TREATING CHILDREN AS PEOPLE: EXPLORING NURSES' PRACTICE TO
PRESERVE CHILDREN'S PERSONAL INTEGRITY

by

GLADYS I. MCPHERSON

B.Sc.N., University of Alberta, 1981

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MASTER OF SCIENCE IN NURSING

in

THE FACULTY OF GRADUATE STUDIES

(School of Nursing)

We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

October 1999

© Gladys I. McPherson, 1999
In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Department of GRADUATE STUDIES (School of Nursing)

The University of British Columbia
Vancouver, Canada

Date Oct 15/99.
ABSTRACT

TREATING CHILDREN AS PEOPLE: EXPLORING NURSES’ PRACTICE TO PRESERVE CHILDREN’S PERSONAL INTEGRITY

Serious illness and hospitalization threaten children’s sense of self and alter their ability to act on their own behalf. Personal integrity, conceptualized as the capacity to sustain a sense of self and to live in congruence with one’s own intentions and desires, is fundamental to being human. Children, like all people, strive to develop and maintain personal integrity. Because nurses care for children at times when their personal integrity is threatened by illness and its treatment, they are in a position to act to preserve children’s sense of self and support their sense of personal agency. Nurses’ work in preserving children’s personal integrity when children are ill and hospitalized was the focus of this project.

This qualitative research project was guided by the methodology of interpretive description. Accounts of practice with seriously ill children were elicited from nine pediatric critical care nurses. Five of these nurses were interviewed twice. For these nurses, work to preserve children’s personal integrity entailed practices that address four threats to children’s sense of self and their personal agency. These threats are objectification, loss of control, separation and isolation, and physical pain and intrusion.

The participants’ enactment of practice to preserve children’s personal integrity was greatly influenced by personal, relational and environmental factors. In particular, practices to attend to children as fully human beings often competed with other priorities in the practice arena – specifically the priorities of saving/fixing children’s bodies, and facilitating efficient system functioning. The nature of work that attends to the human element of care in particular moments of practice were determined by (a) the nurse’s commitment to attend to the child’s personhood, (b) the nurse’s knowledge of the child, and (c) the nurse’s personal agency. Each of these determinants is a complex and dynamic influence. Moral distress occurred when, for a
variety of reasons, the participants were unable to practice in congruence with their beliefs about the humanness of seriously ill children and about their responsibilities as nurses. The findings of this study point to a need to draw attention to the issue of children’s personal integrity when children are ill and hospitalized. To do this, nurses need to develop a language that is powerful and compelling in the communication of these concerns.
# TABLE OF CONTENTS

ABSTRACT .................................................................................................................. ii

TABLE OF CONTENTS ............................................................................................... iv

LIST OF TABLES ......................................................................................................... viii

LIST OF FIGURES ...................................................................................................... ix

ACKNOWLEDGEMENTS ............................................................................................. x

CHAPTER 1 INTRODUCTION ......................................................................................... 1
   Background to the Problem .................................................................................... 2
   Purpose of the Study .............................................................................................. 5
   Research Questions ............................................................................................... 6
   Significance of the Study ....................................................................................... 6
   Assumptions .......................................................................................................... 6
   Summary ............................................................................................................... 7

CHAPTER 2 LITERATURE REVIEW .............................................................................. 8
   Personal Integrity ................................................................................................ 8
      Perspectives on Personal Integrity .................................................................. 9
         Detached Approaches to Personal Integrity .............................................. 10
         Attached Approaches to Personal Integrity .............................................. 12
      Age and Personal Integrity ............................................................................. Error! Bookmark not defined.
   Illness and Personal Integrity ............................................................................. 17
   Nurses' Work in Preserving Children's Personal Integrity ................................. 19
      Knowing the Child ........................................................................................... 19
      Knowing the Case ........................................................................................... 20
      Knowing the Patient ....................................................................................... 24
      Knowing the Person ....................................................................................... 28
      Considering the Context ............................................................................... 31
   Analytic Framework ............................................................................................. 33
   Definition of Terms .............................................................................................. 34
   Summary ............................................................................................................... 35
Chapter 3 METHODOLOGY

Research Design ................................................................. 36
Sample Selection ............................................................... 37
  Method of Sampling .......................................................... 37
  Human Subjects Approval ..................................................... 38
  Rationale for Site Selection ................................................... 38
  Procedure for Approaching Participants ................................. 39
  Procedure for Informing Participants ...................................... 39
  Sample Size ........................................................................ 39
Data Collection ....................................................................... 40
  Data Sources ...................................................................... 40
  The Interview Process ............................................................ 40
Data Analysis .......................................................................... 40
Rigor ..................................................................................... 43
  Triangulation ..................................................................... 43
  Construct Validity ................................................................. 44
  Face Validity ....................................................................... 46
  Catalytic Validity ................................................................. 47
Ethical Considerations .......................................................... 47
  Informed Consent ................................................................. 48
  Confidentiality ..................................................................... 48
  Avoiding Appropriation .......................................................... 49
Limitations of the Study .......................................................... 50
Summary ................................................................................. 51

CHAPTER 4 FINDINGS................................................................. 52

Description of the Participants .................................................. 52
Understanding Personal Integrity ............................................... 53
  The Language We Use .......................................................... 53
  Personal Integrity is Both Relational and Contextual ................. 53
Discourses of the Practice Environment ..................................... 55
  Dominant Discourses: Attending to the Body and the System ...... 56
    Saving/Fixing Children's Bodies ............................................. 57
    Vigilantly Monitoring Children's Bodies ............................... 58
    Providing Technically Excellent Care .................................... 59
    Facilitating Efficient Unit Functioning ................................. 62
  Secondary Discourse: Treating Children as People ..................... 66
    Threats to Children's Personal Integrity ................................ 68
    Secondary Patterns of Practice: Treating Children as People ... 70
      Engaging in Relationships with Children ................................ 70
      Creating Tangible Reminders of Children's Humanity ............. 73
      Coordinating Care ............................................................ 74
Enhancing Children's Control ................................................. 75
Supporting Children's Connection with Family and Others .......... 78
Minimizing and Relieving Children's Pain ............................... 79
Mediating Painful and Invasive Events ................................. 80

Enactment of Practice to Treat Children as People ....................... 82
Commitment: The Will to Act ............................................... 84
Remembering the Child is a Person ........................................ 85
Weighing the Consequences ................................................. 86
Practical Consequences .................................................... 86
Emotional Consequences ................................................... 87
Political Consequences ..................................................... 89

Knowledge: The Substance of Action ...................................... 91
Drawing on General Knowledge ............................................ 92
Sources of General Knowledge ............................................. 93
The Limits of General Knowledge ......................................... 94
Drawing on Particular Knowledge ........................................ 95
Sources of Particular Knowledge ......................................... 95
Limits of Particular Knowledge ........................................... 99

The Dialectic of Personal and Particular Knowledge .................... 101
Agency: The Capacity and Opportunity to Act ......................... 104
Developing Knowledge and Skills ....................................... 104
Finding Energy and Time ................................................. 107
Creating Space to Speak and Act ........................................ 108

Summary of Findings ....................................................... 112

CHAPTER 5 DISCUSSION OF FINDINGS ................................... 114

The Nature of Nursing Practice to Preserve Children's Personal Integrity .................. 115
Understanding Threats to Children's Personal Integrity .................. 115
The Importance of Family .................................................. 116
Nurse-Child Relationships ............................................... 117
Attending to the Context ................................................... 118

Constraints on Nurses' Practice to Preserve Children's Personal Integrity .............. 119
Forgetting that Children are People ...................................... 119
The Lack of a Language to Convey Concerns ............................ 123

Nurses' Moral Agency in Enacting Practice to Preserve Children's Personal Integrity ........ 124
Personal Determinants of Moral Agency ................................ 126
Contextual Determinants of Nurses' Moral Agency ...................... 126

Summary ................................................................. 128

CHAPTER 6 SUMMARY, CONCLUSIONS, AND IMPLICATIONS .................. 129

Summary of the Study .................................................... 129
LIST OF TABLES

Treating children as people.................................................................................................................. 69
LIST OF FIGURES

Figure 1 Contrasting approaches to the concept of personal integrity ................................................. 9
Figure 2 Personal integrity in childhood ........................................................................................................ 14
Figure 3 Analytic framework: Nurses' work to preserve children's personal integrity .............................. 34
Figure 4 Discourses of the practice environment ......................................................................................... 56
Figure 5 Enactment of practice to treat children as people ....................................................................... 84
ACKNOWLEDGEMENTS

This thesis represents the efforts of many people, those who supported me academically and personally throughout this process.

To the participants: Thank you for giving of your time and of yourselves, generously and openly sharing your stories of nursing practice with me.

To my thesis committee: To Dr. Sally Thorne, for your unwavering optimism and support, and your patience and brilliance in advising; to Dr. Colleen Varcoe, your great mind and sensitivity enabled me to move forward at times when I couldn’t see the forest for the trees; and to Connie Canam, for your review of my proposal and thesis that moved my thinking and supported my efforts. Thank-you.

To all my friends and colleagues: To my many colleagues at BCIT who have gone this path before and who generously shared their time and knowledge. To my friend Lori Irwin, whose encouragement and thoughtfulness was a constant support throughout this process; to Rosella Jefferson, who constantly encouraged me, and facilitated the process in very practical ways. Thank-you.

Most of all, to my family; To my husband Dugald, who forever believes in me; to Stuart who has challenged my thinking about children and childhood, and has tolerated mommy’s endless hours at the computer; and to my sister Audrey, who graciously edited this work and who is a constant source of inspiration and support. Thank you.
CHAPTER 1 INTRODUCTION

Serious illness and hospitalization threaten children’s sense of self and alter their ability to act on their own behalf. Personal integrity, seen as the capacity to sustain a sense of self and to live in congruence with one’s own intentions and desires, is fundamental to personhood (Alderson, 1992, Babbitt, 1996, Liaschenko, 1995). Children, like all people, strive to develop and maintain personal integrity. Because nurses care for children at times when their personal integrity is threatened by illness and its treatment, they are in a position to act to preserve children’s sense of self and support their sense of personal agency. Nurses’ work in preserving children’s personal integrity when children are ill and hospitalized was the focus of this project.

In this research project, I elicited and interpreted pediatric nurses’ perceptions of the ways in which they come to know individual children and their understandings of how that knowledge shapes nursing practice. The participants in this study were pediatric nurses who care for seriously ill children. My intent in this project was, through interpreting data from interviews with participants, to describe these nurses’ understanding of children’s wishes and desires, and to articulate how this understanding is translated into nursing practice. As the project proceeded, I came to understand nursing work to preserve children’s personal integrity as all those activities that nurses engage in that attend to the human aspects of care. As this shift occurred, I focused more intently on the spectrum of factors that influence nurses’ practice as they attend to children as fully human beings. This chapter introduces the research project, briefly describing the background to the research problem and purpose, the questions that were addressed in the project, and my beliefs about the significance of this study.
Background to the Problem

This research project, including the foundational concept of personal integrity, evolved from my intrigue with the notion of children's voice. I believe that all persons, regardless of gender, race, or age have the right to have a voice\(^1\) -- to have their desires and intentions taken into consideration in matters concerning them. Children's right to have a voice in matters concerning them is enshrined in the United Nations Convention on the Rights of the Child (1989). Article 12 of this convention states,

\[\ldots\text{the child who is capable of forming his or her own views [has] the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.}\]

This international policy has raised awareness of children's position in decisions affecting them. However, critical questions remain -- questions that have implications for the practice of pediatric nursing. How do nurses decide what "due weight in accordance with the age and maturity of the child" means in any given situation? How does the environment shape children's expressions of thoughts and feelings? How does illness shape a child's capacity to express his or her own views?

The issue of children's right to have a voice becomes more problematic when we consider the inherent or imposed limitations of childhood. Children are a group whose voices are often suppressed or silenced within their families, communities and the world at large (Jenks, 1996; Mayall, 1996; Qvortrup, Bardy, Sgritta, & Winterberger, 1994). This silencing of voice is magnified when children are seriously ill and hospitalized. As a pediatric nurse, I am aware that, when children are ill and hospitalized, not only are their voices suppressed by the illness itself, their voices may be further silenced by their social and political positioning within the health care system.

\(^1\) 'Voice', used in this way, is a metaphor for a person's expression of intentions and desires in the context of relationships with others.
The concept of voice as a metaphor for a person's expression of intentions and desires has been developed by feminist theorists and researchers in their work to illuminate the relational nature of development, knowing, and being-in-the-world that is characteristic of women's lives, and in their call to legitimize women's ways of knowing and being in our society (Belenky, Clinchy, Goldberger, & Tarule, 1987; Brown & Gilligan, 1992; Gilligan, 1982/1993). Because the formation of intentions and desires is closely related to the idea of self, and because the expression of those intentions and desires is linked to the idea of agency², voice represents the interrelationship between a person's developing and evolving sense of self and that person's capacity and opportunity to express intentions and desires. A sense of self and a sense of personal agency are key components of personal integrity as it is conceptualized here³. The metaphor of voice highlights the complex and dynamic nature of personal integrity.

Feminist conceptualizations of the notion of voice were not originally developed with children in mind. In fact, children have rarely had a place in feminist agendas. Writing from a position as an early childhood educator, Goldstein (1998) summarizes the awkward relationship between feminisms and children: “Feminism, as it has evolved historically, is about women and women’s experiences. Feminism is not primarily about children. In fact, children can be seen as a wrench in the works of feminism”(p. 56). She points out that children become problematic when feminists claim to be concerned with inclusion and opportunity for all people. Tension exists between, on one hand, feminist concerns for children’s right to have a voice, and on the other hand, the traditional linking of women’s oppression to childbearing and childcare. This

² In this paper, the term “agency” refers to a person’s opportunity and capacity to initiate action on his or her own behalf. Without personal agency, an individual is unable to communicate desires and intentions to others and is unable to live in congruence with his/her own sense of self. In these situations, personal integrity is threatened.

³ While this perspective on personal integrity is somewhat simplistic, identifying two key components of personal integrity is a useful way in which to begin to understand this concept in the context of nursing practice with children. The concept of personal integrity is developed further in Chapter 2.
issue must be reconciled if children, as group whose voices are often suppressed or silenced, are to become a focus for nurses influenced by feminist philosophy.

Underlying the issue of preserving children's personal integrity is the question of whether or not children really are an oppressed group. Children share with women two characteristics that influence their voices and have consequences for personal integrity. First, women and children are members of social minority groups and consequently are deprived of certain rights and opportunities (Oakley, 1994). Their personal agency is affected by social and political positioning. For example, children are subject to adult conceptualizations of who they should be and how they ought to behave. Being or acting outside these expectations invites sanctions against them. Several theorists (Alderson, 1994; Jenks, 1996; James, Jenks, & Prout, 1998; Mayall, 1996) argue that adult understandings of childhood tend to be oppressive because they inhibit children's authentic expression of their intentions and desires, potentially suppressing and silencing their voices.

The second characteristic that influences children's voices is that, like women, children typically engage in relational ways of knowing and being (Alderson, 1993), patterns of learning and developing that are not traditionally legitimatized in contemporary society. In Chapter Two, I outline contrasting perspectives on the nature of human development and relationships that address this critical issue. Must the development of intentions and desires and a sense of self, occur independently and in isolation from others? Or, can the development of intentions and desires and a sense of self take place in intimate relationships with others?

The perspective that children experience oppression because of their social positioning, including the devaluing of relational ways of learning and knowing, leads to concern about the ways in which different perspectives on children and childhood held by adults influence

---

4 As it is used here, the word minority refers children's and women's position as a social rather than a demographic minority (Oakley, 1994).
children's personal integrity. Different perspectives on childhood will lead to different understandings of children's sense of self. Likewise, different perspectives on childhood will lead to different understandings of children's agency; including the ability of children to act in a rational manner consistent with their own intentions and desires. This perspective that children experience oppression, and that oppression threatens personal integrity leads to questioning many of prevailing assumptions about childhood that shape adult relationships with children, including nurses' relationships with children. These assumptions include beliefs about (a) who children are, (b) children's competence and rationality, (c) children's abilities to communicate, and, contingent on these first three, (d) the purpose and nature of child-adult relationships.

In the nursing literature, there is no research addressing how nurses' perceptions of children and childhood shape their interactions with children. If children's personal integrity, i.e. their sense of self and personal agency, is threatened both by their social positioning and by experiences of illness and hospitalization; and if nurses' beliefs about children and childhood shape and constrain the experiences of children; then nurses have the opportunity and responsibility to act to preserve children's personal integrity. Through an analysis of interviews with pediatric critical care nurses, this research project explored pediatric nurses' beliefs about children's personhood and identities, about children's capacity to express themselves, about the nature of nursing practice to preserve children's sense of self and enhance their agency, and in regard to the relational and contextual influences on that practice.

Purpose of the Study

The purpose of this study was to explore pediatric nurses' perceptions of preserving children's personal integrity when children are ill and hospitalized. In particular, though semi-structured interviews with pediatric nurses this study explored (a) these nurses' perceptions about children's opportunity and capacity to express intentions and desires, (b) their perceptions
of the threats to children’s personal integrity in the practice environment, and (c) the nature of their nursing practice to preserve children’s personal integrity.

Research Questions

The question addressed in this research study was: What is the nature of nurses’ practice to preserve children’s personal integrity?

Significance of the Study

Children are at great risk for injury to their sense of self and the silencing of their voices when they are ill and hospitalized. We have little empirical knowledge of threats to children’s personal integrity or of the practices nurses’ engage in to address these threats. The findings of this study contribute to knowledge about nurses’ beliefs and practices related to the preservation of children’s personal integrity.

If we accept that nurses have the responsibility to attend to children as fully human beings, then children’s personal integrity can be understood as an important element of children’s health. Expanding our knowledge about threats to children’s personal integrity and nursing practices that address these threats, may enhance the care of children when they are seriously ill and hospitalized. In addition to its relevance to nursing practice, this knowledge may inform decisions in nursing education and administration, as we seek to prepare nurses for practice and as we seek to create the conditions in which nurses can enact practice to preserve children’s personal integrity.

Assumptions

The following assumptions underlie this research and shaped my thinking throughout the research process:

1. Children, like all people, are unique individuals with a right to personal integrity.
   Children ought to have opportunity to be participants in their own lives and to have their desires and intentions taken into consideration in matters concerning them.
2. Nurses are concerned about children as fully human beings, and consequently have interest in any matters that influence children’s physical or psychological health.

Summary

This chapter was an introduction to this research project, including the background that led to its inception and the purpose of the study. In addition, in this chapter I delineated the assumptions that underlie this study. The remainder of this thesis is organized in the following way. In Chapter Two, I review relevant literature and present the analytic framework that guided the initial phases of this project. Chapter Three outlines the methodology I used in this study including the research design and ethical considerations and the limitations of the research. In Chapter Four I present my findings. Chapter Five is a discussion of some of the highlights of the research findings, considering these in light of the original analytic framework. Chapter Six presents a summary of this research project and the implications of the research findings for nursing practice, education and research.
CHAPTER 2 LITERATURE REVIEW

In this chapter, I explore empirical research and theoretical literature about children’s personal integrity; about threats to children’s sense of self and personal agency, particularly when children are ill and hospitalized; and about nurses’ work to preserve children’s personal integrity. In this process I examine literature from a variety of disciplines that has relevance to the research question and the beliefs in which that question is grounded.

In the first section of this review focuses on theoretical literature and empirical research related to personal integrity, including existing knowledge about threats to individuals’ sense of self and personal agency. Relevant to this is the exploration of the vulnerabilities of childhood, both natural and imposed, that make children at risk for injury to personal integrity. Specific threats to children’s personal integrity that arise in the context of illness and hospitalization are highlighted. In the second section of this chapter, I look at literature about nurse-client relationships in light of a focus on preserving children’s personal integrity.

The endpoint of my understanding prior to commencement of the study, and the state of my understanding as I embarked on the research process are consolidated as the analytic framework. Within the methodology of interpretive description, the analytic framework represents what I see as the linkages between the question I posed and the state of existing knowledge (Thorne, Reimer Kirkham, MacDonald-Emes, 1997). In the final section of this chapter, I present my analytic framework.

Personal Integrity

In the literature relevant to ‘children’s integrity’, this actual phrase is almost entirely absent; it is assumed that the child’s personality is too partial and fragmented to form an integrated whole (Alderson, 1994, p. 47).

As Alderson suggests, explicit discussion of the concept of personal integrity is absent from most literature about children and childhood, including nursing research and theoretical literature about the care of ill and hospitalized children. However, while the term ‘personal
integrity' may not appear in the literature about children, perspectives on children’s sense of self and personal agency are implicit in many discussions of children’s rights and needs, as well as in discussions of their autonomy and their vulnerabilities. In order to be clear about the relevance of the literature on these topics to this project, I begin by critically examining what I mean by the term “personal integrity”. I do this by drawing on the literature from nursing (Benner & Wrubel, 1989; Liaschenko, 1993, 1995a), women’s studies (Davion, 1991; Gilligan 1982/1993), sociology (Alderson, 1994), and philosophy (Babbitt, 1996; Taylor, 1985).

Perspectives on Personal Integrity

Alderson (1994) places notions of ‘a sense of self’ and ‘personal agency’ in a relational framework that is particularly useful when researching nurses’ understanding of their actions in preserving children’s personal integrity. Drawing on Gilligan’s (1982/1993) work on human development and relationships, Alderson outlines two dichotomous views of personal integrity: detached approaches and attached approaches. As illustrated in figure 1, these perspectives are dichotomous because they are grounded in contrasting values. This framework provides a useful vehicle to refine the concept of personal integrity to thinking about real life interactions between nurses and children.

![Diagram](image)

**Figure 1.** Contrasting approaches to the concept of personal integrity.
Detached Approaches to Personal Integrity

Detached approaches to personal integrity are those that value independence and avoid intimacy, reflecting what Alderson (1994) labels a masculine perspective. From this perspective, if an individual has integrity, that individual has developed a sense of self as an isolated and autonomous entity, an entity that is independent of events and relationships. Assuming this perspective, personal integrity means making choices and acting on those choices in isolation, free from the influence of others. For example, Taylor (1985) is using a detached approach to integrity when she writes, "... the person of integrity is not corrupt, she is autonomous and takes responsibility for her choices and actions. What she does or chooses is truly hers" (p. 109). Personal integrity is, from this perspective, a virtue that a person owns or lacks. It is not dependent on circumstances or relationships.

In building her description of the differences between attached and detached approaches to personal integrity, Alderson (1994) articulates a detached approach to personal integrity as it applies to children in this way:

If common assumptions about adult and child integrity were expressed in visual terms, these could be as two circles. The adult one would have a firm, thick circumference, signifying a clear sense of self as distinct from other, around an intricate, sharply delineated network pattern, illustrating the complex, unique relationships developed between sensation, memory, foresights and countless other factors. The child’s circle would be a dotted line, symbolizing the weak sense of self, as theorized, for example, by Freud and Piaget, around blank spaces and fuzzy pale shapes -- the fragmented rudimentary features of the emerging personality (p. 47).

Conventional wisdom holds that the younger the child, the less the child’s sense of self has been developed, and the less capable the child is of the rationality and autonomy needed to make good choices. This wisdom is reflected in the following statement from the work of Belenky, Clinchy, Goldberger, and Tarule (1986) in their description of silence in Women’s Ways of Knowing: “As is common with young children (Rosenberg, 1979), these women believe that the source of self-knowledge is lodged in others - not in the self” (p. 31). In this
statement, children are positioned as the example of silence, as the ones who are incomplete and largely undeveloped. This gives credence to metaphor of the circle with dotted lines, blank spaces, and fuzzy pale shapes that Alderson (1994) uses to describe a child’s sense of self. From a detached approach, if personal integrity is present, individuals must have the ability to make decisions autonomously and without consultation with others. Given this perspective, most children could be excluded from considerations of personal integrity.

Much of the discipline of nursing’s theoretical literature about topics such as promoting self-esteem in children (Sieving & Zirbel-Donish, 1990) and communicating with children (Wong, 1995) relies heavily on developmental theories. Traditional developmental theorists view ‘self’ as an autonomous agent. Consequently, they view personhood as an assemblage of traits such as self-esteem, control, and ego-centrism (Leonard, 1994). Self as an assemblage of traits leads to a detached understanding of the concept of personal integrity. In the following excerpt, Alderson (1994) emphasizes the isolationist and decontextual perspective on children’s developing sense of self depicted in these theories.

Freud’s work (1914) on the ‘narcissistic infant’ was continued by Piaget (1932) on the ‘egocentric child’, Erikson (1971) on the adolescent’s need for isolation (‘in order to become conscious of one’s ego, it is necessary to liberate oneself from the thought and will of others’) and Kohlberg (1981) on the goal of impersonal morality. Piaget based his theories of egocentrism on evidence from his mountain test, in which he asked children to point to a spot among three model mountains which could not be seen from another spot. He found them unable to do so until they were about seven years old, and from this he inferred that they were incapable of understanding another person’s point of view. If you believe that a child is not able to distinguish between the view held by herself and by others, then you are likely to assume that the child has little sense of personal identity, or of an integrity which could be invaded (p. 50).

The understanding of self on which developmental theories rely is one of self in binary opposition to others. Using Alderson’s (1993) metaphor of the personal integrity as a circle, these theories suggest that as self becomes more defined, the band around the circle becomes thicker and more solid and the contents become more defined.
Attached Approaches to Personal Integrity

In contrast to the detached approaches, Alderson (1993) maintains that an attached approach to personal integrity values intimacy and relationship, reflecting a feminine perspective. From this stance, personal integrity is considered to be developed and sustained in the context of relationships with others. Making choices and acting on those choices occurs in the context of relationships with others rather than in autonomous isolation. This perspective has implications for how we think about individuals’ sense of self and their agency.

Emphasizing the personal agency component of personal integrity, Liaschenko (1993) describes personal integrity as “... faithfulness or fidelity to one’s identity and values ... a matter of the continuity with having lived one’s life in a certain way” (p. 205). From this perspective, personal integrity depends upon an individual’s sense of wholeness or intactness and the ability and opportunity to live in congruence with that “whole” or “intact” self. Elsewhere, Liaschenko (1995a) has emphasized the contextual nature of personal agency, describing it as the ability of a person to initiate meaningful action on his or her own behalf, meaningful action that stems from both the individual and the social structures, institutions and relationships within which the person is situated.

Alderson’s (1994) definition of personal integrity echoes these themes of a sense of self and personal agency, with an even more explicit emphasis on the relational nature of agency than is evident in Liaschenko’s (1993, 1995a) work. She writes “(...) integrity (...) mean[s] an integrated, coherent and distinct personality, with a sense of self and of personal relations with others through which one’s own integrity can be enriched or threatened” (p. 51). Like Liaschenko, Alderson holds a view of the self as an integrated, intact, or whole entity. Alderson’s strong emphasis on relationality is congruent with feminist perspectives on human development and voice (Belenky, Clinchy, Goldberger, & Tarule, 1986; Gilligan, 1982/1993).
In advocating an attached approach to understanding children’s sense of self, James, Jenks, and Prout (1998) suggest reconceptualizing this static dichotomy between self and others as a fluid and dynamic process of establishing “identity-with and difference-from” (p. 202). They write:

Thus children’s, as anyone’s, journey into identity is about forging a relationship with the problem of order such that any definition of self and not-self can be sustained. Children learn who they are through interaction with (usually) the adult other. The spatiality of this journey has therefore been both cognitive and interactional, and intimately enmeshed with the persistent question of reflexivity (p. 203).

