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The Parent perspective on child symptom management as an outcome of care for the emergency department : a qualitative descriptive study

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The Parent Perspective on Child Symptom Management as an Outcome of Care for the
Emergency Department: A Qualitative Descriptive Study

By

Donald W. Mitchell

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Abstract

TITLE: Parents' Perception of Child Symptom Management as an Outcome of Care for the Emergency Department: A Qualitative Descriptive Study

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This qualitative descriptive study describes parents' perspectives on their young (birth-8 years of age) child's symptom management as an outcome of treatment in the Emergency Department (ED). The study had two specific aims: the first was to describe parental perceptions of their young children's illness symptoms when they bring their child to the ED; and the second is to describe what is important to parents about their young children's illness symptom management after visiting the ED. Thirteen eligible parents participated in post-visit interviews with a semi-structured format. Interview transcripts were analyzed and coded for descriptive concepts as articulated by parents regarding the study aims. Three main interactive categories were identified. The first was a cyclical process of *symptom management*. The cycle starts with parents noticing *something is wrong* with their child, becoming *alarmed*, learning about and *knowing* the *illness*, learning to *manage* the *illness*, and returning their child to their normal health state. The second category is *provider interactions*, which can affect each step of the cycle. These interactions were: 1) communications involving discussions with providers, parental expectations, communication around care, and provider behaviors; and 2) the *interventions* involved. The third category entails the underlying family contexts of *social supports* and *life logistics* that affect both the symptom management cycle, and provider interactions. Understanding the parents' perspective on the important patient-centered outcome of their young child's symptom management adds to the body of knowledge in this area.

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Chapter 1: Introduction

Researching outcomes of health care has been a growing science since Donabedian (1966) identified the need to study them as part of determining treatment effectiveness. Clancy and Eisenberg (1998) define outcomes research as “the study of the end results of health services that takes patients’ experiences, preferences, and values into account” (p. 245). The effective management of symptoms is recognized as an important outcome of care (Clancy & Eisenberg, 1998; Hegyvary, 1993), and has been theoretically identified as a central outcome of quality health care in the Quality Health Outcomes Model (QHOM) (Mitchell & Lang, 2004; Mitchell, Ferketich, & Jennings, 1998). Both the classic Donabedian model of structure-process-outcomes, and the QHOM, in which interventions act through patient (client) and system factors to create outcomes, provide the theoretical positioning for the phenomenon of parents’ perception of symptom management described in this study. It is important to differentiate this definition of outcomes from the definition more familiar to nurse researchers in symptom management of “outcomes” as a periodic benchmark to measure the trajectory of chronic illness, such as cancer (*cf.* Brant, Beck, & Miaskowski, 2010).

Symptom Management

Symptom management research has largely evolved in the context of chronic illness, such as cancer, and is viewed as controlling symptoms over extended periods of time (as in the UCSF Symptom Management Theory) (Brant, Beck, & Miaskowski, 2010; Humphreys et al., 2008; Dodd et al., 2001). *Outcomes* from this perspective are thus viewed as part of an iterative process to optimize health states such as health-

related quality of life, or controlling the symptom experience over time, through continuous assessment, intervention, and reassessment. An example of symptom management from this perspective would be maintaining an oncology patient's pain level at 3 or less on a standard 10-point scale. However, Sidani (2011) provides a definition of symptom management more applicable to the ED setting: "the end result of symptom management is symptom control, [which] refers to the resolution of the presenting symptom or the attenuation of its level of severity and/or distress" (p. 131). This describes amelioration of the *symptom experience*, which in nursing research has been defined to include the frequency, intensity, distress, and meaning of the symptoms (Armstrong, 2003).

There are no existing empirical measures of symptom management in the ED. Several instruments exist that are frequently used under the symptom management rubric. These include the Memorial Symptoms Assessment Scale, which has been adopted for use with children as young as 5 years of age (Collins et al., 2002; Collins et al., 2000), the Symptom Distress Scale (SDS) (McCorkle & Young, 1978), as well as individual symptom measures such as age-specific pain intensity scales applicable to children older than 3 years of age. However, these instruments primarily reflect the occurrence and severity of specific, select symptoms, such as measuring pain level on a standard 10-point scale. They are aimed at adults and older children, and were developed expressly for use with cancer patients and cancer-related symptoms. A review of the literature reveals a lack of an instrument to measure parents' perception of their child's symptom management outcome after taking their child to the ED. The

findings from this study will, however, provide a qualitative base for the subsequent development of such an empirical instrument to fill this gap.

The Emergency Department (ED)

Emergency Departments (EDs) have a central role in the United States health care system. They are expected to be able to manage and treat a broad range of illnesses and injuries as patients seek care either as walk-in patients or as those arriving by ambulance. Many of these presenting problems are life-threatening and require immediate intervention. Unfortunately, EDs increasingly fill the widening gaps in the American health care system, treating not only the severe and life-threatening illnesses and injuries for which EDs are intended, but also treating an ever-increasing level of routine illnesses in patients unable to access health care otherwise. Due to the federal Emergency Medical Treatment and Active Labor Act (EMTALA), EDs are the only places in the United States that are required to examine and treat patients regardless of ability to pay (IOM, 2006). In 2009 (the most recent data available), there were over 28 million visits to EDs by children under the age of 15 years (increased from 23 million visits in 2008); over half of the visits were by young children under five years of age. The overwhelming majority were brought to the ED by their family for treatment of illness symptoms such as fever, cough, or vomiting (the three most frequently reported symptoms). Of these patients under 15 years of age, only 5.3% arrived in the ED by ambulance and a scant 3.2% required admission to the hospital (National Hospital Medical Ambulatory Care Survey, CDC, 2009). The overwhelming majority (96.8%) of these pediatric patients were treated for low acuity concerns and discharged. Assessing the effectiveness of care for this population, who may have no further contact

with the health care system, requires developing ways to capture the perception of symptom management as an outcome of treatment in the ED setting.

Parents Speak For Their Young Children

Young children experience both acute and chronic illness symptoms for which they are treated in the ED, but they may lack the language and/or cognitive developmental level to express their symptom experience. This requires someone, usually their parent(s), to communicate their needs to health care providers. This includes the perception of the outcome of ED symptom management. Until the age of seven or eight years, children are in the *preoperational* cognitive developmental phase. Piaget characterized children at this level of development as having semi-logical thinking, in which they may be able to identify an object but have difficulty quantifying or identifying conservation or change. They also have trouble with reversibility (Hetherington et al., 2008; Dixon & Stein, 2006), making comparisons to past and present conditions difficult. Although the child's parent could possibly assist in the task of describing and comparing symptoms, young children's responses have been found to be highly *suggestible*. They tend to answer questions in a way they think will please the adult and interpret cues from the adult to accomplish this, rather than giving the desired objective response. Reliable information can be garnered from young children with sufficient care and attention to their cognitive developmental level by carefully trained interviewers (Bruck & Ceci, 1999). However, this requires considerable resources of time and professional assessment, making it impractical as an approach to outcomes evaluation.

Parents are ideally positioned to report on their children's health and illness (Seid et al., 2001), as they routinely monitor and interpret their children's symptoms and illness behaviors (Neill, 2000). There is good evidence to support the accuracy of parents' observations of their young children's symptoms in the context of pain status (cf. Zisk et al., 2007; Chambers et al., 2002), including the cognitively impaired child (Voepel-Lewis, Malviya, & Tait, 2005). A parent observation measure of pain developed for use in both clinical management and research, the Parents' Postoperative Pain Measure, has shown excellent reliability and validity in practice (Von Baeyer, Chambers, & Eakins, 2011), demonstrating the potential of this approach.

Parent report of child behaviors has validity because they share the bioecological context of the family and community. The bioecological theory of development posits that children develop within concentric layers of influence that affect their personality and expressiveness. These layers or spheres of influence include the *microsystem* of parents, family, and peers; the *mesosystem* in which they interact; and the *exo-* and *macrosystems* of culture and social institutions (White & Klein, 2008; Bronfenbrenner & Morris, 2006). How children express themselves is strongly influenced by this context (Hetherington et al., 2006), and the expression of symptoms such as pain can change over time as children develop and learn to express themselves in ways unique to their individual ecosystems (Hadjistavropoulos & Craig, 2002). For example, in infancy and toddlerhood, pain is typically expressed by crying, but with development and socialization, some learn to express pain verbally or with stoicism. Children's symptom experience is communicated through both *voluntary* (such as verbal complaints) and *involuntary* (such as lethargy) illness behaviors, which are interpreted and responded to

by their parents (Craig & Riddell, 2003). Successful symptom management in young children by ED clinicians should thus be based on the parents' criteria for resolution of the concerning illness behaviors.

Registered Nurses (RNs) in the ED

Registered Nurses (RNs) are critical to providing services in the ED. ED RNs possess a broad range of expertise. Unlike most nursing specialty areas that focus on an age group or medical and surgical specialties such as cardiac care, ED RNs must be able to provide immediate and competent care to patients across the lifespan. Their concerns traverse the entire span of illness from myocardial infarction, to sepsis, to traumatic injury. ED RNs apply the nursing process to the care of these patients, assessing, diagnosing, planning, implementing, and evaluating the care they receive in collaboration with specialty physicians and other licensed independent providers. Beginning with the process of RN triage, in which patients are assigned priority order according to the acuity of their illness or injury, the ED RN must constantly evaluate patient needs and prioritize ED resources to optimize patient care. Other responsibilities include providing patient/family education, and assessing the understanding of this education and the resources patients and families have to make use of this teaching. The skilled ED RN is very much a driver of the care and management patients receive while in the ED.

Purpose and Aims

The purpose of this qualitative descriptive study was to describe parental perceptions of their young children's (birth to eight years of age) illness symptoms and the symptom management outcomes parents care about when they bring their children

to the Emergency Department (ED). Patient reported outcomes are increasingly viewed as critical to providing quality health care, but the parent perspective has not been adequately explored in the ED context. Parent-reported symptom management outcomes are defined as the young child's intentional and unintentional illness symptom behaviors that parents recognize as potentially threatening to their child's health that they do not feel able to manage (Mitchell, in press).

The specific aims of this study were to:

1. Describe parental perceptions of their young children's (birth to eight years of age) illness symptoms when they bring their child to the ED.
2. Describe what is important to parents about their young children's illness symptom management after visiting the ED.

The qualitative descriptive findings from this study will contribute to the knowledge base for the subsequent development of an empirical instrument to measure parents' report of their child's symptom management as an outcome of visiting the ED.

Significance to nursing

Evaluating health care outcomes, particularly as viewed from the patients' perspective, is viewed as an inescapable area of study as health care costs skyrocket, and accountability for services is demanded (Doran & Pringle, 2011). However, developing measures that are reliable and valid requires a solid theoretical base that is applied to a particular population and enriched by contextual qualitative data (Turner et al., 2007). The qualitative descriptive research undertaken here can contribute to this base for subsequent empirical instrument development.

Symptom management has long been an outcome of interest to nurse researchers, as nursing can have a significant impact in this area of health care (*cf.* Sidani, 2011; Dodd et al., 2001; Mitchell, Ferketich, & Jennings, 1998; Hegyvary, 1993). However, outcomes research increasingly recognizes the importance of the patient's perspective, including pediatric emergency health care (Clancy, Dougherty, & Walker, 2002). This study addressed the parent perceptions of the symptom management outcomes from their child's visit.

Registered nurses have a significant presence in the ED and are generally positioned to have a profound impact on family perceptions of the care they receive. RNs are generally the first clinical contact parents have in the ED, and the course of the care they receive is initially dictated by the triage process. RNs serve as the primary contact and caregiver in the ED for patients and families, monitoring their status, intervening, or advocating medical intervention as patient condition warrants. The RN who discharges the patient is usually the final clinical contact as well, ensuring the patient's and family's needs for teaching and follow-up are clearly understood. Because of the principal role of RNs in the ED, they can benefit significantly from better understanding how parents perceive the outcomes of their young child's symptom management.

Chapter 2: Review of the Literature

This chapter will review the relevant literature for the key conceptual areas that serve as background for this qualitative descriptive study. Outcomes of health care and the nursing-developed Quality Health Outcomes Model are reviewed to situate symptom management as an appropriate outcome for study. Symptom management is discussed as it has evolved, with an emphasis on nursing science. The importance of parent report for their young children is reviewed from both a validity perspective and from the cognitive developmental standpoint of young children's ability to reflexively report. Two theoretical models are reviewed that inform the ED symptom management experience. Finally, the bioecological theoretical framework that supports the family perspective and parent/child dyad approach implicit in this qualitative descriptive research is reviewed.

Study of Outcomes

Interest in health care outcomes has grown since the landmark publication of Donabedian's (1966) "Evaluating the Quality of Medical Care." Donabedian described the concern that the same medical problems were being treated differently by different providers, with very different results for patients, yet there was no systematic evaluation to substantiate this. The Donabedian model described the *outcomes* of care as the result of both *structures* and *processes*. Structural factors are materials, human resources, and organizational structures. Processes describe what actually happens with patients and caregivers during treatment. Outcomes are measurable improvements in the patient's health status (Donabedian, 1988). The ability to evaluate health care outcomes is critical because it allows not only for assessment of the treatment quality administered by health care providers, but additionally allows for the

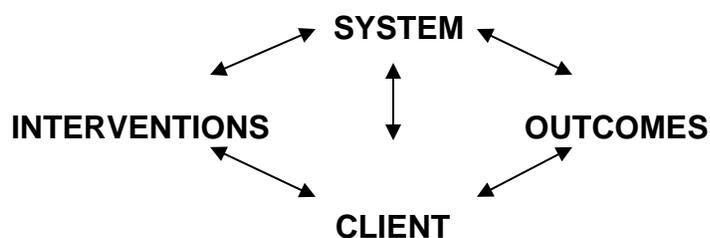
evaluation of the comparative effectiveness of different treatments (Clancy & Eisenberg, 1998), including the ED (Clancy, Dougherty, & Walker, 2003).

Measurement of health care outcomes, however, has overwhelmingly been concerned with the “five D’s of death, disability, disease, discomfort, and dissatisfaction” (Mitchell, Ferketich, & Jennings, 1998, p. 43). More recently, interest in outcomes research has moved from clinical observations to patient-reported outcomes such as satisfaction and health-related quality of life (Kane, 2006). American public policy has supported this shift with the creation of the federally-funded Patient Centered Outcomes Research Institute (PCORI). Patient-centered data are central to outcomes research as they allow for comparison across treatments and providers. Patient-centered data encompass individual characteristics, preferences, and needs that promote individually targeted care. PCORI has defined the patient-centered approach as focusing on “outcomes that patients notice and care about,” such as health-related quality of life, level of functioning, and symptoms (PCORI, 2012). Nurse scientists have explored this approach to patient-reported outcomes through the emerging Quality Health Outcomes Model. This model situates symptom management as an important outcome of care to measure.

The Quality Health Outcomes Model

The Quality Health Outcomes Model (QHOM) is an adaptation of the classical Donabedian structure-process-outcome theoretical framework by nurse scientists for evaluating health care that reflects the recent emphasis on patient-reported outcomes. The QHOM has been used in peer-reviewed dissemination of research in oncology (Radwin et al., 2000, 2002, 2009), surgical (Mark & Harless, 2010), perinatal (Wilson,

Effken, & Butler, 2010), and psychiatric (Gerolamo, 2004, 2006) nursing. The QHOM is the resulting consensus of the American Academy of Nursing Expert Panel on Quality Health Care, first presented in 1997, and posits a dynamic interaction between four elements: system, client, intervention, and outcome.



The classical structure and process aspects of outcomes measurement are incorporated into the *system* characteristics, and include agency traits such as size, staffing levels, skill mix, and technological resources. *Interventions* are direct and indirect clinical processes and include their delivery method. *Client* characteristics include demographics, risk for disease, overall health and illness, and related individual factors that can affect quality care outcomes. The conceptualization of *outcomes*, however, marks a significant departure from prevailing measurement paradigms. It embraces not only morbidity and mortality data but further reflects the patient's experience of health and illness, which encompasses nursing's contribution to care as well as that of other disciplines. The QHOM also has the advantage of applicability at different levels of analysis, such as individual, group, or organizational (Mitchell, Ferketich, & Jennings, 1998).

The original QHOM recommended measuring outcomes in five key areas beyond morbidity and mortality. These key areas included the achievement of self-care, the demonstration of health-promoting behaviors, the perception of being well-cared-for,

health-related quality of life, and symptom management. *Symptom management* is not explicitly defined in the original model, but in a more recent update, Mitchell and Lang (2004) presented the outcome of symptom management in terms of *symptom management to criterion*. Symptom management to criterion was a conceptual shift to patient-defined outcomes and thereby the outcomes of the management of specific symptoms. The emphasis is on the patient's criterion, so that reduction of any symptom to a patient-defined level of tolerance or acceptability qualifies.

The QHOM is an emerging framework in nursing research (Doran et al., 2006; Swan & Boruch, 2004) that allows for multiple levels of analysis. Further, it incorporates the positive health and psychosocial outcomes that nurses can readily influence beyond the traditional morbidity and mortality metrics. Patient-defined symptom management measurement is a crucial outcome component that remains elusive (Mitchell & Lang, 2004). This proposed qualitative descriptive study for parents of young children treated in the ED will provide the base to begin to address this gap.

Symptom management

While the symptom management literature and science has proceeded apace, the dominant frameworks are intended for research with adult patients and are seldom used in child symptom management research (Hockenberry, 2004), although the UCSF Theory of Symptom Management has been applied to children eight years of age and older with cancer (Linder, 2010). These models are generally less applicable to young children if at all, who rely on their parents for their needs, including symptom management. Although no symptom management model exists for studying young children, the related concepts in the existing adult literature can contribute to a

conceptual understanding of symptom management for young children brought by their parents to the ED.

There is no shortage of symptom management models for adults. Much thinking in this area is informed by Leventhal's Common Sense Model of Illness Representation (see below), whereby the symptom experience is recognized as a subjective phenomenon (Leventhal, Nerenz, & Straus, 1982). This is the basis for the Symptom Interpretation Model (SIM), which is a linear model from symptom stimulus, to action, to outcome (Teel et al., 1997). The Symptom Perception Model (Kolk et al., 2003) is similar, but parses the input and interpretation analogues slightly differently by principally recognizing the physical and psychological differences in symptom interpretation. The Theory of Unpleasant Symptoms (TUS) (Lenz et al., 1997; Lenz & Pugh, 2008) mirrors the SIM in that physiological, psychological, and situational factors are viewed as antecedents to a person's symptom experience. The Theory of Symptom Management (TSM) (Humphreys et al., 2008; Dodd et al., 2001) models a dynamic relationship between the symptom experience, symptom management strategies, and symptom status, and situates these within each individual's unique circumstances. The TSM was more recently modified to incorporate symptom trajectory measurement. Symptom trajectory was added to reflect the status of symptoms as they are periodically measured over the course of treatment (Brant, Beck, & Miaskowski, 2010).

