less acculturated working class immigrants, (3) professionals equally comfortable in both cultures, and (4) Chinese Americans who are born in the United States and are the most acculturated. Ting's family was in the second category so their attitudes and beliefs remained more in line with traditional Chinese culture.

Ting's quality of life was restricted, but it was not yet minimal. Therefore, it was important to have many extensive conversations with this family to address supporting their need to care for her, resource utilization, and planning for Ting's eventual death.

Most discussions regarding Ting's care occurred (using an interpreter) with her mother, as the father was unable to take time off from work during the day. Ting's father was the decision maker in this traditional Chinese family, and ~~given the importance to him of working hard, decision making was not facilitated as well as if critical conversations could have been planned at a time when he could be present. It was critical he have the information first hand rather than through two translations (an interpreter and his wife) direct, important conversations were hampered by his work schedule and his inability to be present.~~

The healthcare team needed to understand the impact of this family's culture on their ability to freely discuss their concerns regarding Ting and her care. Privacy and lack of sharing of emotions and concerns are cultural norms that may be interpreted as lack of understanding and knowledge. The healthcare team may have had concerns regarding the family's ability to care for Ting because of this perceived lack of understanding. The family may have been uncomfortable asking questions because that would be unacceptable given their culturally based respect for physicians and acceptance of physician paternalism. It was important to be sensitive to the cultural collision course this family was traveling between Chinese and American cultures as well as between the cultures of medicine and lay people (Kleinman & Benson, 2006).

#### **Outcome**

It was agreed that with appropriate in home support Ting's parents would likely be able to provide for her physical needs and to fulfill their innate cultural and parental obligations to care for their child with this life limiting condition. The medical team did not believe Ting's demise was imminent, and in fact her life expectancy was unknown. It could be a few weeks or several years (with diligent care). Based on this information, the medical and palliative care

teams agreed it was too early in Ting's case to have the palliative care team actively involved. They withdrew from involvement in her care, but offered to be available as needed.

The healthcare team worked diligently with the family to develop a relationship that allowed discussion of their needs to care for Ting, and support them in their care of her. This also provided ongoing opportunities for discussions about whether or not more surgeries might be performed; whether or not she will be readmitted to the hospital; how to continue nutritional support and pain management; completing Advance Directives and POLST forms; and to understand what it will mean for Ting to die a good death.

**Current health status update.** Ting has been back in the care of her parents for two years. Proper lifting equipment and other assistive devices were secured for the home as well as daily nursing assistant care. Ting has not had any significant illnesses, emergency department visits, or hospitalizations since discharge to her parents' home. With weekly in home physical therapy sessions she has been ambulating up to 50 feet with minimal assistance. She is able to feed herself the small amounts of food she is allowed for oral pleasure and stimulation. Ting is back in school on a daily basis and gaining verbal skills. Her pain seems well controlled and she rarely gets agitated. She receives great pleasure from playing with balloons with her sisters and nursing assistants. At her last visit to the Pediatric Pain Management Clinic it was noted, Ting "looked" good (relaxed, making eye contact when spoke to, occasionally smiling, no scrapes or bruises), she was interactive and responsive to conversation, and her mother never stopped smiling!



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**Table**

<p align="center"><b>MEDICAL INDICATIONS</b> Ethical principles beneficence and nonmaleficence</p>	<p align="center"><b>Patient Preferences</b> Ethical principle of respect for autonomy</p>
<p><i>Information about patient's health which directs appropriate medical interventions</i></p> <p>Medical history            Diagnosis            Prognosis            Treatment options            Is condition critical, emergent, acute, or chronic            Is situation/condition reversible            Probability of success of treatment</p>	<p><i>Decision made based on patient's values and preferences</i></p> <p>Patient Preference (if competent)            Appropriate surrogate (if incompetent) preferences</p>
<p align="center"><b>Quality of Life</b> Ethical principles beneficence, nonmaleficence, and respect for autonomy</p>	<p align="center"><b>Contextual Features</b> Ethical principles of loyalty and fairness</p>
<p><i>Ability to performance and have pleasure from social role, health and cognitive function; and satisfaction with well-being</i></p> <p>Prospects with or without treatment            Will there be physical or mental deficits            Any plan to forgo treatment            Plans for comfort/palliative care</p>	<p><i>Social, legal, economic, institutional, and societal circumstances of patient's care</i></p> <p>Family issues influencing decisions            Provider issues influencing decisions            Financial/economic factors            Religion            Culture            Allocation of resources            Laws effecting decision            Research or teaching involved            Any conflict of interest</p>

Ms. Ref. No.: JPEDIATRNURS-D-09-00005R1  
Title: Parental Preference or Child Wellbeing: An Ethical Dilemma  
Journal of Pediatric Nursing

Dear Ms Helen N Turner,

The reviewers have commented on your above paper. The reviewers recommended that the paper be accepted pending editorial review of the final draft, which incorporates their requests for revisions listed below. They indicated that the paper requires additional minor revisions before it is accepted for publication.

However, if you feel that you can suitably address the reviewers' comments (included below), I invite you to revise and resubmit your manuscript by Apr 29, 2009.

Please carefully address the issues raised in the comments.

If you are submitting a revised manuscript, please also:

a) outline each change made (point by point) as raised in the reviewer comments

AND/OR

b) provide a suitable rebuttal to each reviewer comment not addressed

To submit your revision, please do the following:

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I look forward to receiving your revised manuscript.