Like other theorists (Belenky et al., 1986; Brown & Gilligan, 1994) who believe that relationships shape and are shaped by one’s sense of self, James, Jenks, and Prout paint a picture of a journey, an ongoing dialectic in which self is continuously created and re-created in interaction with others and the environment.

Babbitt (1996) takes this emphasis on the relational nature of personal integrity one step further. Unlike Alderson’s (1994) perspective that personal integrity requires an integrated, coherent and distinct personality, Babbitt contends that a person’s sense of self is, in a very significant way, shaped by the social and political structures which determine the life a person may live. Integrity is not purely a matter of translating one’s inner desires and intentions into words or action. Babbitt writes:

Personal integrity has to do not primarily with any deeply held core beliefs or commitments but with possibilities for certain kinds of growth within a specific situation. And this has to do (...) with careful attention to the contingent values and circumstances upon which identities depend (p111).

From this perspective, both key elements of personal integrity -- a sense of self and personal agency -- are contingent on social structures and the moral values inherent in them.

Taken together, these perspectives point to the complex and dynamic nature of personal integrity and the importance of exploring multiple avenues when considering nurses’ practice in preserving children’s integrity. These avenues include attending to the children’s ‘self’ as a
responsive and evolving entity, considering the relational context in which children's voices are heard, and focusing on the social and political structures which shape who children are and how they can express themselves. My conceptualization of children's personal integrity is illustrated in Figure 2.

That personal integrity is relational and contingent was a critical and guiding principle in the research project. The research question for this project arose out of concerns about children's voice and personal integrity, particularly when children are ill and hospitalized, and the ways in which nurses act to preserve children's personal integrity. The assumptions underlying this concern are congruent with the attached model of personal integrity. A perspective on personal integrity that values intimacy, relationship, and shared decision-making had implications for sample selection, data collection and data analysis, topics that are discussed in Chapter 3.

![Figure 2. Personal integrity in childhood.](image)

**Age and Personal Integrity**

The statement in The United Nations Convention on the Rights of the Child that children have the right to express their opinions, and to have these opinions taken into account in matters affecting them (United Nations Children's Fund, 1987) has relevance to the concept of personal
integrity as conceptualized here. The translation of this right into practice, while assuming an attached approach to personal integrity is challenging.

At the heart of the issue of children’s rights to personal integrity lies the question of the degree to which children possess the same human rights that adults claim. The debate centers on discussions of rationality and autonomy, characteristics generally associated with adulthood. To what extent are children less capable than adults to participate in shaping their own lives?

Mayall (1996) makes a claim that protection and exclusion rather than participation and integration characterize children’s position in society. She draws attention to the many consequences of this positioning for children. She raises the following questions. What are the characteristics of children that make protection and exclusion justifiable orientations toward children? In what ways are children more vulnerable than adults to injury to their sense of self? Which of these vulnerabilities are inherent in childhood, and which are imposed on children by the political and social structures of this society?

Addressing similar issues, Lansdown (1994) explores the tension that exists between inherent and structural vulnerabilities in childhood. Inherently, children can be seen to be vulnerable to injury to their sense of self because of their physical, cognitive, and social immaturity. Young children are completely dependent on adults for survival. As they grow older, the degree of vulnerability decreases and they become increasingly capable of surviving independently. In this context, survival refers to more than physical existence, implying that a persons’ sense of self and personal agency are crucial to existence as a fully human being.

In reference to the structural vulnerabilities of childhood, Lansdown (1994) writes:

Children are also vulnerable because of their complete lack of political and economic power and their lack of civil rights in our society. This childhood derives from historical attitudes and presumptions about the nature of childhood. It is a social and political construct and not an inherent and inevitable consequence of childhood itself. Children have, in general, no access to money, no right to vote, no right to express an opinion or be taken seriously, no access to the courts, no rights ... to challenge decisions made on their behalf, no right to make choices about their education ... (p. 35).
What are the sources of these imposed or structural vulnerabilities of childhood? Theory, tradition, religion and cultural values are examples of the sources of beliefs about childhood.

On important influence on our western beliefs about childhood has been theory and research from the discipline of developmental psychology. Many of the beliefs about children’s vulnerabilities that shape adult orientations toward children in our society have their origins in the theories developed by the developmental psychology, particularly the work of Piaget and Kohlburg. These theorists, writing at a time when the social sciences were beginning to seek credibility through positivistic research frameworks, established stages of cognitive and moral development through which they believed children must successfully pass if they are become productive and well socialized adults. In particular, Piaget’s theory of cognitive development has had a great impact on pediatric nursing practice (Hauck, 1991; Knott, Beyer, Villarruel, Denyes, Erickson & Willard, 1994; Jost, 1996) and education. It has provided a foundation for much of the nursing research with children. Piaget’s theory delineates sequential steps of children’s emerging abilities to think and reason, beginning in infancy with the sensory-motor stage progressing through childhood to the development of adolescents’ capacity ability to think abstractly (Pulaski, 1980).

The fact that the research of Kohlberg and Piaget was conducted by men, with research subjects that were almost exclusively white, middle-class boys, has led to critique from researchers and theorists concerned with women’s issues (Belenky et al., 1986; Gilligan, 1982/1993). In particular, Gilligan’s questioning the equation of men’s development with human development has opened the door to new ways of understanding the development of girls and women. Pollack (1995) adds his voice to this critique of the ways in which traditional developmental psychology has influenced male development. He writes about the unconscious societal demands for a separation model of male growth and development. Pollock suggests that
a decontextual and isolationist perspective of human development injures boys as well as girls, although boys tend to experience this injury in a different way.

Another critique of the developmental theories that has relevance for this study, is the tendency of these theories to overlook the influence of the social and political context in which children live on their cognitive and moral development (Gilligan, 1982/1993, Ingleby, 1986). If, as feminist and other theorists are claiming, children’s development of a sense of self occurs in dynamic interaction within a social and political context, then research about development must go beyond acknowledging that the environment is one of many variables in development, to seeing it as a crucial determinant in the individual’s development of a sense of self and the their capacity to formulate and express thoughts and feelings.

Illness and Personal Integrity

Cancer Destroys
It ravaged my sense of Self.
My body betrayed me: it could no longer be trusted, especially since I had treated it so well.
Suddenly, every body part was suspect.
I was no longer whole.

Stephanie Byram

Stephanie Byram, a woman who lives with breast cancer and whose life expectancy is short, wrote this poem. As this poem makes explicit, serious illness has profoundly shaped Stephanie’s sense of self, altered what she believes about herself – particularly her body. This theme recurs through the literature on serious and critical illness. Most of this literature is about and by adults -- with a few exceptions.

In a recent study, Leidy and Haase (1999) explored the meaning of moderate to severe chronic obstructive pulmonary disease to older adults. They found that the meaning these

---

5 Stephanie has documented her experiences of living with breast cancer in a photo essay located at www.cmu.edu/cfu/design/people/sford/stephanie.
individuals attached to their disease was less related to symptoms and severity of the illness than to their ability to maintain a sense of personal integrity. Based on this research, Leidy and Haase describe personal integrity as “a sense of one’s individuality and wholeness as a human being” (p. 70). For these people, personal integrity was sustained through a sense of being effective, being able to participate meaningfully in life, and being connected with others.

In a philosophic exploration of children’s experience of terminal illness, Attig (1996) draws parallels between children’s experience of illness and adults’ experience of illness. He suggests that children, like adults, suffer an assault to their sense of self when their lives are interrupted by serious physical illness.

Loss of our physical integrity shakes our personal integrity. In and through our bodies we inhabit the world as the unique individuals we are. As ours do for us, children’s bodies enable them to experience the things and places around them, pursue interests in activities and projects, express themselves and engage with others, and orient themselves in space and time (p. 21).

These words echo Leidy and Haase’s understanding of personal integrity during severe illness, emphasizing the central determinants -- being able to participate meaningfully in life and being able to engage with other human beings.

The notion of orientation in space and time as an element of personal integrity, elements that are threatened during times of serious illness, arises in this work of Attig (1996) as well as in the writing of Kleinman (1988) and Liaschenko (1997). Describing his sense of disorientation during his own illness, sociologist Arthur Frank (1995) describes his experience as a “loss of the destination and map that had previously guided (...) life” (p. 1). If a child’s sense of self is a responsive and evolving entity, then circumstances of illness and hospitalization have the potential to influence that child’s sense of self. The physical, social and political structures determining the life the child can live have been dramatically altered. Consequently, the child’s sense of location in time and space can be altered.
In one of the few studies exploring critically ill children’s experiences, Carnevale (1997) described the assault to self that occurs when children are seriously ill. He found that critical illness begins a process of "unmaking of the self" which must be followed, if the child survives, by a period of months or years of "remaking of the self." These findings are similar to Frank’s (1995) perspective on the experience of serious illness. Unfortunately, few details of Carnavale’s study are available in the published literature and there is no published record of the analytic process that led him to describe the themes of "unmaking and remaking of the self". This is important and interesting work; work that calls for further research.

**Nurses’ Work in Preserving Children’s Personal Integrity**

As discussed earlier, to a great extent, personal integrity can be understood to be shaped in the context of relationships with other people. Given this perspective, it is in these relationships, or absence thereof, that personal integrity is developed and preserved or injured and destroyed. Because of their social positioning, all children are at risk for injury to or destruction of personal integrity. In addition, when children are seriously ill, the illness itself, its treatment and the experience of hospitalization pose great threats to the child’s identity and agency.

Nurses are in a position to have intimate and ongoing relationships with seriously ill children. Taking an attached perspective on personal integrity, we are led to believe that it is in the context of relationships with children that much of nurses’ work to preserve children’s personal integrity takes place. For this reason, relationships between nurses and children deserve exploration for the ways in which children’s personal integrity is preserved or injured in nurse-child relationships.

**Knowing the Child**

To this point I have argued that children’s sense of self and personal agency are predominantly shaped in the context of relationships with others. For children who are ill and
hospitalized, these relationships include relationships with nurses. From this perspective, nurse-child relationships are of paramount importance if nurses are come to understand particular children’s intentions and desires and to make decisions based on those understandings. For that reason, this section focuses on how nurses come to know children and on what that knowledge is.

Based on her research with nurses that care for adults, Liaschenko (1997) describes three distinct knowledges of human beings that nurses bring to their practice. These knowledges are (a) *case knowledge*, generalized understandings of a particular sort of person or type of disease; (b) *patient knowledge*, the understanding a particular patients’ patterns of response; and (c) *person knowledge*, knowledge of an individual “as a subject who acts with his or her own desires and intentions” (p. 26). This approach provides a useful framework for considering various perspectives on knowing children that exist in the theoretical and research literature.

Knowing the Case

To have case knowledge of a child is to understand the child as an example of a particular type of illness or state of being. “Case knowledge is the generalized knowledge of physiology, diagnosis, treatment possibilities, and statistical outcomes. No particular physical body, nor indeed any body, is required for a nurse to have case knowledge” (Liaschenko, 1997, p. 24, 25). Although Liaschenko emphasizes the biomedical nature of case knowledge, it seems to me that there are two main bodies of literature that inform nurses’ case knowledge as they work with children who are ill and hospitalized, only one of which can be described as biomedical. The first is nurses’ generalized knowledge of physiology and disease. The second body of literature has to do with generalized knowledge about how children grow and develop and how they respond to the events of their lives. As mentioned earlier, the discipline of developmental psychology has been a major contributor to this knowledge.
Nursing knowledge about the care of children with particular diseases, whether physical or psychological, has been closely linked the development of biomedical knowledge. Generalized knowledge about the physical effects of particular diseases and the implications of this knowledge for the care of children comprises much of the nursing literature about the care of ill and hospitalized children. This knowledge is theoretically well developed, and is largely based on medical research. It is the mainstay of pediatric nursing knowledge. Pediatric nursing textbooks, (Curley, Smith, & Moloney-Harmon, 1996; Wong, 1995) are organized to provide nurses with this knowledge. For example, theory and research on such topics as managing respiratory distress, shifts between the fluid compartments of the body (Hazinski, 1988), and the assessment and management of pain (McCain & Morwessel, 1995; Vessey, Carlson, & McGill, 1994) provide essential foundational knowledge that nurses bring to their nursing care of children.

The second body of literature that contributes to case knowledge about children is the plethora of research and theory about child development (Ahmann, 1994; Curley, Smith & Moloney-Harmon, 1996; Johnson, Jeppson, & Redburn, 1992; Wong, 1995). Particularly influential have been the guidelines for health professionals working with children in hospitals developed by the American Association for the Care of Children's Health (Johnson, Jeppson, & Redburn, 1992). Based on theories of growth and development and theories about the impact of illness and hospitalization on children, these guidelines are intended to bring concern for children's developmental needs into discussions of nursing practice with children.

Children's perceptions of and responses to hospital care are shaped by their age, developmental stage, and previous life experience. The care they receive in the hospital profoundly affects their ability to cope with this challenging experience. It is possible to plan and deliver services that support individual development, minimize the negative potential of a hospital experience, and promote growth and mastery (p. 203).

Authors of nursing textbooks and other clinical literature tend to rely on developmental perspectives of children as a primary basis for thinking about the creation and maintenance of
nurse-child relationships (Curley, Smith, & Moloney-Harmon, 1996; Wong, 1995) and as a guide for nursing practice related to meeting children's psychosocial needs (Denzholm & Fergusen, 1987; Erlen, 1987; Hauck, 1991; Wong, 1995). Children's perceptions of illness, hospitalization, pain, separation from parents, and death are explained from a perspective of social and cognitive developmental stages (Rushforth, 1996). Efforts to minimize the impact of these "psychosocial" problems revolve around mitigating the effects of these stressors through an understanding of how they impact children according to stage of cognitive and emotional development.

For example, cognitive developmental theories, particularly the work of Piaget, have been influential in shaping research that explores children's understanding of illness. In the early 1980's, three studies about children's understanding of illness were published in the medical journal *Pediatrics*. These studies, by Bibace and Walsh (1980), Perrin and Gerrity (1981), and Brewster (1982), created the foundation for much of the subsequent research in this area and have provided theoretical direction for health professionals working with children. Taken together, these studies demonstrated that children's understandings of illness followed a stage like process consistent with Piaget's theory of cognitive development, and that these understandings are largely unaffected by personal experience with illness. While influential, traditional theories of cognitive and social development have been criticized for their positivistic and patriarchal vision (Hauser & Jipson, 1998; James, Jenks, & Prout, 1998; Prout and James, 1997; Mayall, 1996). The results of studies that exploring children's understanding of illness have been critiqued on the basis of the sources of the data, the methods of data collection, and gaps in logical reasoning that may have led the researchers toward their predicted findings. For example, the data for these studies were collected using research tools developed from Piaget's theory of cognitive development, questions were asked (to white, middle-classed children) in an experimental setting, and the results interpreted according to Piaget's theory. Some scholars
believe this tautological reasoning demonstrates the researchers' commitment to a generalizable, decontextualized perspective on children's experience of illness, a perspective consistent with the Cartesian world view that underlies the work.

In keeping with this critique, Robinson (1987) questions the methodology of some of the earlier research based on developmental theories. She suggests that the verbal statements that are interpreted solely from a cognitive developmental perspective, and are used as the only source of data, represent only a small part of children's understanding of illness. Over reliance on these statements as a window to children's experience may lead to findings that do not capture the complexity and diversity of children's experiences nor the relational and contingent nature of their thinking.

In spite of their limitations, I believe that developmental perspectives on children and childhood provide an important contribution to nursing practice with children. Theories such as those of Piaget, and Kohlberg have enabled us to find ways of thinking about the vulnerabilities of childhood. Researchers using these theories began the work of exploring potentially harmful consequences of illness and hospitalization in childhood. Most importantly, these theories have served the health care professions by redirecting the focus of concern for children away from a purely biomedical perspective, legitimizing attention to the psychosocial needs of children.

Case knowledge, while not sufficient, is essential foundational knowledge for nurses concerned with preserving children's personal integrity. Danger exists in that, if taken alone, this generalized knowledge provides no specific information about individual children. By singularly relying on case knowledge, children are potentially objectified and stripped of (Liaschenko, 1997). From this perspective, nursing practice grounded only in case knowledge will not address the preservation of personal integrity. No particular child is needed to "know the case". Case knowledge provides no access to the intentions and desires of particular children. To begin to understand the intentions and desires of particular children, this
generalized knowledge must be contextualized in the care of specific children. This contextualized knowledge is the knowledge that Liaschenko describes as “knowing the patient”.

Knowing the Patient

“Knowledge of the patient requires the particularity of a body. When the generalized knowledge of physiology, pathology, diagnosis, and therapeutics becomes concrete in the body of the sick individual, case knowledge is transformed into patient knowledge” (Liaschenko, 1997, p. 26). Over the last decade, “knowing the patient” has emerged as a major concept in discussions of nurse-client relationships. Radwin (1996) conducted a review of six research studies published between 1990 and 1995 in which the concept of “knowing the patient” had emerged as a crucial component of decision making in nursing practice. Based on these studies, she concluded that “knowing the patient” refers to nurses’ acquisition of knowledge about particular patients; knowledge used as a basis for developing individualized interventions. Radwin describes three factors that determine the degree to which a nurse can know a patient: the nurse’s experience in caring for similar patients, the time spent with the particular patient, and the “sense of closeness” that develops between the nurse and patient. This summary seems a simplistic view of what the various researchers portrayed as knowing a patient. In seeking to generate a comprehensive understanding of the concept of knowing the patient, Radwin may have overlooked some of the richness portrayed by the concept in such studies as those by Jenny and Logan (1992) and Tanner, Benner, Chesla, and Gordon (1993).

In addition, because Radwin’s (1996) review was restricted to only those projects that specifically identified “knowing” as a theme in nurse-client relationships, studies that may have dealt with how nurses come to understand particular patients in more abstract and philosophical ways were excluded. For example, theoretical and research literature by Liaschenko (1993), Gadow (1980, 1989) and Raines (1993) examining how nurses come to know clients as
subjective, embodied human beings in difficult circumstances, were not included and may have added another dimension to this review.

One of the studies included in Radwin’s (1995) review of research addressing the concept of “knowing the patient” is Jenny and Logan’s (1992) research exploring nurses’ decision making in weaning adult patients from mechanical ventilation. These researchers were interested in examining the clinical knowledge that nurses use in this very specific context, particularly nurses’ practice in making judgments about the sequencing and pace in the process of weaning patients from mechanical ventilation. Jenny and Logan emphasize both the cognitive and relational components of decision making as well as the contextual nature of decision making in nursing practice. The cognitive component can be seen to represent the case knowledge that nurses bring to the decision-making processes. The relational component can be seen as the meshing of general knowledge with the knowledge of the particular patient. In this sense, “knowing the patient” is a cognitive and relational process, bringing together case and patient knowledges.

Since the publication of Radwin’s review (1996), Benner, Tanner, and Chesla (1996) have published the findings of their phenomenological study exploring nurses’ acquisition of clinical expertise. In that study, “knowing the patient” emerged as contributor to skilled clinical judgment. They identify five aspects of knowing a particular patient: (1) responses to therapeutic measures; (2) routines and habits; (3) coping resources; (4) physical capacities and endurance; and (5) body topology and characteristics. These themes are congruent with Liaschenko’s (1997) perspective that knowing a patient occurs at the place where a nurse’s generalized knowledge meets with the specific characteristics of a particular client.

*‘Weaning’ refers to the gradual reduction in the delivery of mechanical ventilation, enabling the patient to progressively take over breathing on their own. Generally, the goal of weaning is to discontinue mechanical ventilation and subsequently remove the patient’s endotracheal tube.*
How do nurses “transform case knowledge into patient knowledge” (Liaschenko, 1995a, p. 26) when the patient is a child? What does this have to do with preserving children’s personal integrity? Perhaps the clearest example of this is found in the theoretical and research literature about assessing children. Gadow (1995a) conceptualizes assessment as the process through which nurses bring general knowledge from a variety of sources into the care of particular patients. She wrote:

Clinical assessment [combines] knowledge from nursing theory and research with knowledge about a specific client. Clinical assessment, in short, creates a synthesis of general and particular knowledge (p. 25).

Knowing a child as a patient, that is, knowing the child’s patterns of responses and planning care in congruence with this knowledge provides a basis on which nurses may begin to make judgments about intentions and desires of particular children.

A second body of literature that illustrates bringing generalized knowledge to particular nurse-child relationships has to do with nursing practice to facilitate children’s coping and adaptation to illness and hospitalization. For example, in reviewing studies that explore children’s responses to medical procedures, LaMontagne (1993) concludes that children beliefs about control shape the way they experience stressful events. She concludes that interventions that “bolster personal control” such as giving information, using play, and teaching coping skills may ameliorate the distress caused by these events.

Family-centered care represents another important body of literature that is influential in the care of children who are ill and hospitalized. Discussions of family-centered care have been particularly dominant in the literature about relationship between nurses and children over the past decade (Ahmann, 1994, Johnson, Jeppson & Redburn, 1992, Purcell, 1993). Through this dialogue, parents and family members are brought into focus as vital contributors to the care of children.
Casey (1995) conducted a study in which she investigated the participation of parents in the care of hospitalized children. On the basis of her findings, she created a model describing four approaches by nurses to the involvement of children and their families. These were: permission, negotiation, exclusion, and assumption. These approaches are based on the extent to which the nurse engaged in communication with the child and family and the extent to which the nurse acted in a nurse-centered or family-centered manner. For example, a nurse who is communicative and nurse-centered will approach the family from a stance of permission, i.e. parents’ participation is allowed on the nurse’s terms. A nurse who communicates and is family-centered will approach the family from a stance of negotiation, where knowledge and expertise are shared and both parties participate in the decision making process.

While Casey’s (1995) model provides useful fodder for thought about variations in nurse-family relations, this study has significant logical gaps and methodological limitations. It is an example of a study where the child and family’s interests are assumed to be the same. In addition, methodological concerns include the fact that the data is gathered from indirect sources – through interviews with nurses, and through examining medical and nursing records about parents’ and children’s reasons for participation or non-participation in care. Information about the nature of the data and the process of data analysis is not explicitly addressed although it is evident that a quantitative approach to analysis was used. Casey’s work has been theoretically important in very influential in pediatric critical care nursing literature (Curley et al., 1996, Hazinski, 1991, Purcell, 1993).

As mentioned earlier, during the past decade, discussions of family-centered care have become dominant in discussions of pediatric nursing practice. While these discussions have enhanced the care of children in many ways, a new concern arises. This is a concern about whether or not children’s voices may be lost in our efforts to apply principles of family-centered
care to the care of particular children. Specifically, the relationship between family concerns and children’s concerns needs attention.

Knowing the Person

“In contrast to case and patient knowledge, to know an individual as a person is to know her or him as a subject who acts with her or his own desires and intentions” (Liaschenko, 1997, p. 26). What do we mean when we say we strive to know a child as a person? How is this different from patient knowledge?

Within the work of Benner, Tanner, and Chesla (1996) and Jenny and Logan (1992) is evidence of the concept that Liaschenko (1997) describes as “knowing the person”. Jenny and Logan write about nursing interventions intended to personalize care through collaboration with patients. What appears to distinguish Jenny and Logan’s “knowing the patient” from Liaschenko’s perspective on “knowing the person” is the emphasis on the subjective, embodied experience of the person. In Logan and Jenny’s work, the focus is largely on what the nurse does; specifically “perceiving/envisioning, communicating, self-presentation and showing concern” (p. 256). Liaschenko’s perspective on knowing the patient calls for an increasing complex understanding of a client’s life, attending to many dimensions of the individual and the values and beliefs that shape that person’s intentions and desires.

Gadow (1980) proposes a very philosophic orientation to understanding nurses’ knowledge of patients as persons. Working from the premise that autonomy and self-determination are the most fundamental human rights, and consequently are of great interest to nurses; Gadow proposes what she calls “existential advocacy” as the foundation of nursing practice.

The ideal which existential advocacy expresses is this: that individuals be assisted by nursing to authentically exercise their freedom of self-determination. By authentic is meant a way of reaching decisions which are truly one’s own -- decisions that express all that one believes important about oneself and the world, the entire complexity of one’s values (p. 84).
The emphasis on authenticity and autonomy in this excerpt may at first appear to be supporting a perspective that individuals are independent, autonomous beings, whose desires and intentions are shaped in isolation from the influence of others. As we have already seen, this position is problematic as we consider children's personal integrity. A relational and contingent perspective on the development of desires and intentions creates a much more complex picture than is implied by an image of a separate autonomous self. Children, because of their inexperience and immaturity, develop their understandings of the world and create and formulate wishes in context of interaction with others.

Although Gadow (1980) does not make an explicit distinction between perspectives on self as an autonomous, isolated entity and self as a relational and contingent entity, her description of the practice of existential advocacy points to the contribution of the relationship between nurses and clients to the development and expression of a patient's intentions and desires. She sees the practice of existential advocacy as a way in which nurses and clients can overcome the problems that arise from two related conflicts: the distinction between personal and professional involvement of the nurse, and the distinction between the lived body and the object body of the patient. Separating the personal from the professional and/or the lived body from the object body results in fragmentation of the individual, whether that individual is the nurse or the child. Fragmentation of the child results in the loss of personal integrity. Fragmentation of the nurse, as happens when a personal/professional dichotomy is created, prevents the nurse's participation in the nurse-child relationship as an entire self. When this happens, nurses' opportunities to bring ways of knowing such as intuitive and personal knowledge to the relationship are devalued.
Liaschenko (1997) suggests that “knowing the person” may, in some cases, lead to patterns of practice based purely on beyond rational, logical thinking to incorporate patterns of practice that are based largely on knowledge of a particular individual.

Knowing the person becomes critically important when the moral work of nursing practice includes acting for individuals, with the aim of helping them to maintain the integrity of their lives, to take up their lives after disease or injury, and to face progressive deterioration and death (p. 30).

Here, Liaschenko is referring to practices that can only take place when the nurse knows the personal as a subjective, embodied being.

In the nursing literature, there are few studies exploring how nurses come to know children as subjective, embodied human beings. In a phenomenological study exploring the meaning of engagement for nurses who care for children and their families, Burns (1994) used the analogy of “creating a safe passage” to describe nurses’ orientation to children and families when engagement is present. Burns’ use of the word ‘engagement’ is closely related to the concept of ‘knowing the person’. Drawing on the work of Paterson and Zderad (1988), Burns describes engagement as “a commitment to reach out and understand the patient that is directed toward nurturing human potential” (p. 211). Burns found that, for the nurses in her study, engagement meant acting as a guide in a shared journey with a child and family, hence “creating a safe passage”. While this interpretation makes intuitive sense, it is difficult to follow Burns’ line of reasoning in arriving at this finding. The lack of examples and quotations from the data raises questions about the relationship between the data and the findings. A second concern arising from Burns’ research is once again an uncritical amalgamation of the interests of the child and family members.