While not directly applicable to symptom management with young children and families, the models contribute to the broader conceptualization of symptom management. Reflective of its grounding in chronic illness, symptom management is generally defined as a process that occurs over time. The outcomes of this process are

of interest. For example, a concept analysis of symptom management in adult cancer patients (Fu et al., 2004) proposed the definition as: “a dynamic and multidimensional process in which patients intentionally and purposefully act on and interact with the perception of the symptom(s) to initiate activities or direct others to perform activities to relieve or decrease distress from, and prevent the occurrence of a symptom” (p. 68).

The idea of symptom management as a process can be seen in several of the prevailing models. For example, the Symptom Interpretation Model (SIM) has three sequential components: input, interpretation, and outcome. Input refers to an event of sufficient magnitude to trigger a concern. Interpretation is concerned with the ongoing recognition, categorization, and evaluation of stimuli. Outcomes are what the patient decides to do about it (Teel et al., 1997). According to the TSM perspective (Humphreys et al, 2008; Dodd et al., 2001), symptom management is an explicitly dynamic and iterative process, with continuous feedback between symptom status, symptom management strategies, and symptom outcomes.

Current thinking about the meaning of symptoms is the result of an evolution in the theoretical base. The traditional biomedical model relies on a naïve realism view that physical symptom reporting is a face value reflection of health status (Watson & Pennebaker, 1991). Symptom reporting is actually highly variable, and is significantly associated with individual situational and personality traits. According to Benner (1989), symptoms are part of an individual’s lived experience, and their subjective meaning plays a large part in that individual’s decision to take action on their symptom or not. Other prominent scholars have also advocated for an emphasis on patients’ subjective symptom interpretations (*cf.* Kleinman, 1989). Cioffi (1991) delineated the difference

between the biomedical model and a cognitive-perceptual model in which individuals assign labels to their somatic sensations; this is also consistent with Leventhal's Common Sense Model. Often these labels are quite different than what a medical practitioner would assign; instead, they reflect the individual perceiver's situation, and the beliefs and assumptions that they and others hold.

Dodd and colleagues (2001) proposed a widely accepted definition of *symptom* as "a subjective experience reflecting changes in the biopsychosocial functioning, sensations, or cognition of an individual" (p. 669). This definition reflects a move away from the prevailing biomedical view of symptom study that takes a dualistic view of the mind and body, whereby a specific symptom indicates the presence of illness that must be acted upon. This results in the current conceptualization of symptoms as individually patient-based perceptions, which are not necessarily measurable except by patient report of their symptom experience.

Symptom experience is the broadest category in symptom management, and is described in terms of input, distress, and knowledge. A seminal concept analysis yielded the definition of symptom experience as "the perception of the frequency, intensity, distress, and meaning of symptoms as they are produced and expressed" (Armstrong, 2003). Input is a newer term, arising primarily from information processing approaches such as the SIM. It has been parsed out from the distress associated with the symptom because it is the occurrence, frequency, and severity of the symptom stimulus that triggers the symptom management process. Symptom distress is the stress and concern associated with symptom presence or the degree of discomfort experienced from the specific symptom (McCorkle & Young, 1978). This definition

formed the conceptual basis of the Symptom Distress Scale (SDS), one of the first widely used symptom management measures for cancer patients. The SDS asked patients to rate the severity of cancer-related symptoms that they were experiencing, such as pain, fatigue, or mood changes. This basic approach was included and expanded to increase the number of symptoms in the Memorial Symptom Assessment Scale (MSAS), which asked patients to rate the *frequency* and *severity* of the symptoms listed (Portenoy et al., 1994). This measurement effort began to get at patients' experiences with their symptoms, contributing to the evolution of the symptom experience concept.

Another critical element of symptom management is the symptom-related interventions or *symptom management strategies*. These are strategies employed by individuals or health care providers on their behalf to halt, delay, or ameliorate the symptom experience. These may include self-management strategies, by which patients use learned or invented techniques to manage their symptoms (Humphreys et al., 2008). In the SIM, interventions are referred to as outcomes, and are the actions individuals decide to take in response to their symptoms. These actions include anything from accessing the health care system, to self-management, to choosing to do nothing. Symptom management interventions in the current context were formalized in the TSM (Humphreys et al., 2008; Dodd et al., 2001).

Symptom outcomes are of interest here, because they lack a consensus definition. The term appears consistently in the symptom management literature, but its usage differs slightly from 'outcomes' as described in the Donabedian tradition. In SMT, it is defined as whether the symptoms were resolved or controlled as part of an ongoing

iterative process, reflecting the idea of symptom trajectory. With the original SMT model, outcomes included quality of life, functional status, costs, morbidity, and mortality (Humphreys et al., 2008). Outcomes can be positive or negative based on measures of symptom occurrence, symptom distress, and quality of life (Fu et al., 2004). In the most recent SMT modification put forward (Brant, Beck, & Miaskowski, 2010), measures of quality of life, survival, function, and adjustment were included to reflect the management of a *symptom trajectory*, or the course of symptom management over time. Interest in the temporal element of symptom management (*cf.* Henly et al., 2003) has been a developing focus that reflects the symptom management field's grounding in cancer and chronic illness. Short term longitudinal trajectories, however, should also be applicable to the symptom management process of the transient, acute illnesses that are often seen in ambulatory care settings like the ED, yet have not been studied or incorporated into existing models. Exploring parents' perception of child symptom management is a logical approach, hearing from those best equipped by shared experience and cultural norms to represent their young children's experiences.

Ultimately, symptoms and the change in physical and psychological status they represent are the primary reason for seeking health care (Sidani, 2011), including emergency services. Symptom management is thus an important outcome of care that can be evaluated in many ways. While clinical observations and measures can certainly be used, they are not necessarily patient-centered; what is satisfactory for a clinician may or may not constitute adequate management from the patient's perspective. Thus, it is important to measure the patient's perception of symptom management, which is informed by their unique socioeconomic, historic, and cultural circumstances. It is also

important to measure the perceptions of parents as the caregivers of young children, who are the decision-makers for their wards. Exploring parents' perceptions of management of their child's symptom(s) requires asking them for their perspective, rooted in their unique family ecology.

The Bioecological Model and Family Research

The bioecological model is the theoretical background for the family-based research approach employed in this study, particularly as described by Bronfenbrenner. This approach refers to viewing child development as an adaptive interaction between the child and their environment. Reflecting the model's ecological roots, the theory identifies *niches*, or specific roles/activities that members of an ecosystem inhabit. Young children primarily occupy a niche where they are dependent on their parents or caregivers to meet their needs in what is termed a *commensal* relationship in this framework. The *microsystem* is the immediate influence in this model, and describes the role and relationships of individuals. This implicitly makes the dyad, such as a parent and child, the smallest unit of analysis. The immediate family and parents in particular, are the dominant developmental influence for young children, accounting for significant variance between individuals from different family ecosystems. The family microsystem is concentrically nested within a *mesosystem*, in which microsystems interact, an *exosystem* that affects these interactions, and a *macrosystem* of the overall sociocultural and historical context in which the family dwells (White & Klein, 2008).

Bronfenbrenner's original bioecological formulation has more recently shifted to a more dynamic formulation of interactions, rather than a simple consideration of environmental influences on development, although this does not affect the research

here. This involves identifying and defining four principal components essential to the bioecological model: process, person, context, and time. Proximal *processes* are the interactions between individuals and their environments that are the primary source of development. *Persons* have three influential characteristics that affect their development from proximal processes: disposition, resources such as ability and knowledge, and personal demand for reactions from their social environment. *Contexts* are the previously described system environments in which the individual develops. Finally, *time* is the most significant addition to the bioecological model, being incorporated at the micro-, meso-, and macrosystem levels. This reformulation of the bioecological model explicitly distinguishes between *process* and *environment* (Bronfenbrenner & Morris, 2006). While this reformulation of the model shows promise for improving future family research designs, the critical contribution of the bioecological model to this qualitative descriptive research is to support the importance of exploring parents' perceptions from the unique bioecological perspective of their family.

Parent report

Symptom experiences can be very subjective, so the person experiencing the symptom(s) is therefore best positioned to report on them. However, when the patient cannot sufficiently articulate their sensations and perceptions, it has been considered reasonable to ask questions of a surrogate reporter that knows the patient the best (Dodd et al., 2001). In the case of young children, this is generally their parent or primary caregiver. The question then becomes: at what age is it reasonable to ask the child to respond rather than their caregiver? This is especially important when planning to develop an instrument intended for wide use in outcomes research, as it is not

feasible to assess the cognitive development level and family dynamics for each child/parent dyad prior to administration. Based on developmental theory and scientific evidence for reliability and validity, it argued here that it is appropriate to rely on parents to respond for their children's symptom management outcomes from birth to eight years of age. The ability of parents to interpret their children's behaviors is also supported by family theory, as they are both a part of and a significant influence on their children's bioecological environment.

Riley (2004) considered the question of parents reporting for their young children and recommended reviewing evidence from five areas to inform the discussion of parent report versus child self-report on health measures. These areas regarding children's developing cognitive abilities are: cognitive interviewing studies of children's abilities to complete questionnaires with true responses, psychometrics of child-report instruments, parent-child agreement on the child's health status, and the value of child self-report over time. She concluded that children's response quality matures gradually from six to eight years of age, at which point they can respond effectively to age-appropriate questions. Riley cautioned, however, that the conclusions reached from these findings may differ somewhat based on the research perspective and context.

Riley's findings provide a lens to consider the challenge of evaluating young children's symptom management in a family context. For young children up to eight years of age, it is best to ask parents to respond, rather than their children. While younger children may be able to address their symptoms under the right circumstances, the barriers to obtaining those answers are too great. The barriers to child response include cognitive development, suggestibility, and verbal ability. Conversely, parents

routinely observe and monitor their children's health status (Neill, 2000), and are more familiar with their children's unique illness expressions than clinicians. Exploring parents' perceptions of their child's symptom management outcomes requires asking them for their observations, which are grounded in their unique family biopsychosocial ecology.

Developmental background

Leading theorists in child development (Piaget, Bandura, Bronfenbrenner, and Vygotsky) are consistent in identifying the importance of a child's social context and environment to their learning and cognitive development. Piaget proposed a series of cognitive developmental stages. These roughly correspond with a child's age through which a child progresses based on their *assimilation* of information in their environment, altering their understandings to *accommodate* new situations or challenges, and creating new mental approaches or *schemas*. Bandura's social learning theory was built on the behaviorist traditions of Pavlov and Skinner which posited that child behaviors developed when rewarded and disappeared when punished. Bandura's significant contribution was to delineate modeling as salient for behavior development, and that children are better able to identify appropriate models and creating their own styles of behavior as they mature. For young children, their parents are the most frequent model. Vygotsky described child development in terms of mentored learning, whereby children cognitively develop in relationship with parents, teachers, and others in their social environment, which encourage them to operate at or near their *potential level* of functioning. In Vygotsky's perspective, the child cannot be evaluated free of their sociocultural context (Dixon & Stein, 2006; Hetherington et al., 2006).

Bronfenbrenner's bioecological theory extends the importance of the environmental influence on development to an entire network of different system levels, from parent/family *microsystems* to *macrosystems* that encompass societal values and laws. Each family is the product of its environment; thus it is difficult for a clinician, as an outsider, to appraise each family's status and its changing conditions. For example, social development and cultural context dramatically influence the expression of pain, even at a very young age (von Baeyer & Spagrud, 2003; Craig & Pillai-Riddell, 2003). Thus, a parent who shares the sociocultural context with their child is in a much better position to rate their child's pain than a given clinician.

Barriers to child report

Piagetian stage terminology is useful for discussing the cognitive developmental progression of young children. During the sixth year is when many children begin the transition from *preoperational* to *operational* thinking, at which point they can classify and sort objects, and understand simple interrelationships between ideas. There is no exact time at which a child's cognitive abilities include the ability to understand serial relationships such as number or rating systems, although they are thought to occur generally between the ages of five and seven years (the "5/7 shift") (Dixon & Stein, 2006). This suggests that child self-report could be sought by age seven years for broad measures, although this age still presents considerable challenges to self-report. The concrete operations stage, at which children can effectively sort, classify, and group things logically, is traditionally thought to appear at about seven years, yet their thinking remains concrete, dealing with things that are tangible and present. Children at this age

have difficulty with abstract thinking and taking a comparative or alternate perspective when discussing particular subjects (Hetherington et al., 2006).

There are several important differences in children's ability to report their symptoms between the pre- and operational stages, a transition that is generally complete by nine years of age. Principally, preoperational children cannot *decenter* (think objectively) about a state or process, making them unreliable reporters when asking them to reflect on a process such as symptom management. They may demonstrate and report fear of a 'shot' to relieve pain symptoms, rather than understanding the beneficial consequences. This immediacy reflects the *present orientation* of the preoperational child: they cannot anticipate the relief to come nor make a reflective connection between the medication and their pain relief. They may also misattribute the cause of pain to something like punishment for misbehaving, as they have difficulty making the logical connection between pain and injury or illness (Gedaly-Duff, 1991). From a developmental perspective, there is uncertainty about when a given child will develop operational thinking. It is not typically possible to screen each child's developmental level, and thus it is reasonable to accept parents' reports for their young children from infancy through eight years of age.

Evidence from children's self-report of their health tends to bear this out. A cognitive interviewing study using the Child Health & Illness Profile-Child Edition with elementary school-age children found that five-year-olds could not sufficiently understand the items to adequately describe their health. Six- and seven-year-olds needed help with concepts, and tended to use either extreme or average responses, essentially thinking categorically. Children eight years and older, however, were able to

understand the items, use the full 5-point response scale, and could recall a four-week time period (Rebok et al., 2001).

A study of 414 parent-child pairs found that children as young as seven years old were reliable and valid reporters of their asthma-related health status, with the caveat that there was a statistically significantly higher rate of missing data collected from seven- and eight-year-old subjects (Olson et al., 2007). This finding reflects similar measurement challenges with young children's self-report found by Varni and colleagues (Varni, Limbers, & Burwinkle, 2007). In their study of children's health-related quality of life using the PedsQL instrument, they concluded that children as young as 5 years of age could make reliable and valid self-reports. However, there were significant missing data among responses from children aged five to seven years, and low internal consistency for this group in the subscales of emotional functioning (0.7 to 0.73), social functioning (0.68 to 0.71), and school functioning (0.63 to 0.62). Additionally, the response scales were changed for these younger children, from 5-point Likert responses to 3-point ratings; arguably, this changes the entire psychometric nature of the PedsQL instrument when administered to this demographic. This move to a categorical response format was perhaps an effort to neutralize the tendency of young children to respond with extreme scores, particularly in emotion-based responses (Chambers & Johnston, 2002). This response tendency must be taken into account by researchers when they interpret young children's self-reported ratings.

Some of these challenges are related to young children's verbal ability. Children experience symptoms as "feeling states," and young children lack the symptom-specific language generally found in symptom measurement (Woodgate et al., 2003). This may

be attributable to the fact that *metalinguistic awareness*, when children understand that words are separate from the objects to which they are attached, does not emerge until they are eight to ten years old. Children also do not develop the ability to draw inferences from reading until they reach the upper elementary levels (McDevitt & Ormond, 2012), which limits ways to explore their experiences.

A significant barrier to obtaining young children's symptom management reports is children's *suggestibility*, which has not been examined by child health researchers in the context of data collection. Suggestibility refers to the ease with which young children are susceptible to misleading suggestions by those interviewing them. Obtaining factually accurate reports is possible but requires specific and conscious efforts by interviewers not to influence children's reports with their own biases. In fact, the reliability of children's memory has been found to depend more on the interviewer's skill than limitations on children's own memories. Children are highly subject to interviewer bias in their responses because they generally trust adults and want to please them, so may adjust their answers based on cues from their interviewer.

Children have been found to respond accurately to open-ended questions but, when questionnaire administration is necessary as with the potential instrument to be developed, the validity of child report is compromised. Forced choice questions are problematic for young children, because they will attempt to answer them in a way that will please the adult giving the questions, including fabricating a response when they do not understand the question or do not have an answer (Krahenbuhl & Blades, 2007; Bruck & Ceci, 1999).

Given this available evidence for limitations to children's cognitive development and the measurement challenges with young children, sufficient support exists to justify parental report for their young children's symptom management. This does not preclude seeking child responses in other circumstances. Specifically for the measurement approach that will be the next step in this proposed research project, parental report for their young children's symptom management will provide the data for analysis.

Validity of parent report

Parents are ideally positioned as family reporters for their children's health care (Seid et al., 2001), as they share the social and cultural context with their children. Further, parents are the decision-makers regarding symptom management choices for their children. How children express their pain, for example, is constantly changing as they grow and adapt to their physical and social environment (Hadjistavropoulos & Craig, 2002). Parents also monitor their children's health status continually, and are able to determine when a symptom is out of the ordinary (Neill, 2000). Parent report has historically been considered essential for evaluation when a child is too young, too ill, or too cognitively impaired to self-report (Varni, Limbers, & Burwinkle, 2007).

Parents and their children occupy the same unique psychosocial and cultural ecosystem. In this context, young children and their parents inhabit the same family and school *microsystems* and societal and cultural *macrosystems*. The interrelationships between children and their parents form part of the *mesosystem*, in which things like behaviors and values begin to take shape (White & Klein, 2007; Bronfenbrenner & Morris, 2006; Hetherington et al., 2006). Because the parent/child microsystem interactions are such a dominant part of the developmental process for the first few

years of life, parents have a uniquely valuable perspective on their young children's illness behaviors, as their expression has been shaped by their shared interactions.

A bioecological perspective to validate parents' interpretive responses has been explicitly applied to the symptom of pain in children (Craig & Pillai-Riddell, 2003), but should extend to other symptom expression behaviors as well. Craig and Pillai-Riddell (2003) separated these expressive behaviors into *intentional* or purposeful complaints and actions, and *unintentional* or reflexive and physiological responses. Both intentional and unintentional behaviors are observed and assessed by parents for possible intervention.