Yours sincerely,

Maura MacPhee, RN, PhD  
Associate Editor  
Journal of Pediatric Nursing

Reviewers' comments:

Thank you for making the requested revisions. This will be an excellent article for the Clinical Practice Column. We would like you to make a few, additional changes:

1. Please put the table in a separate document and include examples for each quadrant.
2. On page 10, in the paragraph: "No laws were broken..." a few sentences can be combined and edited for clarity. Please change the text to say: "She was 12 years old, an age when children can assent to care. Her cognitive status, however, precluded her ability to assent."
3. On page 12, the first paragraph: "Ting's father was the decision maker in this traditional Chinese family, and direct, important conversations were hamped by his work schedule and his inability to be

present." Leave out the last sentence of that paragraph.  
4. Please read thoroughly for any typos or grammatical errors.

There may be some other, minor edits, but most of the text is easy to read and informative. We look forward to publishing your case study.

RESPONSE:

I have made the edits recommended in the manuscript using the track changes option.

I have moved the table to a separate document and made changes as suggested.

-----Original Message-----

From: [ees.jpediatrnurs.e.674d.bb83638c@eesmail.elsevier.com](mailto:ees.jpediatrnurs.e.674d.bb83638c@eesmail.elsevier.com)

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Sent: Friday, April 17, 2009 2:20 PM

To: Helen Turner

Subject: Your Submission

Ms. Ref. No.: JPEDIATRNUURS-D-09-00005R2

Title: Parental Preference or Child Wellbeing: An Ethical Dilemma

Journal of Pediatric Nursing

Dear Ms Helen N Turner,

I am pleased to inform you that your paper "Parental Preference or Child Wellbeing: An Ethical Dilemma" has been accepted for publication in Journal of Pediatric Nursing.

Below are comments from the editor and reviewers.

Thank you for submitting your work to Journal of Pediatric Nursing.

Yours sincerely,

Maura MacPhee, RN, PhD

Associate Editor

Journal of Pediatric Nursing

Comments from the editors and reviewers:

Thank you for making the suggested revisions to your article. It will make an excellent addition to our pediatric nursing knowledge base.

## Journal Author Guidelines

Retrieved April 8, 2009, from <http://www.pediatricnursing.org/authorinfo>



The *Journal of Pediatric Nursing: Nursing Care of Children and Families* (JPN) is interested in publishing clinical, theory, programmatic and research papers on a variety of topics. JPN is the official journal of the Society of Pediatric Nurses and Pediatric Endocrinology Nursing Society. Papers are published covering the life span from birth to adolescence. Subject matter pertinent to the nursing care needs of healthy and ill infants, children and adolescents addressing their biopsychosocial needs is disseminated in the Journal. In addition, the Journal features regular columns to which authors are encouraged to submit brief papers and announcements. These columns include Child Health Policy, International Pediatric Nursing, Child in the Community: Nursing Makes a Difference, Clinical Practice, SPN News and PENS News. Also, as a special feature, selected articles exemplifying timely topics are published as an Editor's Choice selection. Cecily L. Betz, PhD, RN, FAAN is the Founder and Editor-in-Chief and Maura MacPhee, PhD, RN is the Associate Editor.

### EDITORIAL CORRESPONDENCE

Authors are encouraged to contact the Editor either by phone, in writing, or via email to discuss potential ideas/articles for submission. Correspondence via email is preferred. Dr. Betz can be contacted via [cbetz@chla.usc.edu](mailto:cbetz@chla.usc.edu) or via the JPN website.

Feedback and advice about the topic and its development will be provided. It is important to note that the Journal has a strong commitment to assisting first time authors in developing publishable papers. Therefore, prospective writers are encouraged to contact the Editor-in-Chief directly to seek additional assistance and encouragement to facilitate their publishing goal.

The Clinical Practice Column is a practice-based column that features case studies, reviews, and other information of relevance to nurses in a variety of practice settings. Articles in this column are reviewed by the column editor: they are not blind-reviewed. Please contact the column editor, Dr. Maura MacPhee, at [maura.macphee@nursing.ubc.ca](mailto:maura.macphee@nursing.ubc.ca) for column submission details.

## THE REVIEW PROCESS

This is a referred journal. All manuscripts received by the Editor-in-Chief and sent to reviewers are treated as privileged communication. Manuscripts are submitted electronically via the JPN website, <http://ees.elsevier.com/jpediatr Nurs/>. Manuscripts will be assigned to reviewers for blind review. Generally, manuscripts are sent to two review experts. The original review team reviews manuscripts requiring revisions to ensure consistency. Scoring guides used by the reviewers for clinical, theoretical, and review research papers are available from the Editor-in-Chief upon request. The review process takes approximately 1 month.

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The text and reference of the manuscript must conform in style to the American Psychological Association (APA) Guidelines 5th Edition. The information required for the electronic submission is detailed below:

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SCHOOL OF NURSING  
Ashland Klamath Falls La Grande Portland

## DNP Clinical Inquiry Project Report & DNP Portfolio Approval

Student Name: Helen Nadine Turner

Degree: Doctor of Nursing Practice

Title of Study:

Evaluating the Effect of a Pain Resource Nurse Program on Barriers to Pediatric Pain Management

APPROVED:

Committee Chair: Deborah Eldredge, PhD, RN  
(name and credentials)

Signature: Deborah Eldredge

Committee Member: Judith Baggs, PhD, RN, FAAN  
(name and credentials)

Signature: Judith Baggs

Committee Member: Susan O'Conner-Von, DNSc, RNC  
(name and credentials)

Signature: Susan O'Conner-Von

Michael R. Bleich, PhD, RN, MPH, FAAN  
Dean, School of Nursing

Signature: Michael R Bleich

Date: 6/4/09

Submit completed original form to the Graduate Program office.