Woodgate (1998a, 1998b) conducted a grounded theory study to describe chronically ill adolescents’ perceptions of how nurses can best care for them. Among the themes that emerged are two themes that resonate with the notion of knowing the person: treat me like a person and
try to understand. She includes the following excerpt from one of the interviews in which an adolescent was expressing how she wants health professionals to show an interest in her life, not only in her illness. In response to questions about how a nurse should be with a patient, this adolescent comments:

Probably talk to them. Some nurses, not a lot, but when I go down to the ward, they don’t just come in and put on my mask on my face and leave, they ask you how are you doing and check your pulse or whatever, just communication really helps. (...) I think the best thing to say to me would be just to talk to me as a person, not as a patient and talk to me about whatever.

How do nurses come to know children in a subjective, embodied sense, in ways that counter objectification and preserve personal integrity? Research in this area is just beginning.

Throughout this section I have focused on the relational nature of nursing practice to preserve children’s personal integrity. My experience as a critical care nurse, and my discussion with colleagues, and my exploration of the literature have led me to suspect that not all work to preserve ill children’s personal integrity takes place in the context of nurse-child relationships. The political, social, economic and physical environments in which ill children live influences their developing sense of self and shapes their opportunities and capacities to express intentions and desires. The influence of the context of hospitalization and health care deserves consideration, examining the ways in which these environments preserve or injure children’s personal integrity. The impact of practice environment on children’s sense of self and personal agency as well as nurses’ work to shape the environment are important considerations.

Considering the Context

Many authors have described the potentially dehumanizing effects of health care contexts. Two issues emerge that have relevance to nursing practice in preservation of children’s personal integrity. The first is the extent to which health care contexts dehumanize and alienate children with resulting injury to children’s sense of self and personal agency. The second issue has to do with the extent to which the social and political context in which health
care is delivered shapes and constrains nurses’ capacities and opportunities to develop relationships in which children’s personal integrity can be preserved.

Studies exploring the context of pediatric nursing are rare. Research and theoretical literature tends to focus on the relationships between nurses and children and nurses and families, and less on the physical, social, economic and political environment in which these take place. Studies exploring the nature of nursing practice in critical care and emergency settings have begun to look at these issues in other settings (Rodney, 1988; Rodney & Starzomski, 1993; Varcoe, 1997; Walters, 1995).

Smith (1989) and Schroeder (1998) have written compelling accounts of their experiences in pediatric intensive care units. Each of these authors is a parent of a child who has been hospitalized in a PICU with a serious illness, Schroeder’s newborn daughter because of a severe congenital heart defect, and Smith’s four-year-old son following open-heart surgery. The claims of these authors suggest that the tendency to objectification of children within a pediatric intensive care unit can cause harm to children and families.

Schroeder (1998) writes of the powerlessness and the isolation she felt when a nurse failed to attend to the inconsistencies in communication and the fragmentation of care that characterized her daughter’s medical treatment.

An ICU nurse watched silently as a cardiologist examined Morgan. Following the examination, the cardiologist exclaimed, “This baby is dying, she should not be allowed to languish away in the nursery. It’s criminal.” Five minutes later, the cardiac surgeon examined Morgan and said all was fine. “We’ll proceed just as we have been doing.” I could not believe my ears, and looked at the nurse who listened to the two exchanges for help. She just looked away; mutely refusing to get involved (p.16).

Smith writes of a similar concern, of his perception that his son’s need for pain control was less important than the “paperwork” that nurses need to do. He wrote:

The last of the morphine is wearing off, so I ring for the nurse to come and give him some more medication. “I’m sorry,” says the nurse, “but I can only give him Demerol every six hours, and it is only four hours [now]. All I can give him now is Tylenol. I’ll come back in a few minutes with it.” He falls asleep waiting for her to return, sleeping
for over an hour. It is now close to two hours since he first indicated his discomfort. I go
to the nurses’ station to seek some assistance for my child and am told that someone will
be there shortly. Again we are left waiting as the pain grows steadily worse. I wonder
why there can be so much paper work to be done when my child is in such distress just
down the corridor (p. 145).

These accounts emphasize the importance of attending to the context in which children
experience illness and its treatment, and the ways in which nurses and other health care
professional shape that context.

**Analytic Framework**

The analytic framework for this research project was a synthesis of the stated purpose
and assumptions with my understanding of the current state of knowledge in relation to nurses
actions in preserving children’s personal integrity. It represented my thinking at the beginning
of this project. The visual depiction of the analytic framework (Figure 3) illustrates the key
ideas and the links between the ideas.

To summarize, nurses’ actions to preserve children’s personal integrity must be
mediated by knowledge of the child as a person and may be described as advocacy. Knowing
the child as more than a case or a patient (Liaschenko, 1997) creates a context in which nurses
can consider the implications of natural and imposed vulnerabilities of childhood in
combination with the threats posed by illness and hospitalization, to make judgments related to
preserving a child’s identity and agency.

This framework raised several guiding questions that shaped the initial interviews with
participants. These include: (a) What do these nurses believe about the children they care for?
(b) How do nurses come to ‘know’ children when children are sick and hospitalized? (c) What
are the nursing practices that address children’s personal integrity? (d) How does the social and
political context shape the opportunities of nurses to ‘know’ particular children and to act in
congruence with that knowledge?
Figure 3. Analytic framework: Nurses’ work to preserve children’s personal integrity

Definition of Terms

For the purposes of this study, the key terms are used in the following ways:

Child: a young human being, boy or girl; a person typically described as an infant, child or adolescent.

Personal integrity: the capacity to sustain a sense of self and personal agency.

Pediatric nurse: a registered nurse who primarily cares for children.

Serious illness: illness that interrupts a child’s life in a significant and prolonged way, and that has consequences for the child’s future.
Summary

In the process of engaged inquiry, as explained by Gadow (1995b), exists a risk of losing one’s way “back to the familiar” (p. 212). In one sense, the literature review and the analytic framework represent “the familiar”; the consolidation of my understanding of the state of knowledge about children’s personal integrity, their experiences of illness and hospitalization, and nurses’ work with children in the realm of preservation of personal integrity as I began this research project. Through the process of data collection and analysis, I went on a journey to different understandings than could have been precisely predicted from the map provided by the analytic framework. Chapters 3 and 4 are my account of that journey.
CHAPTER 3 METHODOLOGY

My goal in this research project was to hear and interpret nurses' stories of their work with children as they attend to the preservation of the personal integrity of children who are ill and hospitalized. My intentions in doing this were threefold. Firstly, I wanted to explore and make explicit the nature of nurses' practice in their work to preserve children's personal integrity when children are ill and hospitalized. Secondly, I intended to interpret these stories from a perspective that children's voices ought to be heard and their personal integrity preserved. Finally, I wanted to explore how the health care context shapes nurses' practices in preserving children's personal integrity. These intentions shaped choices about the methodology that guided this research.

The research process I undertook was neither theoretically or politically neutral. Decisions I made about the research question, the selection of participants, the process of data collection and the method of data analysis reflected my beliefs that children have a right to have a voice, that children are an oppressed group whose personal integrity is further threatened when the child is ill or hospitalized, and that the health care system serves to sustain children and nurses in particular positions that undermine children's personal integrity and nurses' opportunities to preserve children's personal integrity. The following sections describe the research process of this study.

Research Design

I selected interpretive description, a qualitative research methodology developed by Thorne, Kirkham, and MacDonald-Emes (1997), as a guide to the design of this study. Originally designed as an approach to exploring the health and illness experience of individuals, this methodology is based on the premises that nursing knowledge must reflect the complexity of people's lives as they live through health and illness experiences, and that it ought to bring understanding of patterns within this complexity to the context of caring for individual people.
As a methodology, interpretive description is grounded in an “interpretive orientation that acknowledges the constructed and contextual nature of much of the health-illness experience, yet also allows for shared realities” (p. 172).

I have applied the tenets of this methodology to an interpretation of nurses’ experience of practice rather than clients’ health-illness experiences. Nursing practice is contextualized and complex. As a result, making sense of the experiences of nurses and their clients can be difficult and challenging. As a research methodology, interpretive description provided a vehicle through which I could develop an understanding of nurses’ “shared realities” while attending to the complexity and diversity of practice.

Sample Selection

The data collection process consisted of in-depth, open-ended interviews with pediatric nurses who work in a hospital setting with seriously ill children. All the nurses work in the intensive care unit of a tertiary pediatric hospital.

Method of Sampling

Theoretical, purposive sampling guided the selection of participants for this study. The sample was composed of nine participants. All of the participants were Caucasian and female with a range of one and twenty-four years of nursing experience. The initial participants were selected based on recommendations by a nurse leader, the clinical nurse specialist in the nursing unit, familiar with the intent of this research. These were nurses identified by this nurse leader as known to be skilled in connecting with individual children in their day-to-day practice of nursing. The initial six participants were selected on this basis. As the process of data collection continued, and as the analysis process began, the focus of sampling shifted.

As I began to identify themes within the transcripts of the first interviews, I shifted the criteria for sampling. The analysis was pointing to significant issues in the practice context that shaped how and when nursing practice addressing children’s personal integrity could be
enacted. For this reason, the final three participants were selected from broader criteria, to include nurses with less nursing experience. These nurses were included because I believed that they may have different perspectives on the enactment of practices related to children's personal integrity.

In the initial interview I collected demographic data about each participant. This data included gender, educational background and years of nursing experience. The form for gathering demographic data is included in Appendix C.

Human Subjects Approval

Approval for research with human subjects was obtained prior to initiating this study. This approval was sought from the University of British Columbia's research ethics committee. In addition, because the nurses who were to be approached to participate in this study were employees of British Columbia's Children's Hospital (BCCH), approval for research was obtained from the BCCH research review committee prior to approaching potential participants and commencing data collection.

Rationale for Site Selection

Because I was seeking to examine nursing practice in relationship to preserving the personal integrity of ill and hospitalized children, I needed a hospital setting where nurses have opportunity to get to know individual children and where the children are seriously ill. For these reasons, I chose to recruit participants from the pediatric intensive care unit in a tertiary care pediatric hospital. The ages of the children cared for in this unit range from birth to approximately sixteen years old.

I met with the Patient Services Director in this unit to explain the project. Because this director was not necessarily best positioned to identify nurses most appropriate for participation in this study, I gained her approval to contact the clinical nurse specialist (CNS) on the unit to identify nurses for the study.
Procedure for Approaching Participants

I met with the CNS in the PICU to discuss potential participants for this study. Nurses who were identified as meeting the criteria were approached by the CNS in the PICU and provided with the information sheet (Appendix A). They were asked to contact me by phone if they wished to participate in the study. Initially, two nurses from the practice area were approached. Once the nurses contacted me and expressed their willingness to participate in this research project, we arranged a mutually convenient time and place to meet.

In my present position as an instructor in the pediatric nursing specialty program at a local technical institute, I have ongoing contact with many of the nurses on this unit. Some nurses working in this unit have been students in the courses I teach. Because of the potential intermixing of roles and the possibility of actual or perceived consequences for these students, these nurses were excluded from participation in this study.

Procedure for Informing Participants

At the initial interview, the research project was discussed and the participants were given opportunity to ask questions or raise concerns about the research. Once both the participant and I were satisfied that these questions and concerns had been sufficiently addressed, written consent from the participant was obtained (Appendix B). This consent form emphasized the voluntary nature of participation, the participant’s right to ask questions, access information, and to withdraw from the study at any point, and my commitment to maintain confidentiality of the participants.

Sample Size

I anticipated interviewing approximately 8 nurses for this research. Decisions about actual sample size were made during the research process. In order to build a sufficiently strong database, I interviewed nine nurses and conducted second interviews with five of these.
Data Collection

Data Sources

The primary source of data in this research project was interviews with nurses. The interviews were conducted over a period of three months. In addition, I kept field notes following each interview. In these field notes I noted my observations and impressions of the essence of each interview, the interview process, and recorded information provided by participants after taping had ended and the interview was formally complete. These field notes were one way in which I was able to attend to the contextual nature of communication and to promote a process of concurrent analysis.

The Interview Process

Interviews with nurses took place at a mutually convenient time and outside of the participants’ scheduled work time. The interviews took place either in a private office at the hospital or in the participants’ homes. Considerations in choosing the setting were convenience, privacy, the ability to tape record the interview, and the maintenance of confidentiality of the participants. All interviews were tape recorded and transcribed.

At the beginning of the initial interview, the consent forms were discussed and signed. The first interview with each participant began with the collection of demographic data (Appendix C). The length of the interviews ranged from 45 minutes to 2 hours.

The initial interviews were guided by questions grounded in the research question and informed by the analytic framework. Sample questions for the initial interview are outlined in Appendix D. As the project progressed, the questions used within the interview evolved, becoming more focused.

Data Analysis

Thorne, Kirkham and MacDonald-Emes (1997) recommend that data analysis techniques support inductive rather than deductive thinking. For this reason, the data analysis
process was informed by the analytic techniques of Lincoln and Guba (1985). Their approach to data analysis acknowledges that data are created within the interaction between researcher and participant, rather than being representations of an external reality.

Following each interview, the audiotape was transcribed verbatim by a professional transcriptionist. I checked the transcripts for accuracy, reread them several times, and listened to the tapes to get an overall sense of the initial data. Initially, notes about commonalties and differences were made in the margins and very tentative initial themes or categories were developed. In keeping with a process of constant comparison, my thinking constantly moved back and forth between the small units of data within the interviews and the tentative categories I was testing. In order to ensure that the analysis process was inductive and emergent, I needed to engage in thinking that not only sought convergence, but also looked for shades of difference. Once identified, data segments were compared to other data segments in the same category and data in other categories. In this stage of data analysis, as new incidents were assigned to the tentative categories, they were compared to the rules for inclusion that had been identified for that category. This process raised new questions and led to the refinement of the categories.

As the categories became more stable, integration of the categories began and I began to construct a framework to represent nurses’ perceptions of their work to preserve children’s personal integrity. Conflicts or discrepancies constantly emerged and the categories remained in a state of flux. Questions were continually posed to the data in order to try out emerging themes without prematurely reducing the data into those themes (Thorne, Kirkham & MacDonald-Emes, 1997). These questions came from discussions with colleagues and from sustaining careful attention to any sense of cognitive dissonance. Through this process I endeavored to sustain a dialectic relationship between the emerging themes and the data, privileging neither.

Throughout this stage of assigning data segments and testing themes and categories, I had difficulty establishing categories that were well enough delineated to inform the ongoing
analysis while avoiding reduction of what appeared to be very complex data. I needed to find another way of thinking that would enable me to establish themes while sustaining attention the complexities and tensions that were so rich in the data. At that point I drew on the work of D. E. Smith (1999) as a vehicle for seeing and writing about various discourses that shape the social environments in which people live and work. In reading the work of other researchers, specifically the writing of Varcoe (1997) in her ethnographic study of nurses’ practice in emergency settings, the use of discourse as a means of examining the broader influences that shape nurses work became more clear. In this thesis, I have come to think about the discourses of the pediatric intensive care unit as those “socially organized complexes of actions and material conditions” (Smith, p. 232) including the concepts, practices, language, and conversations that create the world where ill children are treated and nurses provide care. The contribution of Smith’s work and my use of discourse as a means of organizing thinking about the practice environment will become more evident in Chapter 4.

As the properties of the tentative categories became clearer, and as new incidents were assigned to the categories, they were constantly compared to the rules for inclusion that had been identified for that category. This process raised new questions and led to the refinement of the categories. As the categories became more stable, integration of the categories began and I began to construct a framework representing nurses’ actions to preserve children’s personal integrity.

In the later stages of analysis there was a moving back and forth between the categories and the emerging reconstruction of the data, identifying and testing relationships between categories. Because of the complexity of this process, I kept a journal to track and clarify thoughts and ideas about the data. As analysis proceeded, data from ongoing interviews challenged or confirmed the emerging reconstruction. As I found new ways of thinking about the data, I returned to earlier interviews to test those ideas.
This final stage of analysis involved the writing of the reconstructed meanings. Relationships were explicated, with support from the data provided to justify the categories and the integration of data. This work is located in Chapter 4.

Rigor

Several principles guided my thoughts as I considered the issue of rigor in this research process. These principles were drawn from the work of feminist researchers (Hall & Stevens, 1991; Lather, 1991), the philosophic orientation that has guided this study. The first of these principles relates to the nature of the knowledge that this research sought to create. From a postpositivist perspective, it is crucial to continually resist the temptation to reduce complex ideas and phenomena to ideas that can be easily understood. The second guiding principle has to do with the goal of this research project, particularly the critical goal of increasing awareness of nurses’ work in acting to preserve children’s personal integrity. I needed to continually reflect on some critical questions. In what way does this research process support nurses to increase their understanding of children’s personal integrity? How does it illuminate ways in which nurses act to preserve children’s personal integrity? Does the research process expose the social and political factors that threaten the personal integrity of children and limit nurse’s opportunities to act on behalf of children? In seeking to address similar issues, Lather described four issues to be considered when addressing rigor in research that claims to have a feminist, postpositivist orientation. These are triangulation, construct validity, face validity, and catalytic validity.

Triangulation

In Lather’s (1991) interpretation, triangulation involves the inclusion of multiple data sources, methods and theoretical schemes. Rather than creating a design that will produce data that tend to converge, the design must use methods that invite illumination of differences and introduce “counter patterns”. Seen in this way, triangulation has implications for decisions about
sources of data, the selection of participants, and the questions or probes used to seek additional information during interviews.

All the data in this research was obtained through interviews with the participants. In the interviews, and particularly while themes were being tested, I sought to hear the diversity in the participants accounts of their practice. In addition to probing for similarities to other data or fit with my construction, I attempted to attend to the differences and to represent these in the reconstruction. The fieldnotes and the journal that I kept assisted in the process of exploring the data from more than one perspective.

Construct Validity

Construct validity addresses the credibility of the emerging interpretation of the data -- the extent to which the interpretation is true to the data, utilizes various theoretical approaches, and sustains attention to the complexity of human experience.

Lather (1991) calls for a "systematic reflexivity which reveals how a priori theory has been changed by the logic of the data" (p. 67). To this end, I kept a journal throughout the process of data collection and analysis in order to track how the data challenged my a priori thinking (as represented by the analytic framework). However, as Lather emphasizes, systematic reflexivity is more than the tracking of logical shifts in thinking throughout the research process. It involves interrogating the emerging interpretation, looking for the influences of personal biases, sensing shades of premature grouping or coding, and guarding against the tendency to theoretical imposition. "A reflexive approach to research fosters integrative thinking, appreciation of the relativity of truth, awareness of theory as ideology, and willingness to make values explicit" (Hall & Stevens, 1991, p. 10). This research project challenged my views about issues such as why some nurses seem better able than others to attend to children's personhood, and raised questions about who is responsible for children's experiences of depersonalization
and objectification. Constant reminders to stay close and true to the data were an essential element of construct validity in this project.

A crucial consideration in this research project is the consideration of who I am as a researcher in relation to the participants and the data. Gadow (1995b) explores our quest to gain understanding through the metaphor of being on a journey. In particular, she challenges us to think about the type of knowledge that we wish to gain through practice and research: "... we can decide whether knowledge ought to accomplish for us distance from the world or engagement with it" (p. 211). Knowledge of the complexity of nurses' work with children, and the contextual and constructed nature of encounters between nurses and children, ought to provide ways for us to be engaged with the world. To fail to do so would be to reduce nurses' experience to essentialized understandings, knowledge that may distance us from the world where children live and essentialize the nature of nursing practice with children. Another element of construct validity is attending to the location of myself as researcher in relation to the participants and the data.

The class, race, culture and gender assumptions and beliefs and behaviors of the researcher her/himself must be placed within the frame of the picture that she/he paints ... Thus the researcher appears in these analyses not as an invisible, anonymous, disembodied voice of authority but as a real, historical individual with concrete, specific desires and interests -- and ones that are sometimes in tension with each other. (Harding, 1995, p. 121)

Engaging in reflexivity is one way to enhance the construct validity of this study. Another way is through working with others, particularly experienced researchers. Hall and Stevens (1991) comment that "collaborative working methods are a means of increasing reflexivity, accuracy, mutuality, and therefore the adequacy of feminist research" (p. 26). During the process of planning and conducting this research project, interaction with the members of the thesis committee enhanced the credibility of the study. Critical questioning of the process and findings was crucial and created a forum in which thoughts could be
consolidated or in which the foundations of particular conceptualizations began to dissolve.

Each person on the thesis committee for this project was an experienced researcher. Collaboration with these people increased the potential for coherent and meaningful research. Likewise, dialogue with other nurses who have interest in this field about the research process and the emerging findings, provided both support and challenge my thoughts as I proceeded with this project.

Face Validity

To what extent does the emerging interpretation “ring true” for the participants? This is a crucial question and the answers to it address the issue of face validity. In the second interview with each participant I discussed my emerging interpretation of the data with the participant, seeking the participant’s perspectives on how well the interpretations ‘fit’, paying particular attention to the ways in which it did not fit. The intent of this process was not necessarily to change the emerging construction, but rather to open up new points of dialogue and understanding for myself as researcher and for the participant.

Hall and Stevens (1991) address the issue of face validity by stating, “A feminist research report is credible when it presents such faithful interpretations of participants’ experiences that they are able to recognize them as their own” (p. 21). Other researchers (Lather, 1991; Sandelowski, 1993) have questioned whether credibility ought to rely on absolute congruence between the interpretations and the participants’ perspectives. Lather (1991) describes one limitation to the practice of checking with the participants about the extent to which the interpretations “ring true”. False consciousness, the tendency to believe that the dominant ways of thinking are one’s own, must be considered in making decisions about the extent to which the interpretations must be approved by each participant. At this point, the researcher’s master narrative must be scrutinized.
Face validity was also addressed by the practice of returning frequently to the data in the process of data analysis. Rereading the transcripts and listening to the tapes increased the likelihood of producing credible interpretations by the continual regrounding of my thinking in the data itself.

**Catalytic Validity**

Praxis oriented research strives for more than description of what is, or construction of theories about what might be. In praxis oriented research, the research process is as important as the product that emerges. Lather (1991) describes this aspect of credibility in this way, "Catalytic validity represents the degree to which the research process re-orient, focuses, and energizes participants toward knowing reality in order to transform it" (p. 68).

Throughout the research process, even as some of the participants struggled to find words to describe practices related to preserving children's personal integrity, many commented on how thinking and talking about children's sense of self and their agency increased their awareness and shaped their practice. Commenting on the effect of being involved in this study, one participant noted:

[I've] just been more aware. I think of [children’s personhood], in my practice as I work with the children down there. We've got a boy in right now with really bad burns, sixty percent burns, and I was thinking, what could we do to enhance his personhood while he’s here? So we were discussing that in the coffee room -- what we could do for him.

**Ethical Considerations**

Ethical considerations in this project ranged from practical issues of ensuring informed consent and confidentiality to the more theoretical issue of avoiding appropriation of the data into *a priori* understandings. Each of these considerations demanded that measures be built into the research process to ensure an ethically sound research process.
Informed Consent

Informed consent in this research project involved ensuring that the nurses' participation was voluntary and that they were informed about research process and purpose. In order to ensure that participation was voluntary and to minimize the possibility of coercion, the clinical nurse specialist (CNS) on the nursing unit in which the participants of this study all work conducted initial contact with potential participants. I had discussions with the CNS about the process for approaching participants and about the necessity of voluntary and willing participation.

Potential participants that were interested in being part of this study were asked to contact me by phone. In that initial conversation the voluntary nature of participation was once again emphasized and the participants were informed that they could choose to withdraw from participating in the study at any time. Each participant was provided with both a verbal and written (Appendix A) explanation of the study, including its purposes, the research process and the proposed dissemination of results. Before commencing the initial interview, participants were asked to sign a consent form (Appendix B), indicating their understanding of this project and their willingness to participate.

Confidentiality

As with all qualitative studies, confidentiality was a crucial ethical concern in this study. Ramos (1989) suggests that confidentiality can be particularly difficult to maintain when the sample size is small and the descriptions of the data may point to particular individuals. Efforts to maintain confidentiality in this study included practical efforts to prevent unintended access to the tapes, transcripts and preliminary analysis. Specifically, the following measures were taken to maximize confidentiality.
1. Each interview was conducted in a private setting – either in an office at the hospital or in the participants’ home. No one other than myself had access to the names of the participants.

2. All tapes and transcripts were kept in a locked cabinet.

3. Names used in the reporting of results are pseudonyms. Participants were given a code name, which appeared on the transcripts. Participants are not identified in any way in this written report.

4. Participants were given opportunity to specifically identify stories that they wished to remain undocumented although none of the participants had concerns about this. The specific details of one of the stories were altered to protect the identities of those involved.

Avoiding Appropriation

From my first moment with children, I knew that their experiences so far exceeded any adult categorizations and descriptions and that our efforts to do so were comical in their best incarnation, cruel and abusive in their worst (Bailey, 1998, p. 45).

Throughout this project, I was cognizant of a temptation to appropriate children’s or nurses’ experiences into categorizations. The problem of reductionism has been already partially addressed in the earlier section on construct validity. Appropriation is a form of reductionism that is of particular concern to feminist researchers. Opie (1992) locates the problem of appropriation in the realm of power relations between the researched and the researcher. One goal of feminist research is to undermine domination of one group by another. Appropriation, seen as a practice in which the experiences and words of the participants are used to support a particular perspective or ideological stance, is an exercise in domination. In the following excerpt, Opie articulates the importance of attending to this issue.

Although feminist researchers have questioned many aspects of the construction and management of [researcher--researched] relationships within mainstream social science research, there is a need for further, more reflexive analysis to avoid textual
appropriation of the researched; and to focus attention on difference as a means of more fully representing the complexities of the social world. Avoiding appropriation and highlighting difference are crucial means by which a research may empower participants in her research (p. 53).

Avoiding appropriation, attending to difference are processes of ethical significance in feminist research such as this study.

**Limitations of the Study**

One of the limitations of this study is the reliance on one type of data – data from interviews with the participants. Although the interview process provided rich and diverse data, in a study of a larger scale, additional data sources might be used. This would strengthen the credibility of the findings. For example, participant observation might provide new dimensions for thinking about and interpreting nurses’ actions in preserving the personal integrity of children. Published anecdotal accounts, poetry, and short stories by nurses and parents about children’s experiences of serious illness and hospitalization may be another useful source of data.

The complexity of this study is influenced by the fact that this is my first research project. Experienced researchers have described the advanced skills required in conducting interviews and engaging in methods of qualitative research (May, 1989; Paterson, 1994; Thorne, 1991). These are skills I began to develop in the process of this research. As I gained experience in interviewing and as the analysis process began, the interviews tended to become more focused and the data more detailed and rich.

The scope of this study limits the exploration of nurses’ work to preserve children’s personal integrity to the perspectives of nurses. Children’s voices are represented only in the stories of the participants. Children and their families have no direct opportunity to express their thoughts and opinions about children’s personal integrity in times of illness and hospitalization. This may be a consideration for future research.
Summary

In this section, I have described the design of this research project. Interpretive description was the methodology used in this study. In addition, feminist thinking guided many of my decisions such as the research question, the methods of data collection and ethical issues. In the Chapter 4, I document my findings in this study, endeavor to portray my interpretation of the participants' practice to preserve children's personal integrity.
CHAPTER 4  FINDINGS

The participants in this study spoke with passion about their nursing practice with children and their commitment to provide nursing care that attends to the personhood and agency of children. They recounted many stories of their practice with individual children of many ages and with a variety of serious health concerns. In addition, they spoke with candor about the challenges they face in enacting practice that attends to children’s personal integrity.