Parent report relies on correctly interpreting their young child's behavior. It is possible, therefore, that the parent's level of attachment or sensitivity to their child may affect their reporting, so this relationship should be explored as part of instrument validation in the future. Bowlby conceptualized attachment as the biological basis of infant and parental responsiveness, and defined it as an organization of behaviors that provides the infant with care and protection. Both mothers and fathers can form secure attachments to their children, although these can be different levels of attachment even in the same family (Bowlby, 1988). *Secure attachment* is characterized by a young child who is confident exploring a new environment, is only mildly bothered by brief separation from their mother, and is comforted by their return (Ainsworth, 1979). This optimal state was found in two thirds of families, and represents the desirable attachment organization. *Insecure attachment* can manifest in maladaptive patterns, which are subdivided into *avoidant*, *resistant*, or *disorganized attachment*. This relationship has been found to persist through children's sixth year of age. The pattern

of attachment can be measured through use of the Attachment Q Sort (AQS) and observations that require trained observers. There are also parent self-reports of child and parent behaviors associated with a securely attached relationship (Hetherington et al., 2008).

Parental *sensitivity* is vital to developing secure attachment, and is characterized by recognizing and responding to infants signaling their needs (Hetherington, 2006). A sensitive parent engages in a process of mutually-reinforcing communications, such that parent and child learn each other's contingent signals and respond to them appropriately (Van Egeren, Barratt, & Roach, 2001). Pedersen and colleagues (1990) developed the Maternal Behavior Q-Set (MBQS) to specifically measure parental sensitivity. The items include behaviors that reflect parental interactive style and are thought to reflect the theoretical and observed actions associated with a sensitive parenting style (Pedersen & Moran, 1995b). Although not in the scope of the current research, parental sensitivity and attachment patterns likely warrant investigation in future studies of parent report validity.

Empirical Parent Report

Evidence to support the subsequent empirical approach to parent report exists. Previous instruments explicitly developed as quality metrics for pediatric health care have been found to have reasonable initial reliability and validity using a parent report approach. One measure is the Parents' Perception of Primary Care (P3C; Seid et al., 2001) and another is a measure of parents' perspective of quality of inpatient care for their child in the hospital (Homer et al., 1999). The P3C is a 23-item measure that generates a total score, and subscale scores in the areas of longitudinal continuity,

access, contextual knowledge, communication, comprehensiveness, and coordination. Its brevity allows the potential for widespread use. The inpatient quality measure, by contrast, consists of 122 items, and was administered periodically by trained telephone interviewers to a broad sample of recently treated families to identify parent perceptions of quality.

Considerable research has examined the validity of parents reporting on their children's status in the areas of pain and of health-related quality of life (HRQOL). There is good evidence to support parent reporting on their young child's pain status (*cf.* Zisk et al., 2007; Chambers et al., 2002), including the cognitively impaired child (Voepel-Lewis, Malviya, & Tait, 2005), and hydration status (Porter et al., 2003). Thus, parents can be reliable and valid reporters for their young children's symptoms. In a massive study (sample size 13,878) by Varni and colleagues of HRQOL report, parents' reports were found reliable and valid across all age subgroups from two to 16 years (Varni et al., 2007). The parent report approach was similarly used successfully to compare HRQOL and fatigue in pediatric patients, between two and 18 years, with acute lymphoblastic leukemia or brain tumors (Meeske et al., 2004). An earlier review of research involving parents' reporting on their children's HRQOL found better agreement for observable factors (physical) than internal factors (emotional or social), and better agreement between parents and their chronically ill children versus parents and their healthy children. However, no effect on agreement was found for child age or gender, and the overall agreement was more than adequate (Eiser & Morse, 2001). Thus, the measurement evidence supports that parents have the ability to report on their young child's illness-related condition.

Perceived Threat and Symptom Control

Parents respond rationally to their children's illness symptoms. Kai (1996) performed a seminal grounded theory exploration of what worried parents when their children were acutely ill, and why. This study generated a model that involves an interaction between parents' sense of personal control and the perceived threat from the child's symptoms. *Perceived threat* is a parent's gestalt of the illness symptom behaviors where they integrate their observations of their child's behavior and symptoms (such as cough or fever) with their experience of illness to decide whether their child's illness is merely discomforting or potentially life-threatening. Moderating this perceived threat is the parent's sense of *personal control*, or how capable they feel to monitor and control their child's symptoms. The lower their sense of personal control of their child's illness symptoms, the more likely parents are to view the symptoms as a serious threat and seek urgent medical treatment (Kai, 1996). Although research in this area is limited, at least two other studies of parents seeking treatment for their child's acute illness echo these findings, particularly the relationship between perceived threat and related worry regarding acute illness symptom behavior (Gross & Howard, 2001; Turk et al., 1985). Clearly, parents' sense of control over symptoms will be an important area to focus on when exploring parents' perceptions of their child's symptom management outcomes.

This interaction has also been described more generally in the Common Sense Model of illness representation (CSM), although it has not been applied in a family context. The CSM is an iterative information processing model, in which bothersome sensations (symptoms) are identified and categorized (Leventhal, Nerenz, & Straus

1982). It has long been applied to symptom management theory and, as previously discussed, significantly informs prevailing thought. In the CSM, an individual assesses their symptoms for their potential threat and initiates coping actions to mitigate them according to the individual's experience and level of concern. The results of these coping actions are appraised and continued or modified based on their effectiveness.

Four symptom appraisal factors are primarily identified in the CSM: identity, timeline, consequences, and cause. *Identity* refers to identifying the symptoms and their meaning; *timeline* refers to expectations of symptom duration and acuteness or chronicity; *consequences* are the expected effects of the symptoms/illness; and *cause* is the perceived trigger for the illness and associated symptoms (Lau, Bernard, & Hartman, 1989; Leventhal, Nerenz, & Straus, 1982). These concepts collectively inform what Kai (1996) terms the perceived threat from symptoms. A meta-analysis of studies employing the CSM described consistent findings that the degree of perceived control regarding the illness was strongly associated with positive reported outcomes such as well-being (Hagger & Orbell, 2003). The consonance between Kai's (1996) grounded theory study findings and a prevailing symptom management model such as the CSM, supports the further exploration of the concepts he identifies.

Most acutely ill young children will be sent home from the ED with their parents with a plan for illness symptom management, and Kai (1996) found that it is critical that information be communicated to parents before discharge. When Kai explored how the interactions between parents and providers affected their sense of personal control, a number of potential communication barriers were identified that further negatively impacted the perceived threat from the illness. Parents generally preferred an active

treatment course, and were frustrated when an illness was not described as having a ready cure or medication to treat it. Providers often failed to explore parents' beliefs and concerns about their child's illness, leaving them feeling disempowered and doubting their own judgment as well as the provider's judgment. These findings further suggest ways to improve parents' sense of personal control over their child's illness symptoms, and it is an area that was explored in this qualitative descriptive study.

Chapter 3: Research Design and Method

This section describes the research design and methods used to explore parents' perceptions of their young children's symptom management after treatment in the Emergency Department. This was a qualitative descriptive study, rooted in the constructivist/interpretive philosophy of scientific enquiry. A brief review of scientific philosophy is followed by an overview of the qualitative descriptive approach and specific methods that were employed in this study. A discussion of quality benchmarks for qualitative inquiry and how they were met by this research design and measures for the protection of human subjects complete the chapter.

Philosophy of science

Because this qualitative descriptive study was rooted in the constructivist-interpretive research paradigm, it is important to acknowledge the philosophical differences between this paradigm and the dominant empirical framework. These differences are primarily in the philosophical domains of epistemology and ontology.

Ontological perspectives explore the nature of reality and what can be known about it. The empirical paradigm holds that there is an objectively knowable reality, but that human observations can only achieve an approximate understanding of that reality. However, the empirical goal is the prediction and control of phenomena, reflecting the scientific traditions of fields such as physics or chemistry. Studying people requires exploring their perceptions and the meanings they attach to them, and empirical ontology is often inappropriate for this purpose. The constructivist-interpretive ontological view is that reality is relative, rather than objective. Individuals process their perceptions of the world differently, and can thus hold different mentally-constructed

views of reality, which are influenced by their own social and psychological circumstances.

Epistemological stance reflects beliefs about who can know, and how knowledge can be communicated. The empirical perspective holds that by employing rigorous methods, the scientist can record objective observations about their research subjects, which can then be generalized as objective findings. The constructivist-interpretive approach holds that because reality is subjectively understood, scientists must form partnerships with their research informants to discover how they describe their thoughts and perceptions (Denzin & Lincoln 2011; Ponterotto 2005).

In order to build an initial understanding of how parents of young children view the outcomes of care from the ED, research conducted using the constructivist-interpretive paradigm was the most appropriate. In this case, parents of young children are the knowers. Analyzing this knowledge after it is elicited can lead to a valid qualitative understanding of parents' perceptions of their young child's symptom management outcomes.

Qualitative descriptive research

Qualitative descriptive research is a qualitative methodological approach whose purpose is the simple description of the elements of research inquiry into a phenomenon. While not a purely atheoretical or non-paradigmatic approach, as any extrapolation requires some interpretation by the researcher, qualitative descriptive research findings nonetheless stay fairly close to the data gathered from interviews and observations. It does not seek to transform and interpret data to the extent that such approaches as grounded theory or hermeneutics would. The results extracted from the

data are simple descriptions of the data as best fits the findings, which most observers would agree are present in the data without special inference. This is referred to as “staying close to the data.” Qualitative descriptive research may borrow from other approaches as they are warranted based on the inquiry, such as the constant comparison method of data analysis from grounded theory, but remains a distinct category of research based on the outcome of its findings (Sandelowski, 2010, 2000). The research methods employed in this qualitative descriptive inquiry are outlined below.

Procedural Methods and Data Collection

Sampling

While empirical research approaches provide a specifically calculated sample size, the needed sample for a qualitative study can only be approximated in advance. Rather than achieving *significance* or other statistical goal, the objective for qualitative approaches is data saturation, or *redundancy*. Redundancy means that no new data are being gleaned from interviews, so the researcher has achieved an adequate sample size to capture the needed data for analysis (Patton, 2002). Sample size and selection are dependent on the data as it emerges, and the criteria are described below. A maximum variation sample size of 13 parents who brought their young children to the ED for symptom management was determined to be sufficient to reach the goal of data saturation given the results of the interviews (see Appendix I).

Several factors were considered when estimating the sample size needed for a qualitative study (Morse, 2000). Studies that are broader in scope require a larger sample to reach saturation. If the topic is clear and obvious so that data are relatively

easy to elicit from study participants, a smaller sample may be needed. The quality of the data gathered from interviews can affect the sample needed; if participants have difficulty articulating their thoughts, difficulty reflecting on the questions of interest, or insufficient time for a research interview, they may contribute little to the data.

“Shadowed data” are obtained when participants refer to the experiences that others have had, often to compare and contrast their own. Shadowed data can provide great insight and accelerate the process of analysis, and will be incorporated if found. The overarching principle is that the richer the data gained from each participant, the fewer participants that are needed (Morse, 2000). These factors were considered when the sample size for this qualitative descriptive study was determined.

Sample selection was another important factor. Whereas empirical research emphasizes random selection of subjects for the purpose of generalization to a larger population based on probability theory, qualitative researchers purposefully seek research participants who can provide rich interview data and have in-depth understanding (Maxwell, 2013; Patton, 2002). Patton (2002) described several approaches to purposeful sampling for qualitative inquiry where the researcher’s choice among them is dictated by the research questions and design. For the qualitative descriptive study outlined here, a *maximum variation* sampling approach was used. Variation was sought with respect to circumstances contributing to the maximum variation of samples including: socioeconomic status, race/ethnicity, child gender and age, the nature of the symptom complaint, and number of previous visits to the ED with their young children. The goals of this strategy were to identify both the uniqueness of heterogeneous participants’ perceptions, and the common perceptions of participants

regardless of their background (Patton, 2002). However, to avoid cultural confounding in the data, United States-born parents were selected. Other demographic screens to accomplish maximum variation sampling included: age, symptom complaint, and insurance category as a proxy for socioeconomic status (private/public/no insurance), prior to obtaining actual reported income ranges. This approach accomplished the objective of obtaining broadly representative data from parents who had brought their young children to the ED for management of illness symptoms.

Setting

The department selected for this initial development research is a specialized children's hospital pediatric ED in the urban Pacific Northwestern United States that sees approximately 20,000 patients annually, newborn to 17 years of age, of whom 12% are admitted to the hospital for further treatment (internal hospital data for previous 12 months as of April 2012). The hospital is a tertiary care facility whose ED provides care to children with both acute illnesses (such as fever or vomiting) and acute exacerbations of chronic illness (such as asthma); this broad case mix provided good variability within the sample. The nurse to patient ratio is generally 1:3, although this can vary depending on patient volume and acuity. The department is medically staffed primarily with board-certified physicians in pediatric emergency medicine, and augmented at higher census times with board-certified physicians in general emergency medicine; there are no mid-level providers.

Recruitment

Parents of young children with circumstances contributing to the maximum variation sampling strategy listed above were approached to inquire about their

willingness to participate in the study while in the ED. Parents were approached by the investigator in a non-clinical capacity during their visit; it was made clear that if they declined to participate, it would have no effect on the treatment they received. If they indicated interest, the nurse researcher discussed the research project and requirements of involvement as an informant. Written informed consent and contact information to schedule the follow up research interview were obtained. The research interview was conducted in the family's residence or other site of their choosing. In some cases where parents could only make themselves available by telephone for an interview, this exception was made. Five of the thirteen interviews were completed by telephone. Only one interview per parent was planned, but permission for subsequent contact for clarification and respondent validation was obtained. No participants declined further contact after completing an interview. Criteria for inclusion entailed: participant must be the parent or primary caregiver who accompanied the child to the ED; able to speak, read, and write English. Originally, hospitalized patients were to be excluded for concern that parents could not distinguish between ED treatment and other treatment. However, parents of hospitalized patients in fact yielded some of the richest interviews, so their inclusion was valuable.

Remuneration

A \$10 Fred Meyer gift card was provided to the parent at the completion of the research interview as a token of appreciation.

Data

Two types of data were collected for this study: simple descriptive data and the transcripts of recorded semi-structured interviews with parents of young children who

have been recently treated in the ED. Basic descriptive information collected from parent informants included the following: child age, chief complaint (and whether acute or chronic in nature), race/ethnicity, income range, and previous ED experience. Parents were asked for permission for future contact as well in the event clarification or further information was needed. Parents who declined to participate were asked to volunteer why, and the answer anonymously recorded to identify barriers to response and improve the quality of initial contact by the researcher. When a reason for decline was volunteered, this was uniformly lack of time and/or lack of interest in participation.

Semi-structured interview

A semi-structured interview guide (see Appendix II) was used to frame the research interview. Patton (2002) identifies three main approaches to the qualitative research interview: informal conversational, guided, and standardized open-ended. In an informal conversational interview, questions are not predetermined, but arise naturally from discussions of the context of interest. This has the strength of flexibility for each individual's interview to be tailored for them, but can yield less systematic and comprehensive data for comparison between individuals. An interview guide outlines the interview topics and issues in advance, but the interviewer has flexibility to decide on the wording and sequence of questions. This has the advantages of keeping the interview conversational, but situated in the relevant topic, and increasing the comprehensiveness and comparability of interview data. However, this decreases the flexibility and naturalness of the interview. In a standardized open-ended interview, the sequence and wording of questions are predetermined. This approach permits easier

organization and comparison of informant responses, but may constrain those responses.

The semi-structured interview developed here is closest to this last approach. Because this qualitative descriptive research has a fairly tight focus, this type of interview was expected to yield the best results for analysis, while still permitting respondents to expand on their perceptions and feelings. When a topic of interest arose that was not included, further questions beyond the guide were asked. Main questions in the interview guide were accompanied by a number of probes, which were clarifying questions for those being interviewed. These were intended to deepen the informant's response and are common to this type of semi-structured interview (Patton, 2002).

Transcription

Transcription of interview data is an important area of consideration, as it is an inherently context-reducing process. How interviews are transcribed reflects the theoretical and methodological approach of both transcriptionist and researcher. Few transcription decisions had to be made regarding such contextual factors as timing, mood, tone, setting, and phonetic or orthographic spelling, as transcripts were deemed accurate on review. Occasional words had to be replaced by the researcher as they were misunderstood or left as 'unintelligible' by the transcriptionist. Because these interview transcripts are the basis for analysis, it is important for the qualitative researcher to be transparent about the choices they make as they should be consistent with the research approach (MacLean, Meyer, & Estable, 2004; Lapadat & Lindsay, 1999).

Qualitative descriptive research has an objective to summarily describe ideas in their everyday terms, so the analysis remains fairly close to surface meanings and contexts (Sandelowski, 2000). The transcription process proceeded with this in mind. This study initially made use of commercially-available vocal transcription software for a first-pass written transcript. Interviews were translated by speaking over, in which the interview was listened to through headphones, and verbally dictated to the software. It was speculated that vocal transcription would maintain continuity of interpretation between the recorded interview and its transcript better than employing a third party transcriptionist. The transcription document was then manually read along with re-listening to the interview to improve integrity. This comparison also allowed for insertion of markers for significant vocal tone and non-verbal conversational context such as crying or laughter, when applicable. However, after three interviews, the process was discovered to be so time-consuming for the investigator, that a confidential professional transcription service was hired for the remaining transcripts to maintain timely progression of the study.

Data Analysis

Description is the basis of all qualitative research, although how that description is organized can vary tremendously, depending on the purpose of the research. Analysis begins with the first interview, as the researcher begins to understand the phenomenon of interest from the informant's perspective. Data, comprised of interview transcripts, were iteratively reviewed for topics and concepts that can be coded for later comparison. Coding refers to identifying and labeling important ideas and/or themes that emerge from an interview and facilitate later comparison. The analysis was

completed entirely by the researcher based on the insights gained from engaging with the data, in consultation with the dissertation study committee. The iterative process of coding created a framework for the interpretation of the qualitative data collected from interviews (Patton, 2002).

The conventional qualitative content analysis process is well described by Hsieh and Shannon (2005). This is a textual analysis approach often used in qualitative research, in which interview transcripts are intensely analyzed for conceptual language that can be efficiently coded and categorized based on their actual or inferred meaning. In this approach, the researcher tries to avoid preconceiving codes and categories, instead immersing themselves in the data and allowing the organizational codes to emerge naturally from the data and particularly from the language used. The initial approach was to read the interview transcript in its entirety, and record initial thoughts and impressions. As the researcher reflected on these impressions, codes began to emerge, which formed themselves into meaningful category clusters that provided the investigator a basis for data interpretation (Hsieh & Shannon, 2005). Patton (2002) suggests seeking convergence (how well data fit together into descriptive categories) and divergence (distinct differences) in the interview data as a way to begin identifying patterns. Important final steps in this interpretive description are to consider negative cases (when case data do not fit with other findings) if they are present, and to triangulate data interpretation with previous or related research findings. Both processes lend support to the validity of research findings (Maxwell, 2013). Data interpretation is discussed with regard to related research findings in Chapter 5.