In the following sections I describe what I came to understand about the participants’ nursing practice in attending to children’s personal integrity. In addition, where possible I attempt to provide a map of how I arrived at these understandings, documenting the questions that the participants accounts posed to my thinking and the consequent shifts in direction my thinking underwent. I begin with a description of the participants of this study and then proceed to re-examining the foundational concept of personal integrity as I heard it in the participants’ accounts of their practice.

Description of the Participants

Nine nurses participated in this study. Education among these participants varied -- two had nursing diplomas, four had baccalaureate degrees, and two had graduate level education. Most of the participants also had completed post-basic specialization in pediatric critical care nursing. Clinical experience among the participants also varied; with from one to twenty-four years of nursing experience. Many of the participants had cared for children in other pediatric health care settings, including oncology, post-anesthetic, and neonatal intensive care. On a personal level, only one of participants was a parent. Although not intentional, all of the participants in this study were female. Because of this, all indications of participant gender in this report are feminine.
Understanding Personal Integrity

I came the data collection and analysis processes of this project with a perspective that personal integrity is a sense wholeness or intactness that is shaped by each person's sense of self and their sense of personal agency (see Figure 2, p. 14). In addition, I held the perspective that personal integrity is both relational and contingent. It is in within relationships with others that an individual's sense of self is created and re-created. Likewise, individual's sense of self and the abilities to act on their own behalf are determined by both relationships and by the multiple contingencies of life. For the children who are portrayed in the data of this study, one of those contingencies is their experience of serious illness and hospitalization.

The Language

As I examined the transcripts, a variety of ways in which the participants spoke of ideas related to children's personal integrity came to light. Many of these had to do with the nurse's responsibility to attend to the child as a whole person. In my original conceptualizations, I hadn't thought about the language we use, but it was in that language that I found a great deal of evidence of the participants' beliefs about children's personal integrity. One participant spoke of the importance of attending to children's emotional and psychological safety. Another spoke of nurses' responsibility to attend to the child in a way the "makes sure that he's going to recover and an intact person." While at times we struggled to find words and phases to describe these practices, the participants accounts confirmed for me that a perspective on the personal integrity is a sense of wholeness or intactness as a person is valued by these nurses and guides much of their practice in this domain.

Personal Integrity is Both Relational and Contextual

In the earliest interviews for this project, I focused on the relational aspects of children's personal integrity, particularly the participants' accounts of how they came to 'know' individual children or how they connected with particular children. Although this provided rich
information about nurses' beliefs about children, in order to make sense of their accounts of practice I needed to expand my vision to think more about the contextual and contingent component of personal integrity. Although I had begun to explore this notion theoretically, it was the participants' accounts that led me to ask new questions about how the contingencies of children's lives shaped children's personal integrity and how the contingencies of nurses' work shaped their practice to preserve children's personal integrity.

In the early stages of analysis, I was overwhelmed by the array of contextual factors that apparently shaped and constrained the participants' practice. In spite of a desire to provide care that recognizes and supports personhood and enhances the agency of children, all the participants recounted ways in which their practice is constrained by factors within the practice environment of the Pediatric Intensive Care Unit (PICU). Although all the participants believed that attending to children's personhood is an important element of nursing work; sometimes other interests competed for priority in action. In order to make sense of some of the complexities within the participants' accounts of their practice, I found myself focusing on the environment in which practice is enacted. I began to explore how the participants described their practice environment and to think about how that environment shaped their work with and for children.

For this reason, the first section of this chapter focuses on the practice environment as I discerned it in the participants' accounts of their practice. Specifically, I explore some of the patterns of practice and patterns of communication that compose the social, political and physical environment of the PICU -- the place where children experience illness and treatment and where nurses practice to facilitate the well being of these children. In this process, I have come to understand three distinct discourses that shape nurses' practice as they endeavor to attend to children as whole persons. The first two of these, which I have labeled the dominant
discourses, have a position of relative privilege in policy and practice. I have named these discourses: (a) saving/fixing children’s bodies, and (b) facilitating efficient unit functioning.

A third and separate discourse I perceive in the practice environment has to do with nurses’ work to attend to threats to children’s sense of self, work that attends to the wholeness or intactness of children as people. I have labeled this discourse *treating children as people*. I describe this as a *secondary* discourse because, although acknowledged as important, practices within this discourse can be considered dispensable whereas practices within the dominant discourses are not. The participants’ accounts of their practice illustrate how this secondary discourse has varying relationships to the dominant discourses – at times shaping and informing practices within the dominant discourses; other times competing or conflicting with practices of the dominant discourses; and at yet other times, existing as practices that are separate from practices within the dominant discourses. My conceptualization of the discourses of the practice environment and of the practices within each of the discourses is illustrated in Figure 4.

**Discourses of the Practice Environment**

My understanding of the discourses within the intensive care unit where the participants in this study all work is influenced by my focus on nurses’ practice to preserve children’s personal integrity as outlined in Chapter 1. This perspective brought my attention to thinking about those practice issues that influence how nurses can and do attend to children as fully human beings. The participants’ accounts of these practices led me to an increasing complex understanding of the influences on nursing practice. One of the ways I have made sense of this complexity by examining the various discourses of the practice environment that I could discern within the participants’ accounts. The following sections summarize my understanding of the dominant and secondary discourses within the practice environment of the PICU.
Discourses of the Practice Environment

**Dominant discourses:**
- Saving/fixing children’s bodies
- Facilitating efficient unit functioning

**Secondary discourse:**
- Treating children as people

**Predominant patterns of practice:**
- Vigilantly monitoring children’s bodies
- Providing technically excellent care
- Using resources efficiently

**Secondary patterns of practice:**
- Engaging in relationships with children
- Creating tangible reminders of the presence of children
- Coordinating care
- Enhancing children’s control
- Supporting connection with family members
- Minimizing and relieving pain
- Meditating painful and invasive events

---

Figure 4. Discourses of the Practice Environment

**Dominant Discourses: Attending to the Body and the System**

There's definitely times where it is so busy that all you can do is get the basic done (...) maintain the stability of your patient and improve the health of your patient so that that patient can be discharged out to open a bed to admit somebody new in.

“All you can do is get the basic done.” This comment and the participant’s description of “the basic” that follows, summarize what I see as the dominant discourses of the practice environment of the PICU. Nurses’ crucial work revolves around two activities: getting children better, and moving them out of the unit. These constitute what I have come to understand as the two dominant discourses of the participants’ practice environment: saving/fixing children’s bodies and facilitating efficient unit functioning. In the following pages I attempt to paint a picture of the practice environment as I heard it in the participants’ stories. I focus particularly
on the participants’ descriptions of their nursing practice and consider how these practices are shaped by the dominant discourses of the environment.

Saving/Fixing Children’s Bodies

Pediatric intensive care units are designed to provide highly skilled, technologically advanced medical and nursing care to children who are seriously ill or injured. This is the reason for their existence. The very nature and purpose of the intensive care unit — its physical layout, the focus on technology, and the way nursing work is organized — predispose a focus on saving and/or fixing children’s physical bodies. The discourse of saving/fixing children’s bodies is evident in the participants’ accounts of practice. In this section, I want to focus on the patterns of communication and the patterns of nursing practice that can be understood as part of that discourse.

In regard to patterns of communication, the focus on children’s physical bodies is evident in the words and phrases that nurses and other health professionals use to talk about children and their treatment. Words and phrases that bring focus to children’s bodies, illness and injury permeate descriptions of practice. Speaking of way that language is used within the unit, one participant commented:

People will go by and say, “When the heart coming?” “When's the lap due?” “Do you need help with your set up for the kidney transplant?” ... [The children] consist of little pieces of anatomy at that point.

Another participant pointed to the problems associated with using language in this way. She explained, “We do this thing that we were always taught never to do, don't call them ‘the back’, don’t call them ‘the cranium’, but we do that.”

More subtly, the priority of saving/fixing children’s bodies is evident in the words and phrases that the participants used as they described their own nursing practice to me. For example, when describing a particular child, the story generally began with a description of the child’s illness or injury. Early in their description of children, the participants frequently made
comments such as, "I had to take care of the diaphragmatic hernia that's on the ECLS program" or “He's a post op cardiac.”

This use of language does not imply that the participants see the children only as diagnoses and procedures. Rather, as two of the participants pointed out, this kind of language serves a purpose – simple efficiency of communication.

It’s done for convenience and [sometimes] you don't know the child's name. You'd be saying all the time, “Oh Carly, that head injury”, “Carly, the heart”, “When is Carly the heart coming?” Nobody would know who you meant.

That this language is an important tool in maintaining efficiency underscores the priorities of work of the pediatric intensive care unit – saving/fixing children’s bodies and facilitating efficient system functioning.

In thinking about the patterns of nursing practice within this discourse of saving/fixing children’s bodies, two themes are apparent. These are patterns of practice related to: (a) vigilantly monitoring children’s bodies and (b) providing technically excellent care. Much of priority nursing work falls within these patterns of practice.

Vigilantly monitoring children’s bodies. One of the primary responsibilities of nurses in the PICU is to carefully assess and to sustain continual monitoring of children’s physical conditions. It is upon this assessment that visible nursing care – the provisions of technically excellent care -- is based. The following excerpt from one of the transcripts illustrates this focus on monitoring. The participant is describing her work and how she integrates attention to children as individuals in her process of assessment.

The first thing is to check him over, top to tail, check out all their systems, check all the safety equipment at the bedside. I have a routine; I have a ritual I go through first thing in the morning. Part of that ritual of when I'm checking their systems, when I'm checking his cardiovascular system or his respiratory system, is to also [check the] neurological. How awake are they? How responsive are they? That gives me guidance right away.
There was general agreement among the participants that without accurate, ongoing physical assessment, children’s health is compromised. One participant illustrated the importance of accomplishing this goal, regardless of how the child or family may perceive it. She said:

[The assessments] that you need to do are often frightening, invasive or nasty. Even something as simple as [a child] who has had a craniotomy -- you're waking them up every hour and making them go through neurological checks. You've got to do it. If you miss anything it would be horrific, like [if] they suddenly [deteriorated] because you had missed pupil changes. But I know that for both the parent and for that child it is really irritating because they just want to sleep.

The participants’ accounts demonstrated that skilled assessment, as the foundation of monitoring children’s physical conditions and the provision of technically excellent care, and is a crucial and valued skill in the pediatric intensive care unit. To these nurses, this is the most basic and most important part of their work. The participants recounted some very sophisticated judgements they made as they monitored children’s physical function. Below, one participant spoke of caring of a severely burned seven-year-old boy and her process of assessing of this child’s nutritional state. In this account she described some of the multiple factors that must be taken into consideration in making judgments about this aspect of the child’s care.

He's not getting a lot of nutrition because he can't tolerate [enteral] feeds. He's getting [total parental nutrition] which isn't really adequate for the metabolic needs of a burn. You are trying to minimize [the level of activity] so that hopefully he gets enough caloric intake to heal.

Clinical judgements, based on the integration of knowledge about particular health conditions and treatment, continued with assessment of a particular child’s responses to illness and treatment were seen as crucial in meeting this priority in the pediatric intensive care unit – to save and fix children’s physical bodies.

Providing technically excellent care. In addition to skilled monitoring of children’s physical conditions, the priority of providing technically excellent care was evident in the participants’ accounts of practice. Again and again, the participants described the technical work they do. As well, in general, the more ill the child and the busier the unit, the more technical the
focus of the work. Technical excellence and the knowledge that supports it are highly valued in
the practice environment. All of the participants in this study agreed that when children are very
ill, the provision of skilled technical care in conjunction with astute assessment is a crucial
responsibility of nurses. The following excerpt from one of the transcripts emphasizes these
priorities and their relationship to issues related to less pressing concerns.

We will get as personal as we can but our main goal is to keep that child safe, period.
Pull them through this crisis ...Once we've done that or the process part is taken care of
we'll go on and do the fluffy stuff.

While agreeing that a focus on children's bodies is a crucial element of their work,
several of the participants described how the emphasis on the priority of saving/fixing children’s
bodies sometimes distracts them from thinking about children as human beings. Some of the
participants specifically blamed this distraction on physicians and the biomedical focus they
bring to the care of children. To these participants, the discourse of saving/fixing children’s
bodies was epitomized in the practice of some physicians. They described a mechanistic and
dehumanized environment created by these physicians' singular focus on physical bodies. This
problem is seen at times as embodied in the intensive care physicians' medical practice. Below,
one participant outlines her perspective on this issue. However, the contradictions that
characterize nursing (and perhaps medical) practice become evident as the participant finds
herself wavering between blaming the medical profession yet agreeing with priorities of medical
care.

I always think of medicine as 'fix it' -- to do with the body. And nursing deals with the
person and the aftermath. Medicine doesn't always get that, they think that what they do
is the most important. And I agree, without medicine there's not going to be a person.
But I think there's a lot of conflict for nursing when we get stuck between the physician
wanting to go ahead and do a procedure and our need to make sure that this child is
addressed.
Later in the same interview the participant restated her perspective that in the practice of medicine, children can be objectified. She contrasts this with nurses’ responsibility to create a more humane environment, one that attends to children as fully human beings.

I find it really frustrating to work with medicine who doesn’t understand. (...) They go to do a bronchoscopy -- they’re looking down an airway. A bronchoscopy on a child who is prepared for it, who is sedated appropriately, and who has some input and some control and somebody who is there supporting them, it’s a very different experience for the child than just being an airway. And I find that medicine doesn’t always understand that. They’re there to do a procedure and do it quickly.

Another participant had a somewhat different perspective on the physicians’ rather singular focus on children’s bodies. This nurse believed that for physicians to do the job they need to do -- the job that nurses and families want them to do -- they must stay focused on children as physical beings. Overemphasis on children as people at risk for injury to their sense of self may immobilize physicians in their work.

I mean you’re talking about kids who are so devastating ill, a lot of the time the focus is on the illness. But the, the virtue behind it is quite pure because it’s an effort to make the child better, not just to take the illness away. [The physicians] are actually trying to make that particular child better not just kill this disease or fix this heart. (...) But that’s not our focus (...) shouldn’t be ours.

None of the participants debated the overall importance of monitoring children’s physical conditions or of providing technically excellent nursing care. However, their accounts revealed tensions that can arise when practices within this dominant discourse of saving/fixing children’s bodies were indispensable while practices attend to children’s personhood were optional. In addition, as I show later, the participants had insight into the ways in which prioritizing practices of monitoring children’s bodies and providing technically excellent care over practices that address children as individuals can create an atmosphere that threatens children’s sense wholeness or intactness and may suppress their voices.
Facilitating Efficient Unit Functioning

In addition to focusing on saving/fixing children’s bodies, the participants’ descriptions of practice reflected their understanding that they are expected to facilitate smooth and efficient functioning of the unit. This included taking on extra work to accommodate busy periods, being cognizant of budget constraints, and being diligent in getting children out of the unit as quickly as possible.

The participants described how, in the PICU, each nurse is assigned one or two children for whom he/she is responsible during the shift. Generally, the overall stability of the child, and particularly, whether or not the child is intubated, determines whether a particular child is “doubled” with another child. Consequently, workload for nurses is primarily based on the amount of technical care required. The child’s physical condition and the nature of treatment largely shape the amount of technical work. According to the participants, so-called “psychosocial needs” are rarely, if ever, factored into nurses’ work in this practice environment.

Assisting in keeping costs, particularly staffing costs, controlled is a component of nurses’ work to facilitate efficient unit functioning. Justification of the need for additional staff in order to attend to children as individual human beings does not carry the same weight as an argument for increased staffing in order to attend to the physical care of the children. While several participants commented how a lack of designated time for attending to children’s psychosocial or interpersonal needs shapes their practice, only one participant directly addressed the way fiscal issues affect practice. In the following excerpt she illustrates this how fiscal concerns play out in day-to-day practice.

I think there's an economic thing that definitely influences what we can do in maintaining the integrity of a child. If we have a situation where we know we've got an admission coming [and] we don’t have a nurse, they're reluctant to call in overtime. [So] we have to get the child that we have out-- upstairs, transferred upstairs. And then, you don't always have the time to explain to this child about where he's going to go to, give him choices and take the time to involve him or her in what's going on. It is more; you just start doing the bits and pieces that need to be done, the technical stuff. Get that kid
upstairs. (...) Get ready to admit the second child. (...) So I think that the sort of running of the unit and the whole economics of staffing influences our ability to take the time to really do the job right.

This participant delineated her beliefs about the relationship of practice to preserve children's personal integrity to practices related to facilitating efficient unit functioning when she commented, “Having the time to actually look after the child and make sure that he's going to recover as a person intact and not be scarred, that's definitely low on the food chain.”

In a similar way, the use of space on the unit is justified according to how children may be cared for efficiently, rather than how children's sense of self, dignity and agency might be preserved. One participant described a fifteen-year-old boy who was hospitalized in the intensive care unit for a prolonged period. This adolescent was frequently moved to different places in the unit depending on the configuration of patients in the unit at any particular time. He resented the lack of privacy and the frequent intrusions into his space.

I think part of it that he was moved a number of times and they would be, I mean sometimes he was moved to the acute area for reasons that were obvious and then other times he'd be in an isolation room where he'd have this wonderful privacy. But if somebody came in and we needed that isolation room, he had his whole bedroom moved to a spot that was a traffic area where curtains were the only privacy.

In order to be ready to admit new children or to attend to whatever crisis might lie ahead, the participants were expected to sustain the rhythm of admitting, fixing and discharging children to other units in the hospital as quickly as possible. This topic came up frequently as the participants described their practice. One participant emphasized this pressure to keep children on a rapid path to discharge when she used to analogy of the PICU as a ‘factory’.

Do nurses have time to devote to addressing children’s personhood or are practices related to preserving children’s integrity squelched by demands to facilitate efficient unit functioning? There were different perspectives on this issue among the participants. While several of the participants provided examples of times when they believed that their ability to attend to children as persons rather than merely bodies was compromised by time constraints,
one participant questioned whether the constraints were real or perceived. She believed that, in general, nurses have time to address children as people. In fact, attending to children as fully human beings is not actual work in itself but rather, represents the approach the nurse takes to the work.

[We are working] to get them out to get somebody else in and all I can focus in on is getting this kid better is giving them their medications, suctioning their airway doing things like that. But I don't think that that is the vast majority of the time; I think that is an extreme. (...) The vast majority of the time is when you have work to do and your goal, your focus, is to improve your patient's status, to get your patient out of ICU and hopefully out of the hospital. And one of the ways of getting your patient better is by addressing them as an individual.

Perhaps the issue is not whether or not nurses have the time and resources to practice in ways that address children’s personhood and support their agency but rather revolves around the value placed on these practices in PICU. The values within the practice environment are reflected in the participants’ account of how decisions about the use of resources, including nursing time, are made. None of the participants disputed that saving/fixing children’s bodies and facilitating efficient unit functioning ought to be important priorities the intensive care unit. However, several participants questioned the extent to which these priorities ought to dominate other issues, including treating children as people.

The participants’ accounts of practice reflected a belief that attending only to the saving/fixing children’s bodies and facilitating efficient unit functioning can result in harm to children’s sense of self and lead to the suppression of their voices. One participant articulated her understanding of how the priority of saving/fixing children’s bodies tends to drown out attention to children as people.

Because when you're in ICU I find what it means to a lot of people, this is a very general statement but it is saying that, people say they're here for life versus death, you know, and life means at all costs we do this, this and that. And when you're fighting or working towards life versus death, the human element sits in the background.
Another participant described one experience caring for a critically ill infant and family. The physical care required for this infant was complex and challenging for this nurse. Because of the volume and intensity of the work that needed to be done, this nurse’s focus was restricted to doing tasks, monitoring the infant’s responses to treatment and care, and attending to the monitors and equipment being used to support life.

[The care was] very depersonalized. I came in, I’d never met the family before and I’m there the night they’re being told that, who knows which way it will go here. And you feel like you don’t have time to connect with the family or the child in a very difficult time, you’re just busy doing the technical side of it. You don't get into the personal side of it.

Particularly troublesome to some participants was the perception that privileging attention to children’s bodies and to the system not only served to displace attention to children’s personhood, it also undermined that personhood by creating an environment that potentially injures and/or invades children’s sense of self and silences their voices. Yet another participant described the moral distress that arose for her at a moment when she became aware of the way that the technical nature of the work led to an impersonal approach toward one baby.

It was just, oh God, what have we become. And you could see people, I was watching people, when I became aware of it, I was watching people go around the bed and it was just things, there were so many things to do. (...) Nobody is even talking to this child. There's no little music playing like there would be for any other kid. You know, the baby can't open its eyes because they've paralyzed him, there's no little mobiles or anything. There is only baby and machines, the room was actually was physically full of machines. And I would just think, oh God, that is probably one of the first times that I've really noticed that nobody even saw this child. Nobody sees this child. Which is quite shocking. I don't think it happens that often. But (...) the fact that it can.

This example illustrates one of the most prominent threats to children’s personal integrity that recurred throughout the participants’ accounts of practice. This is the threat of objectification of children, the loss of a perspective of children as subjects – fully human beings with rights to dignity and respect. In the next section of this chapter, I shift my attention to the participants’ accounts of their practice as they sought to attend to the human elements of care. I focus on the
threats to personal integrity that the accounts illuminated and the practices the participants engaged in as they endeavored to address these threats.

Secondary Discourse: Treating Children as People

As I have already mentioned, within the participants’ accounts of their practice is evidence of a secondary discourse that exists in the practice environment of the PICU. This is a discourse of children as human beings, people vulnerable to injury to their sense of self and personal agency. This is the discourse of treating children as people.

Evidence of the relative positioning of the secondary discourse of ‘treating children as people’ to the dominant discourses of the unit exists throughout the participants’ descriptions of practice. Examples of the less privileged position of the secondary discourse can be found in what the participants said, how they said it, and in what they didn’t say. Consider, for example, the comments of one participant. She was describing a time when she was successful in attending to a child’s need to know what is happening in a difficult situation. The seven-year-old child she was caring for was rapidly deteriorating and the physician and respiratory therapist were poised to perform endotracheal intubation. The participant described how, at that moment, she took action to connect with the patient, to describe to the child what was happening and what was about to happen. Speaking of the physician she commented, “And he just stood there with his hands clasped and he was all set to go and I was quick because (...) I know that it’s not a priority.” What is significant about this story is that the physician had the authority to intervene and prevent this nurse from connecting with this child and that the participant understood that attending the child’s needs was secondary to the priority of medical intervention. In this and other examples, practices that address children as people are portrayed as extra, outside the mainstream work of caring for children in the intensive care unit. At various times the participants used terms such as “fluffy work”, “extras”, or “the touchy-feely
stuff” to describe nursing practice that is outside of the dominant discourses of the practice environment.

The following example illustrates how managing children’s pain can compete with the nurses’ obligations to facilitate efficient unit functioning. This participant spoke of advocating for a child’s pain control in a situation where there was a push to discharge the child from the unit to the pediatric ward. For this child, leaving the intensive care unit required reducing the dosage of analgesic he could receive. In the following excerpt, the participant describes the tensions that can arise when a child’s need for adequate sedation and/or analgesia competes with the staff’s need to discharge the child to the ward.

To me if [children] have to be intubated for one more day to get through another twenty-four hours of uncomfortable, severe pain -- give pain medication. What does it matter really? What's it matter? I mean [that] if they're in pain and they're not going to be taking deep breaths anyway, pneumonia is going to set in. So why not control their pain and keep them ventilated? (...) It makes sense to me [but] it doesn't happen all the time. [But] they can't go upstairs if they're on forty of morphine [even though] he's breathing fine, he's a big kid and he's tolerating it. Why not?

In this particular example, the participant felt that pain control for this child was compromised by the drive to discharge him from the unit and by the institutionalized policies regarding medication administration. Although this example may be an exception, it illustrates how, when tensions arise between the practices within the dominant discourses and practices intended to address children as people, nurses may find themselves in the difficult position of having to implement practices that are contrary to their moral beliefs.

---

7 As I describe later in this section, I have come to understand pain management as an example of the kinds of practices nurses engage in as they endeavor to treat children as people.

8 Continuous intravenous morphine infusions are a common method of managing children’s pain. In the PICU, there are no regulations about the amount of morphine that can be administered by nurses. Generally children receive between ten and forty micrograms per kilogram per hour although much higher doses are used for children with prolonged, severe pain. In the other units of the hospital, policy states that morphine by continuous infusion can only be administered up to dosage of 20 mcg/kg/hr. This policy is based on potential risks that can be associated with morphine administration at high doses.
Threats to Children's Personal Integrity

The participants described a spectrum of practices that they believed served to preserve children's personhood and enhanced children's personal agency when children are ill and hospitalized. Within each account of action to preserving children's personal integrity can be discerned a belief about threats to children's sense of self and agency. I have identified four threats to children's integrity from these stories: (a) objectification of children, (b) children's loss of control over self and the environment, (c) isolation and separation and from family and others, and (d) physical pain and intrusion.

Although the four threats to children's personal integrity that I describe are neither discrete nor necessarily comprehensive, each category represents a significant theme within the participants' accounts of their practice with children. In spite of, or perhaps because of the subordinate relationship of the secondary discourse to the dominant discourses, the participants were able to articulate in compelling and personal ways the nature of their practice as they sought to attend to the human elements of care. In the following sections I endeavor to portray these threats and the patterns of practice that address each. The threats to children's personal integrity, patterns of practice associated with each, as well as specific examples of these practices are summarized in Table 1.
<table>
<thead>
<tr>
<th>Threats to children’s integrity</th>
<th>Related patterns of practice</th>
<th>Specific examples of practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objectification</td>
<td>Engaging in relationships with children</td>
<td>Spending time with and listening to children</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Attending to cues</td>
</tr>
<tr>
<td></td>
<td>Creating tangible reminders of children’s humanity</td>
<td>Inviting participation of family members</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Displaying pictures, toys, etc</td>
</tr>
<tr>
<td>Coordinating care</td>
<td></td>
<td>Raising awareness of fragmented communication to children and families</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negotiating between various medical specialties</td>
</tr>
<tr>
<td>Loss of control over self and the environment</td>
<td>Enhancing children’s and families’ control</td>
<td>Reframing embarrassing experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Maintaining privacy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Providing information to children and their families</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Enhancing children’s ability to communicate</td>
</tr>
<tr>
<td>Separation from family, isolation</td>
<td>Supporting children’s connection with family and others.</td>
<td>Facilitating family presence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Establishing a connection with the child</td>
</tr>
<tr>
<td>Pain and intrusion</td>
<td>Minimizing and relieving children’s pain</td>
<td>Providing analgesia and sedation.</td>
</tr>
<tr>
<td></td>
<td>Mediating physically invasive events</td>
<td>Providing information and support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Encouraging family presence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Avoiding unnecessary procedures</td>
</tr>
</tbody>
</table>
Secondary Patterns of Practice

In their accounts, the participants described an array of practices that they believed countered threats to children's personal integrity and that support attention to children as fully human beings. In the following sections I explore how the participants addressed each of the threats to personal integrity described above. Seven patterns of nursing practice are apparent. These are (a) engaging in relationships with children, (b) creating tangible reminders of children's presence, and (c) coordinating care, (d) enhancing children's control over self and the environment, (e) supporting children's connections with family and others, (f) minimizing and relieving children's pain, and (g) mediating physically intrusive or painful events.

The first three patterns of practice relate the participants' understanding of the threat objectification poses to children's sense of self and personhood. Their accounts reflected a belief that when objectification occurs, the dignity and respect generally afforded human beings can be stripped away, potentially injuring children's sense of self. As becomes evident in the participants' accounts, objectification is almost never a conscious choice, but rather, tends to be a normative perspective within the practice environment. Engaging in relationships with children, creating tangible reminders of children's presence and coordinating children's care are the kinds of practices that the participants engaged in in their efforts to prevent or mediate the effects of objectification.

Engaging in relationships with children. Prominent in the participants' accounts of their practice is a belief that a lack of meaningful connection with others, particularly in an environment full of people, can be a very depersonalizing experience for children. Below, one participant recounts an interaction with a fourteen-year old boy, recalling how this boy described his sense of depersonalization during an extended hospitalization in the PICU.

He [said], "Well [the nurses] don't care. They are so worried about writing down numbers and getting this and that. And I ask them to be moved or to have some ice. They go, 'Okay, okay, just in a second, I have to write this down.' Then they do
something else. Five minutes later they're sitting there talking to their friends and they've forgotten all about me. And I'm just sitting here.”

Engaging meaningfully with children, thereby prioritizing their needs, was portrayed by the participants as an important pattern of practice in mediating their own tendency to objectification of children and children's sense of dehumanization within a foreign environment.

Even when children are unable to respond, several of the participants believed that there were ways of connecting with children as people. At times, there is a human connection with children that nurses experience and that shapes their practice. This connection seems to be grounded in a sense of shared humanity rather than in any particular knowledge of the individual child. In the following excerpt, one participant describes how this human connection with children shapes her nursing care.

I can look after a body without ever attending to the child. I can have a child who is paralyzed and ventilated and I can turn him and just do it and just move his body. Or I can turn him and touch him in a way that (...) I touch him before I start to move him and move his limbs in a way that would show him that I'm being gentle with his body and caring about him. And then I can also add words on top of that so it's like a whole different way. I don't always have to talk to the child to let them know that I care about what they like or don't like or, or how they want to be treated. I'm still doing a task, it's that I'm doing it in such a way that I'm turning her, I'm not turning it.

In the excerpt about, the participant has eloquently described her relationship with the child as a way of being with the child rather than a task or process in itself. Engaging in relationships with children, as a pattern of practice to treat children as human beings includes both nurses' approach to children and the substance of their actions in connecting with children.

Human connection with children took a variety of forms in the participants' stories of practice. The nurses' relationships with children were shaped by a multitude of factors including the age of the child, the child's ability to communicate, the nature of the child's health condition, the presence of family members, and the amount of time spent with the child. These are only a few of the variables mentioned by the participants. Below, one participant describes her relationship with an adolescent boy. The participant was the primary nurse for this boy over
a period of several weeks. She describes how, over time, the purposeful development of shared interests and the use of humor became part of the connection between nurse and patient.

When Tim [pseudonym] got well and we were able to interact and talk more. We had a lot of fun teasing each other about music. He read magazines about them and we'd sit down together and he'd talk about the groups -- who was doing what and what new bands were coming out. His uncle had got him the newest Nirvana and someone had taken him to a concert. Those kinds of things where we could connect because I had some knowledge of his taste -- though we teased a lot, teased each other.

In this example, the participant’s relationship with the child reflected the nurse’s sincere engagement with the child, practical efforts to find a place in which to connect, and effort to create and sustain the relationship. As in this case, the nature of the participants’ relationships with children were shaped by children’s age, the amount of time nurses spent with particular children, children’s willingness to interact with nurses, and children’s physical conditions. I explore these factors later in this chapter when I look at nurses’ enactment of practices addressing children’s personal integrity in specific situations.

The participants hinted at another theme that has relevance for relationships with children. It seemed apparent that family members must be respected. Two of the participants described how they believed that respect for children’s families is another component of developing a relationship with children. In the following excerpt one of these participants describes an important connection between children and family members.

[The child’s connection to her mother] was very strong, very much a part of her own integrity. It was important that her mother was treated with respect. If we had not treated her mother with respect that would have hurt Janis [pseudonym]. She wouldn't have trusted us. She would have been in a position where she was trying to protect her mother and trying to deal with these alien people that come in and hurt both of them because her identity was quite wrapped up with her mother.

This perspective suggests that children’s relationships with nurses may be deeply intertwined with their family’s relationships with nurses and other health care providers. As one participant commented, “The family and child are so intertwined. In essence they are one unit.”
Creating tangible reminders of children’s humanity. Creating tangible reminders of children’s humanity is another way in which the participants sought to minimize the objectification of children in the PICU. Many of the participants’ stories included descriptions of tangible ways in which they sought to make children’s humanness visible. These efforts were intended to remind themselves and others of the personhood of children. From my own experience in this pediatric intensive care unit, I am aware that the PICU is mainly one large room with curtained cubicles for the children. A few painted pictures brighten up the walls and mobiles hang over the central nursing station. The cubicles are stark and filled with equipment and supplies, various lights and one or two chairs where family members can sit.

The participants described how they sought to bring cues and reminders of who specific children are into the immediate practice environment. The purpose of this effort is twofold, to remind nurses and other health care professionals of the humanness of the child, and to personalize the environment for the sake of the child and family. In this way, the tendency of toward objectification of children is reduced and children’s experience of dehumanization may be ameliorated. Many of the participants spoke of encouraging parents to bring in their children’s favorite music, posters and toys as well as pictures of family members and other important people and pets.

I never hesitate and I know a lot of nurses put music on at the bedside. For the kids that are paralyzed, I always say to parents if they’ve got a special tape or CD that they listen to, can you bring it in and we’ll play it for them. Do they have bedtime music or a story? Do they like those taped stories or videos? We’ll play it for them so they’ve got something at the bedside with them. Quite often we’ll take creative license -- I had a couple of tapes from home that I would bring in for the kids and play them.

Another participant described similar practices.

We encourage parents to bring in photos of when the child was well. Also, special toys or if they’re at a certain age and their blanket is still pretty important, you’ve got the blanket there. Even when they’re paralyzed and sedated and stuff, you’ll put their blanket in to their hand so that it’s there or it’s against their face or around their head or something. It’s partially for the child and it’s partially for the family that you are treating their child as a child, as a human entity as opposed to just a project, a thing.
Several of the participants described how they rely on family members, particularly parents, to guide them in finding ways to tangibly create an environment that acknowledges the personhood of the child. Parents do this by providing information about children’s likes and dislikes and children’s interests and concerns. Describing her work with a head-injured adolescent boy and his mother, one participant recounted:

I was able to help his mother with bringing Tim [pseudonym] into the ICU, bringing familiar pieces of his life into the ICU. One of them was this, his music (laughing) which was ... well very loud and sort of bordering on rock and roll but kind of grunge music. We suggested that she bring in some of his music and play it for him, bring in some of his posters. He had a lot of posters of bands and things.

Participants’ actions to create tangible reminders of children’s humanity also took the form of raising awareness of children’s personhood in interactions with other nurses and health care professionals. Within the interviews, the participants recounted numerous times in which they directly reminded others that children are human beings. For example, one participant described her response when a physician spoke of a child’s likely demise in the child’s presence without directly speaking to the child.

I looked at [the physician] and said, “The patient is [pharmacologically paralyzed], he is not deaf.” The physician turned bright red and he said “Oh my God, thank you.” And he went over to the child and he talked to him.

These practical efforts, whether through shaping the physical environment, or through policing others’ behavior toward children were seen as actions that counter objectification and thereby prevent injury to children’s intactness or wholeness as human beings.

Coordinating care. Several participants identified fragmentation of care as another factor within the practice environment that can lead to objectification of children. These participants articulated a problem that is created when a great number of health professionals, representing different services and medical specialties, are involved in the care of a single child. One
One participant summarized consequences of fragmentation of care in the PICU in the following way.

I think probably one of the most frustrating things from a nursing point of view is this lack of communication between teams. Because in an intensive care like this [no single physician has overall responsibility for the child’s ongoing care]. They’ll probably come in under [the service of] surgery. What good is that? Surgeons don't do this kind of thing. [The surgeons] come in, they have to take advice from cardiology, and they have to listen to intensive care. (...) Cardiology comes in and kind of throws out a few things. There is absolutely no advocate, like a primary person.

One participant described her efforts to discuss the coordination of a particular child’s care during medical rounds.

This was what I brought up in rounds today -- there are always different consultants coming in talking about this child. Everybody has a different take, focusing on a different system, but they all tie together to get this kid to get better, but nobody was looking at it in an integrated way, they are only looking at it from their [own] perspective.

The participants’ efforts to treat children as people took many forms – from placing pictures at the bedside to making the health care team aware of effects of fragmentation of care for particular children. Although not always successful, these efforts were intended to counteract the effects of the objectification associated with serious illness and with hospitalization in an intensive care unit.

Enhancing children’s control. A second threat to children’s personal integrity that was evident in the participants’ accounts of practice is the loss of control that children experience when they are ill and hospitalized. Children’s abilities to communicate, to move physically into and out of situations, and to have control over their bodies were compromised during illness and hospitalization in the PICU. Practices that are related to enhancing children’s control included mediating the effects of potentially humiliating events, providing information to children, and facilitating children’s abilities to communicate.

One participant described how a severely burned seven year old child, already unable to move because of burns and dressings, was further immobilized by the restraining of his hands.
We have to restrain his hands too because he tries to scratch at himself. We're worried about him knocking off bits of bandage, graft and whatever else. (...) I don't know if he'd try to reach for [the endotracheal tube] that is wired around his tooth because there is no place to tape it to his face. That's a precarious airway that we are trying to protect as well.

In this and other examples, children's personal integrity was threatened by the loss of control inherent in the treatment of illness or injury. This paradox that arises when treatment of children's physical problems threatens children's personal integrity creates, for many nurses, some challenging dilemmas. As in this example, there are times when nurses are expected to implement practices intended to save or fix children's bodies that are potentially humiliating or dehumanizing for children.

For some children, one of the consequences of loss of control is embarrassment and humiliation. In the following example, the participant draws on her knowledge that, for five-year-old children, defecating in a diaper may represent regression to an earlier stage of development and the loss of relatively newly acquired skill — a very threatening experience. She describes her efforts to reframe the situation in a way that would reduce the child's humiliation.

There was a little guy who was very sick. He was five [so] we called his diapers paper underwear. He wasn't very awake but at one point he did wake up enough to have a bowel movement and was very concerned about [how he was going] to get up. So we explained [the diaper was] special pants, special paper pants. When you have to stay in bed, you're allowed to go in these paper pants. And we'll take the paper pants away and give him fresh ones. He relaxed when that was explained to him. And we never called them diapers because you could see that a five-year-old would be very concerned.

Similarly, many of the participants described the importance of maintaining children's privacy as a way of preventing or mediating embarrassment and humiliation. The PICU is not designed to provide privacy; rather it is designed to allow maximum observation of the children at all times. One participant eloquently described her beliefs about the consequences of children's loss of privacy.

Children are very bare when they're in the hospital; everything is stripped from them. And just to preserve that little bit [of dignity] because they've lost all control over what's going on when their covers are off.
Several participants described specific ways in which they try to maintain some privacy for children. One participant commented, “Even with small children you try and keep their privacy. Even in the ICU -- I notice almost every nurse does this -- they put a cloth over the genital area.” Another participant said:

You think, okay, they're fourteen. Therefore, anytime I give any kind of procedure that requires them to be exposed, I'm going to draw the drapes so that they will always be assured of some privacy whether they're awake or not, I'm going to do that just in case they're aware at any level.

Children’s sense of loss of control is compounded by their diminished capacity to ask questions and seek the information they need and want. Several of the participants' accounts of their practice demonstrated that they believed providing accurate and appropriate information to children is an important aspect of treating children as people. The threats posed by inadequate information are illustrated in the following story recounted by one of the participants.

We had a fifteen-year-old who had meningococcal septicemia. He was critically ill. This kid teetered on the brink [of death] for two weeks. He was [from another country] and so we couldn't say very much to him. I could talk to his parents and his parents could interpret. He probably spoke quite a bit of English but his parents couldn’t. Ventilated, paralyzed, heavily sedated on drugs [then] he was extubated one morning when I had him. And later that afternoon he said his first words and the first words to his mother were, “Do I have AIDS? Am I dying?” So this kid who had been intubated, ventilated, paralyzed for weeks and nobody had talked to him about what it was he had. I mean I'd told him he had a blood infection. He was thinking HIV. None of us thought that this is a fifteen-year-old who is a very independent young man, who has a life his parents perhaps don't know about. Maybe he had a girlfriend, maybe he had experimented in drugs, and maybe his mind was just confused about what different things were. But nobody had talked to him in that whole two weeks because we had been so busy looking after him physically.

As this story illustrates, the participants described how providing information can be challenging when there is little or no feedback from the child. This issue of enhancing control by providing information to seriously ill children is fraught with such challenges. One participant described how she endeavors to anticipate children’s information needs.

And [I try to] keep them knowing what's going on so they have control or at least some understanding of what's going on. Even if I don't know the child, that's something that
everybody deserves. (...) I think most children would want that, they'd want to know what's going on. Why am I so frightened? (...) Or what are you going to do to me next that's going to hurt? Everybody deserves that basic respect and communication and I'm trying to deliver it in a way that is appropriate for the child's age.

Other participants described specific creative and innovative ways in which they tried to improve children's abilities to communicate and thereby enhance their control. In this excerpt, the participant describes her care of a six-year-old boy who is isolated in a private room and is immobilized except for the ability to move his hands very slightly.

I've been thinking about him, now he's starting to move his hands a bit, maybe we should get one of those big button things so the he could tap it with his hand and it will put the call bell on. So he'll feel that there's some control, that he can call somebody in, maybe to take maybe some of the fear away. I don't know how much fear he has because our ability to communicate is so little.

Where possible, enhancing children's abilities to communicate included enabling them to ask questions and to speak out for themselves. One participant described her practice with a fourteen-year-old boy. Medical rounds took place twice daily at his bedside but consistently there was no acknowledgment of the boy as a member of the team. This nurse sought to bring this child into discussions about his own care.

After that when it happened again, I just said to the patient, "Do you have any questions for the doctors?" He did and then he asked his questions. I mean he's a smart kid, he had some great questions. And I don't need to ask them, he can.

Supporting children's connection with family. Within the participants accounts of their practice was an understanding that, although children hospitalized in an intensive care unit are rarely physically alone, they generally have little opportunity to engage with others in meaningful ways. In addition, the children in PICU are separated from their families for varying periods of time. The loneliness and isolation created by separation from family and limited abilities to communicate are understood by the participants as threats to children's personal integrity. In the following excerpt, one participant speaks about the importance of parents for
one little boy and how the benefit of the presence of his mother was manifest in the child’s demeanor.

Now that his mom is coming in more, he's a lot more responsive. She reads him stories and things like this and he, he doesn't indicate that he’s in pain when she's there. (...) It’s been really hard because his parents haven't been there. Now that they're there, it’s better because they know him.

Several participants described practical ways in which they supported parent’s presence with their children in the intensive care unit. Providing family members places to sleep, space to sit at the bedside, and assisting parents to see through the technology were examples of practices to enhance the connection between children and their families. As is evident in this and other accounts, the participants viewed supporting children’s connection with family members as an important pattern of practice in efforts to treat children as people.

Minimizing pain. Physical pain and suffering were seen by many of the participants as threats to children’s personal integrity. Consequently, minimizing children’s pain was an important component of attending to the human aspects of care. Minimizing pain involved providing adequate analgesic as well as taking other measures to provide comfort, to reduce anxiety and alleviate concerns. For example, speaking of her beliefs about the provision of analgesic medication to a severely injured child, one participant commented:

I think sometimes he's so frightened and he says yes to pain in order to get another [dose of morphine] so he swims back into the dream world. So he doesn't have to be here. (...) And I don't even know how awake he is. (...) I don't want to wake him up so much that I can get these answers because then I think he'll be really in pain. And then I think, what if he's going to die? I want to make sure he's as comfortable as possible. I want him to be swimming around surfing somewhere having great dreams so that if his body can't survive this, he hasn't gone through anguish.

In general, adequate pain control through provision of analgesic medications is supported and encouraged in the practice environment. In spite of this, the participants described times when they needed to speak out for adequate pain management, making it a priority in the child’s care. One participant described one specific situation where a child’s pain management
needs were not given priority and recounted her work to endeavored to draw attention to this issue.

I did recall one day where the doctors were in and I said, "Today is his bone marrow aspiration." And one of the doctors turned to me and said, "Well he's on Tylenol isn't he?" and walked away. I quickly hurried after them and I knew this was a big anxiety for both [the child and parent], a huge thing for Tim [pseudonym]. It was very painful for him and I went to the physician and said, "That just won't do, he needs to have some sedation and something for pain that we can give him." And with a bit of sort of arguing we were able to get that in this particular case.

Mediating painful and invasive events. Related to the pattern of practice of reducing and minimizing pain is a separate pattern of practice of mediating painful and invasive events. Intrusion into or invasion of children’s physical bodies was understood by the several of the participants as a threat to children’s sense of self, having the potential to damage their sense of wholeness and intactness. This understanding influenced how these participants prepared children for invasive procedures and how they supported them during and after procedures such as dressing changes, lumbar punctures, and intravenous and line insertions.

For example, one participant described her approach to the procedure of suctioning endotracheal tubes⁹. This participant believed that suctioning is an uncomfortable and invasive procedure.

[I know] that when you're suctioned, you feel like someone is taking your breath away and it doesn't come back for a long time. So when I'm doing that, I'll say to a child, "I'm going to take your breath away now... Okay, I'm taking your breath away ... Hang on, the breath is going to come in a minute, [the] breath is going to come in a minute ... I'm going to connect you up" [to the ventilator]. I give him that breath and say “There, that's the breath, there you go, you're alright now.” (...) I just keep talking to them.

This practice of mediating painful and intrusive procedures recurred throughout the interviews as the participants spoke of practices such as coordinating the timing of procedures, ensuring parents’ presence during procedures and, as is illustrated in the excerpt above,

---

⁹ Most children in the PICU have an endotracheal tube in place to support their airway and/or to support mechanical ventilation. The endotracheal tube is suctioned periodically, the frequency of the procedure depending on the size of the airway and the amount and tenacity of the secretions.
attempting to provide ongoing information to children. At other times, mediating painful and intrusive events involved speaking on behalf of the child. In this case, the participant portrayed what she saw as a baby’s experience of dyspnea and hypoxia during a trial of extubation.\(^\text{10}\)

I mean he's wriggling around and he gets so, because he's in congestive heart failure and he gets --- and it was amazing actually, it was the first time I've ever seen an extubated baby that actually had that look of fear. Just stunning -- I've seen adults or older kids recognize they can't breathe. But a baby? And it was just like, I remember bringing it up in rounds and I said, "He was actually frightened. I've never seen that before."

Part of mediating intrusive and invasive procedures was communicating with children in an effort to reduce the trauma of the event and assisting them to find ways to cope during the procedure. One participant described her practice this way:

Let's face it, a lot of times you've got to do a lot of nasty things to children. I like to be able to tell children, "It's okay for you to yell while we're doing this, it's okay for you to scream, one thing you can't do is move the arm that we're working on. We need you to be still with that arm, you can yell and you can scream and I'll try and keep my ear away from your mouth." That sort of thing. If you give them some sort of out that you tell this is what they need to. There are a lot of things I picked up from children where, it's not very nice to tell them that you're going to tie them down, (...) that you're going to restrain them. It's better to tell them we need to do this to help [them] remember to keep their arm still. "I'm going to help you hold your arm still." When you're holding half their body down, right? You know, "I'm going to help you do this as opposed to I'm just going to lie on you and crush you and keep you still."

This attention to the child during invasive events extended to the participants' vigilance in policing other health professionals' behavior during procedures. Describing her role in caring for a severely burned child, one participant described her responsibility to ensure that others did not cause unnecessary pain and that they approach the child in a respectful way. As she listed the overwhelming array of responsibilities she felt, this participant said:

And then making sure that people don't touch him the wrong way. We had to do an abdominal x-ray on him in the morning. The x-ray person came in and she went to grab his arm and move it. And I'm like, "Oh no. You have to have sterile gloves on first of all and he's a burn, you don't grab anything and start reefing."

\(^{10}\) "Trial of extubation" refers to removing a child’s endotracheal tube and observing whether or not a child can breathe well enough with the support of an artificial airway or mechanical ventilation.
Another participant described a similar practice:

I've had to say to doctors in particular, because they're the ones that often come up and talk and do things to children. I say, "You know, the child is pharmacologically paralyzed, but they can still hear you. So before you touch them, tell them that you exist, that you are at the bedside, that you are about to do something."

Several participants described the important role of family members in mediating intrusive and painful events. In the following excerpt one participant emphasizes the importance of family at these times.

Usually we work with the child's parent and the child too to get through painful invasive procedures -- like lumbar punctures. The family is really an extension of the child so the personal integrity of the child could also be safeguarded by making sure that the family members were included in the child's care and their wishes and needs were addressed.

Throughout this section I have explored seven patterns of practice that I have discerned within the secondary discourse of the environment of the PICU. These capture some of the diversity and complexity of the participants' practice as they endeavor to treat children as people – to attend to the human aspects of care. In the next section I look at how these practices are enacted in the participants' day-to-day practice, including the relational and contextual factors that shape and constrain practice to preserve children's sense of self and agency when children are ill and hospitalized.

**Enactment of Practice to Treat Children as People**

As is evident in the sections above, the participants were able to articulate ways in which they believed they attended to children as fully human beings. It became clear to me, however, that to believe that decisions were shaped purely by the desire to act in children's best interests is to overlook to the influences of the competing priorities and demands on the participants' practice. What determined how the participants enacted practice to preserve children's personal integrity in the unique and complex environments in which they work? How did individual participants, caring for a particular children and families, at a specific times and places act to preserve children's personal integrity? How did the various priorities contribute to the
participants' decisions? The intent of this section is to explore and analyze the data with these questions in mind, seeking to create a deeper understanding of the practice decisions the participants reported as part of their everyday practice.

The participants’ decisions can be understood as the product of the interplay of the various discourses. Sometimes the practices to attend to children as people complemented the participants’ technical work and their efforts to facilitate efficient unit functioning. Other times these practices seemed separate from the work of saving/fixing children’s bodies. At yet other times, the participants’ efforts to treat children as fully human beings competed for time and place with other priorities in the practice environment of the PICU.

Although this perspective provides a way to think about the complexity of practice decisions, it does not begin to address how different nurses make different decisions in similar practice situations. Neither does it explain why the same nurse at different times will make different decisions in similar practice situations. At this point, two other broad groups of variables come into play. These are: (a) the characteristics and commitments of the individuals involved in the practice decision -- including the child, the family members, the nurse and other health care professionals, and (b) the immediate time and place location in which nursing practice takes place.

These variables – the people and the time and place – influenced the participants’ practice in very significant ways. In particular, in specific practice situations, these variables shaped the participants’ commitment to attend to the human aspects of care, and the nature and extent of knowledge they had of the particular children, and participants’ personal agency. These three factors, the nurses’ commitment, knowledge of the child, and personal agency provide the framework I use here to explore the participants’ accounts of practice in specific practice situations. Commitment describes the participant’s will or desire to attend to a child as a person in a specific situation. Knowledge of the child determines the substance of the
participants' action in addressing the personhood of the child. The participant's agency in the practice situation addresses the capacity and opportunity to act in accordance with her beliefs in a particular moment of practice. My conceptualization of the participants' enactment of practice to as they sought to treat children as people is summarized in Figure 5.

Figure 5. Enactment of practice to treat children as people.

Commitment: The Will to Act

Practicing in ways intended to address children's humanness demands commitment to a particular perspective toward children and the discipline of nursing. This is a perspective that, when children are ill and hospitalized, they are at risk for injury not only to their bodies, but also to their sense of self and personal agency. Because nurses' are concerned with every aspect of the health of individuals, nurses have the opportunity and responsibility to mediate that risk and
minimize this injury. The following statements by one of the participants illustrate her beliefs about the humanity of children and the potential harm to children’s sense of self that arises when children are seriously ill and hospitalized. She focuses on some of the differences between the disciplines of medicine and nursing—medicine’s focus on biomedicine and nursing’s responsibility to attend to the child as a whole person.

For nursing, cells are connected to a person. And most of what we do is with a person. So it’s the child’s experience of what has happened, his ability to say six months down the road, “Yes, I was in ICU. It wasn’t that great. But look at me -- I survived and I’m okay now.”

Although all the participants philosophically agreed that serious illness and hospitalization may threaten children’s sense of wholeness or intactness as human beings, many of the participants described times when their will to act in ways that address these threats wavered. For these participants, commitment to attending to children as fully human beings was not a once and for all decision. Rather, the people, time and place that compose specific practice situations mediated commitment.

Overall, two factors tempered the participants’ will to practice in ways intended to address children’s humanity. First, and most foundationally, the participants described ways in which the commitment to treat children as people was contingent on remembering that the child is a person. Secondly, several participants’ described how their commitment could shift from day to day and from situation to situation depending on their perception of the risks and benefits associated with particular actions.

Remembering the Child is a Person

Many of the participants described how, at different times they ‘forgot’ that a child they were caring for was a person. Generally, these were times when there were few cues to the child’s personhood. The will to attend to children’s personhood was diminished when a participant lost sight of the humanness of a child. When the child’s family is absent, when the
child is heavily sedated or pharmacologically paralyzed, or during procedures, it is possible to forget that children are people. One participant recalled a particularly poignant example of how easily a child’s personhood can be overlooked. In this excerpt the participant described her experience with a very critically ill infant whose care was complex and very technical.

She was a newborn, post-op open heart; they couldn't get her off the heart-lung pump. One morning on rounds there were twenty-eight people beside this bed. (...) I went in and I just looked at this baby and I turned around to her so I was looking at her and [thought], you know, nobody even sees there's a baby in here. (...) And I remember we were pushing this little kid into the OR and mom and dad came in to say good-bye, just to give her a kiss or whatever. I was just looking at this mother and I [thought], we've really forgotten that this is a child, somebody's child. And her tears were actually dropping on the bed. We have completely neglected to see this child.

In this and other stories, the presence of the parents brought a reminder that the child is a human being, not merely the object of medical and nursing technical expertise. It is likely that few or none of the twenty-eight people at the bedside would consciously claim that this infant ought not to be treated as a person. Yet, when the cues to personhood are few, the temptation to dehumanize children may be great. One participant summarized this tendency to ‘forget’ saying, “When you're really busy it’s easy to forget. And if you're really busy it is honestly quite easy to treat them as a body and just get on with physical stuff that you have to do.”

Weighing the Consequences

Even when the participants sustained awareness of the humanness of children, commitment to treat children as people could be mediated by other personal and contextual factors. The participants’ commitment to attend to children’s personhood in particular situations was shaped by their perception of the associated costs and benefits. The participants recounted practical, emotional and political consequences that shaped their decisions in practice.