Maintaining a research journal is important to the inductive qualitative descriptive process, and allows for research auditing. This is not just a record of decisions made about the research plan, although these are included, but includes the researcher's thoughts about the data as it emerges. This self-reflexivity requires the researcher to constantly question their assumptions, perspective, and motivations. Patton (2002) described the reflexive process as a balanced inquiry between the researcher questioning knowledge and assumptions about themselves, the informants being studied, and the audience that will receive the findings. This ongoing process of reflexivity greatly improves the quality and validity of qualitative research. Notes were kept by the researcher through the process of data collection and analysis. These notes began with brief thoughts about interview content and quality, before proceeding to initial coding of interviews. These initial codes were compared; collapsing similar codes into one then were grouped into multiple categories that appeared to arise. These categories were reflected on, including their interactions. Through this iterative process of analysis, qualitative descriptive findings emerged; these are discussed in chapter 4.

When the interpretation is complete, respondent validation (member checking) is a valuable addition to support the validity of qualitative findings. This involves presenting the researcher's interpretations to informants to see to what extent they agree with the findings. Weak endorsement of the findings by informants may undermine the validity of conclusions, although this can depend on the research topic (Maxwell, 2013). There is no prescribed number of respondents in the methodological literature for this process, but two or three may be considered reasonable. Two participants were able to be subsequently contacted, and indicated the findings sounded reasonable.

The data analysis process described above resulted in a strong qualitative descriptive report of what outcomes parents notice and care about when they bring their young children to the ED for illness symptom management. Great care was taken to ensure the quality and validity of the research findings through the methods as detailed.

Quality in qualitative research

While empirical researchers have largely embraced the common quality-related concepts of reliability and validity, qualitative researchers have had an ongoing evolution in the benchmarks that constitute quality in research. Tracy (2010) proposed a pragmatic list of eight criteria for quality research that cuts across paradigms, and as such is particularly useful for this qualitative descriptive research project. The criteria are: topic worthiness, rich rigor in data collection, research sincerity, credibility, resonance, significance of contribution, ethical conduct, and the coherence of study design and results.

A worthy topic is one that is timely and significant to expanding understanding of a concept or phenomenon (Tracy, 2010). Maxwell (2013) considers this part of the research study goals and justification. The justification for this qualitative descriptive study was addressed in the previous introductory and literature review chapters. Expanding understanding of parent-reported outcomes for their young children is a worthy topic both because it addresses the focus area of outcomes research and addresses an understudied population.

Rich and rigorous exploration of the research topic requires the researcher both familiarizing themselves with existing research and theoretical frameworks, and spending sufficient time on data collection. Questions of how much data is sufficient,

and whether the informant sample is appropriate for the research inquiry must be addressed (Tracy, 2010). Existing research and theoretical frameworks relevant to this project were reviewed in the previous background chapters. Sample selection and data collection endpoints are discussed below.

Sincerity encompasses transparency about research methods and challenges, and self-reflexivity by the researcher. Transparency, also referred to as the auditing process, casts an important light on understanding research decisions. This involves keeping a record of such activities as interview environment, immersion and engagement with informants, and decisions about the interview transcription process. Having a well-documented audit trail increases the openness of the qualitative research process (Tracy, 2010). Self-reflexivity is critical in qualitative research, as it requires the researcher not only to record their thoughts about data collection and analysis, but to challenge their own assumptions and line of inquiry. The reflexive process is iterative, and should be present from design through recruitment, data collection, and analysis. This critical reflection allows the qualitative researcher to hone in on the concept of interest and related phenomenon, rather than adhering to an empirically rigid measurement protocol that could obscure important data (Maxwell, 2013; Tracy, 2010; Patton, 2002). Reflexive journaling was used during this project, both to reflect on interview experiences as well as to challenge the researcher's own assumptions.

Credibility is the heart of what many would call qualitative research validity: rich data, triangulation, and member reflections (Tracy, 2010). Rich, thick, descriptive data is a common goal of qualitative research. The term describes obtaining sufficient data from informants through detailed descriptions so that a full picture of their views can be

obtained in the analysis stage. It is important to be rigorous in the process of collecting this data and to sufficiently explore the research topic with informants to obtain their perspective during interviews, as well as accurately transcribe them for analysis.

Triangulation refers to using multiple data sources, theoretical bases, and types of data to reduce threats to validity, primarily from bias (Maxwell, 2013; Tracy 2010; Patton, 2002). The importance of triangulation is not just to identify similarities but to notice incongruities that that can allow deeper insight into the research phenomenon (Patton, 2002). Procedures outlined in the data process, particularly with regard to the challenges of transcription, addressed this rigor, and existing research and theoretical literature previously reviewed provided triangulation for the interview data.

Resonance refers to how effectively research reaches the reader's sensibilities, and has two main areas of impact: aesthetic merit and transferability. Aesthetic merit refers to the research presentation and how well findings are written such that they affect the reader and communicate a subjective sense of the research findings, rather than mere summation (Tracy, 2010). Transferability is a common term in qualitative research that refers to elements of the phenomenon being researched, such as emotional duress, which may be experienced in other related phenomena of interest. This is similar to but distinct from empirical generalizability. Generalizability has a context-free connotation, while transferability of findings is only possible when the research contexts have a similar situational fit (Tracy, 2010; Patton, 2013). Every effort was made to frame analysis findings in as elegantly descriptive a fashion as possible.

Tracy (2010) identified five areas in which research can make a significant contribution: conceptually, morally, practically, methodologically, and heuristically.

Conceptual or theoretical contributions extend and explore the research knowledge base, not only seeing how current theories fit but developing new understandings through data analysis. Heuristic contributions occur in two ways: when research findings inspire further exploration by other researchers and when findings inspire policymakers and/or the public to create change. Heuristic contributions thus overlap with the practical: reframing problems, pointing toward solutions, and empowering people to enact change. Finally, methodological contributions are precisely that: using novel research and/or analysis techniques that may allow for improved understandings of research findings. This study makes conceptual contributions by describing parents' perceptions of child symptom management outcomes and heuristic contributions by reframing outcomes for young children in the ED.

Ethical conduct is a requirement of any research endeavor, and falls into three categories: procedural, situational, and relational ethics. Procedural ethics refers to research conduct requirements from governing bodies such as Institutional Review Boards, and is the most encompassing category, involving research justification, confidentiality, and the informed consent process. Situational ethics encompasses the unique and context-dependent ethical dilemmas that are not anticipated, such as unexpected disclosures from research informants, under which circumstances first principals of ethical research should be adhered to. Relational ethics are concerned with respect and mutuality between researchers and informants, which means respecting personal boundaries, the safety of participants, and reciprocity between the researcher and participants (Tracy, 2010; Patton, 2002). This topic is addressed in the protection of human subjects section below.

Meaningful coherence is the final quality criterion, and refers to how well the study fits together. A good qualitative research study should attain its stated purpose, and make consistent use of data collection and analysis methods that links existing theories with research findings (Tracy, 2010). The fit of findings from this study with existing theory is discussed in chapter 5 below.

Protection of human subjects

In 1979, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research published the Belmont Report, which guides the ethical conduct of human subjects research in the United States. The report contained three guiding principles: respect for persons, beneficence, and justice. Respect for persons entails recognition of people as autonomous individuals who can make decisions for themselves; however, this principle includes the corollary that extra protections must be afforded to those individuals in circumstances of reduced autonomy of decision-making. Beneficence refers to the obligation of researchers to do no harm and to maximize the possible benefits to research participants. Justice is concerned with the distribution of research risks, benefits, and burden for research participants. These principles are operationalized in three areas of concentration: informed consent, assessment of risks and benefits, and subject selection. Every effort was made to follow these guidelines.

Institutional Review Boards are independent groups charged with reviewing and overseeing all proposed research to be conducted within their purview to ensure ethical guidelines are adhered to. Approval for procedural ethics of this research was provided by the Institutional Review Boards (IRB) of Legacy Health System, of which the target

hospital is a part, with the supervising academic institution, Oregon Health & Science University IRB waiving oversight to Legacy. No situational or relational ethical dilemmas requiring special review by the IRB arose in the course of conducting research.

Signed informed consent was obtained from participants (parents) who brought their child to the ED for treatment prior to participant data collection. Informed consent comprises three elements: information, comprehension, and voluntariness (The Belmont Report, 1979). The informed consent (see appendix) covered: the proposed research and procedures (interviewing), potential risks and benefits, and the right of participants to ask questions of the researcher and to withdraw from the study at any time. The main risk was the potential for participants to experience discomfort or distress during the interview process, and this was specifically disclosed in the informed consent form. It was also noted that the investigator is a mandated child abuse reporter, and any disclosure of such facts cannot be kept confidential. Because the interviewing researcher is an employee of the target hospital department, recruitment was conducted outside of scheduled shifts, in a non-clinical capacity. It was emphasized to parents that their child's treatment is separate and independent of their participation in the study. If potential participants expressed interest in the study, the researcher approached them to explain the project and obtain informed consent.

Confidentiality was explicitly maintained by data anonymization, and retaining all identifying information and raw data in the secured possession of the researcher. Only the investigator and the dissertation committee were able to access raw interview data.

Chapter 4: Results

The purposes of this study were to describe parental perceptions of their young children's illness symptoms when they bring their child to the Emergency Department (ED), and to describe what is important to parents about their child's illness symptom management after visiting the ED. Thirteen post-visit interviews were conducted with a maximum variation sample of parents (as described in Chapter Three; see Appendix I) who had brought their young children to the ED for treatment of illness symptoms. Data from these interviews were analyzed according to the procedures described in Chapter Three. The concepts listed below are descriptions of common interview data findings from participating parents, and represent the aspects of their child's illness symptom management that they notice and hold a perspective on. There are three main groupings in the results. *Parental perceptions of illness symptoms and management* are central themes in the process of symptom management. *Provider relationships* encompass parents' interactions with, and perceptions of, health care providers such as physicians and nurses. *Contexts* are the social background of families that can affect both the symptom management process and the interactions parents have with providers.

Data Analysis

Parental perceptions of illness symptoms and management

Something is wrong: Parents focus on observable changes or verbalized complaints from their child that deviate from how their child normally is, day-to-day. These changes can be anything from energy level to oral intake to temperature. Verbalized complaints can range from identifying a source of pain to a child describing a

physical problem in their terms. Parents know their young children better than anyone. They have the best understanding of the unique characteristics that constitute how their child is normally. A noticeable change from their child's normal is what draws the parents' attention.

Steve describes his wife noticing their daughter's change from her normal self:

P: [My wife] looked over and she [the child] had fallen asleep, which is pretty rare. It was like 10:00 in the morning, she'd fallen asleep. She's a really energetic kid and she... And then my wife texted me and was like, hey, I'm glad I kept her home. She's... she's conked out, you know. She really must be sick.

A father and mother have noticed their daughter was starting to become ill and had kept her home from school as a result. They describe noticing a significant change in their daughter's normal behavior in terms of her energy level, and become more concerned about her with this new observation. In this case, the parents thought they were seeing more and worsening symptoms, which ultimately led to their daughter being hospitalized.

This is what Sophie, a young single mother, noticed in her daughter:

P: ...she just didn't want to do anything and just all, she was all just ill and didn't want to play. That to me didn't seem normal...

She describes the concerning change in her daughter's behavior that led to her seeking help from the ED for what was diagnosed as viral gastroenteritis.

Dan describes his asthmatic son's trouble breathing:

P: [H]e was complaining about his chest hurting. And he kept saying, 'owee' and pointing to his chest...

In this case, a young child with asthmatic symptoms verbalizes his symptom in his own terms to his father, who interprets the complaint and realizes his son is ill and might require medical help. In all three cases, parents have noticed a change in their child from how their children are normally, a change that is alarming to them.

Parents' observations are based on knowing their child's normal condition better than anyone else. This unique knowledge of their child makes the parents' perceptions of their child's symptoms an important factor in management. Consider the following examples:

P: ...we know him more than anybody else. (Dan, the parent of a child hospitalized for asthma)

P: I mean, I can tell, like just being her mom, that's she's obviously doing a lot better, you know. (Ashley, the parent of a child treated for pinworms)

In the case of assessment and decision-making, parents who were married or cohabiting consistently seemed to negotiate a consensus about their concerns for their child and seeking health care. It is certainly possible that there are couples where this is not the case, but none such were encountered in the course of these interviews.

As Pam, mother of a child with complications from Hirschprung disease replies:

P: Any difference? I think we're pretty similar. I think we're pretty similar, actually. But my husband, he's pretty amazing. He's very nurturing and he loves our son as much as I do. I think we're pretty similar.... We talk about everything. Collaborate on everything...

This mother is responding to an interview question as to whether she sees any difference in her husband's perspective and approach to their son's illness from her own.

Steve reflects on joint decision-making with his wife:

P: ...I mean, taking her away and denying this did not seem like an option. I mean, my wife and I would certainly have to be aligned on a decision like that. She was not well, you know. And so she needed to be in the hospital.

This father of a 3-year-old child hospitalized for pneumonia is reflecting on his original ambivalence over whether he thought his daughter needed to stay in the hospital. He was convinced by talking it over with his wife and taking the advice of providers.

Alarm: Noticing that something is wrong triggers a sense of alarm and fear in parents, the degree of which depends on their experience and comfort level with the illness-related change/complaint. The more uncertain they are about what is happening with their child, the more scared they are about the implications of what they are seeing. Parents interpret the symptoms through the lens of their experience of illness in conjunction with knowledge of their child. There is often an interaction for parents between uncertainty, fear, and how well they think they can manage their child's symptom(s) by themselves. Generally, the less certain parents are about the cause of their child's illness, the more likely they are to fear these symptoms may have some catastrophic result. The passages below illustrate the fear and uncertainty in parents that leads to their alarm. The frequent use of the adjectives "scary" and "scared" by parents is highlighted.

Marcia, whose son was brought by ambulance to the ED from his day care:

P: *What was really **scary**, I wasn't really sure what was wrong and being a first-time mom, he's actually been to this hospital before for stridor when he was like 2 ½ months old, so it was with a breathing issue... I thought that was going to be the one and only time we would have to be here, and then having this episode happen again I was like 'oh no maybe there is something more you know that they would catch that was wrong with him', so that was going in the back of my mind. That it's something more severe and this was just the start of... I don't know, us being here all the time...*

This is the mother of a young child who passed out in daycare and was brought to the ED by ambulance as she reflects on the emotions she felt riding with her ill child to the hospital. The natural parental worry for her ill child is exacerbated by the uncertainty of not knowing what was happening with her son. The uncertainty and fear create a feedback loop in parents that increases their distress until they feel more in control of their child's situation.

Gina, mother of a blended family, describes her thinking process:

P: *Well, I was just going to say if [child has]...like, what [my husband's] sister has, just the way my mother-in-law explained to me how it happened with her daughter, fifteen years ago, um, and now it's happening with him, that really concerns me. Just because I don't know where the fever is from...*

As in this case with the mother of a child with frequent febrile seizures, who is very afraid that her son will end up in the same intractable condition as another member of her extended family, what is unknown or uncertain can continue to gnaw at parents.

And at a basic level, parents are simply responding to their child's symptom-related distress when they are unable to resolve it, as Pam describes:

P: It was awful. Yeah, because he'd been sick for a while, but when he woke up not feeling well and I knew his tummy was definitely harder, and seeing him miserable, it was awful! I wasn't going to tolerate it... It was intolerable. Yeah, I had to get him some help.

In this instance, the mother of a young boy with a chronic intestinal disorder (Hirschsprung disease) responds to her son's expressed (appearing miserable) and observed (hardening abdomen) symptoms by seeking medical help.

Some other examples of the emotional language of fear and uncertainty that parents use to describe their alarm over their child's illness symptoms across participants include:

*P: What was really **scary**, I was really, wasn't really sure what was wrong... (Sophie)*

*P: I guess I was just **scared**. Like I...I just thought, oh, my God, something terrible is happening... (Ashley)*

*P: ...it was pretty **scary**. I mean, uh, you know, him breathing...the way he was breathing, like he'd be...it...You know, we felt like he wasn't getting enough oxygen... It was a **scary** time. (Dan)*

P: *I was kind of worried it was something_serious, just because I'd never seen him look how he looked, and it was really **scary**.* (Marcia)

P: *Seriously, **scary**. And I get anxiety so bad, because I don't...I don't know what to do.* (Gina)

These comments, all from different interviews, illustrate the interplay between the fear and uncertainty that parents feel when observing their child's illness symptoms, a fear that ultimately drives them to bring their child to the ED. Parents just want to know what is wrong with their child, and how they can get them back to normal.

Knowing illness: Parents ideally want to put a name to illness, and may be disappointed when not given a specific diagnosis. Emotions for parents are entwined throughout the process of returning their child to normal health. Parents' fear and uncertainty begin to resolve as providers are able to address their concerns for their children. Parents are still reconciling their emotions about their child's illness, and seem to feel more empowered the more definitive the explanation is.

Pam, who kept pressing for an explanation for her son's symptoms:

P: *There was an element of relief in there that there was, you know, that finally we had seen something was wrong. You know, that there was an answer as to why he was feeling that way. Earlier in the week they just said it was a virus, and I thought it was something more but, you know, you listen to your doctor. And so then this time it's like, oh yeah, I knew there was something going on in there. So there was kind of an element of I knew it, but you know, it's scary too when*

your doctor's telling you to go straight to the emergency room. That's not a good thing.