Practical consequences. Several of the participants identified practical benefits associated with attending to children as individual people. For example, in many instances the participants described how developing a connection with a child and supporting the family’s
presence facilitated efficient nursing work. In a practice environment that values skilled and efficient practice, connecting with the child and enlisting the child’s and family’s support often made that nursing work easier and more expedient.

Some days it’s going to be so much easier to spend five minutes in the morning, getting to know [the child], having him get to know you and get to trust you. Then your day is just a breeze. Because instead of saying to this little kid okay, now sit up and take a couple of deep breaths, you can make a game out of it. You can engage him on a level that lets him make the decisions. He trusts you a bit more, you know him a bit better and the day just improves.

Another participant echoed a similar sentiment, describing the benefits of connecting with children.

And the way you get them to cough or the way you get them to move around and take bigger breaths is by knowing the patient. What's going to work? Is this child going to blow bubbles? Can you get the child up to sing with you? You know they're still on a ventilator and if they're conscious and you start singing Teddy Bears Picnic, well maybe this kiddie will start to mouth the words and in turn will actually [breathe and cough]. By knowing the patient, you can address those basic needs more efficiently, more effectively.

These two examples portray actions that attend to the child’s identity and encourage connection with the child as a vehicle to efficient nursing work. In other instances, however, the participants spoke of the practical costs of getting to know individual children. Most frequently the practical cost was time, time that was taken away from the valued work of providing physical care and meeting system demands. One participant commented, “When they’re able to talk it’s, it’s time consuming and it takes a fair bit of effort to connect and to find out about that kid.”

Emotional consequences. In addition to the practical costs and benefits, several of the participants identified emotional consequences of attending to children’s personal integrity. How much can nurses give to others without jeopardizing their own well being? On the other hand how can nurses ignore children’s personal integrity and yet maintain their own integrity?
Throughout the interviews, most of the participants grappled with these questions in one way or another.

The participants described an emotional toll associated with the varying levels of involvement with children and their families. For some of the participants, this emotional toll could, at times, outweighed the benefits of attending to the human aspects of care. One participant, while describing her most recent set of shifts, was tearful as she described the anguish of the child with whom she worked. In addition to the distress created by watching the child’s suffering, the responsibility of decision making for this child weighed heavily on her mind. This participant’s response to this situation was not to withdraw emotionally from the child and family, but rather, to physically withdraw from the situation, taking time off from work.

In addition, several of the participants described how the intense, yet time-limited nature of their relationships with seriously children ill children often resulted in feelings of loss at the end of the relationship – when the child is assigned to other nurses, when the child left the unit to go to another ward, or when the child died. One participant described an experience early in her career when she cared for a very ill three-year-old child for a number of weeks. She commented on her feelings after the child was discharged.

For a time period I was very important to her, to her life, to her well being, to her health. But once she got past a certain stage she still needed help from others but it wasn't going to be from me. And so my importance in her life had ceased to be from her point of view. Whereas her importance in my life was I had cared for her, I had looked after her and I felt good about the fact that I was helping to make her better. (...) When she was discharged, I missed her (...) and I was sad.

For some participants, children of particular ages or with particular health conditions tended to exact a higher emotional toll than other children did. One participant spoke of her struggle when caring for children with critical traumatic injuries or burns.

I tend to keep my distance from knowing those child[ren] because the more you get to know them, the more you get involved. It’s a preservation thing (...) if I'm pretty
convinced the child is going to die. Because to imagine what, what it's like for that child is just, I can't imagine, it's overwhelming. And to try and get to know that child and get inside that child's mind even to begin imagining that is just horrendous. So in those situations I tend to move myself away -- I really struggle with getting to know them because I'm almost afraid, afraid for me.

Although the emotional toll could be high, the participants’ passion for caring for children and their families and the satisfaction that they gained from participating in that care was evident in their stories. The participants rarely made direct reference to the emotional satisfaction that they felt although their commitment and interest were evident in what they chose to speak about and how they said it. Speaking of the satisfaction of working in the pediatric intensive care unit, one participant commented, “There are opportunities everywhere, it's beautiful. It’s the most transforming place I've ever seen, I just see nothing but opportunity and possibility.”

Political consequences. The participants’ accounts of the political consequences of attending to the human aspects of care revealed many actual or potential costs and few benefits. Several of the participants described how sanctions within the practice environment inhibited them in acting in ways that attend to children as people. Generally, these sanctions arose when these practices collided with the priority of work of saving/fixing children’s bodies or facilitating efficient unit functioning. When this happened, the participants had to consider whether the perceived benefits of action outweighed the political price they may pay.

Three participants identified one political risk – being personally categorized as over-reactive and overly concerned with largely irrelevant issues. Work to preserve children’s personal integrity, particularly making children’s humanity visible and supporting connections with family and others, can be seen a ‘fluffy’ or even ‘laughable’ work by some nursing and medical colleagues. Being labeled as a touchy-feely nurse can place a nurse in an uncomfortable and immobilizing position. Other times, rather than uncomfortable and immobilizing, the participants described a more patronizing attitude of colleagues – an attitude that suggest that a
particular nurse's desire to attend to the human needs of children, while unnecessary, could be tolerated. Speaking of her reputation as a nurse who is known to spend time providing extra comforts to patients, one participant commented:

“I've got this really big thing and some people think that I'm nuts about it but it's my big thing about having people be comfortable and be clean. (...) And it's funny because people that I used to work with used to be a big joke, 'Oh Sarah [pseudonym], she's in fluffing and bluffing her patient’.”

One participant spoke of the technical focus of practice in the PICU and how she perceived an undermining of her own concerns about the objectification of one particular child. She commented, “I had somebody tell me that they weren't sure that I had seen the whole picture.” She went on to commented on how this perception detracted from her ability to speak on behalf of her patient. This participant spoke of her feelings during and interaction with a more senior nurse, during which her concerns were dismissed. She said:

I thought, you haven't heard a word that I've spoken to you at all. I know this because I was telling her [about the child's need for privacy and integration of care] and they thought that well you don't see the whole patient because you're not focusing on [the technical care].

A few of the participants recalled incidents in which their efforts to treat children as people resulted in anger directed toward them from their nursing and medical colleagues. One participant described her efforts during morning rounds to bring attention an infant's severe pain and the fragmentation of care in the management of that pain. The issues of pain management for this infant were complex and involved several different medical specialties. Frustration and anger among the nurses and physicians in rounds left her questioning if she had made a mistake. About her feelings at that time, the participant commented:

I sit there and I wonder am I explaining myself succinctly? It makes you uncomfortable when people that you work with are getting angry. I think it is because I brought up issues [related to the child's personhood]. (...) Maybe I stepped outside the way that rounds are supposed to be. It was busy on the unit.
In this excerpt, there is evidence that the participant attributes her apparent ineffectiveness in this situation to both personal and contextual factors. Summarizing the effect of this experience on her commitment to attend to children as fully human beings, the participant commented, "And then I think, what's the use?"

In this section, I have tried to portray how the participants' will or intentions to engage in practices that, in specific situations, bring focus to children as fully human beings was tempered by two influential factors: the extent to which the participant remembered that the child is a person, and participants' perception of the consequences of action. When a commitment to treat a child as a person existed and was sustained, that nature of action addressing threats to the child’s personal integrity was determined by the knowledge, both general and particular, that the participant utilized in decision making. In the next section I explore the nature of the knowledge that the participants used in making actual practice decisions related to the preservation of children’s personal integrity.

Knowledge: The Substance of Action

Where the will to act to preserve children’s personal integrity existed, it was the participants’ knowledge of the child that determined the substance of action. The participants' accounts of practice revealed a spectrum of sources of knowledge about individual children and a wide array of factors that influenced the nature of that knowledge.

Knowledge of the child, as the substance of actions directed at treating children as people, can be understood as a dialectic of a nurse’s general knowledge -- knowledge gained from sources external to a particular child or situation -- and the specific knowledge the nurse acquires of the particular child. In some circumstances, particularly times when there was little specific information available about a child, the participants relied heavily on general knowledge in making care decisions. At other times, the participants had intimate knowledge of children, knowledge gained over time through frequent and ongoing interaction with a particular
child and family. At these times, attention to the human aspects of care was largely grounded in the specific knowledge of the child. Most often, the participants utilized both general and particular knowledge in making these practice decisions.

In general, in initial interactions with children, the participants tended to rely on more general knowledge as they sought to attend to children as fully human beings. As a participant interacted with and observed a child over time, general knowledge was complemented by specific knowledge of the child. One participant described the relationship between general and particular knowledge in this way.

You meet a child and you respond to them initially basically on an age sort of appropriate level. You try that when you don't know them at all. [For example, if] they are five and they're a little girl, let's talk about the Spice Girls. See what kind of response (...) Then you find out what their individual needs and tastes are and you work from there. Some kids are really different than what you expect; they handle things a lot differently than you think.

This participant described a temporal relationship between particular and general knowledge. This suggests that general knowledge provided a starting place for action until more specific knowledge became available. Other participants’ accounts illustrated that the relationships between general and particular knowledge were not only temporal in nature. Rather, participants’ utilized both types of knowledge in making care decisions.

Drawing on General Knowledge

It seems to me that if practice to preserve children’s personal integrity must be based solely on knowledge of individual children, nurses’ capacity to act for children will be severely restricted at those times when access to a particular child’s wishes and desires is limited. Yet, within the participants’ accounts of their practice are many examples of the ways in which they used knowledge from sources other than the individual child her/himself to engage in practices intended to counter objectification, increase control, support connection with family, and to
minimize pain and intrusion. In particular, the participants emphasized how personal and professional experience informed their thinking in new situations.

Sources of general knowledge. Throughout the participants’ accounts of their practice, there was little direct reference to theoretical knowledge. Yet, within the participants’ accounts of their practice is evidence of a body of theoretical knowledge that they bring to all practice situations. Knowledge of pain management, the effects of bodily invasion on self-esteem, the detrimental effects of excessive anxiety, and developmental norms apparently influenced many of the decisions the participants made. In the following segment, one participant describes how developmental norms shaped her practice. She did not elaborate on whether her understanding of these norms was derived from theoretical knowledge, personal experience or both.

Knowing the age of the patient and, [developmentally] at this age what they should be doing. Or at this age, this is important. [For] teenagers, privacy is very much an issue and so when I go to turn the patient I want to make sure that he or she is not exposed.

Several participants described how their own experiences of illness and hospitalization colored their understanding of children’s experiences and contributed to the general knowledge they brought the practice decisions. One participant described how her own personal experience of the premature delivery of her child and how that experience shapes her understanding of the how others may feel in similar situations.

What has really made a difference though was the troubles that I had with my pregnancy -- having [my son] early. (...) It was the shock and the loss of control that really upset me the most. When I see parents come in with a little baby and the mom is crying at the bedside and they just look absolutely shell-shocked, I get tears in my eyes every time. I go back to that moment when I looked at [my son] in an incubator. (...) When I see these parents my heart just goes out to them. And these little kids, a lot of people look at them that they’re just little babies, what do they know? But they’re little people and they give you such feedback and they deserve to be loved and cuddled no matter how many tubes they have in and no matter what happens.

Similarly, other participants described the profound influence of their own experiences of being ill and hospitalized on their approach to seriously ill children and their families. One
participant described the intense fear and humiliation she felt when, as an adolescent, she was hospitalized following surgery.

[When] that nurse went home she said, “Call the nurses if you need anything.” In the middle of night I called and the nurse came in. [She said], “What are you calling for? You're a big girl, get out of bed. Go to the bathroom, up you get.” The other nurse had said, “Make sure you get help.” I can remember basically crawling to that bathroom. (...) [It was] humiliating, really humiliating.

For this participant, the profound impact of being in a very vulnerable position, and being humiliated rather than understood and cared for, shapes her approach to children.

The limits of general knowledge. Most often, general knowledge was portrayed as a reliable and unquestioned source in understanding individual children. However, occasionally the participants described limits to practice based on general knowledge or identified ways in which reliance on general knowledge can lead to mistakes. One participant identified that practice based on general knowledge tends to be based on many assumptions. Speaking about children who have little or no ability to communicate, she said:

You've got a paralyzed, ventilated child lying there and you're looking at the vital signs and we are assuming that this child can hear, that this child can still feel, that this child still has an active person spirit happening underneath that body. So we are assuming a lot. We are trying to meet those needs in the hopes that we're doing the right thing.

Another participant spoke of some of the obvious mistakes that nurses can make when they lack specific information about particular children and must rely solely on generalized understandings.

It's really tricky if you have a kid who is developmentally delayed. If you've got a twelve year old and you're talking to them like you do a twelve-year-old but he's got the understanding of a two-year-old level – that’s hard. The reverse is also true if you have a child who is physically quite disabled but is mentally age appropriate -- without the parent there initially to tell you where this child is at.

Yet another participant spoke of the strengths and limitations of her general knowledge drawn from her personal experience with her own children, and of her need to be reflective about the consequences of drawing on that knowledge in specific situations.
I think [having my own children] has given me a better understanding of how kids are. It's definitely made me more aware of the developmental milestones. My kids are really independent. So I still probably think that a lot of the kids are more independent than they are and I forget that they are [unique].

These accounts illustrate some the few times that the participants spoke of the limits to general knowledge.

**Drawing on Particular Knowledge**

Knowledge of individual children -- including their unique characteristics, concerns and needs -- was evident in many of the participants' stories of practice. In the following excerpt, one participant spoke of the vast difference among children, and how knowledge of individual children influences practice. She described how in similar situations, some children want a lot of information, while other children want much less information. The participant was speaking about an adolescent boy, hospitalized with severe abdominal injuries.

He noticed I was hanging TPN on him and with every kid I'm different, I wait to see where they're at, how much information they want to be told. Do they want to be told every time I do something? Every kid is totally different -- some kids will turn away, they don't want to know. And until you try and figure out where they're at, you don't know. [This boy] asked about everything. I was hanging his TPN and he asked what it was. I said the fat was the cheeseburger and the chocolate milk shake and the other was just sugar and water. He thought that was quite funny (...) but every kid is different and that's what's really unique about it.

In this section, I explore sources of particular knowledge and document some of the limits to that knowledge that were evident in the participants' accounts of their practice with children.

**Sources of particular knowledge.** The participants described an array of sources of particular knowledge of individual children. In specific practice situations, sources of particular knowledge about a child could include the child him/herself, family members, other health care professionals, and written documentation.

The participants' accounts of particular knowledge obtained through direct interaction with children illustrate the diverse forms of children's voices. The participants understood communication with children to include a spectrum of human expressions including speech,
facial expressions and gestures, crying, and even vital signs and other physiologic indicators.

Nevertheless, the more diminished children’s capacity to interact, the greater the challenge faced by the participants as they sought to gain particular knowledge of individual children. Knowing the wishes and desires of very young children, children who were intubated, children who were pharmacologically paralyzed, and children with neurologic injuries was seen as very challenging. Speaking of gaining particular knowledge of a child that was unable to communicate, one participant commented:

[When] I have a paralyzed ventilated child (...) I don't know what's going on their head; I'm not getting that kind of feedback. So I'm purely getting numbers and a picture of their physical and how they're appearing (...) but that's still, that's still a way of finding out what they need.

As in this example, several participants expressed a belief that they could discern some knowledge of a child’s experience through physiologic indicators. These physiologic indicators were either from direct assessment of the child’s physical state or assessed indirectly from monitors that measure heart rate, respiratory patterns, blood pressure or intracranial pressure. The following excerpt illustrates how one participant used specific physiologic knowledge to make judgements about children’s pain and distress.

[I get to know children through] the translation of their vital signs at times when they are paralyzed and ventilated. You suction and you see that their heart rate goes up and their blood pressure might come down a bit or some response that you see on the monitor. Or if you turn them on one side and physically they can't respond but their vital signs show you that that's just not good, then that would add to my understanding of what they like and what they don't like.

At the other end of the spectrum, several of the participants described situations in which they gained particular knowledge a child through direct verbal communication with that child. These tended to be relationships with school-age children and adolescents, who, although seriously ill, had periods of time in which they were able to verbally interact. Often, these were accounts of children who were hospitalized for a long period of time.
One participant spoke in detail about her experience as the primary nurse for a fourteen-year-old boy hospitalized in the PICU for several weeks. This excerpt illustrates how this boy used both verbal expressions and silence to communicate his needs for respect and privacy.

I knew times when he was very frustrated with me though. [When that happened] he wouldn't talk to me or there would be a period of time when he just didn't want me in the room. Some of that would be after having to do things to him that were really painful that he didn't want to have done. So it wasn't all roses. There were [also] times where he was very, very vocal and sort of just didn't, just didn't want to have me around.

The following story provides an illustration of the kind of creative care that can occur when the nurse has intimate particular knowledge of a child. This participant described the death of an adolescent girl she had cared for and how she believed she was able attend to the humanity of this child even after death. In this case, the knowledge was once again drawn mainly from the participant's direct interaction with the child.

There was a young girl who died very rapidly (...) and it was a big surprise. It was three in the morning, and her dad was with her. He went to pick up the mother and the two younger sisters to bring them to see Eleni [pseudonym] after she had died. I knew Eleni a little bit and I knew she was a big sister. It was really important to her that her younger sisters are cared for and that they weren't afraid of her -- when she lost her hair and things like this. She loved her little sisters a lot, they were really important to her. So we cleaned her body up and cleaned all the sheets and we put her in her pajamas and we put her hat back on. We tried to keep her body as warm as possible, we put the big bags of [warm] dialysis fluid around her and we wrapped her up in these big pink blankets (...) she looked like she was sleeping. We really felt that we were carrying out her wishes because when her sisters came to see her they just felt that she was sleeping, she still felt warm, and she was in her pajamas. So we felt that we had done something good there, that we had carried Eleni's wishes.

Most of the participants’ accounts of their practice with children were about children whose abilities to formulate feelings and desires and/or ability to communicate those thoughts were limited in some way — because of age, illness or treatment. The participants’ accounts revealed how in these situations, they looked to children’s gestures and cues as a way of coming to know each child in an individual way. About attending to cues when caring for infants, one participant commented:
Baby cues [are] a resource about what their needs are — if they're disorganized or if you can tell that they just don't want me doing what I'm doing. Putting them into positions, finding from them that they get maybe a little bit fussy if they're really bundled tightly [while] others love to be bundled tightly.

Speaking of ways in which nurses come to ‘know’ individual children, one participant described how, as she spent time with a child with a severe head injury, a child whose ability to think and communicate were altered, she became able to interpret the child’s facial expressions and gestures. These expressions and gestures might be meaningless outside of knowledge of the particular child.

When you actually did something to him he would grimace, stare very slightly. You had to know him to be able to see that. You had to spend time; you couldn't walk in the room for five minutes and get a sense of that.

In addition to their own interactions with children, all the participants spoke of the vital role of family members in gaining specific knowledge of children. Many of the participants’ stories of practice demonstrated how family members, particularly parents, contributed to their knowledge of particular children. In several instances, parents were cited as the first source of particular knowledge of a child. For example, in recounting her care of a child who was in the PICU for a long time, one participant commented:

I think the first way in which I got to know him as a person was through his mother. [The mother] was a single parent and was always at her son’s bedside when he was critically ill. So the first way in which I got to know [this boy] was through talking to his mother about things that he liked: his music, stories about him at home, [as well as] the way he was.

Similarly, another participant described her belief that parents bring information about children to which nurses may otherwise never have access. Parents contribute in a unique way, bringing their intimate knowledge of the child into situations where nurses have few other cues to the child as a unique person.

In order to know the child, you have to know the family. Like it’s, we rely so much on the monitors and the feedback that we’re getting from the physical needs but I think that the families cue into what isn't happening up on the screen (...) they get that intuitive sense of what's happening for their child.
More than simply seeking information from the parents, one participant described how she looks for children's expression of thoughts and wishes in their interactions with their parents. Children interact with their parents in ways that are different than their interactions with nurses. In this excerpt the participant is describing how children often express thoughts and feelings to parents that they will not or cannot express to nurses. This hints at how the power relationship within nurse-child interactions may shape nurses' particular knowledge of individual children.

[The parent is] a safe person to tell everything to. I've noticed this with kids. It's okay when you're angry with your parents, to redirect the anger from the doctors and the nurses to your parents because that's a safe outlet. They will continue to love you even when you're angry. And you feel safe enough that they won't abandon you, they won't run away, they won't hit you etc., so it's safe enough to express your anger.

Finally, other health professionals, particularly nursing colleagues, were cited by a few of the participants as sources of particular knowledge about children. Although the participants rarely spoke of how particular knowledge is passed from one nurse to the next, this participant stresses how different nurses are differently concerned about passing on information relevant to the unique, human characteristics of children.

On the nursing kardex you can write down what their comfort measures are -- they like their blankey or they [like to be] loved or they don't want to be touched or they are very independent. You can put things down like that, but more often than not I think it gets passed on verbally. I find that for some nurses, that's part of their style. They consistently pass that on. Other nurses never address [these issues], you have to ask them about information for the family, never mind asking them information about the individual child. It's just that they focus very much on the physical aspects of what it says on the flow sheet and, what it says on the kardex and psychosocial need don't enter their or when they're giving report. It might be part of their care when they're actually doing it but when they're actually giving the report they don't pass it on.

**Limits of particular knowledge.** Within the participants' accounts of practice I could discern few limitations to practice based on particular knowledge of children. Most accounts of preserving children's personal integrity upheld particular knowledge as the best source of
knowledge to inform action to preserve children's personal integrity. However, a few participants expressed concern.

One participant expressed concern about the highly subjective and interpretive nature of nurses' knowledge of any child. In the example that she provided, the tensions between generally held beliefs about what is good and right, for some nurses, come into conflict with the particular knowledge of a child.

We put a lot of effort into being aware that they are children and they have needs, they're not just a body with a heart condition. But it's our perspective on what they need as opposed to theirs. [For example, one child] used to like wrestling. If you are three- or four-years-old maybe it's not the best [show] to be watching. But that's what he watches at home. (...) There were a lot of [nurses] who had real issues about this -- how wrong it was for a young child to watch wrestling because it's violent. [But] if you saw the difference in him watching it -- it completely made his day. You take that away from him and he's going to be sitting here depressed. You give him that -- he's happy. Who is right?

In this passage, it is evident that, while some nurses might believe that watching wrestling on television is in itself a threat to this child's developing sense of self, this participant believed that a more important issue was the child's contentment and his opportunities to have continuity in his life. In this instance, different values led to different understandings of the child.

Two of the participants described how they believed that power within nurse-child relationships influences children's freedom to express their thoughts and desires, even when children are able to verbally express what they think. One of these participants describes how, in the initial stages of her relationship with an adolescent girl, she had to persist in encouraging this girl to express her concerns and feelings.

Especially at first when we were getting to know each other, [I would say], "Carmen (pseudonym), I want you to be comfortable. What will make you comfortable?" And you just don't go away; you keep coming back with the same question. She was very shy and very polite. You meet a lot of girls especially who are very polite and that they won't put their needs ahead of you doing your job. They won't interfere. They're going to be good; they don't want to piss anybody off.
The participants’ accounts of the contribution of particular knowledge of specific children to their practice demonstrated the complex and diverse nature of this knowledge. While seen as the most accurate source of knowledge about a child’s wishes and desires, some of the participants were able to articulate how nurse’s individual interpretations as well as power relationships within the nurse-child interaction may shape the nurse the knowledge the nurse creates from that information.

The Dialectic of General and Particular Knowledge

Many of the participants’ stories illustrated the impact of increasingly specific knowledge of individual children on nursing care. One participant described how her knowledge of a child became increasingly specific as she developed a relationship with the child. The child, two and a half-year-old child Jesse (pseudonym), had had heart surgery the previous day. Although sedated and intubated, he was able to interact in various ways with the participant. In the following excerpt the participant describes her initial interaction with Jesse.

I had not met his parents, his mom or dad; I had just met him and got a report from the nurse. Quite early in the morning, he was awake, his eyes were open and he was visually attentive. [If] I would make a sound or make a movement he would watch. He was quite alert so my first way of getting to know this kid was by getting eye contact with him. So I looked at him and he didn't look away. He looked at me so he was willing to connect with me.

The same participant goes on to describe how this early knowledge of Jesse became richer as, over the next hours, she attended to his expressions and gestures, and to his responses to her. In this segment, the participant’s description reveals the dialectic between general and particular knowledge. General knowledge about children’s expressions of fear and pain and about what it might feel like for Jesse to be repositioned in bed is combined with increasingly specific knowledge of his responses.

Quite early in the morning [I] was wanting to turn him from one side to the other and talking to him -- he was paying attention to me -- but he couldn't make any noise because of the endotracheal tube and he wasn't mouthing words. I would ask him questions and I could tell by his facial expression that he was paying attention to me. But I could also
tell by his facial expression that he was frightened. You know he was holding himself stiff, the fact that he wouldn't respond to me [by] nodding or mouthing at that time. (...) The very first time I turned him I told him what I was going to do. And I tried to do it as gently and as comfortably as possibly for him. He did not cry with the turn, it seemed to be that he was okay with it. But I discovered right then that he liked to be touched, you could tell when I had my hands on him that he was less stiff than when I had my hands off him.

The participant continues to describe how, as Jesse gained trust in her and as the relationship between them developed the child’s participation in his care increased.

Later on in the morning he did start to talk to me. He did start to tell me things. (...) Later in the day when I went to turn him again I got very close to him right, in his face, and told him what I was going to do. I asked him if he could help me and he reached up and put his hand onto my shoulder. So I had gone from first thing in the morning where he wouldn't touch me and wouldn't talk to me to later on the morning where he would, so I was getting compliance from him but I was also getting trust from him. I think the reason why I was getting trust from him was because I was getting to know him and he was getting to know me.

This story illustrates a dynamic interplay between the participant’s general and particular knowledge of the child. General knowledge guided the participant’s approach to the child, the child’s responses shaped the participant’s practice, and, as time passed, her care of the child became increasingly specific and sophisticated.

In contrast to general knowledge, which was seen by the participants to provide a strong foundation for nursing practice, particular knowledge of specific children apparently led to increasingly relevant and creative nursing care. The following account by one of the participants exemplifies the way that particular knowledge of a specific child can shape nursing care. In the following excerpt the participant is recounting her experience as a primary nurse caring for a very ill infant with cardiac and pulmonary anomalies. In this story, the participant’s general knowledge about hypoxia, anatomy and physiology meets with particular knowledge of the infant’s unique responses and the family’s unique needs leading to creative and complex decision-making.
Then he started to have these really bad spells and he would just collapse his airway and
would go absolutely black. And you couldn't bag\(^\text{11}\) him or anything. So he was heavily
sedated. I guess I got to know his cues very well. At one point his mom was diagnosed
with post-partum depression. She was sort of a high maintenance parent, she needed a
lot of support and she wanted to hold him a lot and I encouraged her to do that. [In] one
particular situation, she held him and he started to have this spell and the RT [respiratory
therapist] was freaking out and saying, “We've got to put him back in the bed, we've got
to put him back in the bed.” And I said to the mom, “Are you comfortable?” And she
goes, “I don't want to put him back.” And I, I was a little anxious because that's a
completely foreign situation for me (...) to see a child whose basically passing out in
front of your eyes and not whisking him onto the bed. But I knew [there was nothing we
could do.] So mom really wanted to hold him and we let her hold him and he actually
got, was able to get out of this himself.

The actions described by this participant are not actions based solely on general knowledge of
infants and of usual practices in managing respiratory distress. Neither are the actions based
solely on particular knowledge. Rather, this participant’s story reveals how the dialectic of
particular and general knowledge can lead to creative practice; practice that in this case
reinforced connection between mother and infant and avoided an invasive event. Later in the
same interview, the participant describes how a different nurse who had little particular
knowledge of the same infant responded in a completely different way to a similar event.

Somebody was looking after him who [didn't know him well]. They jumped on him,
absolutely jumped on him, and they were like fully resuscitating him. Oh my God, it was
just horrid. The poor mom was standing outside. And he was doing the things that he
normally would do ... he went black and [his heart rate dropped], and that's what he
normally did.

In this example, the nurse had less particular of the child and relied more on general knowledge
-- resulting in a very different practice decision.

The substance of the participants’ actions as they attended to children as individual and
unique human beings, was shaped by both general knowledge and by knowledge of particular
children. The use of this knowledge is a complex process that I have only begun to explore here.

---

\(^{11}\) To “bag” refers to efforts to manually ventilate children using hand ventilation devices.
Agency: The Capacity and Opportunity to Act

The participants' enactment of practice to preserve children's personal integrity is not fully accounted for by thinking about the participants' commitment to act and their knowledge of the child. Within the stories of practice are examples of when participants intended to attend to the human aspects of a child's care but were either prevented from acting or their actions were ineffective. This lack of personal agency, the capacity and opportunity to act in congruence with one's beliefs, was variously attributed to personal and professional inadequacies or to the demands and expectations of the practice environment. Personal agency was enhanced when the participants' were perceived by themselves and others to have the knowledge and skills to act, when they had time and energy to act, and when they had the social and political space to speak and act in congruence with their moral commitments.

Developing Knowledge and Skills

Several participants described specific knowledge and skills, particularly related to communication, that are central to nurses' personal agency. Communicating with children was described by several participants as fundamental to getting to know children and in attending to the human aspects of children's care. For these participants, learning to communicate with children, especially when children are ill or injured, takes time and practice. Discovering the words to use, what to talk about, when to speak, when not to speak with children is an art. One participant explains this phenomena:

It takes a while to learn the words to use. I sometimes hear people saying some things to children that the kids can't possibly understand. For example, "You've got an ET\textsuperscript{12} tube down your throat, we're just going to suction you before you are extubated." Oh yeah, a five-year-old gets that.

Another participant provides an example of the consequences of underdeveloped communication skills for both the child and the nurse. In this story, what might have been a

\\textsuperscript{12} Endotracheal tube
routine oral medication administration turned into a fiasco because of a gap in communication between a child and a nurse.

I was involved with one situation where a nurse came in with a syringe to a little guy -- I think he was about four or five. She came in with a syringe and he just started to cry and [screamed], "NO," and got really upset. She kept saying to him, "It's not a needle, it's not a needle." It is my observation that if she'd actually just taken the time to ask him which way he takes his medicine, [she would have known]. Most kids of that age have had to take some kind of medicine but there are kids that absolutely have to have them in a syringe -- they, squirt it in [their mouths] themselves. If she actually knew ahead of time that this little guy had never really used a syringe before...

As illustrated earlier, some of the participants also articulated their beliefs that they are better able to communicate with some children than others. For personal reasons, whether due to personality or experience, they found their skills in communicating with children of particular age groups or with particular health problems stronger than their skills in communicating with other children.

Two participants identified assertiveness as another communication skill that influences nurse’s agency. Assertiveness was seen as a personal skill, one that nurses can bring to specific practice contexts that creates the opportunity to act in congruence with beliefs about children’s personal integrity. On participant commented:

I think some people just aren't assertive enough. They don't trust their own judgement enough. They're not confident in their skills. (...) I also believe it is cultural as well, I really do. I mean some of our [specific racial group] nurses are very, very timid and they're very quiet and you would never know that anything was going on.

Several of the participants expressed a belief that nursing experience is central to developing the knowledge and skills needed to effectively attend to humanness and personhood of children. They described how, as they gained experience and expertise in practice, their repertoire of relevant skills expanded. One participant recounted her initial months and years as a nurse, and the ways in which her efforts to address her patient’s personhood were less sophisticated than they are now. This excerpt illustrates this participant’s understanding of the process of learning. She believed that she needed to master the technical and organizational
skills involved in caring for seriously ill children before she was able to focus on refining her interpersonal skills.

For the first year and a half, I was still in that student role where I was learning, learning, and learning. I was learning the physical care, the dexterity, the organizational skills, and the documentation. Part of my care was also pain management and helping people to deal with the psychological aspects of injury but when I look back on that, did I know my patients? Not like I do now. It took a period of time for me to get comfortable with my knowledge base, with my skill level and to trust my knowledge base and my skill level and my instinct. So it took time before I could then put my energies towards knowing my patients. And that was developing a level of expertise, and then that became, and I think this was a maturational thing, it was having the confidence to, to do something and if it worked great and if it didn't work to be comfortable with well? Or to say I don't know, do you have any suggestions? Whether it’s to the patient or to the family or to whomever else. So that I think I had to get comfortable with what I was doing and then get comfortable with what I knew ... and then get comfortable with what I didn't know.

This perspective is echoed in the words of another participant who was a relatively new nurse. She comments on how she can still become overwhelmed with the demands of caring for a critically ill child and how that shapes the extent to which she is able to attend to the child’s personal integrity.

If I'm having a very busy day and there's a lot of technical challenges or the patient [is unstable], I'm not thinking about advocating for the child. I'm overwhelmed with what's going on at the moment. I'm not too sure if that's something that experience and time will [change] so I'll be able to deal with everything that's going on all at once.

In addition to experience, one participant believed that education influences the knowledge and skills nurses bring to practice. Alluding to different types of nursing education, she commented, “Your education base as well [shapes your practice with children]. Some of our nurses are very technically based in their care.” None of the other participants addressed the issue of education. Although all but one of the participants have a minimum of baccalaureate education, no specific distinctions were made by the participants about the differences between educational levels.
Finding Energy and Time

Examining personal agency from the perspective of developing knowledge and skills tends to place the onus for personal agency on the individual nurse. In addition to linking nurses’ personal agency with their individual attributes, they also described how characteristics of the practice environment, including demands on time and energy, influenced their practice.

As mentioned earlier, the participants had varying thoughts about the time and energy involved in practices that attend to the humanness of children. Nevertheless, the participants described time and energy as important determinants of whether or not nurses have the opportunity or capacity to attend to children as fully human beings. In part, demands on time and energy were determined by the perceived threat to a child’s integrity and the nature of action required in preventing or minimizing injury to the child’s sense of self and agency.

One participant commented on the time and energy required when the child is able to actively participate in the communication process.

When they're able to talk it's time consuming and it takes a fair bit of effort to connect and to find out about that kid. When they're unconscious and ventilated and everything like that it's easier to ask the parents but when you're really busy it’s also easy to forget.

Similarly, another participant gave an example of the time commitment that can be required when children’s ability to communicate is compromised.

And he was on an alphabet board pointing out letters and I mean most kids you think would just kind of get the basic idea, he would give me ten word sentences. And it was very frustrating for both of us because he was taking up a lot of time that I needed to be doing tasks and he had to spell out all the words.

In addition to time, the participants’ accounts illustrated how work to preserve children’s personal integrity takes energy. One of the participants commented on how shifts in her own energy will influence her practice:

I'm not very good late at night. (...) I'm sorry, I'm tired, I'll do my work, I'll look after the kid and I'll care for the kid, for the patient. But I just can't give that extra. That's just who I am on nights.
Several of the participants spoke of the angst they experience when unable to address children’s needs because of time constraints. One participant described a time when she had a two children to care for, one of whom was physically deteriorating. The other was a sixteen-year-old boy who had just found out he needed a heart transplant.

So, here we have this sixteen-year-old who has this information and who is mulling it over. It’s my first day, I get this double assignment, I am supposed to be trying to get this baby upstairs but he’s getting sicker and sicker and sicker and needing more and more of my time and I’m taking away from this sixteen year old with this devastating diagnosis. And I had no time to go and deal with any of that. (...) He was alone and yet the unit was busy, my kid was crumping\textsuperscript{13} (...) I had no choice but I felt it. I felt bad but I knew that there was nothing I could do.

As in this example, a sense of no control over allocation of nursing staff time was evident in many of the participants’ accounts of their practice. In this instance, this participant’s belief that she has a responsibility to support the older boy collided with the pressing physical needs of the infant. While not disputing that the infant’s physical condition as the priority, her perception that she had to choose between two important practice issues led to great deal of distress for this participant.

Creating Space to Speak and Act

When the participants spoke of creating space to speak and act, the determinants of nurses’ agency shifted further from personal responsibility for nurse’s agency to placing a large portion of the responsibility on the practice environment in which nurses work. In many of the participants’ accounts of practice, having the knowledge and skills as well as the energy and time to attend to children as people was sufficient lead to action. However, some participants emphasized other factors related to the practice environment came to bear and shaped their practice. In particular, I see how at times when practices within the primary and secondary discourses competed for priority, attempts to preserve children’s personal integrity could be

\textsuperscript{13} Two of the participants used the term “crumping” to describe the process of a child’s unexpected physical deterioration.
trivialized and devalued, leaving the participants feeling disempowered and disrespected. One participant summarized her beliefs about the influence of the environment on practice and how it shapes and constrains practice to preserve children’s personal integrity.

When you're giving a child a voice, the environment affects how you are. I absolutely firmly believe that. Because it influences you. You can consciously make the choice about what you're going to be and what you're going to do that day, but it is very hard to [do] that in an environment that's not conducive.

The same participant went on to describe her feelings when her efforts to advocate for a child were dismissed as trite and misguided. She spoke of “that …choking feeling, it’s like you lose your voice.” This silencing of nurses’ voices represents what I see as one of the most severe consequences of the underprivileging of practices within the discourse of treating children as people. As in this example, several of the participants were able to articulate times when their efforts to act to treat children as fully human beings were ineffective or counterproductive because of resistance within the practice environment.

The participants attributed difficulty in finding the political or social space to speak and act as they sought to attend to the human aspects of care to two distinct, yet intertwined factors. First, the participants sometimes found themselves battling a perspective held by many within the practice context that concerns about children’s sense of self or personal agency are trite and inconsequential. At these moments, the participants found themselves justifying concerns about issues such as children’s pain or experience of objectification to their nursing and/or medical colleagues. Secondly, and in conjunction with the first factor, some the participants struggled to make their own voices heard and believed and that the trivialization of their concerns had to do with their own personal attributes and political position within the PICU.

One participant spoke at length about her concern for a particular child and how she struggled to make her voice heard as she endeavored to call attention to a child’s experience of fragmentation of care and severe pain.
I wanted to say, “Come in and see him. We are out in the hall discussing him. You haven’t seen him for yourself. You are relying on my [observations] (...) yet you are not listening.” So what’s the point you sometimes want to say. But on the other hand I will dig my heels in and keep trying.

This participant ascribed her perceived ineffectiveness in addressing this child’s needs to her own personal limitations as well as to the limitations imposed on her by her political position in the specific context.

It’s almost a respect thing. I don’t want to call it that -- I wonder. Because it is not like that with all physicians – with me. It could be very different. They could have even said to me (...) “It’s busy in here and we’ll come back to it”. And I would have been very happy to say, “Great, I’ll be ready and waiting but you know this is really important.” All day yesterday, all last night, and we are going into today and how much further back does this go, this really needs to be addressed... Maybe my approach [should] have been different (...) The outspoken nurse or the nurse that is respected or listened to because maybe they are perceived as having more knowledge or has more of a relationship with the physicians might be listened to. I think if I look at myself in that way -- I think people sometimes think of me as a quiet person.

Confirming the notion that personal characteristics influence whether or not a nurse’s voice is heard, one participant spoke of how she believes she enjoys a relatively privileged position in the unit because of her seniority, experience and personality.

I do think it [the fact that people listen to me] is a reflection of who I am -- who I am in terms of how senior I’ve been, how long I’ve been around and therefore who I know, because I know pretty much everybody. And then also who I am as a personality in terms of assertiveness. (...) Last week I spent three days looking after a patient who is a burn victim and so very complex care, very time consuming and requiring a lot of organization. With him, people like physio, the occupational therapist, the dietitian would come up to me and say, “When were you thinking of doing this? Or when would you like me to come? Or, we did this yesterday, would that work today?” So very collaborative -- where I have (...) seen other situations with a nurse who hasn’t been around as long so the people don't know her as well. They'll come up and say; “I’m showing up at ten.” And so for that reason I think it’s a bit easier for me to organize based on my patient's needs and knowing my patient because it’s unusual for someone to come up to me and say to me, authoritatively, “I’m doing this here”. It’s usually done very collaboratively with me. Or maybe not even collaboratively but a little bit as a request.

Even when able to speak on behalf of a child, the problem of who to convey some concerns to was a problem for some participants. Speaking of the care of an infant with complex health problems, one participant expressed her frustration about the limits to her abilities to
coordinate the various pieces of the nursing care. Specifically, she described her efforts were limited by the way the medical and nursing care is organized in the unit.

I've said it. You can see it. Is anybody actually going to do anything? I don't think -- it's not, it's not that medicine doesn't listen. It's just there is no one person who brings the same thing up everyday, who says this is what is needed for this patient's care. It's a lack of communication because when the three different disciplines are, talking about this patient, they're not talking about the child lying in the bed. They're talking about a body that has this disease. And there's nobody saying, "Well if you leave him go for another two weeks to blow and grow," he's starting to get depressed and he's having all these signs." Why not take that into consideration in your decision making?

Confounding the problem of the nurses' political and social positioning in the unit, several participants described how concerns about how some children in the unit are more readily heard than concerns about other children. Children who have physically recovered and are ready for discharge, as well as children with chronic long-term health problems, tend to occupy a less privileged political position that those with acute, unstable health problems. Describing the general orientation toward children who are less ill, one participant commented "Let's get them out because the next intubated kid is coming in ... And they just get lower and lower in the order of priorities."

In addition, certain families seem able to command a higher positioning for their child. In the following excerpt, one participant identifies this issue. She has just described the care of a Jacob [pseudonym], whose parents, although they cared deeply for their child, lacked the skills to make demands on medical and nursing staff. She contrasted this child's care with the care of another child whose parents were lawyers, well educated and articulate.

I think genuinely they're not the type of people to [make demands about care]. But what I, there's a good example of these parents and another baby that was in the unit at the time. (...) That child technically speaking is the one that should have died, why didn't he die or why did he get the care he got. His parents are lawyers. Jacob was in the unit at the same time. Jacob has much better survival or had a chance to survive. This child

14 "Blow and grow" is an expression that refers to maintaining a child on mechanical ventilation (blowing) while providing enteral and/or parental nutrition (growing) for a period of days or weeks until the child has the capacity to thrive without ventilatory support. Generally, these are infants with chronic lung problems.
doesn’t. (...) [Yet] his parents had the ability to advocate or at least bring a threat by their profession. Whereas with this other little kid, there really, there was none of that.

Although this story may represent an extreme example of the positioning of children within the care priorities of the unit, it illustrates the perception of some of the participants’ that children’s treatment and nursing care is contingent on a wide range of factors.

This analysis of the participants’ accounts from the perspective of creating or finding space to speak or act, opens many more doors for thinking about what shapes actual nursing practice with children. The above examples introduce ideas about nurses’, children’s and families’ relative social and political position in the practice environment – ideas that call for further thinking and additional research.

Summary of Findings

Throughout this chapter I have documented my findings of the participants’ accounts practice as they described their nursing practice in the PICU. As the participants spoke of their practice, it became evident to me that there are varying priorities in the practice environment and this has great influence on nurses’ practice. These priorities can be understood as various discourses. In order to make sense of the participants’ accounts of their practice; I have identified three separate discourses in the practice environment. The first two of these, saving/fixing children’s bodies and facilitating efficient unit functioning, elicit priority in communication, practice and policy. The third discourse, which I have named treating children as people, co-exists with but is subordinate to the dominant discourses of the PICU.

The participants’ beliefs about threats to children’s personal integrity drive the patterns of practice that attend to the humanity of children. The four threats I discerned in their accounts are objectification, separation from family and others, loss of control over self and the environment, and physical pain and intrusion. Based on the participants’ practice in relation to these threats, the discourse of treating children as people can be understood to consist of seven
patterns of practice: engaging in relationships with children, creating tangible reminders of children’s humanity, coordinating care, enhancing children’s control, supporting children’s connections with family and others, minimizing and relieving pain, and mediating painful and invasive events.

Yet, through their stories of caring for children and their families and their general comments about practice, the participants described multiple factors that shape and constrain their actual nursing care in specific situations. In particular, enactment of practice to preserve children’s personal integrity appears to be shaped by the nurse’s commitment to attend to the child’s personhood and to enhance the child’s agency, the nurse’s knowledge of the child, and the nurse’s personal agency in the actual practice context. These findings raise many issues about the topic of the preservation of children’s personal integrity when children are ill and hospitalized. I explore some of these issues in Chapter 5.
CHAPTER 5 DISCUSSION OF FINDINGS

The main findings of this research project were related to the participants’ portrayal of the nature of nursing work to preserve children’s personal integrity and to the multiple factors, both personal and contextual, that influence nurses’ enactment of these practices. As is evident in the research findings, the participants were deeply concerned with attending to children as fully human beings -- with preserving children’s sense of self and enhancing their agency.

In my exploration and analysis of the participants’ accounts of practice I came to understand nurses’ work to preserve children’s personal integrity as all the practices that nurses engage in as they attend to children as fully human beings. It is the work they engage in to treat children as people. The nature of practices in this domain were determined by the participants’ understanding of threats to children’s personal integrity and their beliefs about how best to address those threats. The nature of the participants’ practice as they attended to children as people is the focus of the first section of this chapter.

In spite of their beliefs that practices that attend to the subjectivity of children fall within the domain of nursing work, there are many examples of times when the participants did not enact these practices in the actual moments of caring for particular children. The findings suggest that enacting practice that addresses the human elements of care is contingent on several factors. These include the nurse’s commitment to enact these practices and the nurse’s personal agency within the social and political environment of the PICU. The participants’ commitment to act could be influence by both personal and contextual factors. In addition, in many situations, the participants’ opportunities and capacities to act were shaped by a lack a way communicating these concerns to others and/or the absence of a forum in which to voice their concerns. The second section of this chapter focuses on these issues.

Several participants expressed frustration and distress that occurred when there were gaps between the way they believed they ought to practice, and the ways in which they could or
did practice. This distress was evident in descriptions of feelings of personal inadequacy and/or frustration with others within the practice context. In the final section of this chapter, I discuss the issue of moral distress\(^\text{15}\) as nurses endeavor to attend to children as fully human beings in a context where the priorities are saving/fixing children’s bodies and facilitating efficient unit functioning.

**The Nature of Nursing Practice to Preserve Children’s Personal Integrity**

**Understanding Threats to Children’s Personal Integrity**

The findings of this study suggest that nurses’ practice to preserve children’s personal integrity is patterned in response to their perceptions about threats to children’s sense of self and personal agency; particularly those threats that are posed by serious illness and hospitalization. Beliefs about threats to children’s integrity formed the foundation of the participants’ nursing practices as they sought to attend to children as fully human beings. The findings point to four threats to children’s personal integrity when children are ill and hospitalized. These are the threats of objectification, isolation and separation, loss of control, and pain and intrusion.

The threats to children’s personal integrity described in the findings of this study are similar to those identified in the nursing literature regarding stressors children experience during illness and hospitalization (Hazinski, 1999; Smith & Browne, 1996; Wong, 1995). Separation, pain and intrusion procedures and loss of self-control are consistently identified as causes of psychological stress. Authors of pediatric critical care nursing texts also specifically emphasize the stressors created by the PICU environment. They write about the effects of excessive noise and light, unfamiliar sights and people, overstimulation, and sensory deprivation (Hazinski, 1999; Smith & Browne, 1996). The participants’ descriptions of practice tended to have less of a

---

\(^{15}\) Throughout this chapter, the term 'moral distress' refer to the frustration and anger nurses experience when they are unable to practice in congruence with their values and beliefs about how they ought to practice.
focus on these particular environmental stressors than on the broader issue of the
dehumanization that children can experience in the PICU environment. The problem of
objectification of children, as an influence on nurses’ commitment to attend to children as fully
human beings is addressed later in this chapter.

In a study exploring nurses’ perception of coping behaviors in hospitalized preschool
children, Ellerton, Ritchie, and Caty (1989) described ten nursing actions that enhance
children’s coping. Many of these actions, including ‘enabling control’, and ‘providing
information to child’ are similar to the findings of the current study. In addition, they found that
‘normalization’ and ‘offering rewards’ were nursing actions that enhanced coping. While there
are some significant differences between the concept of coping and the concept of preserving
personal integrity, it is interesting that the findings of these studies have many similarities.
However, Ellerton, Ritchie, and Caty’s study did not emphasize actions that target the practice
environment as a strategy to promote coping. There are many other studies that address
children’s experience of hospitalization (Bossert, 1994; Ellerton & Ritchie, 1994; McClowry,
1988). It may be important that we reexamine what it is that we are looking for when we ask
questions about children’s experiences of illness and hospitalization and engage in an analysis
of how these various perspectives contribute to our understanding of how best to care for ill and
hospitalized children.

The Importance of Family Members

The findings of this study bring attention to the importance of family members in nurses’
work to attend to children as fully human beings. Families fulfill many roles in relation to the
health of their children, most of which cannot be transferred to nurses or other health care
professionals. The participants recognized that the very presence of family members, as the
most important people in children’s lives, may serve to reduce the loneliness and isolation
children experience when they are ill and hospitalized. Secondly, families are able to bring
unique knowledge to the care of the child. This includes knowledge about the individuality, patterns of communication and the wishes and desires of individual children. Finally, the communication between children and their parents and other family members is different than children’s communication with nurses. Consequently, family members may be able to provide insights into fears and concerns of children to which nurses and other health care professionals may never have access.

A body of literature exploring family members’ participation in children’s care has been developed in recent years (Brown & Ritchie, 1990; Callery, 1997; Casey, 1998; Coyle 1995, 1996). This literature has variously examined family participation as a partnership with nurses in the care of the child or as the negotiation of care responsibilities. Coyne (1996) suggests that, over the past two decades, the concept of parental participation in care has “evolved from parental involvement to partnership in care and finally to family-centered care” (p. 738). The current study contributes to this discussion by adding clarity to what it is that parents may bring to the care of a seriously ill child. Most importantly, the findings suggest that family members may contribute knowledge of the child to which nurses may rarely have access and that parents mediate the isolation and separation that may threaten children’s sense of intactness as people.

**Nurse-Child Relationships**

The findings suggest that nurses’ relationships with children are an important consideration when we think about the nature of nursing practice to preserve children’s personal integrity. First, the participants believed that meaningful relationships with children could, in themselves, at least partially mitigate the effects of the objectification of children that tend to occur in the practice environment of the PICU. Secondly, it is within nurse-child relations that much of nurse’s work to attend to the human aspect of children’s care takes place. Thirdly, it is within the nurse’s relationship with the child that particular knowledge of the child is created
and shaped. These three considerations make attention to nurse-child relationships an important issue in this discussion.

Of particular relevance is a belief that some of the participants expressed regarding the importance of being critically reflective in their relationships with children. In particular, they provided examples of how the assumptions nurses tend to make based on their own experience may lead to mistakes in practice with specific children. Jerome and Ferraro-McDuffie (1992) have written about the importance of nurse self-awareness in therapeutic relationships. They emphasize how, nurses' own needs can shape the care they provide children, that these needs "serve as a motivation to care and (...) can skew behaviors, goals, and outcomes of the helping relationship" (p. 153). These concerns of Jerome and Ferraro-McDuffie were substantiated in the comments of some of the participants. These authors call for a more systematic exploration of nurses' motives as they approach care situations. Specifically, they encourage nurses to explore how issues of boundaries and connection, self-esteem, the need for control, and the need for belonging may intrude on the development and maintenance of helping relationships in some very complex clinical encounters.

The findings of the current study support an emphasis on the need for nurses to be self-aware in relationships with children and their families. Self-awareness is, however, only one of the many aspects of critical reflection that nurses need to engage in as they work with children and families. The findings point to the need to be reflective about many issues, including the nature of knowledge used in practice decisions and the impact of the practice environment on their decision making and practice.

**Attending to the Context**

The findings of this study support a perspective on personal integrity that, in addition to being created and sustained in the context of relationships with others (Alderson, 1994; Babbitt, 1996) integrity also shaped by environmental factors. Seen this way, we are led to believe that
not all practice to attend to the human aspects of children’s care takes place in the context of relationships but that this practice includes work that nurses engage in as they shape the practice context. When a nurse prevents a painful experience or challenges others to consider the consequences of their actions, children’s personal integrity may be preserved – even if no relationship between the nurse and the child exists. Using Liaschenko’s framework outlining the various knowledges nurses use in their work, it seems that the knowledge that guides these actions could be considered a sort of ‘case knowledge.’ This knowledge is not purely biomedical knowledge, as Liaschenko suggests case knowledge generally is. However, this knowledge is composed of nursing knowledge drawn from other sources including knowledge of growth and development and of stressors children experience when ill and hospitalized.

In the following sections, I focus my much of my attention on the practice context in which children experience illness and it treatment and in which nurses care for seriously ill children. In the findings of this study, the practice environment emerged not only as a target of nursing action, but as an important determinant of the participants’ practice.

**Constraints on Nurses’ Practice to Preserve Children’s Personal Integrity**

Within the findings are many illustrations of occasions where the participants were unable to voice their concerns about threats to children’s personal integrity. In other instances, they were able to articulate their concerns but their voices were not heard. In this section, I address to important constraints on the participants’ practice in their endeavors to treat children as fully human beings. The first is the tendency to lose sight of the humanity of children. The second constraint is that lack of a language to speak of these issues, a language that is respected and legitimized in the practice environment of the PICU.

**Forgetting that Children are People**

The findings support a perspective that the tendency to objectification within the technologic environment of the PICU, and the resulting dehumanization that children may
experience, influences nurses’ and others’ commitments to attend to the human elements of health care. When children are objectified, nurses to lose sight (however briefly) of children as people. When this happens, motivation to practice to preserve children’s personal integrity may wane.

“Nobody sees this child.” As is evident in this statement by one of the participants, the findings of this study point to tensions between nurses’ belief that that children’s personhood is of concern to nurses and the potentially impersonal and dehumanizing nature of the practice environment. In the midst of a practice environment where attention to children’s physical bodies takes precedence, nurses, like other health care professionals, can find themselves focused on children as objects, losing sight of children’s personhood and their subjectivity. Whether this is an inevitable consequence of working in such a technical environment is a matter of debate.

The technologic focus of nurses’ work in the practice setting of the PICU is cited as one of the reasons for the tendency to objectification of children. The findings of this study show that the issue of nurses’ relationship to technology is an important and interesting one. Several authors have described how the biomedical and technologic focus of health care tends to undermine from the subjectivity of individuals, ultimately reducing people to the status of objects. Gadow (1984) summarizes this perspective:

The ‘reign of technology’, as one historian describes modern medicine, often is assumed to undermine the values of dignity and autonomy. Resuscitation and intensive care measures are cited as examples of the violation technology has spawned. But these measures can be viewed not as new moral problems generated by the rise of technology, but as particularly compelling expressions of the ethical problem inherent in health care in any area, the problem of attending to the “objectness” of persons without reducing them to the moral status of objects (p. 63).

In refuting the notion that technology necessarily leads to the objectification of persons,

---

16 This is not Gadow’s belief, but rather her summary of an argument others have made.
Gadow (1984) and Ozbolt (1996) have suggested that the relationship between technology and care can be seen as dialectic rather than opposing and irreconcilable influences on nursing work. They suggest that a synthesized understanding of the contribution of both technology and care will enhance nursing practice and lead to excellence in patient care. This perspective seems logically possible and presents an optimistic way to envision the reconciliation of technology and care in nursing practice -- one that I believe we should embrace. This understanding extends the finding that the participants' knowledge of children is dialectic in nature and that the participants used both general and particular knowledge in their practice decisions. In addition, it provides a way of thinking that allows us to sustain attention to the priorities of saving/fixing children’s bodies while, at the same time, calling attention to the importance of treating children as people.

In spite of this potential way of thinking about the relationship between technology and knowledge, the problems that the participants encountered in their enactment of practice to preserve children’s personal integrity show the profound influence the dominance of biomedicine and the ‘reign of technology’ on nursing practice. Examining these problems helps me to appreciate how critically important it is to continue to unravel and address this issue if we are to shift toward the excellence Gadow (1984) and Ozbolt (1996) envision.

Sandelowski (1997) has also argued that the relationship between technology and knowledge deserves further attention and that technology is an important, yet often unacknowledged, source of knowledge in nursing practice. She eloquently makes the argument that, in our efforts to elevate the practice of nursing from one of “subservience” and to create nursing knowledge that is separate from biomedical knowledge, be have been tempted to undervalue the knowledge that technology provides.

There remains a pervasive, culturally derived tendency in and out of nursing to ignore, trivialize, and even denigrate procedures involving the hands and devices as nothing
more than medically dependent and robotic techniques to devalue the know-how involved in executing these procedures (p. 70).

Sandelowski’s caution against undervaluing technologic needs to be heeded in drawing conclusions from this research study. We are challenged to articulate concerns about threats to children’s personhood that may, in part, arise from the very technology that is so valuable in the delivery of medical and nursing care to seriously ill children. We need to find a way of speaking about nursing practice that values multiple knowledges, including knowledge of technology.

Liaschenko (1995b) contributes to the discussion about the objectification of persons when they become patients in the health care system. In particular, she draws attention to how nurses’ work is constrained by the practice environment. She suggests that nurses work not only for patients but also for institutionalized medicine, although this is largely unacknowledged. She defines institutionalized medicine as:

The complex interconnected network of cultural beliefs, practices and values about the place of medicine in late twentieth century life, and the research and economic interests, structures and policies that ensure such beliefs and practices are enacted and upheld (p.186).

The findings of the current study begin to suggest how tightly interconnected all of these elements can be in creating a context for practice that makes focusing on individual patients problematic for nurses.

The participants in this study expressed distress about the fact that children’s subjectivity could escape their stream of consciousness and that, at times, they were capable of viewing children as objects. The findings of this study suggest, however, that objectification of children may be predominantly a consequence of the relative privileging of practices related to the technological care and to efficient system functioning over attending to the personhood of children. This is important because it locates the source of the problem not only within the personal characteristics of individual nurses but brings attention to the practice environment as a major contributor to nurses’ decisions and to children’s experiences.
The Lack of a Language to Convey Concerns

When the participants of this study are confronted with issues such as those that arise as they attend to the human aspects of care, they lacked an effective way of communicating those concerns. They seemed to be limited by current ways of addressing issues such as children’s suffering when children’s sense of self is injured and their voices are silenced.

In an ethnographic study of the work of nurses working in adult medical units, Björnsdottir (1998) explored the language nurses use in their communication with others, noting a distinct contrast between what she labeled as the public and private discourses of nursing. The public discourse, as evidenced in nurses’ interactions with physicians, their writing in patients’ charts, and their report to other nurses at shift change, was characterized by an objective and impersonal language and style, and tended to focus on patients’ medical conditions and their treatments. The private discourse, a discourse that had no formal place in the working of the practice environment, was characterized by a much more subjective and personal language and tended to focus on the patients’ personal meanings and the relational aspects of nursing care. The findings of Björnsdottir’s study bear resemblance to the findings of the current study as I have described the dominant and secondary discourses\(^{17}\) of the PICU practice environment. The emphasis on language that Björnsdottir brings to the discussion, particularly how language reflects underlying ideologies and how it shapes what is considered legitimate nursing work, provides a helpful way of thinking about some of the frustrations the participants experienced in making their concerns visible.

The importance of creating a way speaking about ethical concerns of nurses is captured in the words of Liaschenko (1993).

As nurses, we struggle to articulate the ethical concerns in our practice but find we are discounted or trivialized or sentimentalized. This has been damaging to individual

\(^{17}\) I use the term ‘discourse’ to describe the concepts, frameworks, and ways of thinking that take place in the practice environment, as well as all the patterns of communication and practice that shape that environment.
nurses, the discipline of nursing, and patients. It is time for change. We need a moral language that will preserve a sense of the tragic reminding us all that each of us is vulnerable to the contingencies of human life. We need a language that will enable us to sustain our patients and each other; that will serve as the vehicle for our ethical reflection; that will give voice to our ethical concerns (p. 9).

A way of speaking about nursing practice, a way of speaking that articulates our concerns and that is legitimized in the political and economic structures of health care, is an important step making concerns for children’s personal integrity more visible.

Although the participants’ descriptions of their practice as they sought to attend to the humanness of children were passionate and detailed, they admitted that, in the practice environment of the PICU, it can be difficult to justify attention to threats to children’s personal integrity. On the other hand, changes in the practice context may help to create a place where concerns can be heard. How can we construct this language, a way of thinking and speaking that enables us to address the human elements of nursing practice and that compels others to listen?

In the following sections of this chapter I discuss the findings about the nature of nursing practice to preserve children’s personal integrity and explore some of the ethical and moral issues that were so prevalent in the findings of this research. Perhaps by contributing to a dialogue that names the issues and identifies the problems, this project may help in the creation of the moral language of which Liaschenko speaks.

**Nurses’ Moral Agency in Enacting Practice to Preserve Children’s Personal Integrity**

The findings of this study show that, even at times when the participants were able to sustain attention to children as individuals, as fully human beings, their intentions to act to preserve children’s integrity are not always translated into action. They sometimes found themselves in situations where competing demands on their time and energy relegated attention

---

18 My attention was drawn to this excerpt from Liaschenko’s work as I read Rodney’s (1997) dissertation. Rodney used this quote in her introduction to her dissertation as which she explored the ethical concerns of nurses.
to the human aspects of nursing care to a lower priority. They seemed to experience confusion in which they sensed that they are not meeting the child’s needs to the best of their ability, but they are uncertain as to the possible implications of the various courses of action they might take. In addition, expressed distress at the complexity of the circumstances that make patient care decisions difficult. Such experiences can be articulated as challenges to moral agency, the opportunities and capacities of nurses to act in congruence with their moral decisions.

The findings of this study indicate that nurses may experience moral distress because, although they insist that they have a responsibility to attend to their clients as whole persons, to resist objectification and advocate for them, they practice in a context where these practices can be disvalued and the work trivialized. “Moral distress occurs when a moral choice cannot be translated into moral action” (Rodney, 1997, p. 8). When a nurse is unable to provide adequate pain management; when a nurse’s voice is silenced in her efforts to address fragmentation of a child’s care; when social pressure within the practice environment leads nurses to restrict families’ access to their children; moral distress may arise.

Recently, nursing scholars have been examining the topic of moral agency, exploring how personal values, beliefs, and attributes (Liaschenko, 1993; Raines, 1999) as well as the demands of the practice environment (Björnsdottir, 1998; Liaschenko, 1993; Rodney, 1997) shape and constrain nurses’ practice. In a study exploring nurses’ enactment of moral agency in hospital and home care settings, Rodney found that the organizational context of practice created problems for nurses as they sought to act in congruence with their moral and ethical beliefs. Of particular relevance to the findings of the present study, she found that fragmentation of care and the disvaluing of nurses’ work created distress for nurses. In Rodney’s study as well as in the findings of this research, the participants variously attributed their moral agency to personal characteristics or to the characteristics of the practice environment.
Personal Determinants of Moral Agency

In this study, the participants identified a variety of personal characteristics that enhance nurses’ capacity to act on behalf of their patients and to attend to the human elements of care. These included possessing the knowledge and technical skills needed to provide excellent nursing care and having the emotional and physical energy to treat children as fully human beings. One of the skills identified was assertiveness, the ability to command attention from others in efforts to attend to children’s subjective needs. The participants attributed variations in assertiveness to factors such as personality, experience, knowledge, and culture.

Raines’ (1994) research on moral agency emphasized the personal characteristics of individual nurses. She defined moral agency as “action by the nurse based upon self-embodied principles and knowledge to facilitate a perceived positive outcome for the patient, family, or society” (p. 7). She went on to describe four attributes that are necessary for moral agency to exist. These are a privileged relationship, a sense of duty, sound knowledge and courage. These add to the personal characteristics that the participants of this study saw as attributes that enhance nurses’ moral agency. While I think it is important that we continue to think about the influence of personal characteristics, at the same time, I believe that even nurses who embody these characteristics continue to experience struggles in the enactment of their moral agency. Personality characteristics of the nurse are only one part of the equation. The findings of the current study suggest that, in addition to personality characteristics, there are influential contextual determinants of nurses’ moral agency.

Contextual Determinants of Nurses’ Moral Agency

A perspective of individual responsibility for moral agency does not adequately explain those times when the participants expressed distress about decisions for which they felt responsibility but over which they felt they had little control. Participants who valued practices that attend to children’s personhood and enhance their agency, admitted that, at times,
contextual factors influenced their abilities to act in congruence with those beliefs. The findings of this study suggest several themes and patterns within the influence the practice environment that shape nurses' enactment of practice to preserve children's personal integrity. Participants described how constraints on time and resources and the lack of social and political space to speak and act could greatly effect their moral agency. Studies by Liaschenko (1993, 1995b) and Rodney (1997) have reported similar findings and their interpretations of this phenomenon are informative in creating a more comprehensive portrait of how the personal and contextual factors may operate within a complex set of relationships that are, as yet, not fully articulated.

In her study exploring the ethical problems nurses experience in their work, Rodney (1997) identified characteristics of the practice environment that serve to undermine nurses' moral agency. In particular, she found that fragmentation of care, fragmentation of communication, as well as the overall disvaluing of nursing work and the disvaluing of those in need of health care services, hinder nurses from engaging in nursing work.

Liaschenko (1995b) was concerned with the conflicts nurses experience when they are required to act for 'institutionalized medicine', having little or no authority for decision-making in regard to those actions. Liaschenko draws on the philosopher, Elizabeth Woglast's description of 'artificial personhood'. "Artificial persons are those who speak and act for others. (...) Nurses act for patients and they act for physicians and institutions" (p. 186). Being required to act for others becomes particularly problematic when the goals of institutionalized medicine and nursing differ. Liaschenko was concerned with the consequences for nurses when they must act for others (whether persons or institutions), particularly when the goals of the 'other' oppose the goals of nursing. She articulates this concern in the following way.

The work of nursing is embedded in complex institutions and networks of power, in which nurses must act on decisions made by others. These are frequently decisions in which they have no say at all. Because of this, nurses are readily reduced to artificial persons. (...) Being reduced to an artificial person has profound implications for nurses'
moral agency and their integrity, and also for the moral distress, and therefore the harm, they experience. (p. 197).

The findings of this study suggest that many of the issues nurses face in their work can be understood as the consequence of the subordinate positioning of the discourse to preserve children's personal integrity in relation to the dominant discourses of saving/fixing children's bodies and facilitating efficient unit functioning. Liachenko (1995) draws attention to the networks of power within the practice contexts where nurses work. These networks of power can be seen to create and sustain the relative positioning of these discourses. If nurses are to challenge the underprivileging of discourse to treat children as people, they need to develop ways of understanding this influence on their practice and on themselves, and to work toward developing a language that will enable them to express these concerns and will compel others to listen.

**Summary**

The findings of this study begin to address some of the issues that face nurses as they enact practice to preserve children's personal integrity. In this chapter I have highlighted three aspects of the findings: the nature of nursing practice to preserve children's personal integrity, nurses' commitment to the preservation of children's personal integrity, and nurses' moral agency in the enactment of practice to preserve children's personal integrity. We need to continue efforts to create a language through which we can articulate our concerns about children's personal integrity, and about nurses' experience of moral distress in the enactment of this practice. Perhaps the findings of this study contribute to those efforts.
CHAPTER 6 SUMMARY, CONCLUSIONS, AND IMPLICATIONS

Summary of the Study

The purpose of this study was to explore nurses’ perceptions of their practices related to the preservation of children’s personal integrity. In coming to this study, I was influenced by my own experience as a pediatric critical care nurse and by my beliefs that children are an oppressed group; a group whose oppression is magnified when they are ill and hospitalized. If personal integrity – children’s sense of self and personal agency – is an important component of health, and if personal integrity is threatened by the inherent and structural characteristics of childhood as well as by serious illness and hospitalization, then nurses have both opportunity and the responsibility to attend to children’s sense of self and to work to enhance children's agency during times of serious illness and hospitalization. The findings of this study focused on the participants’ perceptions of threats to children’s personal integrity when they are seriously ill, the practices of these nurses as they address these threats, and the influences on nurses' enactment of the practices in the environment of the Pediatric Intensive Care Unit (PICU).

Nine nurses who care for children in a tertiary care PICU participated in this study. To gain access to their accounts of practice I interviewed each participant, initially focusing on how they come to “know” individual children and their practices addressing the preservation of children’s sense of self and the enhancement of children's agency. As the study proceeded, the interviews increasing focused on how these practices are shaped and constrained within the practice environment of the PICU.

The findings of this study showed that the participants engaged in a variety of practices intended to protect children’s sense of self and enhance their agency. However, the enactment of these practices in the actual moments of nursing was contingent on three factors: the nurse’s commitment to action, the nurse’s knowledge of the child, and the nurse’s personal agency.
Each of these factors was influenced by the priorities of the practice environment. Although the participants believed that practices attending to the human elements of care are important, within the PICU were seen as less important than practices related to fixing/saving children's bodies and facilitating efficient unit functioning.

**Study Conclusions**

The following represent what I see as the most important conclusions to be drawn from the findings of this study.

1. Nurses in this study believed that they had a responsibility to attend to children as whole human beings, deserving of dignity and respect. They believed that the issue of children's personal integrity deserves explicit attention, and that practices related to preserving children's personal integrity should be examined.

2. The nurses in this study believed that practices related to preserving children's personal integrity, although important, are not valued and rewarded in the practice environment of the PCIU. When attending to children as fully human beings competed for time or priority with the work of saving/fixing children's bodies or keeping the system running, the participants faced ethical challenges. At these moments, practice to preserve children's personal integrity could be suppressed or rendered invisible.

3. The participants themselves experienced distress when they were prevented from acting in congruence with their beliefs about threats to children's personal integrity. This distress arose when the nurses' intentions to attend to children's personhood were trivialized, or when the nurses' work to save/fix children's bodies and facilitate efficient unit functioning consumed all of their time and energy, detracting attention from the more human elements of practice.

4. The substance of practice decisions as the participants attended to the human aspects of care was shaped by the nurse's general knowledge (knowledge the nurse brings to the
particular situation) and the nurse’s knowledge of the particular child (the nurse’s knowledge of the specific child). The process of decision making can be characterized as a dialectic between general knowledge and particular knowledge.

5. Although the participants engaged in a variety of practices they believed attend to children’s sense of self and enhance children’s agency, they lacked a language that values these practices and enables the communication of these practices to others.

Implications

The findings of this study have implications that are important for nursing practice, education, and research. In addition, if nurses’ practice to preserve children’s personal integrity is to be promoted and supported in hospital settings, then we must also consider the implications of these findings for hospital administrators.

Implications for Nursing Practice

The findings of this study summarize the participants’ accounts of their practice to preserve children’s personal integrity. Naming the threats to children’s personal integrity that the participants identified and discussing practice issues related to these threats may be a beginning step in making these practices more visible and in challenging the current social and political structures of the PICU.

Few practice standards exist that address the patterns of practice to preserve personal integrity. This study found that the participants engaged in seven patterns of practice as they worked to preserve children’s sense of self and enhance their agency. These were (a) engaging in relationships with children, (b) creating tangible reminders of children’s humanity, (c) coordinating care, (d) enhancing children’s control over self and the environment, (e) supporting children’s connections with family and others, (f) minimizing and relieving children’s pain, and (g) mediating painful and intrusive events. These practices compose a large part of nurses’
work. Yet, with the exception of guidelines and policies addressing pain management, these practices exist outside of nursing work that is legitimized by institutional and textual practices.

The findings of this study call attention to the import role of family members, particularly parents, if children’s personal integrity is to be preserved during illness and hospitalization. Facilitating the presence of family members, and enhancing the child’s connection with family and hearing the family member’s concerns are important nursing practices in the preservation of children’s personal integrity.

Consistently engaging in these practices in day-to-day work in the PICU was a challenge for many of the participants. The enactment of practice is complex, shaped by an array of personal, relational and environmental factors. It is important that nurses develop strategies that assist them as they engage in practices to preserve children’s personal integrity. Nurses need support in developing and utilizing thinking skills to critically analyze practice issues.

In addition, within the current health care climate, nurses are being asked to increase efficiency and to minimize costs. Nurses may find themselves increasingly expected to focus on the provision of technically excellent care and to facilitate efficient unit functioning. As this happens, the time and energy nurses can devote to practices addressing children’s personal integrity may be significantly decreased. To prevent this from happening, nurses may need to find a collective voice to speak about these practices, in order to make children, families, and other health care professional aware that these compose an important part of nursing work; work that is vital to the health and well-being of seriously ill children and their families.

Implications for Nursing Education

The implications of the research findings for nursing education are far reaching. There are knowledge and skills nurses need if they are to enact practices that attend to children’s personal integrity. The findings show that nurses base their practice to preserve children’s personal integrity on their beliefs about threats to children’s sense of self and agency. Educators
need to be concerned about nursing students’ and practicing nurses’ knowledge about these threats, raising awareness theoretical and research literature that may guide this practice. In addition, educators need to consider how to enable nurses to critically reflect on the interpretive nature of their understanding of threats to children’s personal integrity and to examine the impact of their practice decisions.

I am concerned that, although nurses are taught to attend to clients as fully human beings, the reality of practice for nurses in this setting is that the practice priorities are the provision of technically excellent care and facilitating efficient unit functioning. Nurses need to develop skills to address institutional issues. Nursing students and staff nurses need education that provides the knowledge and skills needed to engage in ethical analysis of institutional practices, to make ethical arguments, and to act politically if they are to begin to tackle these complex issues.

**Implications for Nursing Research**

How children respond to threats to personal integrity is an important question, one not addressed in this study. We have little empirical knowledge about children’s suffering during times of serious physical illness and hospitalization. In particular, we have little knowledge about how and when threats to personal integrity result in injury to children’s sense of self. This is particularly problematic with infants and younger children who, according to developmental theory, have a relatively undeveloped sense of themselves as separate and autonomous persons. Further research with nurses and children, including research that specifically explores differences between age groups, would add to our understanding of this issue.

It seems clear however, that in addition to documenting threats to children’s personal integrity and children's responses to these threats, we need research that explores structural and other interventions that may increase the probability that nurses can attend to children’s personal integrity. This may include research exploring how staffing ratios, unit communication
strategies, and the organization of nursing work (primary nursing, team nursing or case management) influence nurses’ practice.

We have not documented the human and economic costs of failing to attend to children’s personal integrity. At this point we rely on philosophic or anecdotal accounts of the consequences of injury to children’s sense of self and personal agency to guide our practice. The overall costs to our society are unknown. Research into these costs may provide a more compelling justification for increasing resources to support nurses’ work.

**Implications for Hospital Administration**

If any change in to take place in the practice environments in which nurses work, we need hospital administrators who have concerns that extend beyond the medical, economic and legal issues that predominate contemporary health care delivery. We need administrators that are concerned about the human dimensions of illness experiences. The profound impact illness and hospitalization on children seems clear, yet justifying attention to this issue is difficult.

Nurses need strong advocates for their work as they endeavor to attend to children as fully human beings. For this reason, the declining presence of nursing in administrative positions creates cause for concern. We need to ensure that there are practice leaders in the visible, accessible roles to support nurses, particularly nurses new to the profession, as they learn to enact complex roles such attending to the personal integrity of children.

**Conclusion**

In this study I investigated nurses’ perceptions of their practice to preserve children’s personal integrity. The participants concurred that this discussion is important, and were able to articulate practices that they believed attended to the personal integrity of children. The main findings of the study included a description of the participants’ beliefs about their practice to preserve children’s personal integrity and the challenges they face in the enactment of these practices. If nurses are to be supported in attending to the human elements of health care, then
we need to draw attention to some of the contradictions that make that work difficult. If change is to occur, practicing nurses, nurse educators, nurse researchers and hospital administrators have a responsibility to attend to issues that face nurses as they seek to enact their practice to reserve children’s personal integrity.
REFERENCES


APPENDIX A: PARTICIPANT INFORMATION LETTER
UBC School of Nursing Letterhead

Study: Exploring Nurses’ Perceptions of Preserving Children’s Personal Integrity

For my UBC Master’s degree thesis, I am conducting a study to learn about the ways that pediatric nurses care for children in order to preserve the personhood of children. I am aware that many nurses develop relationships with particular children that allow them to incorporate each child’s wishes and desires into decisions about nursing care. I am interested in this study because I believe that increasing understanding about these practices will provide guidance for other nurses and bring attention to the ways in which the health care context may prevent nurses from engaging in these practices.

This letter is to ask you to consider participation in this study. Participation would involve two meetings with me at a convenient time and place. In an initial interview lasting one to one and a half-hours, I will ask you about your experiences working with children, about children that you have come to “know” as persons. The interview will be audiotaped to ensure accurate data collection. The second tape recorded meeting will take about one hour of your time. The purpose of the second interview will be to share results to date, including results from other interview and ask you to comment on and clarify my interpretations.

Confidentiality of participants will be maintained; name or inference in any reporting will not identify participants. Code numbering will identify the tapes and only I will be aware of which tape corresponds to which participant. The code numbering and tapes will be kept in a locked filing cabinet. The tapes will be listened to by a typist, one professor who is supervising my study, and myself.

Participation is completely voluntary; no one is under any obligation to participate. Participation is in no way part of employment at the hospital; nor will it have any affect on the participant’s employment. Participants will be asked to sign a consent form at the first meeting to indicate willingness to participate and be audiotaped. Participants are free to refuse to participate in specific parts of the interview. Participants will be asked for some demographic data, such as years of experience and educational background. Demographic data and results will be reported in my master’s thesis and may be reported in professional publications and at professional conferences. Participants can decide to withdraw consent at any time without penalty.

The potential benefits of participating in this study include an opportunity to share with colleagues your expertise in nursing practice with children.

If you are interested in participating or have any questions, please call me at xxx-xxxx or my thesis chairperson, Dr. Sally Thorne, at xxx-xxxx. Thank you for considering participation in this study.

Sincerely;

Gladys McPherson, RN, BScN

BRITISH COLUMBIA INSTITUTE OF TECHNOLOGY
APPENDIX B: PARTICIPANT INFORMED CONSENT FORM
UBC School of Nursing Letterhead

Study: Exploring Nurses’ Perceptions of Preserving Children’s Personal Integrity

Student Investigator: Gladys McPherson, UBC Graduate Student Thesis,

Purpose
The purpose of this study is to explore pediatric nurses’ perceptions of preserving children’s personal integrity when children are ill and hospitalized. In particular, through interviews with experienced pediatric nurses the researcher will explore these nurses’ perceptions about how they come to know particular children and how they use this understanding in their nursing practice with those children.

Study Procedure
I understand that I will be asked to participate in two one to one and one half-hour meetings with Gladys McPherson, for a total of two to three hours. These meetings will be conducted outside of working time, at mutually convenient times. These meetings will be audiotape recorded. I am also aware that I can ask questions of the researcher during the interview process. I understand that the researcher’s interpretations of the data will be shared with me during the process of analysis and that I will have opportunity to clarify findings and may have input into the interpretation of the results.

Confidentiality
I know that my identity will be protected by code numbering of the tapes and that the only person having access to the code numbering is Gladys McPherson. The tapes will be kept in a locked filing cabinet. I am aware that a typist transcriber and two professors who are members of Gladys’ committee will have access to the anonymous tapes and transcripts. In addition, any persons I mention on the tapes will not have their identity revealed at any time. At any time during the process, I can refuse to answer questions, and/or request that the tape be turned off or erased. I can also end my involvement in this research project at any time.

Contact
If I have any questions or desire further information with respect to this study, I may contact or Gladys McPherson at xxx-xxxx or her supervisor, Dr. Sally Thorne at xxx-xxxx.

If I have any concerns about my treatment or rights as a research subject, I may contact the Director of Research Services at the University of British Columbia, Dr. Richard Spratley at 822-8598.
Consent
I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time.

My signature indicates that I give permission for the information I provide on tape during the interviews to be used in teaching materials, research journals, books, or articles.

I have received a copy of this consent form for my own records.

I consent to participate in this study.

Signature of participant Date
APPENDIX C: DEMOGRAPHIC DATA FORM

Study: Exploring Nurses’ Perceptions of Preserving Children’s Personal Integrity

Current position: 

Educational background: 

Other areas of nursing experience: 

Total years in nursing practice: 

Total years in pediatric nursing practice: 

Experience as a parent 

APPENDIX D: SAMPLE INTERVIEW GUIDE

Study: Exploring Nurses’ Perspectives of Preserving Children’s Personal Integrity

Guide to the first interview

1. Would you tell me about an experience caring for a child where you feel you really got to know that child?
   - Describe the situation.
   - What was happening for the child? Did you have a sense of what this child was thinking/feeling?
   - What role did the family play?
   - How did this understanding influence the care you provided to that child?
   - What factors made it possible/not possible to incorporate this understanding into your care?
   - How did that child’s health condition shape your ability to get to know that child?

2. Tell me about a time when developing a relationship with (getting to know) a child was difficult or impossible.
   - What made the situation difficult?
   - What were the consequences for the child?
   - What were the consequences for you?

3. Is there anything else you could tell me about your practice with children, particular the ways in which you get to know particular children?

Guide to the second interview

(In this interview, clarification of previous data, testing of conceptualizations will take place. The following are examples of questions that may be used.)

1. Would you be willing to talk to me about the child you cared for during your last shift in the pediatric intensive care unit?
   - Who was that child?
   - What did he/she want, think, and feel? How did you know?
   - How did this understanding influence the care you provided to that child?
   - What factors made it possible/not possible to incorporate this understanding into your care?

2. Since we last talked, have you had any further thoughts or ideas about your practice with children, particularly the ways in which you get to know individual children?