This is the mother of the boy with Hirschsprung's disease who had earlier in the week been told her child's abdominal pain was probably the result of a mild viral illness. However, he was referred to the ED when his symptoms did not improve. It turned out he was developing a serious fecal impaction that required hospitalization. Despite the hospitalization, this mother was relieved to know what diagnosis was related to the symptoms she saw in her son, and felt validated for her observations. Conversely, doubts about their child's health may linger when parents do not feel they have a clear answer for the observed symptoms, as Marcia describes:

P: Well, they had said that because he was sick and because babies can't like blow their nose or cough phlegm out it could have made him nauseous from all that stuff draining into his stomach, which could have explained why he threw up and then they said sometimes that can cause like, I don't know the exact words she used, but like a fainting spell or extreme exhaustion like from the act of vomiting and that can wipe them out and so they kind of get, I mean without seeing anything else wrong they kind of guessed you know maybe that's what happened and that that's what was wrong with him that just to keep an eye on him in case other episodes, or something like that happens again. So I mean I guess I was okay with that answer because I knew there was nothing else they could see but at the same time I was like 'well, are we going to be back here again in a little bit because we don't know?' I don't know. So I was happy with

how they dealt with it and the answer, but at the same time I'm like they couldn't find anything wrong so why are we here?

This is the mother of a toddler who became ill in daycare and had to be taken to the ED by ambulance for treatment. While she describes being satisfied with her son's treatment and speculative diagnosis, she is clearly left wondering what other related problems may develop in the absence of a more concrete explanation.

Gina, whose son has been seen in the ED several times over his 18 month life:

P: [Where is] the fever coming from? 'Cause to this day they don't know where the fever's coming from. Nothing's in the blood. Nothing is in the urine. Nothing's in the stool, so they don't know where it's coming from. So until we get all this figured...I mean, that's the one question still in the back of my head, where is the fever coming from?

This mother brought her son in for recurrent fevers and related febrile seizures; she was still seeking a definitive answer at the time of the interview. Knowing what illness is causing their child's symptoms is important to parents to alleviate their fear and uncertainty.

Managing illness: Parents want to know what can be done to control their child's illness; they want to know what to watch for, what to worry about, and what to do as far as actions or interventions. Knowing more about what to do for their child's illness symptom(s) alleviates a lot of the uncertainty and fear that parents feel when confronted by them. This again reflects the emotional aspect of parents' responses to their child's illness symptoms and during the process of returning their child to normal.

Dan reflects on his asthmatic son's course of treatment and recovery:

P: ...[W]hat did I take away from this whole experience? Uh, I guess knowledge is power. So, you know, that, uh, the more you know the better you...you... you know, you can handle, or know what to do at the right time...

...we have the tools now... So now, we have the equipment, so now we have the tools. We can work with them. And, uh, hopefully, it doesn't get as bad...that bad where we have to take him to the hospital...

This father's son was hospitalized for a severe asthmatic episode, with which the family was not familiar, as this was the first time they had seen such severe symptoms.

Knowing what to do for his son is clearly empowering for this father.

Sue, the mother of another child hospitalized with recurrent asthma echoes this sentiment:

P: Well, we...we now have a nebulizer at home. And so that definitely puts me more at ease, because that sometimes can eliminate more hospital visits. I'm also going to be...have steroids to be able to have at home, to be able to take. So with that in the home, I definitely feel more at ease, more comfortable with it because it's like, with the proper training on how to use it, I would know and be able to put that into effect, instead of always having to wait until the hospital...

Gina gives another example of 'managing illness':

P: ...but she explained to me how to use the medicine. And that was new to me, because I didn't know I could use...um, I think it's the Tylenol four hours instead of six and the Ibuprofen six. And I could just, you know, give it to him. I thought that was overdosing him. So when [the doctor] explained [it] to me, it made me feel better because I can control [the fever].

This is the mother of the child with repetitive febrile seizures, who has been really concerned about controlling his temperature any time he has a fever. The ‘managing illness’ finding here also reflects back on this mother’s alarm response to his symptoms. She indicated in her interview that she is very afraid this will become an intractable condition, and knowing how to better manage the alarming symptom of fever is reassuring, as she describes above.

Back to normal: Parents of all children have a mental image of how their child is ‘normally’ in terms of their activity level and behavior, based on their daily interaction, and have a return to this ‘normal’ state as their ideal outcome. The term ‘back to normal’ is an *in vivo* code (a descriptive conceptual term arising from participants’ own language), because it is a phrase used extensively by parents across interviews to describe their young child’s recovery from their illness symptoms. Here are excerpts from three separate interviews to illustrate the point, with code phrase in bold:

P: ...he was just kind of back to his happy self and carried on a normal day. He ate normal, slept normal, um, **back to normal**. (Marcia)

P: ...he’s **back to normal**. He...He’s... You know, he’s a really active, um, busy kid, hyper. So, I mean, you know, he’s...he’s doing that. He’s back to himself.
(Dan)

P: ...he’s doing way better. He’s **back to his normal** little ways. (Pam)

This idea of returning to a child's normal also applies in cases of acute symptoms related to a chronic illness (generally referring to a persistent condition affecting physical health over time) such as cancer.

Amy, whose daughter is undergoing chemotherapy and came to the ED for fever:

P: *[Normal] means today's a good day (laughs)... It means today she gets to be eight... [Normal] is having at least half a day where she has full energy, um... and getting a little bit of school work done... getting some quality in there. Tomorrow we could end up back in the ER with another fever... yeah, so [normal] for her is just getting through another day, doing her chemo treatment, going home, and doing something normal...*

In this case, a child's mother describes how her daughter is normally, day-to-day. While this is not what most people might consider normal for a child, it is her mental image of how her daughter is 'normally,' given her condition. A return to her daughter's day-to-day normal remains her goal for illness symptom management. Another example of this daily normal in the context of chronic illness comes from Mary, the mother of a young girl newly diagnosed with diabetes in the ED:

I: *How would you characterize her now? Like how she is?*

P: *She is back to her old self.*

I: *Okay. And when you say she's back to her old self, like what do you look at? Or what do you look for?*

P: *Well, let's see, the fact that she likes to boss her older sisters all the time.*

[Laughs] She's just, she's back to her... She loves the schedule, she loves routine. And she's really back to that. She's back to playing with the toys she

loves. She kind of had not any interest in when she was ill. She's back to eating really well. And just back to her happy, easy going self.

Even at the outset of a probable life-long chronic illness, this mother is happy seeing her daughter back to acting how she normally is day-to-day.

Provider relationships

Communications: There are four aspects of provider *communications*: discussions with providers, provider behaviors, parental expectations, and communication around care. Communication is a critical aspect of the parent-provider relationship, as it can often influence parents' emotional state and their ability to acquire illness symptom-related knowledge that is critical to the process of getting their child back to normal. Again, there is an important emotional piece for parents in their communication with providers, as with other elements of the illness management process.

In discussing their child's care with providers, parents want a genuine, respectful dialogue with their provider that addresses their knowledge needs. Gina, the mother of a child with recurrent febrile seizures was quite blunt about this expectation:

P: What I liked is that, before anything they consult with me, about anything...

That's what I like. I liked to...for them to be honest. You see what I'm saying?

They don't try to beat the bush or...or sugarcoat anything...That's what I like.

Dan, a father whose son was hospitalized for asthma expresses his appreciation of providers communicating at a language level that he was comfortable with:

P: Um, they explained...They broke down the, you know...I mean, they... You know, they still used medical terminology, but they...you know, they broke it

down. If I had... Um, if I didn't understand, of course, I'll ask more questions. But they were able... They were willing to explain everything to our understanding of what...what was going on.

An excerpt from an interview with Sue, the mother of a different boy hospitalized for asthma nicely summarizes what parents look for in discussing their child with healthcare providers, and how she is grateful for the interest and concern that clinicians display:

P: They are always concerned and always helpful. And they probe to make sure that there's like nothing...like they haven't missed anything. They've covered everything to make sure that, you know, the parents are well informed on what's going on. And if there's anything that they can do to help for when we do go home, anything that they are able to provide or anything helpful. So I can say that is wonderful...

As in the quote from Sue above, parents observe nonverbal behavioral cues from providers during their course of care that influence their perception of both their child's health status as well as how well they are perceived by the hospital staff. In a different example, Steve, a father whose daughter was hospitalized for pneumonia describes seeing how relatively concerned providers were during her treatment:

P: Um...you know, the biggest thing [I notice] is the way the doctors and nurses are treating her. Everyone is just all smiles around us all the time. And at first, they were just like all frowns and crossed arms and like, you know, she's not doing as well as we want her to do...

Parents also discern what providers think about them as individuals, as Ashley relates:

P: ...*[The treatment] was all very respectful. And...yeah, very kind and, you know, I felt respected, like...like we weren't being idiots for showing up.*

This is a mother who throughout her interview indicated chagrin at having brought her daughter to the ED for what turned out to be a minor problem (pinworms). However, at the time, she was alarmed enough to take her to the ED and, in retrospect, appreciated the quality of her interactions with providers. Ashley recognizes that she brought her daughter to the ED for a problem that did not require emergency treatment, and appreciated not being looked down on or chastised for her lack of knowledge.

Parents want to be kept informed of progress and what to expect in terms of the course of medical care and treatment for their child. Parents become frustrated when they do not know what is happening with their child's care or for what they are waiting, as Ashley also describes well:

P: *I mean, the only thing that was maybe slightly frustrating was like I didn't know like what to do, I guess maybe. Or like...They're like, okay, sit here and we'll come back to you. And then I was...We were like waiting and waiting. And I'm like, are we supposed...Am I supposed to be doing something? And usually in hospitals, you kind of wait for a doctor. But the doctor came in. And then we were waiting again. And it just kind of felt like...like are they waiting for me? Or am I waiting for them? You know, like I...like that kind of just more of a communication thing. And, you know, I don't know, it didn't seem particularly busy that night either. And there were people just like sitting at the nurses' station and chatting. And like, are we supposed to do something? Like, am I...I don't know. That was kind of this feeling in my head. Like, are we supposed to*

go home? Are they waiting? Or am I supposed to...do something, you know?

[Laughs] So, that was just kind of an odd thing, I thought, but...Um, yeah.

This mother recalls her conflicting emotions while in the ED with her child: annoyance and confusion when she cannot understand the reasons for waiting, and that the providers' plans and child's progress were not communicated to her.

Parents want communications around their child's care to be coordinated, between both the ED and Primary Care Provider, and the ED and other specialists. Contradictory information and lack of communication between providers are especially frustrating to parents. Pam, whose son is being evaluated for abdominal pain:

P: ...the least helpful thing was the fact they didn't have any of his records, previous records. And they were asking me kind of in a moment of crisis all of the tests that had been done on him in the past year. And I'm like, are you kidding me? They were ordered by a doctor who totally works here. Why can you not get his records? They're all on there. And I couldn't remember them all. And so like I know a couple things...well, one test I know they reordered that I think he already had. But they couldn't see and I couldn't tell them for sure because I couldn't remember. So that was least helpful, was just the lack of access to his chart when he'd had such extensive medical work already.

This is from the mother of the young boy with Hirschsprung disease, expressing her frustration with the problems created with her son's treatment because his previous records were for some reason not available. Already alarmed about her child's condition, she is then further upset by an inexplicable breakdown in clinical communications.

Interventions: Parents want to know why interventions are conducted (or not), and have them implemented smoothly. Interventions can be anything from testing, to medication, to hospitalization. To quote from Pam again:

P: And we questioned the doctor on that and asked her if she really thought she needed that, and why... We thought that was busy work, not necessary.

This mother questions why her son needs a repeated x-ray, when she feels his condition has not changed. Parents advocate for their children with providers, including testing. Consider this excerpt from an interview with Joan, a mother who brought her daughter to the ED for a reaction to an influenza vaccination shot when she was concerned about it being an actual skin infection:

P: I don't think that my concern about it being a staph infection was looked into fully. I mean, doctors know more than I do. But I would have liked for them to have tested. You know, done a skin swab or something and tested for staph, instead of just letting me wait a couple of days to see if it turned into anything.

I: And did you raise that with them? What was the response?

P: I didn't ask them to swab it. I did tell them that she had, over the summer had two other staph infections, and that that was one of my main concerns about why I was bringing her in. And it didn't seem to go very far, like within the chain of command within the hospital. Like I mentioned it to the nurse, but the doctor didn't really pick up on or follow-up with me about that information.

This exchange also reflects on provider communications, as this mother felt her concerns had either been neglected or ignored. This impacts the symptom management process around the aspect of 'knowing illness,' as this mother has not had her concerns

addressed, and now has questions about her daughter's symptoms that remain unresolved.

When procedures are conducted, parents want them completed proficiently. This example is from an interview with Mary, a mother whose daughter's symptoms resulted in a new diagnosis of Type I diabetes in the ED. Because of the nearly seamless evaluation and treatment of her daughter, what could have been a much more upsetting transition for her and her husband was made to minimize emotional upset:

P: ...And I was very impressed with the staff. The nursing staff was just right on top of everything. And they made her comfortable, and got procedures done quickly and with minimal amount of pain or stress. So it was overall, considering what the diagnosis was, it was a good experience for us. We felt very comfortable and very well taken care of. And I felt that [Daughter] was very well taken care of in the ER.

This is the mother whose daughter was newly diagnosed with Type I Diabetes in the ED after she had developed concerning symptoms and signs at home. She appreciated not having to adapt to further stress during her daughter's treatment at the same time as she was cognitively and emotionally digesting her daughter's diagnosis.

Contexts

Life logistics: Parents must deal with the impact of illness on daily family life, work, and finances. Family life recognizes the time and energy requirements from parents to manage the daily rounds of life such as caring for other children, keeping up with housework, and meeting social obligations. Work is necessary for most parents to maintain an income to support their family. Many jobs do not pay employees for time

lost to caring for an ill child, often thereby depriving parents of critical income. This obviously impacts parent/family finances as well, given the cost of copayments or not having insurance can put tremendous strain on them. It is important to note that however concerned they are about the financial impact, the parents in this study uniformly indicated they would provide whatever their child needed, and worry about the cost later. Gina reflects on the possible ramifications of her son's illness:

P: [The illness worries] me in a lot of ways, because... Okay, let's say he does treat...he does need treatment or anything like that, um, I work two jobs. I work fulltime at one and part-time at another one. And then as you see, I have three [kids]. The other two aren't mine. I have three boys. I volunteer at their school. I, um... They do sports. And every year they do sports, I volunteer in that too. And it will affect me in the way that I either have to lose either one of the jobs or the volunteering.

This mother is expressing her concern that if her child ends up needing a lot of extra care from her, it will cost her in terms of work opportunities, and/or social commitments she has made that she believes are valuable. One of her commitments, not mentioned in this quote, is to work with high school kids at risk for gang involvement due to her own teenage involvement. Thus the ripples caused by disrupting a parent/family's life logistics can extend beyond just themselves. Steve, whose daughter needed to be hospitalized:

P: ...I just switched jobs a couple weeks ago. And, uh, my insurance hasn't kicked in yet. That was my first reaction when she said we're going to the ER. I

was like, [expletive], we don't have insurance. Are you sure we have to go to the ER?

This father's daughter was diagnosed with pneumonia and ended up needing extensive treatment. This quote is illustrative of the financial challenge confronted by many parents seeking medical help for their child, although, as in this case, the concern does not stop them from obtaining the care their child needs.

Social support. The more support that parents have from family, friends, and community, the easier it is for them to manage their child's illness and associated symptoms, in the hospital or at home. These supportive people can help in terms of caring for other siblings of the sick child and other life logistics as parents concentrate on the needs of their ill child. They also provide practical advice and emotional support when needed.

In one example, Marcia, the mother of the child who became ill at daycare was able to reach out to a friend for support when her husband needed to work. This support person was not just a friend, but someone who knew her son well, and provided support for this mother's own knowledge of her son.

P: Yeah I had a friend come over after I left here the initial day. Just 'cause my husband was still at work so he went back to work 'cause everything seemed like it was okay but I was still a little bit like 'oh, I don't know if I want to be alone'... In case something else happened, I had a friend come over and just hang out with me and that made me feel a little more confident, and the following day was just he and I and he was fine so... I felt good about it.

I: Did your friend have kids?

P: She's very comforting and so, and she's watched him before when I've gone out, so she has a good sense of his regular, like what he is normally like too... So that was nice to have.

For Mary, the mother whose daughter was newly diagnosed with diabetes, her own parents with their professional medical backgrounds provide not only support caring for their daughters, but additionally serve as an authoritative informational support that her daughter's condition is manageable:

I: And how are you feeling, kind of going into this with this tentative diagnosis?

P: You know, a little apprehensive. Apprehensive, a little nervous. Not quite sure what to expect of everything, but knowing that we would have family help and support that we would be able to get through it, so...

I: How was your husband feeling? Or how was he doing?

P: Pretty much the same way, just everybody was just a little shocked. We don't have Type I diabetes in our family at all. And so he was just kind taking it all in. But again, knowing that we have a huge support system that we're going to be okay.

This example shows the power of strong social supports to help manage even the most serious conditions. While the parents who were willing to complete interviews following their child's treatment in the ED were generally well-supported, it is reasonable to speculate that the absence of social support conversely makes it that much harder for parents to manage their child's illness.

Summary

The aims of this qualitative descriptive study were to describe parental perceptions of their young children's illness symptoms when they bring their child to the Emergency Department (ED) (Aim #1) and to describe what is important to parents about their child's illness symptom management after visiting the ED (Aim #2).

Study aim #1 is addressed by the concepts of something is wrong and alarm. Aim #2 is addressed by the concepts of provider relationships, knowing illness, managing illness, and back to normal. It is noteworthy that regardless of acute or chronic illness, parents have an idea of what is "normal" for their child on a daily basis. It is a change from this individual normal state that parents respond to. The symptom management process occurs in the context of parents' social supports and life logistics that can affect parents' ability to successfully manage symptoms, with the goal of having their child back to how they normally are. It is important to remember that these are the parents' perspectives and may seem to have a different focus than the clinical perspective, which may focus more on objective data such as test results, or adherence to clinical best practice guidelines, for example. This difference is why understanding what the parents of young children notice and value in the course of their child's illness symptom management is so important when considering the outcomes of health care.

The conceptual diagram below, which is simplified for economy of presentation, describes the relative positioning of the identified concepts as they relate to parents' perception of child symptom management as an outcome of care in the ED. The symptom management process begins when parents notice a change from their child's normal status (something is wrong). They experience varying degrees of fear and

uncertainty related to their observations and understandings of the symptoms (alarm). How well parents understand what is causing the symptoms (knowing illness), as well as what to do about it (managing illness) affects the effective management of their children's symptoms. Parents' objective for the outcome of symptom management is a return to how they think their child is normally (return to normal). This return to normal suggests a cyclical path, which is depicted in the diagram. Parent's responses and knowledge of illness and interventions are affected by their interactive relationships with providers (provider relationships). Hence, successful management can be impacted positively or negatively depending on parents' communications with health care providers and the interventions that occur. Because of the multiple parent-provider interactions that occur and how they affect different parts of the process, provider relationships are placed at the center of the symptom management cycle. Finally, the child symptom management process occurs within the overlying context of parents' circumstances. The logistics of life such as finances, insurance coverage, child care, and transportation (life logistics) influence parents' ability to access providers and manage their children's symptoms, as does the availability of social supports to help meet parents' logistical needs (supports).

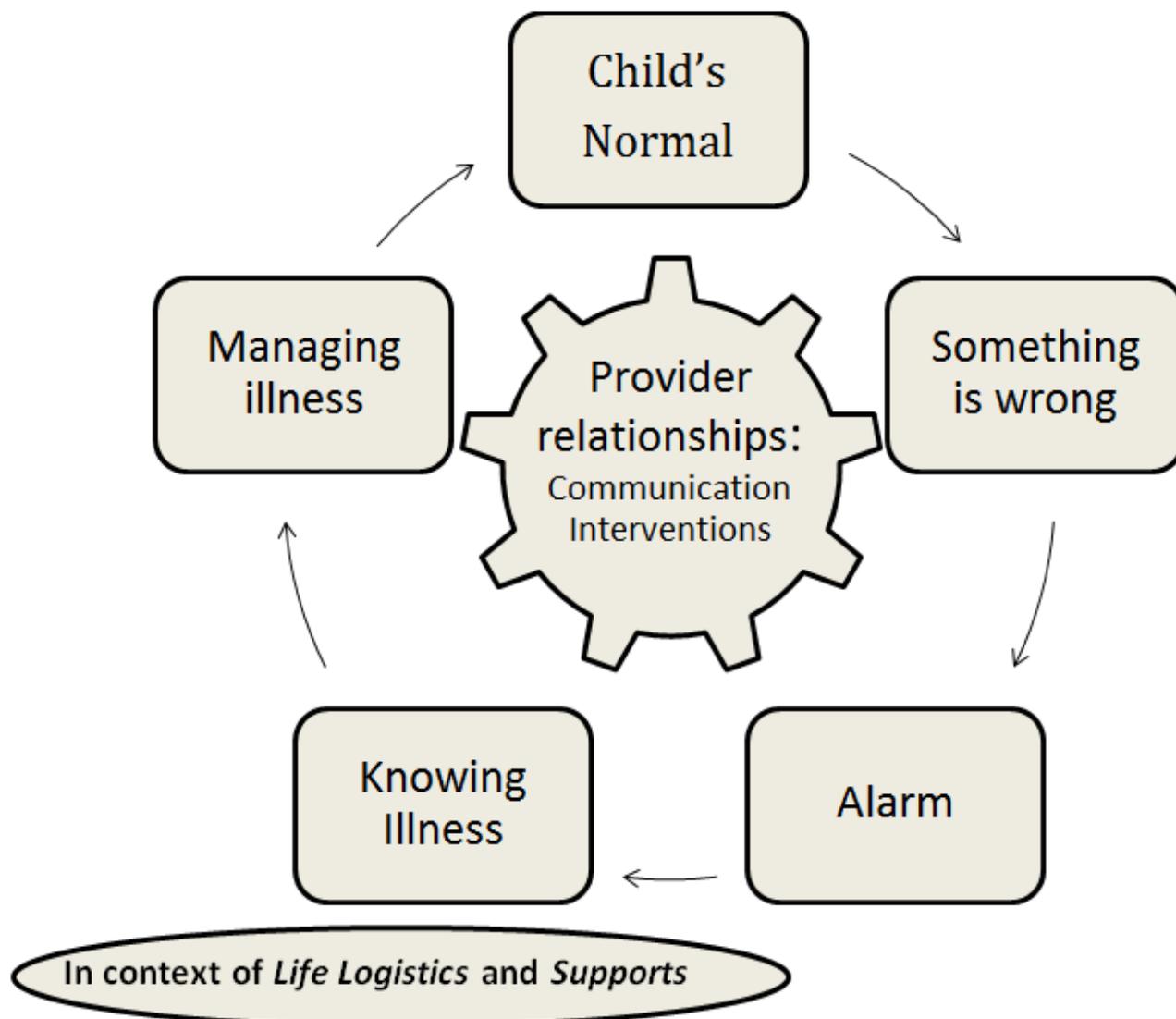


Figure 1. Diagram of relationship between concepts of interest

Parents' Perceptions of Child Symptom Management: Synthesis of Findings

Parents' ultimate goal for their young children's illness symptom management is to have them return to their "normal" everyday selves. The process is a cyclical course involving an alarmed emotional response to their child's observed and/or verbalized symptoms. Parents want to know the illness: what it is and what to expect. Learning observational and recommended medicinal interventions is empowering to parents as they feel better able to manage the illness symptoms. This process ideally results in

their child returning to their “normal” selves, as their parents see them, and parents’ initial alarm resolves. Healthcare providers in the ED interact with parents around the aspects of the process, and can greatly facilitate the symptom management process through effective, respectful communications with parents, and explaining why any interventions such as testing are needed, as well as that these interventions occur smoothly. All of this occurs amidst the contexts of parents’ life logistics and social supports. Life-related logistics, such as work and family commitments and financial concerns, can complicate parents’ ability to manage. The social support of friends and extended family can greatly help mitigate the negative effects of a child’s illness on a family.

Chapter 5: Discussion

The findings from this study describe what parents notice and care about when they bring their young child to the ED for symptom management. There were two specific aims. The first was to describe parental perceptions of their young children's (birth to eight years of age) illness symptoms when they bring their child to the ED. The second was to describe what is important to parents about their young children's illness symptom management after visiting the ED.

There are three major findings from this study which add significantly to existing knowledge of children's acute symptom management in other clinical contexts (study concepts italicized). The first is a cyclical process of parents noticing something is wrong with their child, becoming alarmed enough to seek emergency care, and getting to know and learn about the illness (*knowing illness*) in order to manage the illness symptoms (*managing illness*) until their child returns to how they are normally (*back to normal*). A second finding is that *provider relationships* have a significant influence on this cycle for parents, with interactions or potential interactions at each step of the cyclical process. Finally, the third finding is that the underlying contexts of *social supports* and *life logistics* affect both the cycle of symptom management and provider relationships.

Parents' ultimate focus is, in collaboration with healthcare providers, to return their child to how they are normally on a daily basis after observing an alarming health-related change in them. The findings from this study add to the field of patient-centered outcomes in a population and context not previously studied. These outcomes take patients' and families' experiences, preferences, and values into account. In this

chapter, the research findings are examined in the context of existing symptom management literature, and strengths and limitations of the study are discussed. In each case of existing symptom management theory, the findings of this study add information.

Cycle of Management

Symptom management in young children is a cyclical process that begins with parents observing a change from what they know as their child's day-to-day normal health state (*something is wrong*). It is important to note here that noticing *something is wrong* can include both true symptoms, such as a child expressing pain to their parents, and signs, such as a fever. The term "symptom" was used in this study to encompass both symptoms and signs, as parents did not differentiate between them as clinicians do. In clinical terms, symptoms are individuals' subjective perceptions of their health status, such as nausea or fatigue. Signs are objectively observable and/or measurable indicators of health status, such as temperature or heart rate. When noticing *something is wrong* triggers sufficient fear and/or uncertainty regarding these observations (*alarm*) about their young child, parents bring them to the Emergency Department (ED). Through their interactions with physicians and nurses, parents learn about the causal illness (*knowing illness*) and how to cope with it in terms of what to observe and what to do (*managing illness*). Through the steps of knowing and managing their child's illness, the symptoms resolve and their child returns to how they are normally (*back to normal*). A return to normal is what parents are ultimately most concerned about.

The Quality Health Outcomes Model (QHOM) is an approach to studying patient-reported outcomes to which the current research is targeted. One important outcome of

the QHOM is 'symptom management to criterion', meaning that the patient's perception of how well their symptoms are managed, based on the patient's own expectations, is important to study. Whereas the concept of symptom management to criterion has not been explored in the context of young children's illness symptom management in the ED, the concept is addressed by the findings that emerged from this study.

While exploring the patient's own perceptions is ideal, it was argued in a previous chapter that the cognitive development level of young children (newborn to eight years of age) necessitates asking their parents about their perceptions. Asking parents is also important because the parents are making decisions and providing for their dependent children. The vividness of parents' descriptions clearly spoke to the intimate level at which they experienced their child's illness course, consistent with the family connectedness and shared living context. Accordingly, returning their child to how s/he is on a daily basis (*back to normal*) defines parents' criterion for their young child's symptom management. This contribution to a patient-centered outcomes model such as the QHOM enables the pursuit of measurement development and thereby potentially answers the call to develop outcome measures for children's emergency care that accounts for the perspectives of children and their families (Clancy, Dougherty, & Walker, 2002) in this window of time.

The current study's focus on outcomes has been missing in some of the most relevant literature relating to acute illness in children. In a frequently cited study of what worries parents when their young child is acutely ill, conducted in primary care clinics in England, Kai (1996a) developed a grounded theory model based on interviews with parents that compares well with some of the findings in this study. His model posits that

parental concern about their child's illness is based on an interaction between the parent's perceived threat from the illness, and the perceived control over it. In essence, a greater sense of control diminishes the perceived threat of the illness and, conversely, a lesser sense of control exacerbates the perceived threat of illness. Parents act on their children's behalf, responding to health-related observations. Further, parents take action based on how well they think they understand the symptoms and/or illness and can manage what is occurring. As they become more alarmed, they are more likely to seek medical help.

Some of the concepts of the Kai model are congruent with those that emerged from the current study findings. The concept of *observed effects* from the Kai model is similar to *something is wrong* from the current study. Kai's perceived *threat* from an illness exacerbating when parents feel less in *control* of the illness is congruent with the current study concept of *alarm*. Parents' sense of *control* over their child's illness in the Kai model points to *knowing illness* found in this study.

Critically, the Kai model does not address what outcome parents want. Whereas the Kai model explains why parents seek urgent treatment for their ill child, it does not explore beyond this initial motivation. In a critical review of primarily qualitative studies conducted in England, Neill (2000) found that parents routinely monitor their child's condition at home. Accordingly across studies, when parents take action those actions are in response to an observed change from their child's normal state of being. This change from normal is congruent with the trigger identified in the present study as *something is wrong*. Neill's review did not further describe symptom management and outcomes, but did yield findings regarding provider interactions (described below). The

current study findings thus add considerably to understanding the illness symptom management process as a whole by emphasizing parents' goals for the outcome of their child's illness experience.

Theoretical models of symptom management similarly lack the focus on outcomes developed in the current study. A prominent individual symptom management-related model is Leventhal's (1982) Common Sense Model (CSM) of illness representation. While the CSM is an individual information-processing model, the cognitive process the CSM describes is similar to the several processing steps found in the current study for parents acting as the agent for their young child. Accordingly, the initial trigger for parents' illness appraisal is their observation that something in their child has changed from normal. In the CSM model, the level of alarm and what a person decides to do about it is dictated by how much the person understands the symptoms and their source. Similarly, this study found that the level of *alarm* and what parents decide to do about seeking help for their child depends on how well they know or understand the illness. The person then takes action based on their appraisal and re-evaluates the condition after the action; findings for parents in this study are congruent. There is also an explicit emotional response to the illness, according to the CSM, similar to the emotional threads identified in interviews with parents in this study. What is not defined in the CSM is an explicit outcome. While this allows for a more generalized application of the CSM, the lack of an outcome requires identifying a relevant outcome or outcomes within any specific context. The current findings serve to define one possible patient-centered outcome for this model.

Another prominent model, the Theory of Symptom Management (TSM) (Humphreys, et al., 2008) embraces some but not all elements of the findings from this study. While TSM was also developed from an individual perspective, the TSM specifically considers that proxy responders (such as parents in the current study) may be required when individuals are unable to respond (Dodd et al., 2001). There are three central concepts in TSM: symptom experience, symptom management strategies, and symptom status outcomes (Humphreys et al, 2008). The symptom experience is the perception of a physical change, an interpretation of it, and deciding whether to do something about it. This description of the symptom experience aligns with the concepts of *something is wrong* and *alarm*. Symptom management strategies include efforts to minimize the distress and severity associated with these symptoms, and aligns with the concept of *managing illness* from the current study. Symptom status outcomes are measurable consequences of the management strategies, such as less distress or improved quality of life. Although the outcome of a child returning *back to normal* is not currently measurable, developing a way to operationalize this concept would create a good fit with symptom status outcomes. What is not directly addressed by TSM is the concept of *knowing illness*, in which parents want to understand what is causing the symptoms they are observing.

Findings from earlier studies of parents bringing their children to the ED for treatment of symptoms are also consistent with the findings from the current study. Concern for overuse of EDs for child illness treatment led at least two researchers to study why parents sought care in the ED. Kahn (1973) interviewed parents at St. Louis Children's Hospital ED in Missouri, and discovered that parents' main motivation for

coming to the ED was concern that their child's symptoms were getting worse (63%), with another 18% believing their child was having a true "emergency." Turk and colleagues identified four causal triggers for bringing a child for urgent treatment: experience with the illness, extent of a child's illness behavior, worry about the symptoms, and social situational factors such as support (Turk, Litt, Salovey, & Walker, 1985). The first three factors are consonant with parts of the symptom management cycle yielded from this study, and the last aligns with the contextual findings discussed below.

The outcome focus of the current study, particularly describing how parents ultimately want their child to return to how they are normally, is a significant addition to the existing symptom management research. The concepts identified as part of the symptom management cycle in the current study are highly congruent with existing symptom management theory, providing support for these findings. This study also adds to the existing literature by exploring the phenomenon of child symptom management outcomes in the ED context.

Provider Relationships

Provider relationships are comprised of *communications* and *interventions*. These *communications* have four elements: discussions with providers, parental expectations, communication around care, and provider behaviors. Parents want direct communication with providers that is respectful of them and addresses their knowledge needs regarding their child's illness. Parents also expect to be kept informed about their child's care and what to expect regarding their child's illness course. Parents want communication around care to be coordinated between providers, with conflicting or

failed communications between different providers being especially upsetting to parents. Parents notice nonverbal provider behavioral cues, both with regard to their child's health status and how providers view them, and respond to these cues. With *interventions*, which include medications and diagnostic tests, parents want to know why they are carried out or not, and to have the interventions carried out as smoothly as possible.

The effect of *provider relationships* is not included in the prevailing symptom management frameworks reviewed in Chapter 2, with the possible exception of TSM. TSM includes the major category of "symptom management strategies" which are "efforts to avert, delay, or minimize the symptom experience" and consider who delivers the intervention(s), which could include providers (Humphreys, et al., p. 147). However, the nature of relationships is missing. The presence and conceptual description of *provider relationships* in this study is thus a significant addition to the symptom management field.

This absence of consideration of *provider relationships* in the theoretical base is noteworthy, as there are findings of *provider relationships* affecting the process of symptom management in this and other child illness-related qualitative studies. In her critical review of qualitative studies regarding British parents' needs when their young children are acutely ill, Neill (2000) identified several areas of provider relations that are important to parents. Parents want reassurance that they are doing the right thing for their child, and that their child will be all right. They also want specific, understandable information about the nature of their child's illness and how to care for it. Parents want to be recognized as responsible and competent in caring for their child's illness, and to

have their observations and concerns taken seriously. In some instances, an expectation for being prescribed medication was found, but most of the studies reviewed found that parents were primarily concerned with reassurance and information, rather than insisting on medication.

Neill found across studies that the principle conflict in provider relationships is a “mismatch of expectations” (p. 829) between parents and providers; this mismatch was usually rooted in the knowledge and power differentials. Parents reported not understanding what the provider said in diagnostic terms, particularly when it conflicted with their own perceptions of their child’s illness and symptoms. The perspectives of a child’s illness symptoms are frequently different between parents and providers. When a parent is concerned their child is critically ill, if the provider does not agree, they must help the parent understand why their child does not require intervention. Identifying this breakdown in communication between parents and providers underscores the importance of the provider relationship concept as a critical piece of the child symptom management process.

Contexts

Two concepts were identified in this study that form a contextual background for parents managing their child’s illness symptom(s). *Life logistics* refers to daily realities such as finances and transportation that affect parents’ ability to access providers and manage their child’s illness. *Social supports* are family, friends, and government programs that help parents meet their logistical needs.

TSM (Humphreys et al., 2008) expressly incorporates these important contexts as underlying the cycle of symptom experience, symptom management strategies, and

symptom status outcomes. The concepts identified here as *supports* and *life logistics* are incorporated by TSM into the underlying contextual domains of “person” and “environment.” TSM further includes “health and illness” as an underlying contextual domain (p. 147) that, in this study, is subsumed into parents’ idea of how their child is normally, day-to-day. The Theory of Unpleasant Symptoms (TUS) (Lenz & Pugh, 2008) recognizes these findings as “situational factors [which] encompass[es] the individual’s environment, both social and physical” (p. 169). TUS further identifies physiological factors (which, again, are incorporated into a parent’s idea of how their child is normally), and psychological factors, which were not identified from data in the current study. The Common Sense Model (Hagger & Orbell, 2003) does not expressly address these underlying contexts. In Neill’s (2000) review, family and friends were identified as an important source of support as they were in the current study. The analysis also identified children from lower socioeconomic status families presenting for acute illness symptoms more often, explained by increased prevalence of illness and access to fewer resources. Again, there is significant alignment between the current study findings and the existing symptom management theory and literature.

Summary and Conclusions

Summary

This qualitative descriptive study had two specific aims. The first aim was to describe parental perceptions of their young children’s illness symptoms when they brought their child to the ED. The second aim was to describe what is important to parents about their young children’s illness symptom management after visiting the ED. Parental perspective is important to consider not only because parents are the

guardians and decision-makers for their young children, but also because, from a bioecological perspective, parents know their children better than anyone due to their shared social and cultural contexts. Parents of children, newborn to eight years of age, were recruited at the time of their visit to the ED over a period of six months. Thirteen parent interviews were completed within three weeks of their visit to the ED. Interviews relied on semi-structured questions that allowed for consistent exploration of important themes yet allowed participants to freely expand on their thoughts. Interviews were timed so as to allow for the progressive, iterative analysis of interview data that is part of qualitative research conducted within the constructivist/interpretivist scientific paradigm.

The findings from this study centered around three interlocking themes: the cyclical process of child symptom management involving returning a child to how they are normally, the influence of provider interactions, and the contexts of life logistics and social support. The cycle of young children's symptom management from their parents' perspective begins with noticing that something is wrong with their child's health-related behavior. When parents become alarmed about the observed symptoms, they seek to better know about the causative illness, and to learn what to expect and what they can do to manage the illness. Ultimately, parents want to see their child return to how they are normally. Returning their child to a normal state is the most important outcome for parents.

Provider interactions consist of communications and interventions. Parents want dialogue with providers that are respectful of them and their concerns, want to be told what to expect for their child's care, and want providers to communicate effectively between themselves around care; they perceive nonverbal cues from providers about

their child's condition and what they think about the family. Parents also want to know why interventions are carried out or not, and to have them implemented smoothly. Illness symptom management and the interactions around it take place in the context of parents' life logistics, such as work and child care concerns, and the social supports they have to help them meet these logistical needs while their child is ill. These results are strongly congruent with and extend existing theoretical symptom management models and theories, providing further support for the validity of the findings.

Implications of the study

The findings from this study address a gap in the considerable literature related to symptom management in nursing and allied health. The meaning of acute symptom management, and the management of acute exacerbations of chronic symptoms, has not been previously described for young children in the Emergency Department context, particularly from the patient-centered outcomes perspective. Symptom management as a phenomenon is broadly recognized as an important health care outcome to consider. Expanding understanding in this area adds to researchers' and clinicians' ability to study this outcome as they strive to improve care.

Whereas individual providers may have their own ideas about what matters to families bringing their young children in to the ED for treatment, the findings help inform clinicians about what these parents need from providers and value in their interactions with them. Clinicians can more directly facilitate parents navigating the symptom management cycle through the lens of new understanding provided by the study findings.

Understanding the importance of provider relations with parents trying to manage their young child's illness has important implications for administrators. Certainly evaluations such as clinical guideline adherences are important, yet the findings from this study suggest that hospital and clinical administrators should concentrate on the elements of provider relations that parents notice and care about when both educating and evaluating the providers in their employ. The findings from this study point to much more specific and important evaluation criteria to consider than the popular but generic evaluation of satisfaction: informed about child's illness; coordinated care between providers; explained why interventions are carried out; interventions implemented smoothly; informed what to observe and what to do when discharged from the ED; interactions respectful.

While there is no formal instrument to measure the symptom management process, provider interactions, and the contexts of life logistics and social support described here, the findings point the way toward a potential outcomes measurement. However, even lacking this new measure, existing instruments could potentially be employed that address aspects of the findings from this study. As the United States moves toward an 'accountable care' model, measuring patient-centered outcomes is critical. It becomes the responsibility of organizations and insurers to consider the findings identified in this study when evaluating health care delivery effectiveness for the pediatric population.

Similarly, parents wanting to find the best providers for their child's health care should be informed about the current conceptual findings, and seek treatment for their children in hospital EDs that emphasize the traits from this study. Parents of young

children, especially lower socioeconomic status families, may have often felt they had little or no voice regarding health care provision, particularly in emergency circumstances. Being aware of the findings from this study can give parents a framework to express exactly what aspects of their child's illness symptom management the parents are happy or unhappy about.

Much of the symptom management understanding has been developed in the context of chronic illness, cancer in particular. Most chronic illnesses, life-threatening or not, have unpleasant symptoms associated with them, and this symptom presence is the primary etiology for the study of symptom management. However, acute illnesses also have unpleasant symptoms associated with them yet have remained largely unstudied. This lack of research into the acute illness aspect of symptom management may simply be the result of the wealth of research funding available for studying cancer and other chronic illnesses, while acute illness research has been comparatively starved. The findings from this study enhance and enrich the field of symptom management research and theory.

Limitations and Strengths of the Study

The design approach for this study utilized a qualitative descriptive approach. This approach was selected because the purpose of the study was to identify and describe concepts related to young children's symptom management by their parents. Qualitative descriptive research does not seek to transform or divine deeper meanings in research interview data. It is thus possible that interviews may have been framed and executed differently had another approach been selected. There may also be broader societal themes that were not developed from the data due to the descriptive focus.

The study included a semi-structured interview format for data collection. A disadvantage of the semi-structured style is that it may make it harder for interviews to branch into new and unexpected areas. The rationale for this tradeoff is discussed in Chapter Three. The limitations of this approach could have been a factor in a couple of research interviews being fairly brief and less informative than all the other interviews which were significantly longer and yielded richer data. Also, several interviews were ultimately completed by telephone for the sake of participants' time. A number of interviews could not have been completed without this concession, and some diversity from the sample would have been lost, thereby undermining the strategy of maximum variation. Respect for participants is inherent in the constructivist/interpretivist paradigm. A request for an interview by phone was considered reasonable for parents with young children who have little free time, especially those who work, and particularly for families that did not live close to the hospital. Based on face-to-face interviews in comparison, it is felt that little if anything of consequence was lost.

The participant sample consisted of parents bringing their study-eligible child to the ED, who not only consented to participate in the study but followed up with a completed interview. About half of those agreeing to participate did not complete an interview. It is possible that some of the parents who did not complete interviews had such a lack of time and support that they simply could not justify committing the time for an interview. As these parents did not respond to follow up contact and scheduling efforts, reasons for deciding not to participate could not be examined. It is unlikely death or permanent disability of the child was a factor, as this is a rare outcome for pediatric ED patients.

Participants for this study were recruited solely from a specialized Pediatric ED at a tertiary referral facility in an urban Pacific Northwest setting. The recruitment site could possibly influence the interview data that were collected, as it is possible that the specialized capability of the department creates a different experience for parents. Another limitation of the sample is that only English speaking families were included. While considerable variation is present in the study sample, the perspectives of non-enculturated families are unfortunately absent. Providers (doctors, nurses, etc.) were almost exclusively pediatric specialists. However, time and financial restraints of the researcher precluded multi-site recruitment.

In qualitative research, the researcher is the instrument for data collection and analysis. In this study, the researcher has considerable experience as a Pediatric ED Registered Nurse, and as such, personal experiences and biases could affect the research analysis. It is also possible that lines of interview inquiry may have been foreclosed due to the researcher's familiarity with the process of pediatric ED health care.

This was a qualitative descriptive study rooted in the constructivist/interpretivist philosophical paradigm. Having a consistent scientific philosophy adds strength to the study. From initial design through findings, this philosophical lens was present, and kept the study from deviating methodologically during execution of the research. The qualitative descriptive design was the best choice for conducting this study, as the intent was to identify and describe concepts related to child symptom management that were important to parents.

Data collection consisted of recording and transcribing interviews with parents within a few weeks of their bringing their child to the ED for treatment. Because the interview process required parents to allocate time from their daily lives, elapsed time between the ED visit and parent interview varied from three days to two weeks, depending on their availability. The maximum variation sampling approach dictated flexibility to enable busier parents to participate and add their voice to the data collection. Also, two participants were interviewed 2-3 days after their arrival in the ED while their children were still hospitalized, as they indicated they would not have time to participate after they went home and resumed their daily routines. Interviewing parents while they were actively processing their experience with their child's illness in fact yielded two of the richer interviews completed for this study, and added descriptive fullness for analysis. A semi-structured interview format was used to ensure that the same areas were explored at a minimum with each parent participant. The advantage of this approach was to help organize the interview data and help data to be compared across interviews.

A maximum variation sampling approach was employed to explore the perspectives of families from different backgrounds. Considerable diversity of background was achieved and diversity is a strength of this study. The study findings were enriched by a dual focus on the universality of parents' experience with their child's illness, in the context of maximum variation of parent participants in terms of age, ethnicity, income, and illness acuity.

Recruitment in the selected setting of this ED had significant advantages. Being the largest-volume specialized pediatric ED hospital ensured availability of a reasonable

volume of eligible families. Also, being an urban, tertiary-referral setting afforded access to a very diverse population relative to the Pacific Northwest region as a whole. Both factors contribute significantly to the strength of the study.

To balance any potential prejudice in analysis by the researcher with a strong ED clinical background, the analysis was subject to review by three faculty members. This review enabled triangulation of the data analysis by bringing different perspectives to the process. Memoing and drafting throughout the course of analysis provided an audit trail to review the evolution of identified concepts. Two member checks provided support for the final data analysis.

Recommendations for future research

This study is clearly consistent with existing symptom management and patient-centered outcomes frameworks as described above. However, it also underscores the absence of measures to operationalize study of young children's symptom management as an outcome of care in the ED. The logical next step for future research is to build a valid and reliable measure of this phenomenon, using the findings from this study as a foundation that will be compatible with existing symptom management and outcomes frameworks, such as the QHOM.

Additional research could also be conducted with non-English speaking families, to see if the findings from this study also exist in families who likely are not as enculturated in the United States. Similar findings in these populations would improve transferability of the child symptom management research findings, and any subsequent research using the current findings as a foundation.

Conclusions

This qualitative descriptive study examined parents' perceptions of their young child's illness symptom management after seeking treatment from an Emergency Department with a focus on both parents' observations about their child's illness and what treatment aspects they noticed while receiving care. Descriptive analysis of common themes from thirteen parent interviews yielded three main findings. The first finding was that illness was a cyclical process for parents, starting with noticing something wrong with their child's health and becoming alarmed, to understanding the illness and how to manage it and ending with their child's return to how they are normally, day-to-day. The second finding was for the importance of provider relationships with parents and how parent/provider interactions can influence the cyclical process at every step. The third finding was for the impact family contexts of life logistics and social supports have on this process, making this management harder or easier for parents. These findings extend existing symptom management knowledge, and future research built on these findings can serve the evaluation of child symptom management as an important patient-centered outcome in health care.

References

- Armstrong, T. S. (2003, January). Symptoms experience: a concept analysis. *Oncology Nursing Forum* (Vol. 30, No. 4, pp. 601-606). Oncology Nursing Society.
- Benner, P. E., & Wrubel, J. (1989). *The primacy of caring: Stress and coping in health and illness*. Addison Wesley Longman.
- Bowlby, J. (1988). *A secure base: Clinical applications of attachment theory*. Basic Books.
- Brant, J. M., Beck, S., & Miaskowski, C. (2010). Building dynamic models and theories to advance the science of symptom management research. *Journal of advanced nursing*, 66(1), 228-240.
- Bronfenbrenner, U., & Morris, P. A. (2006). The Bioecological Model of Human Development. *In Handbook of Child Psychology, Volume 1* (6th). Wiley.
- Bruck, M., & Ceci, S. J. (1999). The suggestibility of children's memory. *Annual review of psychology*, 50(1), 419-439.
- Chambers, C. T., & Johnston, C. (2002). Developmental differences in children's use of rating scales. *Journal of Pediatric Psychology*, 27(1), 27-36.
- Cioffi, D. (1991). Beyond attentional strategies: A cognitive-perceptual model of somatic interpretation. *Psychological Bulletin*, 109(1), 25.
- Clancy, C. M., Dougherty, D., & Walker, E. (2002). The importance of outcomes research in pediatric emergency medicine. *Ambulatory Pediatrics*, 2(4), 293-300.
- Clancy, C. M., & Eisenberg, J. M. (1998). Outcomes research: measuring the end results of health care. *Science*, 282(5387), 245-246.
- Collins, J. J., Byrnes, M. E., Dunkel, I. J., Lapin, J., Nadel, T., Thaler, H. T., ... &

- Portenoy, R. K. (2000). The measurement of symptoms in children with cancer. *Journal of pain and symptom management*, 19(5), 363-377.
- Collins, J. J., Devine, T. D., Dick, G. S., Johnson, E. A., Kilham, H. A., Pinkerton, C. R., ... & Portenoy, R. K. (2002). The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in children aged 7–12. *Journal of pain and symptom management*, 23(1), 10-16.
- Craig, K. D., & Riddell, R. P. (2003). Social influences, culture, and ethnicity. Progress *In Pain Research and Management*, 26, 159-182.
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2011). The SAGE handbook of qualitative research. Sage Publications.
- Dixon, S. D., & Stein, M. T. (2006). Encounters with children: pediatric behavior and development (4th). Mosby Elsevier.
- Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E.S., Humphreys, J., Lee, K., Miaskowski, C., Puntillo, K., Rankin, S., Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing* 33(5), 668-676
- Donabedian, A. (1966). Evaluating the quality of medical care. *The Milbank Memorial Fund Quarterly*, 44(3), 166-206.
- Donabedian, A. (1988). The quality of care: How can it be assessed? *Journal of the American Medical Association* 260(12), 1743-1748.
- Doran, D., Harrison, M. B., Laschinger, H., Hirdes, J., Rukholm, E., Sidani, S., Hall, L.M., Tourangeau, L.E., & Cranley, L. (2006). Relationship between nursing interventions and outcome achievement in acute care settings. *Research in Nursing & Health*, 29(1), 61-70.

- Doran, D., & Pringle, D. Patient outcomes as an accountability. *In* Doran, D. (2011). *Nursing Sensitive Outcomes: the State of the Science*. Jones & Bartlett Learning.
- Fu, M. R., LeMone, P., & McDaniel, R. W. (2004, January). An integrated approach to an analysis of symptom management in patients with cancer. *Oncology Nursing Forum* 31(1), 65-70).
- Gerolamo, A. M. (2004). State of the science: outcomes of acute inpatient psychiatric care. *Archives of Psychiatric Nursing*, 18(6), 203.
- Gerolamo, A. M. (2006). The conceptualization of physical restraint as a nursing-sensitive adverse outcome in acute care psychiatric treatment settings. *Archives of Psychiatric Nursing*, 20(4), 175.
- Gross, G.J., Howard, M. (2001). Mothers' decision-making processes regarding health care for their children. *Public Health Nursing* 18(3), 157-168.
- Hadjistavropoulos, T., & Craig, K. D. (2002). A theoretical framework for understanding self-report and observational measures of pain: a communications model. *Behaviour research and therapy*, 40(5), 551-570.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, 18(2), 141-184.
- Hegyvary, S. T. (1993). Patient care outcomes related to management of symptoms. *Annual review of nursing research*, 11, 145-145.
- Henly, S. J., Kallas, K. D., Klatt, C. M., & Swenson, K. K. (2003). The notion of time in symptom experiences. *Nursing research*, 52(6), 410-417.
- Hetherington, E.M., Parke, R.D., Gauvain, M., Locke, V.O. (2006). *Child Psychology: A*

- Contemporary Viewpoint (6th). McGraw-Hill, New York, NY.
- Hockenberry, M. (2004). Symptom management research in children with cancer. *Journal of Pediatric Oncology Nursing*, 21(3), 132-136.
- Homer, C. J., Marino, B., Cleary, P. D., Alpert, H. R., Smith, B., Crowley Ganser, C. M., Brustowicz, R.M., & Goldmann, D. A. (1999). Quality of care at a children's hospital: the parents' perspective. *Archives of pediatrics & adolescent medicine*, 153(11), 1123-1129.
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative health research*, 15(9), 1277-1288.
- Humphreys, J., Lee, K.A., Carrieri-Kohlman, V., Puntillo, K., Faucett, J., Janson, S., Aouizerat, B., Donesky-Cuenco, D., UCSF SON Symptom Management Faculty Group. (2008). Theory of Symptom Management. In Smith, M.J., Liehr, P.R. Middle Range Theory for Nursing (2nd), 159-181. Springer Publishing: New York, NY.
- Kai, J. (1996). What worries parents when their preschool children are acutely ill, and why: a qualitative study. *BMJ*, 313(7063), 983-986.
- Kai, J. (1996). Parents' difficulties and information needs in coping with acute illness in preschool children: a qualitative study. *BMJ*, 313(7063), 987-990.
- Kane, R.L. (2006). Understanding Health Care Outcomes Research (2nd). Jones & Bartlett. Sudbury, MA.
- Kleinman, A. (1989). The illness narratives: Suffering, healing, and the human condition. Basic Books.
- Kolk, A.M., Hanewald, G., Schagen, S., Gisjbers van Wijk, C. (2003). A symptom

- perceptions approach to common physical symptoms. *Social Science & Medicine* 57(12), 2343-54.
- Krahenbuhl, S., Blades, M. (2006). The effect of interviewing techniques on young children's responses to questions. *Child: Care, Health, & Development* 32(3), 321-331.
- Lapadat, J. C., & Lindsay, A. C. (1999). Transcription in research and practice: From standardization of technique to interpretive positionings. *Qualitative Inquiry*, 5(1), 64-86.
- Lau, R. R., Bernard, T. M., & Hartman, K. A. (1989). Further explorations of common-sense representations of common illnesses. *Health Psychology*, 8(2), 195-219.
- Lenz, E.R., Pugh, L.C. (2008). Theory of Unpleasant Symptoms. In Smith, M.J., Liehr, P.R. *Middle Range Theory for Nursing* (2nd), 159-181. Springer Publishing: New York, NY.
- Lenz, E. R., Pugh, L. C., Milligan, R. A., Gift, A., & Suppe, F. (1997). The middle-range theory of unpleasant symptoms: an update. *Advances in Nursing Science*, 19(3), 14-27.
- Leventhal, H., Nerenz, D., & Straus, A. (1982). Self-regulation and the mechanisms for symptom appraisal. *Symptoms, illness behavior, and help-seeking*, 3, 55-86.
- Linder, L. (2010). Analysis of the UCSF Symptom Management Theory: implications for pediatric oncology nursing. *Journal of Pediatric Oncology Nursing*, 27(6), 316-324.
- MacLean, L. M., Meyer, M., & Estable, A. (2004). Improving accuracy of transcripts in

- qualitative research. *Qualitative Health Research*, 14(1), 113-123.
- Mark, B. A., & Harless, D. W. (2010). Nurse staffing and post-surgical complications using the present on admission indicator. *Research in nursing & health*, 33(1), 35-47.
- Maxwell, J. A. (2013). *Qualitative research design: An interactive approach*. Sage Publications.
- McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. *Cancer nursing*, 1(5), 373-378.
- Mitchell, P. H., Ferketich, S., & Jennings, B. M. (2007). Quality health outcomes model. *Journal of Nursing Scholarship*, 30(1), 43-46.
- Mitchell, P. H., & Lang, N. M. (2004). Framing the problem of measuring and improving healthcare quality: Has the Quality Health Outcomes Model been useful?. *Medical Care*, 42(2), II-4.
- Morse, J. M. (2000). Determining sample size. *Qualitative Health Research*, 10(1), 3-5.
- Neill, S. J. (2000). Acute childhood illness at home: the parents' perspective. *Journal of Advanced Nursing*, 31(4), 821-832.
- Olson, L. M., Radecki, L., Frintner, M. P., Weiss, K. B., Korfmacher, J., & Siegel, R. M. (2007). At what age can children report dependably on their asthma health status? *Pediatrics*, 119(1), 93-102.
- Patton, M. Q. (2001). *Qualitative research & evaluation methods*. Sage Publications.
- Pederson, D. R., Moran, G., Sitko, C., Campbell, K., Ghesquire, K., & Acton, H. (1990). Maternal sensitivity and the security of infant-mother attachment: AQ-sort study. *Child Development*, 61(6), 1974-1983.

- Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology; Journal of Counseling Psychology, 52(2)*, 126-136.
- Portenoy, R. K., Thaler, H. T., Kornblith, A. B., McCarthy Lepore, J., Friedlander-Klar, H., Coyle, N., Smart-Curley, T., Kemeney, N., Norton, L., Hoskins, W., & Scher, H. (1994). Symptom prevalence, characteristics and distress in a cancer population. *Quality of Life Research, 3(3)*, 183-189.
- Porter, S. C., Fleisher, G. R., Kohane, I. S., & Mandl, K. D. (2003). The Value of Parental Report for Diagnosis and Management of Dehydration in the Emergency. *Annals of emergency medicine, 41(2)*, 196-205.
- Radwin, L. (2000). Oncology patients' perceptions of quality nursing care. *Research in nursing & health, 23(3)*, 179-190.
- Radwin, L. E., Cabral, H. J., & Wilkes, G. (2009). Relationships between patient-centered cancer nursing interventions and desired health outcomes in the context of the health care system. *Research in nursing & health, 32(1)*, 4-17.
- Radwin, L., & Fawcett, J. (2002). A conceptual model-based programme of nursing research: retrospective and prospective applications. *Journal of advanced nursing, 40(3)*, 355-360.
- Rebok, G., Riley, A., Forrest, C., Starfield, B., Green, B., Robertson, J., & Tambor, E. (2001). Elementary school-aged children's reports of their health: a cognitive interviewing study. *Quality of Life Research, 10(1)*, 59-70.
- Riley, A. W. (2004). Evidence that school-age children can self-report on their health. *Ambulatory Pediatrics, 4(4)*, 371-376.

- Riley, A. W., Forrest, C. B., Rebok, G. W., Starfield, B., Green, B. F., Robertson, J. A., & Friello, P. (2004). The child report form of the CHIP-Child Edition: reliability and validity. *Medical care*, 42(3), 221-231.
- Saldaña, J. (2013). *The coding manual for qualitative researchers* (2nd). Sage Publications.
- Sandelowski, M. (2000). Focus on Research Methods-Whatever Happened to Qualitative Description? *Research in Nursing & Health*, 23(4), 334-340.
- Sandelowski, M. (2009). What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1), 77-84.
- Seid, M., Varni, J. W., Bermudez, L. O., Zivkovic, M., Far, M. D., Nelson, M., & Kurtin, P. S. (2001). Parents' perceptions of primary care: measuring parents' experiences of pediatric primary care quality. *Pediatrics*, 108(2), 264-270.
- Sidani, S. (2011). Symptom management. *In Nursing Outcomes: State of the Science*(2nd), 131-199. Jones& Bartlett Publishers: Boston, MA.
- Swan, B. A., & Boruch, R. F. (2004). Quality of evidence: Usefulness in measuring the quality of health care. *Medical care*, 42(2), 11-12.
- Teel, C.S., Meek, P., McNamara, A.M., Watson, L. (1997). Perspectives unifying symptom interpretation. *Image: Journal of Nursing Scholarship* 29(2), 175-181.
- Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative inquiry*, 16(10), 837-851.
- Turk, D. C., Litt, M. D., Salovey, P., & Walker, J. (1985). Seeking urgent pediatric treatment: Factors contributing to frequency, delay, and appropriateness. *Health Psychology*, 4(1), 43-59.

- Turner, R. R., Quittner, A. L., Parasuraman, B. M., Kallich, J. D., & Cleeland, C. S. (2007). Patient-reported outcomes: instrument development and selection issues. *Value in Health, 10*, S86-S93.
- Van Egeren, L. A., Barratt, M. S., & Roach, M. A. (2001). Mother–infant responsiveness: Timing, mutual regulation, and interactional context. *Developmental psychology, 37*(5), 684.
- Varni, J.W., Limbers, C.A., Burwinkle, T.M. (2007). Parent proxy-report of their children's health-related quality of life: An analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL 4.0 Generic Core Scales. *Health and Quality of Life Outcomes 5*(2).
- Varni, J. W., Seid, M., Knight, T. S., Uzark, K., & Szer, I. S. (2002). The PedsQLTM 4.0 Generic Core Scales: Sensitivity, responsiveness, and impact on clinical decision-making. *Journal of Behavioral Medicine, 25*(2), 175-193.
- Voepel-Lewis, T., Malviya, S., & Tait, A. R. (2005). Validity of parent ratings as proxy measures of pain in children with cognitive impairment. *Pain management nursing: official journal of the American Society of Pain Management Nurses, 6*(4), 168.
- Von Baeyer, C.L., Spagrud, L. (2003). Social development and pain in children. In McGrath, P.J., Finley, G.A. (Eds.) *Pediatric Pain: Biologic and Social Context. Progress in Pain Research and Management 26*: 81-97.
- Von Baeyer, C. L., Chambers, C. T., & Eakins, D. M. (2011). Development of a 10-item short form of the Parents' Postoperative Pain Measure: The PPPM-SF. *The Journal of Pain, 12*(3), 401-406.

- Watson, D., Pennebaker, J. (1991). Situational, dispositional, and genetic basis of symptom reporting. *In* Skelton, J. (Ed.), *Mental Representation in Health & Illness* (60-84). New York: Springer-Verlag.
- White, J.M., Klein, D.M. (2007). The bioecological framework. *In* *Family Theories* (3rd), 241-272. Sage Publications: Thousand Oaks, CA.
- Wilson, B. L., Effken, J., & Butler, R. J. (2010). The relationship between cesarean section and labor induction. *Journal of Nursing Scholarship*, 42(2), 130-138.
- Woodgate, R. L., Degner, L. F., & Yanofsky, R. (2003). A different perspective to approaching cancer symptoms in children. *Journal of Pain and Symptom Management* 30(3), 479-491.
- Zisk, R. Y., Grey, M., Medoff-Cooper, B., & Kain, Z. N. (2007). Accuracy of parental-global-impression of children's acute pain. *Pain Management Nursing*, 8(2), 72-76.

Appendices

Appendix I: Participant demographics

13 total parent participants:

Parents

Age: 18-25 years (3), 25-35 (3), 35 and older (7)

Gender: women (10), men (3)

Annual Income: \$0-\$25k (6), \$25k-\$50k (2), \$50k-75k (1), More than \$75k (4)

Relationship status: Single (3), Living with spouse/partner (9), Separated/divorced (1)

Race/ethnicity: Latino/Hispanic (3), Asian (1), Black (2), White (7)

Previous ED visits with a child: 0-1 (6), 2 or more (7)

Children

Age: birth-12 months (2), 1-3 years (4), 3-8 years (7)

Gender: girls (7), boys (6)

Appendix II: Semi-structured interview guide

I would like to better understand what parents observe in their children that they come to the Emergency Department, and what parents want to happen as a result of the visit. As a recent visitor to an ED, your thoughts can give providers valuable insights into helping parents when their child is sick.

Questions and probes:

1. What was your child doing or not doing that worried you when you brought him/her to the Emergency Department?
 - a. What was different about your child?
 - b. How were they behaving/acting?
2. How concerned about these symptoms were you?
 - a. Were you uncertain about what was going on, and wanted to be sure it was nothing serious, or did you think it was something worse?
3. Did you feel like you knew what the problem was related to?
 - a. Was this something you have experience with?
 - b. Did you get advice from family or friends? Who? What did they say?
4. How well do you think doctors and nurses explained your child's symptoms?
 - a. Did the explanation make sense to you? What did you want to know?
5. What have you noticed about your child's symptoms since you went to the Emergency Department?
 - a. Have they improved?
 - b. Did you need further treatment?

6. Are you comfortable with how your child is now?
 - a. If yes, what makes you comfortable?
 - b. If no, what worries you?
7. What did you hope to get from visiting the Emergency Department with your child?
8. Were those expectations met?
9. What knowledge or resources would help you understand and manage your child's illness?

Thank you very much for your time. Your insights and knowledge are important, and will help providers better understand how we can help parents in the Emergency Department when their child is ill.

Appendix III: Participant demographic questionnaire



Participant Demographic Questions

1. With which of the following ethnic/racial categories do you identify?
 - a. American Indian/Native Alaskan
 - b. Asian
 - c. Black (African American or Islander)
 - d. Latino/Hispanic
 - e. Native Hawaiian/Other Pacific Islander
 - f. White/Caucasian
2. Which of these ethnic/racial categories do you identify your child with?
3. What is your child's age and gender? What is your age?
4. Have you brought your child to the ED for treatment previously? Approximately how many times?
5. In what range would you estimate your household income to be?
 - a. \$0-25,000
 - b. \$25,000-50,000
 - c. \$50,000-75,000
 - d. \$75,000 or above
6. What is your current relationship status?
 - a. Single
 - b. Separated/Divorced
 - c. Living with spouse/domestic partner/significant other

Appendix IV: Participant informed consent form



Research Study Title: <i>The Parent Perspective on Child Symptom Management as an Outcome of Care for the Emergency Department: A Qualitative Descriptive Study</i>
Name of Investigators: Donald W. Mitchell, Gail Houck
Phone Number: (503) 494-3825

1. Introduction

You have been invited to participate in a research study (the “Research Study”) being conducted at Legacy Health. You have been invited because you have brought your child, who is eight years of age or younger, to the Emergency Department for the treatment of illness symptoms, and you are that child’s parent or primary caregiver.

The purpose of this Consent Form is to provide information for you about the nature of the Research Study so you may make a decision as to whether you would like to participate.

To participate in this study, you must meet the following criteria: You must be at least 18 years old; able to speak, read, and write English; and be born in the United States; Your child must have been eight years of age or younger at the time they were treated in the Emergency Department.

2. Purpose

The purpose of this Research Study is to describe parents’ perceptions of their young children’s illness symptoms when they bring their child to the Emergency Department (ED) and was important to parents about the management of their young children’s illness symptoms when visiting the ED. The expected duration of your participation in the Study is one interview within three weeks of your child’s visit to the ED. Up to 40 parents will participate in this study. The Randall Children’s ED is the only site this study is being conducted.

3. Procedures

The Research Study requires scheduling and completing one face-to-face interview approximately one to three weeks after your visit to the Emergency Department. If you agree to participate in this study during your visit to the Emergency Department, the researcher will document your name and phone number, and contact you by phone to schedule a single research interview within a one- to three-week time period following your visit. The interview will take place in your home or other place that is agreed upon between you and the researcher, at a time that is convenient for you. The interview is

anticipated to last 20 minutes, but may be shorter or longer depending on the depth and breadth of the conversation. Some demographic and background information will also be requested at the beginning of the interview. The interview will be audio-recorded.

This will be the entirety of your participation, unless you agree to be contacted subsequently. Subsequent contact would include requests for clarification of interview responses or other statements and occur within 30 days of the interview. In addition, if you agree, you may be contacted up to one year following the interview for sharing the findings of the study and hearing your feedback. Giving permission to contact you does NOT require you to participate in any of these activities.

4. Risks

Because the interview questions ask about your perceptions and feelings as a parent, there is a chance of emotional upset. You may stop the interview at any time if you are uncomfortable.

Because the researcher is a mandated reporter, any discovery of child abuse must by law be reported.

Every effort will be made to keep your personal information confidential, but we cannot guarantee total privacy. There is a small chance that your information could be accidentally released.

5. Benefits

You may or may not personally benefit from being in this study. Some people enjoy the opportunity to share their experiences. However, by serving as a subject, you may help us learn how to benefit patients and families in the future.

6. Alternatives

This Study does not involve any medical care or other medical procedures, and your only alternative is to refuse participation. You are free to decline participation and should you choose to participate, you are free to withdraw from the Study at any time without penalty or loss of benefits that you would otherwise enjoy outside of the Research Study.

8. Compensation

The researcher will compensate you for participating in the Research Study. You will receive a one-time \$10 gift card after completion of the study interview.

10. Voluntary Participation

You are free to refuse to participate or to withdraw from participation at any time and it will in no way affect your relationship with, or treatment at Legacy Health. You will be given a copy of this consent form.

The researcher may end your participation if it does not reasonably prove possible to schedule an interview within the three-week time frame.

11. Costs

There are no costs to you regardless of whether you participate or not.

13. Authorization to Use and Disclose Protected Health Information

You hereby authorize Legacy Health to use and disclose your Protected Health Information (PHI) solely for the purposes of the Research Study. PHI includes any portion of your medical records that could be used to identify you such as name, address, birth date, etc.

You hereby authorize Legacy Health to disclose your PHI to the following Recipient(s): Donald Mitchell (Principal Investigator), Gail Houck (Co-Investigator), Dena Hassouneh, Christopher Lee (Research Committee Members).

You hereby authorize Legacy Health to use and disclose your PHI in accordance with the terms and conditions of this Consent Form until you revoke it at any time by phone or in writing, or the research study is completed.

Once Legacy Health discloses PHI to the Recipient(s) identified above, Legacy Health cannot guarantee that Recipient(s) will not re-disclose PHI to other persons who may not be bound by this Consent Form, or otherwise be permitted to use or disclose PHI in ways that you did not intend.

You may change your mind and revoke this authorization at any time. To revoke this authorization, you must write or call:

Donald Mitchell *or* Gail Houck
Oregon Health & Science University
School of Nursing Portland Campus
3455 SW US Veterans Road, SN-5S
Portland, Ore. 97239
(503) 494-3825

However, if you revoke this authorization, you may no longer be able to participate in the study. In addition, even if you revoke the authorization, the information already obtained by Legacy Health may be used and disclosed as permitted by this authorization and this informed consent.

14. Contacts

If at any time during this Research Study, you feel that you have not been adequately informed as to the risks, benefits, alternative procedures, or your rights as a research subject, or feel under duress to participate against your wishes, you can contact Legacy Health's Research Regulatory Specialist who will be available to speak with you during normal working hours (8:30 a.m. to 5:00 p.m.) at (503) 413-2474.

If you have any questions or need clarifications regarding this study, you may contact Donald Mitchell (Principal Investigator) or Gail Houck (Co-Investigator), at (503) 494-3825 during normal business hours.

The subject has been informed of the (i) nature and purpose of the procedures described above including any risks involved in the Research Study's performance; and (ii) of how his or her Protected Health Information may be used or disclosed. The subject has been asked if any questions have arisen regarding these procedures and the subject's privacy rights, and these questions have been answered to the best of the Legacy Health's ability. A copy of this Compound Consent and Authorization has been provided to the subject.

Date

Investigator's Signature or Designee

I have been informed about the procedures, risks, and benefits of this Research Study and agree to participate. I know that I am free to withdraw my consent and to quit the Research Study at any time. I have read and understand the terms of this Consent Form and I have had an opportunity to ask questions about the Study and to discuss the Study with my doctor and other health care providers and my family and friends. I also have had the opportunity to ask questions about the use and disclosure of my Protected Health Information and my privacy rights. I hereby knowingly and voluntarily authorize Legacy Health to use and disclose my Protected Health Information in the manner described in this Consent Form. I understand that I may decline to participate in this Research Study. I further understand that if I choose to participate, I may withdraw from the Research Study at any time. My decision not to participate in this Research Study or my decision at any time to withdraw from this Research Study will not cause me any penalty or loss of benefits that I am otherwise entitled to enjoy.

Subject's Signature

Date

Subject's Legal Representative
(if applicable)

Date

Appendix V: Research recruitment scripts

Introductory research recruitment:

Hello, my name is Don Mitchell, and I am a doctoral student in nursing at OHSU. I am conducting a research project for my dissertation that involves interviewing parents who have brought their children to the ED for treatment of their illness symptoms. I am interested to learn what is important to parents about the results of their visit. This research is completely separate from the treatment you are receiving and your care will not change regardless of whether you decide to participate. Would you be interested in participating in this research? (IF YES) Then I would like to review some more information about the project with you (summary and informed consent form). (IF NO) Thank you for your time.

To follow up and arrange interview:

Hello, my name is Don Mitchell and I met you at the Randall Children's ED during your visit there on (date). You said you were interested in participating in a study about parents perceptions of their child's illness symptoms when taking them to the ED and what was important about the management of the child's symptoms when there. Are you still interested in participating in an interview? (IF YES) Thank you so much. I would like to schedule an interview with you; it will take from 45 minutes to an hour and a half. We can meet in your home or in another setting that we agree on. What would be a good day and time for you to meet? We will need to meet in a place that is fairly private and as quiet as possible in order to record the interview; where would you like to meet? I will call you the morning of the interview to remind you and make sure your plans have not changed for some reason. Thank you! (IF NO) Thank you for your time.

Appendix VI: IRB approval

2013-Apr-18 12:59 PM LEGACY RCH ED 503-276-9141

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**LEGACY HEALTH INSTITUTIONAL REVIEW BOARD
STUDENT RESEARCH
INITIAL REVIEW APPLICATION AND APPROVAL DOCUMENT**

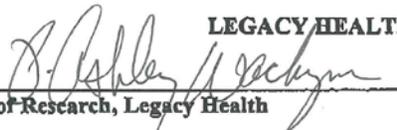
The questionnaire is based on DHHS regulatory requirements and Legacy Health's policy for the protection of human subjects and the administration of research studies. Upon final approval of this study, you will receive this form with the IRB Chairperson's and the Vice President of Research's signature and it will serve as your approval document.

Protocol – Full Title: *The parent perspective on child symptom management as an outcome of care for the emergency department: A qualitative descriptive study*

Principal Investigator: Donald W. Mitchell **Co-Investigator:** Gail Houck

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LEGACY HEALTH IRB APPROVAL



V.P. of Research, Legacy Health

4/23/2013
DATE



Chairperson, Legacy IRB

4-23-13
DATE

Initial Approval Date: 4/23/13

Study Expiration Date: 4/22/14

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PI Address: 6834 N Pittsburg Ave Portland, OR 97203

PI Telephone: 503-816-4685 (Private)

Educational Institution: Oregon Health & Science University

Mentor Name and Phone Number: Dr. Gail Houck, 503-494-3825 (Office and Contact)

Research sites where study will be conducted at Legacy: Randall Children's ED

Submit the Following Documents (as appropriate)
CV, Protocol, Consent form, Advertisement, Questionnaire, Survey, Interview Outline,
IRB approval from College or University

Legacy IRB Tracking Number: