IN SEARCH OF WHAT IT MEANS
TO PRESCHOOL CHILDREN TO BE ILL

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degree of Doctor of Philosophy in Nursing at the
University of Newcastle

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STATEMENT OF ORIGINALITY

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.

ACKNOWLEDGEMENT OF AUTHORSHIP

I hereby certify that the work embodied in this Thesis is the result of original research, completed subsequent to admission to candidature for the degree.

Signature:  Date:

Paul Barry Watson
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# TABLE OF CONTENTS

Statement of originality................................................................................................... i

Acknowledgement of authorship .................................................................................... i

Acknowledgements ........................................................................................................ ii

Table of Contents .......................................................................................................... iv

Abstract ........................................................................................................................ vii

Key to transcripts .......................................................................................................... ix

Editorial style ................................................................................................................... x

Chapter One ......................................................................................................................... 1

The importance of preschool children’s experience of illness................................. 1

Children’s voices in health care .................................................................................... 2

Children’s voices in nursing care ................................................................................ 7

Children’s use of health services in New Zealand ....................................................... 11

Children’s voices in health research ........................................................................... 13

In search of what it means to preschool children to be ill ........................................... 15

Chapter Two ....................................................................................................................... 20

Behavioural revelations of what it is like for children to be ill ................................. 20

The effects of hospitalisation on children ................................................................. 21

The effects of illness on the mental life of children ................................................... 22

The effects of illness on children’s behaviour ......................................................... 25

Chapter Three .................................................................................................................... 33

Cognitive revelations of what it is like for children to be ill ....................................... 33

Preschool children’s ‘cognitive’ conceptions of illness ............................................. 33

Methodological critique ............................................................................................... 65
Insights and implications from the inside-out ............................................................... 178

Children’s experience of illness.................................................................................... 179

Researching with preschool children ........................................................................... 189

Appendix One: University of Newcastle ethics approval ................................................. 195

Appendix Two: Canterbury Ethics Committee approval .................................................. 196

Appendix Three: Plunket Ethics Committee approval .................................................... 197

Appendix Four: Study advertisement .......................................................................... 199

Appendix Five: Community newspaper article ............................................................. 200

Appendix Six: Information sheet .................................................................................. 201

Appendix Seven: Information booklet .......................................................................... 204

Appendix Eight: Consent form ...................................................................................... 224

Appendix Nine: Child protection letter ......................................................................... 226

Appendix Ten: Confidentiality agreement ..................................................................... 227

References .................................................................................................................... 228
ABSTRACT

Preschool children frequently experience illness and consequently are significant users of health services. Despite children’s rights, children’s understandings of illness are rarely given due consideration in health care. Nursing practice tends to rely on adult accounts of the child’s illness. Children’s limited language ability is seen as a barrier to understanding their views. Thus this thesis is a search for what it means to preschool children to be ill.

Careful analysis of the behavioural and cognitive literature on preschool children’s understandings of illness reveals a dependence upon abstract adult models of illness as a point of comparison. Despite being marginalized in the literature children’s kinaesthetic, intersubjective, situational, and spatial understandings of illness are uncovered.

Existing research methodologies present barriers to understanding the world as children do. Drawing on the writings of Maurice Merleau-Ponty, Eugene Gendlin and other phenomenological scholars a new ethnographic phenomenological methodology is detailed. This methodology reveals a relational edge from which adults can begin to understand the world as children do.

The methodology was used to identify how preschool children experience being ill from short-term illnesses and how they communicate those experiences to others. Field data was collected from 49 close observations with 10 children and eight parental interviews. Using field data and contemporary research, I explicate my thesis that preschool children understand illness inside-out, unimpeded by others. I examine how
children, initially devoid of boundaries between inner and outer, and in advance of what they can say, articulate their meaning ('inside’ experience/body sense) of the illness through movement and gesticulation (out) as expression. This inside-out expression of the illness experience is unimpeded by others. Adults in intimate situations with ill children can begin to understand children’s experience of illness by focusing on their own body-sense, which is related to the child’s body sense, because there is an incomplete differentiation between self and other.

Knowing that children understand illness inside-out helps to understand the nature of preschool children’s experience of illness. Such understandings should influence adult interactions with sick children.
KEY TO TRANSCRIPTS

In my thesis I use the following conventions when presenting excerpts from my close observation with children or interviews with parents:

P P in the left hand margin represents me (the initial of my first name).

Initial Any other letter in the left hand margin represents the initial of the pseudonym used for the particular participant(s) involved in the close observation or interview.

Names Pseudonyms are used to identify all study participants or other people referred to in the transcripts.

Bold The children’s verbal content is always in a bold font.

Superscript Nonverbal behaviour is presented in \textit{superscript and in italics} and placed either to the left or the right of the verbal content to reflect its temporal relationship to the verbal content in the context of the interaction.

[-?-] or Indicates a word or phrase too faint, garbled, or obscured to transcribe.

[-?-?-?] The number of question marks suggests the possible number of words.

(( ))) Represents either my thoughts at the time or content added by me to provide clarity or explanation.
EDITORIAL STYLE

This thesis applies ideas from a number of long and complex texts. Consistent with the fifth edition of the *Publication Manual of the American Psychological Association* (p. 121) where I have paraphrased an idea contained in a long text, I have tended to include the page number(s) in my reference to the source in the text of the thesis, in order to aid the interested reader in finding the relevant section.
CHAPTER ONE

THE IMPORTANCE OF PRESCHOOL CHILDREN’S EXPERIENCE OF ILLNESS

All beginnings are hard. I can remember hearing my mother murmur those words while I lay in bed with fever. ‘Children are often sick darling. That’s the way it is with children. All beginnings are hard. You’ll be all right soon.’ (Potok, 1975, p. 3)

Fortunately, like most children, I had learned what is most valuable, most indispensable for life before my school years began. (Hesse, 1945/1973, p. 3)

My interest in how children experience being ill and how they communicate their experience of being ill to others was stimulated by my experiences as a father of two boys and as a registered nurse caring for acutely ill children and their families in a variety of hospital settings over a number of years. The children were commonly preschool children (birth to 4-years-old),¹ who required special attentiveness in order to tailor care to their needs. To orientate the reader to the context for this study I turn to a few of my experiences nursing children and some of the wider socio-political and theoretical factors that influence nursing practice with children in New Zealand.

¹ In New Zealand most children begin school on their fifth birthday although school attendance is not compulsory until the sixth birthday.
I recollect completing a routine preoperative checklist with a child (approximately 8-years-old) and his mother, and asking the mother whether the child was allergic to anything. The mother said “no”, but the child interrupted, saying something like “what about at the party when I was blowing up the balloon?” The mother shrugged off the child’s comment as not important. However, I asked the child to tell me more and he mentioned having tingly lips after blowing up a balloon. I explained to the mother and the child the possible significance of the tingly lips as a sign of an allergy to latex. The anaesthetist was informed; precautions against exposure to latex were taken during the operation and the remainder of the child’s stay in hospital. Subsequent testing confirmed a latex allergy.

I was surprised the boy had made a connection between my question to his mother about allergy and his experience of tingly lips after blowing up a balloon. On reflection, I was surprised because I did not expect a child of that age to make such a connection or to understand what an allergy was, or understand what the signs of an allergy might be. Unfortunately, I never asked the child why he mentioned the tingly lips, or whether he knew it might be a sign of an allergy. This incident highlighted two things for me. Firstly, children frequently surprise me, perhaps because I underestimate their competence. Secondly, the importance of involving children in their health care, including ensuring their voice is heard and given due weight.

When I was planning this research, public awareness about children’s rights in relation to their health care was on the rise in New Zealand. This was in part as a result of
media publicity about two high profile cases involving the treatment of children with cancer ("Further ethical debate after Liam's death could help save lives," 2000; "Son with cancer tried to jump from moving car - mother," 2000). Consequently, there was public and professional debate about children’s rights to be heard and to have their needs treated as paramount (Henaghan, 2001). Cases of child cancer such as those discussed in the media are relatively rare. Short-term passing illnesses are much more common among children. However, children’s right to be heard and to have their needs treated as paramount exists regardless of the cause or outcome of their illness.

The Child Health Strategy (Ministry of Health, 1998b) which forms the basis of the New Zealand Government’s plans for improving child health through to 2010, is framed around a vision of “our children/tamariki: seen, heard and getting what they need” (p. 17). This vision is consistent with Article 12 of the United Nations Convention on the Rights of the Child (United Nations High Commissioner for Human Rights, 1989). Under Article 12 of the Convention, States that have ratified the convention and therefore are party to the Convention have agreed as follows:

States Parties shall assure to the child who is capable of forming his or her own views 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. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the

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2 Tamariki is the Māori word for children and Māori are tangata whenua (the indigenous people) of Aotearoa New Zealand.
child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law. (United Nations High Commissioner for Human Rights, 1989, p. 4)

Thus, the Convention guides health professionals to treat children as people with a right to be heard (Lansdown, 1994; Melton, 1998).

The United Nations Convention on the Rights of the Child is central to the international movement on children’s rights. Those rights include the provision of health care, protection from harm, and full participation in decisions that affect their lives. The Convention was adopted by the General Assembly in 1989 and ratified by New Zealand in 1993. Subsequently, the children’s rights movement is starting to have an impact on practices in the New Zealand justice, social welfare and education systems (Atwool, 1998, 2000; Carr, 2000; Smith, Gollop, & Taylor, 2000; Taylor, Gollop, & Smith, 2000). However, in relation to children’s health, little has changed since McDowell’s (1997) claim that there was scant evidence of children’s rights affecting practices in the New Zealand health care system (Children's Commissioner, 2006).

In New Zealand some legislative support for article 12 of the United Nations Convention on the rights of the child is provided through Section 74 of the Health and Disability Commissioner Act ("Health and Disability Commissioner Act," 1994) pursuant to which regulations have been promulgated prescribing a Code of Health and Disability Services Consumers’ Rights (1996). The Code applies to the provision of all health and disability services in New Zealand, regardless of whether they are provided to children or adults. The Code therefore provides regulatory protection for the rights of children as
consumers of health and disability services. The rights identified in the Code relevant to this discussion include:

- The right to be treated with respect (right 1), which includes the right to be provided with services that take into account the needs, values and beliefs of different cultural, religious, social and ethnic groups, including the needs, values, and beliefs of Māori (right 1 (clause 3)).

- The right to have services provided in a manner that respects the dignity and independence of the individual (right 3).

- The right to effective communication (right 5), which includes the right to an environment that enables both consumers and provider to communicate openly, honestly, and effectively (right 5 (clause 2)).

- The right to make an informed choice and give informed consent (right 7) which includes a presumption of competence, unless there are reasonable grounds for believing that the consumer is not competent (right 7 (clause 2)). Furthermore, individuals who have diminished competence are extended the right to consent, to the extent appropriate to his or her level of competence (right 7 (clause 3)).

One message for providers of child health services within these regulatory rights is that they have a duty to seek and take seriously the views of children in matters concerning children’s health.

Despite these regulatory rights, the United Nations Convention and the vision for child health, children are rarely consulted as health care consumers (Coyne, 2006; Dickinson, 2004; Hart & Chesson, 1998). Not only are children rarely consulted as
consumers, but historical, and to a large extent contemporary clinical practice in child health has relied on adults, usually a parent, to give an account of their child’s illness experience.

At first it seems eminently reasonable for health professionals working with children to rely on parents’/caregivers’ accounts of their child’s illness. After all, parents/caregivers have privileged access to their children’s life experiences and they tend to know and understand their children well (van Manen & Levering, 1996a). However, the assumption that parental/caregiver’s accounts of the child’s illness experience coincide with the child’s experience or the child’s account is questionable. Furthermore, parents/caregivers come to know and understand their children through interaction with their children. Most research on parent-child interaction has utilised a unidirectional approach focusing on the effects of parents on children. Since Bell’s (1968) influential work investigating the effects a child has on a parent, more research has focused on the extent to which the child has an effect on the parent. Bell argues that a unidirectional approach focusing on the effects of parents on children is inadequate and proposes instead an approach that also recognises the child’s effect on the parent. Such an approach is consistent with the research evidence and a philosophy that sees children as social actors and not simply as passive objects in a process of adopting an adult culture. Therefore, in the context of illness, children are presumed to have some role in shaping interactions with others. That is, children both shape and are shaped by contexts that include others.
(especially family / whānau\(^3\)) who share a particular setting in a particular time (Graue & Walsh, 1995; James, Jenks, & Alan, 1998).

The dominant perspective that regards children as developmentally immature and unable to understand and describe their world and life experiences might also contribute to health professionals’ reliance on adults’ accounts of children’s illness experiences rather than the accounts of children themselves. While children’s biological immaturity is a fact, the way in which that immaturity is understood and enacted is socially and culturally constructed (Prout & James, 1997). The view that preschool children are unable to understand and describe their world and life experiences is not supported by research evidence. Research demonstrates that under some conditions children under 5-years-old and as young as 2-years-old can recall, quite accurately, information about personally experienced events (Docherty & Sandelowski, 1999; Fivush, Gray, & Fromhoff, 1987; Fivush & Hamond, 1989; Follmer Greenhoot, Ornstein, Gordon, & Baker-Ward, 1999; Liwag & Stein, 1995; Merritt, Ornstein, & Spicker, 1994; Ornstein, Gordon, & Larus, 1992).

**CHILDREN’S VOICES IN NURSING CARE**

In a nursing context, the meaning of the illness experience from the child’s perspective can be more important than the accuracy of their account of the specific events that were part of that experience. Van Manen (1999) stresses the pathic nature of nursing practice, which focuses directly on the ill person rather than the diagnostic or prognostic

\(^3\) Whānau is Māori for family but its meaning goes beyond Western definitions of family, see Metge (1995).
aspects of the experience. Similarly, Gadow (1995) argues for the centrality of the patient’s meaning of the illness experience in nursing assessment. The meaning of the illness experience from the child’s perspective is also relevant within the medical context. Wulff (1995) distinguishes four components used by physicians in making clinical decisions: the biological, the empirical, the empathic/hermeneutic, and the ethical component. The empathic/hermeneutic component acknowledges that the state of illness cannot be identified without attention to “the patient’s personal experience of the symptoms in the context of his or her own life” (Wulff, 1995, p. 305).

Reports by patients of their experiences of illness are a practical and integral part of the data interpreted by health professionals in the process of making clinical decisions (Good & Good, 1981). Adult accounts of children’s illness experiences in child health care are undoubtedly significant to clinical decision-making. However, Ireland and Holloway (1996) have argued that to focus on adult accounts of children’s illness to the exclusion of the child’s perspective might prevent health professionals from obtaining important and relevant information. This is not an argument to exclude adult accounts of children’s illnesses. Rather, it is an acknowledgement that adult accounts of a child’s illness provide only part of the picture. The missing piece of the puzzle is the child’s perspective which should be obtained and given due weight in clinical decision-making.

Nurses’ reliance on adult accounts of children’s illness experiences might also reflect their commitment to family-centred care. The concept of family-centred care is widely regarded as fundamental to the provision of nursing care to children; at home, in the community and in hospital (Darbyshire, 1995; Nethercott, 1993). The orientation of child
nursing towards the family can create a paradox between the rights and needs of the child and the rights and needs of the family. There is no question that nursing children requires a strong orientation towards caring for the child and the family / whānau. However, very little of the literature on family-centred care acknowledges that the best interests of the child should be the primary consideration and might not always be addressed by focussing on the family rather than the individual child.

These theoretical issues about children’s experience of illness, their ability to communicate their experience, and adult parents’ accounts of their children’s experience have practical consequences, as the examples below demonstrate. In the paediatric area where I worked, calico cloth dolls were available to be given to the children or used in ‘play therapy’. When I first started using these dolls with children, I would draw a face on the doll and place it on the child’s bed before they were admitted to the room. Within a short time I decided not to draw anything on the doll but rather leave some marker pens next to the doll and tell the child they could draw on the doll if they wanted. It was common for children to draw facial features on the doll but the less common features often proved informative. I remember a child with acute abdominal pain drawing a “tummy button”. Another child who I did not know very well, but who had a chronic condition and spent a lot of time in hospital, drew a hot rod car on the body of the doll. Hot rods were a key interest of the young boy. Thus, the children sometimes used the drawings on the dolls as a way of communicating things about themselves.

While working in a children’s acute assessment area I routinely used the calico doll as a model, involving the children in a demonstration and explanation of procedures the
child was to experience (e.g. the insertion of an intravenous catheter or a lumbar puncture). I usually found this an effective means of explaining and demonstrating to children and parents what was going to happen to them. I say, usually, advisedly, because of two experiences that stand out. One, in which the mother told me she didn’t think it would work with her child and might be worse than not telling her anything. I demonstrated the procedure despite the mother’s advice and the child was certainly very distressed during the actual procedure. This experience reminded me of the expertise parents have in relation to their own children and the harm that can be done when that expertise is ignored (Benner & Wrubel, 1989). The second experience occurred following the insertion of an intravenous line and while taking a blood sample. The young child said to me “you didn’t tell me it was going to make me bleed”. This seemed like such a simple and honest explanation of what was happening during the procedure although I had up until then always talked about taking some blood. This highlighted how inadvertently I frequently explained things from my perspective rather than the child’s perspective, and how difficult it can be for adults to see things from a child’s point of view.

Understanding the child’s experience is an important component of nursing children but one that is progressively more difficult the younger the child. Therefore, an understanding of the child’s experience is often neglected in the provision of health services, particularly to preschool children. Despite international conventions and national statutes confirming the rights of children to have their voices heard in relation to health care, nurses and other health professionals face practical challenges in understanding and communicating with preschool children who are significant users of health services.
CHILDREN’S USE OF HEALTH SERVICES IN NEW ZEALAND

Considerable improvements in preventing and treating childhood illnesses have been made since Rousseau (1762/1993) said of children that,

they cut their teeth and are feverish, sharp colics bring on convulsions, they are chocked by fits of coughing and tormented by worms, evil humours corrupt the blood, germs of various kinds ferment in it, causing dangerous eruptions. Sickness and danger play the chief part in infancy. One half of the children who are born die before their eighth year. (p. 16)

Although child mortality in the developed world has improved greatly since 1762, many parents of preschool children today are still familiar with children cutting their teeth, having fevers, colic, convulsions, coughs, worms, infections and skin eruptions.

Without a national minimum dataset in primary care there is a major dearth of reliable data about child morbidity in primary care in New Zealand. Consequently, health practitioners, researchers, and policy makers are reliant on occasional and often dated audits. The National Primary Medical Care Survey, undertaken in 2001-2002 to describe primary health care in New Zealand, including patients’ reasons for attending, does not provide age specific data on child morbidity (Hider, Lay-Yee, & Davis, 2007). In 1991-1992 illnesses such as upper respiratory tract infections, acute bronchitis, tonsillitis, otitis media, and presumed infections were the major reasons for preschool children presenting to a general practitioner (McAvoy, Davis, Raymont, & Gribben, 1994). Preschool children frequently experience this type of short-term, passing illness. Consequently, preschool children are significant users of health care services.
The 1996-97 New Zealand Health Survey found that 42.1% of the nation’s children were seen by a nurse in the previous 12 months (Ministry of Health, 1999). Preschool children in the 0-4 years age group were most likely to see a nurse, with 65.5% doing so in the previous year (Ministry of Health, 1999). Similarly, younger children were more likely than older children to use general practitioner services (Davis, 1987; Ministry of Health, 1999). In fact, preschool children 0-4-years-old have been found to utilise general practitioner services at almost twice the expected level relative to their proportion in the population (McAvoy et al., 1994). Rates of hospitalisation during childhood also decrease with increasing age (Hodges, Maskill, Coulson, Christie, & Quigley, 1998). Children 0-4-years-old consistently account for over 60% of hospitalisations for 0-14-year-olds (Barnett & Laur, 2003; Hodges et al., 1998; Ministry of Health, 2006). Although most of these figures are dated, they attest to the fact that preschool children frequently use health services when they have short-term passing illnesses.

The child health status in New Zealand is not good compared with other OECD countries (Children's Commissioner, 2006; Ministry of Health, 1998b). For child mortality in the age range 0-5, New Zealand was ranked 15th out of 21 OECD countries (Ministry of Health, 1998a). However, the health status of young children from socio-economically disadvantaged communities is even worse. New Zealand children living in a family embedded in a wider context of socio-economic disadvantage are most at risk from short-term passing illnesses. Children from low-income families experience comparatively

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4 The 2002/2003 New Zealand Health Survey targeted the adult population aged 15-years and over and excluded children (Ministry of Health, 2004). The 2006/2007 New Zealand Health Survey will collect data on child health issues in a separate questionnaire but results will not be available until mid 2008.
poorer health than the overall child population (Hodges et al., 1998; Ministry of Social Development, 2004). Children from disadvantaged communities are more likely to get sick or be hospitalised than children from socio-economically advantaged communities (Barwick, 1992; Hodges et al., 1998; Johnston & Lynn, 2004). Tamariki Māori have worse health than non-Māori children (Hodges et al., 1998; Ministry of Social Development, 2004). The greatest disparities occur in the infant and the 1-4 age groups and it is well established that socio economic factors make a major contribution to these disparities (Barnett & Laur, 2003; Blakely, Atkinson, Kiro, Blaiklock, & D'Souza, 2003; Hodges et al., 1998; Ministry of Social Development, 2004). Available data clearly indicate that preschool children frequently experience short-term passing illnesses and, consequently, are significant users of health care services. Yet, there is little research about how preschool children experience being ill and how they express their experience of being ill to others.

**CHILDREN’S VOICES IN HEALTH RESEARCH**

Some research has begun to address how children experience various illnesses and aspects of being ill, from the child’s perspective. However, researchers have tended to focus on school aged children with chronic illnesses such as, asthma (Yoos & McMullen, 1996), attention deficit hyperactivity disorder (Kendall, Hatton, Beckett, & Leo, 2003), cancer (Hockenberry-Eaton & Minick, 1994), diabetes (Miller, 1999), and on liver transplant recipients (Wise, 2002), to name a few. Some researchers have included school aged children with a range of chronic illnesses (e.g. Sartain, Clarke, & Heyman, 2000; Woodgate, 1998). Researchers have also begun to address, from the child’s perspective, how school aged children experience factors associated with being ill, such as
hospitalisation (Boyd & Hunsberger, 1998; Carney et al., 2003; Forsner, Jansson, & Sørlie, 2005) and acute pain (Alex & Ritchie, 1992; Pölkki, Pietilä, & Vehviläinen-Julkunen, 2003; Woodgate & Kristjanson, 1996). This research on the school aged child’s perspective on various, mainly chronic illnesses, cannot be generalised to the experience of preschool children with short term passing illnesses.

Even though preschool children are significant users of health services, research literature has given scant attention to understanding their experience of illness, from their own point of view. Of the studies listed above, only Woodgate and Kristjanson’s (1996) study of young children’s perception of postoperative pain includes preschool children. Carnevale’s (1997) study of what it is like for a child to be critically ill in an intensive care unit included 10 preschool children and was conducted within a phenomenological framework. Carnevale characterised the child’s experience of being critically ill as a process of unmaking and remaking the self, shaped within significant relationships, but the study is rarely referred to in the literature. The scant attention in the research literature to understanding the preschool child’s subjective experience of illness can be attributed in part to the methodological difficulties of conducting research with preschool children. Phenomenological research is suited to understanding experiences as others experience them. However, phenomenological research with children, as with adults, traditionally relies on verbal data (Danaher & Briod, 2005). Thus, the limits of preschool children’s language abilities inevitably limit research that relies on preschool children’s verbal fluency. While non-verbal ways can be used to describe experience these eventually require interpretation (Danaher & Briod, 2005). The scope of most research texts on phenomenological research is limited to methods that rely on verbal and written data, one
of the few notable exceptions being van Manen (1990). When it comes to research with preschool children there is a need to develop new methodologies that move away from traditional forms of research that rely heavily upon verbal data.

In summary, it is clear that preschool children frequently experience short-term passing illnesses and are significant users of health care services. Yet there is little knowledge about how preschool children express their views in matters affecting their health, or whether their views are recognised and given due weight by adults making decisions related to the child’s illness experience. Furthermore, there are clinical benefits to understanding how preschool children experience being ill and to knowing how they communicate their experience of being ill to others. At the same time, there are epistemological barriers to gaining such an understanding, which are explored, in greater depth in the next two chapters.\footnote{There are also ontological barriers but these are not explored until later in the thesis.}

**IN SEARCH OF WHAT IT MEANS TO PRESCHOOL CHILDREN TO BE ILL**

Preschool children have an important contribution to make in helping nurses, other health professionals, and family/whānau understand the nature of illness in early childhood. Richly detailed critical interpretations of experiential anecdotes that take into account the situational context of how preschool children experience being ill and how they express their perceptions of those experiences to others are combined with contemporary research findings to challenge some of the adult interpretations of children’s illness experiences and
influence adults’ interactions with preschool children. The research on which this thesis is based was conducted with two main aims:

1. to identify how preschool children experience being ill from a short-term, passing illness.
2. to identify how preschool children communicate their experience of being ill to others.

The research involved recruiting preschool children aged between two and five-years-old from community-based organisations while they were well. The children were repeatedly visited in their homes over a period of up to five months. Close observation of the children during those visits enabled collection of a range of data from the children and their parents both while the children were well and for some of the children during short-term passing illnesses. Data collection involved a variety of techniques including participant observation, audio and video recordings, photography, drawing, field notes and interviews. Analysis of the data was informed by phenomenological traditions particularly the work of Maurice Merleau-Ponty and Eugene Gendlin.

With respect to the aims of this research, a critical examination of the findings of existing empirical research comprises a significant part of the thesis. In chapter two and chapter three, I take a critical attitude to the existing empirical research and re-evaluate the findings and methods from a phenomenological perspective. The point of engaging with the contemporary literature is not to dismiss the findings but to reveal their limits and their contribution to the aims of this study, particularly what they reveal about the essence of what it means for children to be ill. Thus, I use chapter two and chapter three to present
what is already known about how preschool children experience being ill and how they communicate their experiences to others. In chapter two, I critically re-evaluate research relevant to how illness affects preschool children’s ‘mental life’ and ‘behaviour’. In chapter three, I re-evaluate research relevant to preschool children’s ‘cognitive’ conceptions of illness, particularly their views about getting an illness, being ill, pain during illness, the temporal duration of illness and getting better. My analysis reveals in a limited way the kinaesthetic, intersubjective, situational, and spatial essence of what it is like for preschool children to be ill. In addition I highlight the limitations of the methodological and epistemological frameworks used in the empirical literature and suggest the need for a new methodology.

In order to find out how young children experience being ill from a short-term, passing illness, and how they communicate their experiences to others, I evolved an ethnographic phenomenological research methodology (and method) that overcame some of the limitations of existing methodologies (and methods). The evolution of this methodology and method is a major contribution of this thesis and is described in detail in chapters four and five. In chapter four, I focus on the processes I used to gain access to the children, firstly through communities and community organisations, and then through the parents. There is a significant ethical dimension to conducting research with preschool children in their homes. Attention is given to the way in which I designed the research to address ethical issues. I give particular attention to a booklet and audio-tape that I developed as an important part of obtaining informed consent from the children. I also address the issues of power imbalances, protecting the children and myself from harm, and confidentiality. Having discussed informed consent I turn my attentions to how I gained
access to the children’s experiences, including negotiating the researcher role and data collection, principally through close observation. While the research is principally phenomenological, the process of gaining access to the children’s experiences is characterised as ethnographic.

In chapter five, I discuss the process I used to analyse the data in doing so I explore the enigma of interpreting children’s lived experiences. I discuss the ontological limits of interpreting the child’s experience as the child does. The problematic nature of the conventional process of transcribing data verbatim is explored. I detail how I came to re-present the children’s experiences in a way that aided phenomenological reflection. I also explain how I used Maurice Merleau-Ponty’s work to overcome the introspective nature of my data. However, the intricacies of the situations were always more than the transcripts re-presented. To reflect phenomenologically with what was more than the transcripts re-presented and to determine essential themes I turn to Gendlin’s (2004a) philosophy and process for “Thinking At The Edge” (p. 1) with what was more than I could re-present of the children’s experiences. Following the first five steps of Thinking At The Edge I articulate in a grammatically odd way my original implicit knowledge that emanated from my experience in the field, that is that children know bodily meaning inside-out, unimpeded by other, and that is their preferred passage to articulate in advance of what they can say. Thus in chapters four and five I present a new ethnographic phenomenology for understanding preschool children. In addition at the end of chapter five, I begin to reveal my grasp of the illogical core of my understanding of what it is like for young children to be ill and how they communicate that understanding to others.
As I follow Gendlin and Hendricks’ (2004) process for ‘thinking at the edge’ the illogical core of my understanding of what it is like for young children to be ill and how they communicate that understanding becomes clear and more logical in chapter six. To support the essential theme of my thesis I present a very small proportion of the data collected. Detailed attention is given to a few specific instances from my close observations and interviews with the preschool children and their parents, which carry forward the knowledge implicit in those situations. In doing so I provide a phenomenological description of the essence of how preschool children experience illness and communicate their experience to others. The attention to specific situations uncovers aspects of the ambiguity in the way children understand illness inside-out, unimpeded by others. I explore practical examples of how in advance of what they can say children use their bodies to articulate their felt sense of illness situations inside-out. I also show how adults in intimate situations with ill children can understand what it is like for young children to be ill by focusing on their own felt sense of situations from the inside-out.

In chapter seven, I appraise what I have uncovered through this research. I discuss some of the key implications and insights from the research with a particular focus on what they mean for nursing practice with preschool children and the opportunities for further phenomenological research. My hope is that the research presented here will help people working with young children and their parents to understand them, particularly when they are ill, and that better understanding will lead to better care.
CHAPTER TWO

BEHAVIOURAL REVELATIONS OF WHAT IT IS LIKE FOR CHILDREN TO BE ILL

We know nothing of childhood; and with our mistaken notions the further we advance the further we go astray. The wisest writers devote themselves to what a man [sic] ought to know, without asking what a child is capable of learning. They are always looking for the man [sic] in the child, without considering what he [sic] is before he [sic] becomes a man [sic]. (Rousseau, 1762/1993, pp. 1-2)

The little prince had very different ideas about serious things from those of grown-ups (Saint-Exupéry, 1943/2000, p. 39)

The aim of reviewing the empirical literature in this chapter and the next is two fold. The first is to establish the nature and extent of existing knowledge about how preschool children experience being ill. The second is to uncover the a priori understandings of the essence of what it is like for preschool children to be ill as they are revealed by the empirical literature.

The second aim is linked to the phenomenological research methodology utilised in this study and described fully in chapters four and five. The phenomenological method is often seen as requiring scientific knowledge to be relinquished or bracketed. In spite of this, Merleau-Ponty’s (1945/1962; 1942/1963) phenomenological studies frequently incorporate results from empirical science in support of his thesis (Welsh, 2006). Merleau-Ponty’s use of scientific knowledge is arguably consistent with phenomenological
methodology (Smith, 2005). In considering the relationship between phenomenology and the sciences, Merleau-Ponty (1961/1964b) recognises a fundamental homogeneity between inductive and essential knowledge and claims that “any knowledge of fact always involves an a priori understanding of essence” (p. 72). While he admits pushing Husserl further than he wished to go, Merleau-Ponty (1961/1964b) cites Husserl as saying “every empirical discovery as well as every eidetic discovery made on the one side must correspond to a parallel discovery on the other” (p. 72). Merleau-Ponty (1961/1964b) goes on to assert that experimental studies and the psychoanalysts “must already reveal to us, at least in a confused way, the essence of that with which they are concerned” (p.74). Hence, the second aim of these two chapters is to uncover the a priori understandings of the essence of what it is like for preschool children to be ill, revealed, at least in a limited way, by the empirical literature. According to Merleau-Ponty (1961/1964b) it is essential that phenomenology finds “a way of animating and of organising these facts which might convey them to the reader as they are lived by those who are actually caught up in this context” (p. 91). The a priori understandings of what it is like for preschool children to be ill, presented in this chapter and the next, were revealed through an analysis of the empirical literature, which actually occurred concurrently with the later stages of data analysis. In chapters six the a priori understandings contribute to the phenomenological analysis of the field data generated from this study and help intuit the essence of what it is like for young children to be ill.

**THE EFFECTS OF HOSPITALISATION ON CHILDREN**

Since the 1950s, a large body of research has developed on the effects of hospitalisation on children. Early research tended to focus on the effects on young children
of being separated from their mothers. More recently, research has extended to include the effects of a child’s hospitalisation on parents and family members. Reviews of this research by a number of authors over recent decades are available (see Hall, 1987; Shields, 2001; Thompson, 1986; Wright, 1995). As a consequence of this research significant changes have occurred in the way children and their parents are cared for in hospital (Wright, 1995). Hospitalisation involves a wide range of considerations including separation (particularly in the past), a new unfamiliar physical environment, multiple caretakers, treatment, and the illness itself. Most of the research on the effects of hospitalisation on children did not produce, nor was it intended to produce, knowledge specific to what it is like for young children to be ill. Therefore, this body of research is not discussed further in any detail, except for Anna Freud’s (1952) article *The role of bodily illness in the mental life of children* which has been influential in the literature related to the effects of hospitalisation but largely neglected in the literature related to children’s understandings of illness.

**THE EFFECTS OF ILLNESS ON THE MENTAL LIFE OF CHILDREN**

Rather than describing the effects of hospitalisation and separation, Freud (1952) attempts to arrive at a correct assessment of the role of bodily illness in the mental life of children. She describes the effects on the ill child of other modifiable factors, including the effects of nursing and medical procedures, the attitude of parents to the ill child, the experience of being nursed, restrictions of movement and diet, operations, pain and anxiety. These factors are referred to as “mere by-products of the situation” (p. 70) and are clearly distinguished from her description of the effects of illness itself. Significantly, Freud points out, the child’s mind is not able to make distinctions between these factors and experiences
them as inextricably intermixed within an illness situation. By way of example, Freud asserts that “the child is unable to distinguish between feelings of suffering caused by the disease inside the body and suffering imposed on him from outside for the sake of curing the disease” (p. 70). Thus Freud reveals, at least in a limited way, an essential fact about children’s experience of illness. That is, for the ill child there is no distinction between their felt-sense and their situation. Their felt-sense and situation are not two separate things. Their situation is part of their felt-sense. There is no between. This is consistent with Gendlin’s (1991) view that “body-sense and situation are implicit in each other” (p. 81).

In the situation of children being ‘nursed’, Freud (1952) makes some interesting observations about restricting children’s movement. In the context of minor childhood illnesses where children are cared for at home, Freud points out it is well known how difficult it is to keep children in bed or lying down. Freud also provides examples of the psychological consequences of restraining children’s movement after surgery or in the course of orthopaedic treatments such as traction or plaster casts. Freud contrasts the comparative ease with which children renounce their ego skills and abilities and their acceptance of dietary restrictions with the way “children defend their freedom of movement in the same situation to the utmost wherever they are not defeated by the type or intensity of the illness itself” (p. 72). This observation raises the following questions. Why do ill children defend to the utmost their freedom of movement? What is the significance of movement to children? Long ago Rousseau (1762/1993) recognised the significance of

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6 This sentence has been used in a different context by van den Berg (1972, p. 67).
movement to the child claiming “it is only by movement that we learn the difference between self and not self” (p. 36). More recently Sheets-Johnstone (1999) similarly argues for the primacy of movement and declares “spontaneous movement is the constitutive source of agency, of subjecthood, of selfhood, the dynamic core of our sense of ourselves as agents, subjects, selves” (p. 138). This argument, and the significance of movement to children are developed further in chapter six.

In situations of children’s bodily illness Freud (1952) notes the mother’s “inevitable concentration on bodily matters” (p. 69) and “her preoccupation with the child’s body” (p. 71). Freud also notes that child development involves “advances in detaching his [sic] own body from that of the mother and possessing it at least in part” (p. 71). Furthermore, Freud notes that “mother-child unity is an important fact or in the libido economy of both, through all the phases of childhood” (p. 79). These ideas point to the intersubjective or, as Sheets-Johnstone (1999) might describe it, intercorporeal nature of children’s experiences.

Freud (1952) distinguishes those factors discussed above from changes in libido distribution which she identifies as inherent to the process of illness itself. She notes that the casual observer of the ill child is in danger of disregarding the silent process that occurs under the surface as the child’s ill body demands and attracts a greater amount of the child’s emotional energy. Freud refers to this process as “the heightened demand of the ill body for libidinal cathexis” (p. 77). She notes that some children react by withdrawing from their environment and the object world, concentrating on the needs of the body, while other children claim extra attention from their mothers by becoming demanding and clingy. Freud also recognises the observant mother’s ability to diagnose these signs before
significant bodily symptoms appear, and that return to health is accompanied by a movement of energy away from the body and back toward the object world. This movement between the child’s body and their environment, and its connection to interpersonal relationships, is largely neglected in literature on children’s understandings of health and illness. While Freud’s (1952) observations of ill children are firmly embedded in a Cartesian distinction between mind and body, they do confirm that illness affects movement within body and world, and that movement is recognised and realised within close interpersonal relationships. This movement may represent a qualitative shift in children’s mode of being-in-the-world when they are ill and when they are healthy.

**THE EFFECTS OF ILLNESS ON CHILDREN’S BEHAVIOUR**

Two studies have reported behavioural changes observed by mothers of acutely ill preschool children at home. Shrand’s (1965) United Kingdom-based study of acutely ill children referred to a home-care-unit and cared for at home by their mothers, included 33 children aged 1 to 4 years. The mothers of the children were sent a questionnaire listing changes in children’s behaviour attributed in the literature to hospitalisation. They were asked to answer whether they had observed any of the listed behaviours in their own children when they cared for them at home. Of the 33 children, 16 were less than 1-year-old and many of their mothers reported difficulty observing behavioural changes. Only 3 mothers with children under 1-year-old observed definite changes. For behavioural changes to be detected a pattern would have to be established to begin with, which might be more difficult in the first year of life where rapid change is a normal part of development. Mothers reported one or more changes in behaviour in 19 of the 33 children, including 12 becoming clingy, 9 loving their mother more, 8 afraid to go to bed, 7 afraid to be alone, 6
having feeding problems, 6 started wetting the bed, 4 having nightmares, 3 becoming more babyish, and 2 becoming jealous of other children. None of the mothers reported the children being cold towards their mother. Three of the four most frequently reported behaviours (becoming clingy, loving their mother more, and afraid to be alone) point to the significance of interpersonal relationships in the child’s experience of illness.

Building on Freud’s (1952) observations, Mattsson and Weisberg (1970) describe children’s behavioural changes, as observed by their mothers during 76 episodes of acute illness at home (that is, without the effects of hospitalisation). Fifty-two of the illness episodes occurred when the children were aged between 2 and 4-years, while the children had reached the ages of 4 to 6-years for 24 of the illness episodes. Thirty-five preschool children aged between 2 and 4-years at the onset of the study were recruited from an American paediatrician’s university-based private practice. The paediatrician instructed each mother in everyday observations of her child’s behaviour in the following areas: manifestations of illness, behaviour in the paediatrician’s office, reactions to medical management, changes in mood, behavioural changes in relationships, changes in the use of toys, changes in bodily functions, changes in self care, evidence of increased self gratification, and appearance of specific fears. No details are provided about how the mother’s observations were recorded and analysed. Mattsson and Weisberg found that before any specific physical symptoms had appeared mothers identified behavioural clues that an illness was pending such as irritability and tiredness in only 6 of the 35 children under 4-years-old. By the time children reached 5-years their mothers’ detection of behavioural clues to a pending illness became almost the rule. What is not clear is whether this finding represents a change in the children’s expression of behavioural clues of
pending illness or whether it represents a change in the mothers’ ability to detect behavioural clues of pending illness.

During the acute phase of an illness Mattsson and Weisberg (1970) found that all the children showed some behavioural changes, such as reduced activity, longer sleep periods, and reduced appetite. All children showed different degrees of increased irritability in personal relationships. All children under 4-years-old showed some short-lived setbacks in their level of independent care. Mattsson and Weisberg also found “significant qualitative differences in the changes in the mother-child relationship” (p. 607) and categorized these into two distinct behavioural reactions. Reaction One was characterised as follows:

The principal feature of this reaction was the children’s continuously clingy, whiny dependence on the mother. They insisted on as much physical closeness to her as possible such as sitting in her lap or wanting to be carried around. These children would also repeatedly interrupt any of her activity [sic] with a host of demands. Their mood was one of extreme irritability and intolerance to any frustration. They were unable to occupy themselves when awake and showed little if any interest in their siblings and toys (except for their favourite comforters). (p. 607)

In contrast, Reaction Two was characterised by:

a diminished interest of the child in physical and verbal contact with the mother (and the rest of the family), often to the point of rejecting her attempts at giving him [sic] extra attention. These children frequently withdrew into a self-contained, undemanding state such as resting quietly, looking at picture books, colouring, or watching television. They would occasionally make simple demands for a drink, a
blanket, and so forth, which if not immediately gratified resulted in short lived whining. At times they appeared ‘more independent than usual’ and ‘easy to manage.’ (p. 607)

Mattson and Weisberg (1970) found a statistically significant relationship between the type of reaction and age. When the 2-year-old children were ill 19 of 22 reactions were characterised as Reaction One. When the 3-year-old children were ill 19 of the 30 reactions were characterised as Reaction Two. Of the 24 illnesses observed in children 4-years-old and over, 22 reactions to illness were classified as Reaction Two. Many of the 4-year-olds who displayed Reaction Two to illness had displayed Reaction One when ill at age 2 to 3-years.

Mattsson and Weisberg also found 15 out of 21 two-year-olds verbalised pain and discomfort to their parents during acute illness episodes at home. According to Mattsson and Weisberg “common quotes were, ‘my ear hurts,’ ‘I’m hot,’ and ‘I feel tired’. Two of the youngest patients (2-years-old) pointed to their ears and whimpered, ‘Hurt, hurt’ ” (p. 606).

During the convalescent period, Mattsson and Weisberg (1970) found that mothers noted heightened irritability and short lived anger in all children “as their previous vigor returned” (p. 608). Similar to Freud (1952), Mattsson and Weisberg (1970) reveal the significance of activity and interpersonal relationships to children’s experience of illness.

Both Shrand’s (1965) and Mattson and Weisberg’s (1970) research provide a perspective on the practical activity of the sick preschool child as perceived by the child’s
mother in the context of acute illness in the home. What is missing is the child’s perspective.

Wilkinson (1988) included the perspective of healthy children in his study. Similar to the previous two studies, Wilkinson found that the observed behaviours most relevant to a child’s experience of illness relate to the children’s activity and their interpersonal relationships. Wilkinson studied healthy children from three age groups (3- to 5-year-olds, 7- to 9-year-olds, and 13- to 14-year-olds). The sample of 40 children included 8 children from two nursery schools in Scotland. At the end of the study the nursery school children’s ages ranged from 3-years-1-month to 5-years with a mean age of 4-years-2-months.

Wilkinson’s (1988) study makes a unique contribution to the field in terms of its methodology. The methodological uniqueness of Wilkinson’s interpretative observational study is the intersubjective framework used, which allocates “a primary role in the developmental process to intersubjectivity, rather than building up an ego psychology in which understanding is based primarily on individual qualities” (p. 7). Guided by the intersubjective framework, Wilkinson collected data from the children in pairs and from the children together with their family. Wilkinson acquainted himself with the nursery school children through regular visits to the nursery before the study began and subsequently saw the children in the nursery twice, once in same-sex and once in mixed-sex pairings. Wilkinson describes how he

joined with the children in making up a story about a child who did not feel like getting up in the morning. The rest of the family downstairs were then discussing the child, trying to decide what ‘might be up’ with him or her. The details were
constructed by the children and it was essential that each time some novel ingredients were included so that it became their story. Everytime [sic] the theme chosen by them was illness (and never malingering). These stories were tape-recorded and transcribed. In order to facilitate entry to the child’s way of accounting to other children, the discussion was at times directed to getting the children to explain themselves to each other if there was anything unclear…. In order to establish the seriousness with which the children held their views and to discriminate the serious views from those stated primarily to elicit reaction, I then played them back the tape-recordings and recorded them listening and spontaneously commenting on their earlier comments (a particular difficult form of recording to transcribe). (p. 30)

In addition, Wilkinson met each child together with all those living in the family home. Topics covered in those meetings included: discussion of experience of illness within the family, words used to describe illness, how it was suspected that a child was ill and how the child lets the parents know, how illness in one family member affects everyone else, family’s views on the causes of illness, and the nature of germs. As part of these meeting “each family member checked with the others that they understood what was meant” (p. 31).

Unfortunately, Wilkinson (1988) provides little evidence of reflexivity regarding his role in data collection and interpretation. Furthermore, the five chapters in which Wilkinson interprets the data and presents the research findings include very little supporting data from the youngest group of children. This is in contrast to the two older age groups where greater use is made of vignettes from the children’s data. Wilkinson
presents what he refers to as “the primary structure to the child’s world of illness” (p. 63). This is framed around the family decision-making process for common illnesses in the 3 to 4-year-old children and relies heavily on data from the children’s parents. Wilkinson acknowledges the limitation of relying primarily on the parents’ reports and recognises “an ethological analysis could have revealed a rudimentary signalling system which neither child nor parent was yet fully aware of, or able to reflect on” (p. 67). The lack of verbal data from the youngest children occurred despite the techniques used for data collection. However, the lack of verbal data is to be expected because of their limited vocabulary.

Wilkinson (1988) notes, “the parents did not expect them to, and the majority of nursery school age children could not, tell them about their illness in words” (p. 64). Instead, the parents interpret clues, which depend on noticing changes in the child’s routine. Wilkinson specifically mentions changes in the speed of getting up and dressed in the morning, the size of the child’s appetite, the quantity of speech, and the proximity of the child to the parents. In contrast to Mattson and Weisberg (1970), Wilkinson found children 3-years and older did become more clingy to their parents in times of illness. Parents also noted changes in the child’s mood. In addition, parents assessed the children’s physical appearance, in particular their colour, their eyes, and their forehead. The youngest children typically complained of soreness, directing the parents to the source of their discomfort by pointing to their ears, chest, head, or tummy. Wilkinson also reports the younger children describing themselves as ‘not well’ without localising the feeling.

Wilkinson (1988) proposed that “something counts as illness if it affects an important dimension to the child’s relation with a significant other person and is labelled as
illness” (p. 77). This proposition is based on the importance nursery school aged children placed on the value of their relationships and how they interpret illness based on the way illness affects those relationships. In support of the proposition Wilkinson argues that “not being able to play was one of the cardinal features of illness, but the telling feature for the child was that they then missed their contacts with their friends” (pp. 77-78). Similarly, children with colds did not see themselves as ill; apparently because the colds did not prevent them from going to the nursery school or affect routines involving people important to them. Wilkinson’s proposition supports the intersubjective nature of children’s experience of illness.

In summary, the three behavioural studies used different methodologies but all relied heavily on parents’ (mostly mother’s) observations. Each study examined the effects of acute illness without hospitalisation on preschool children’s behaviour and came to similar conclusions. All three attest to the intersubjective nature of children’s illness experience and the effects illness has on children’s routine activities. These conclusions are largely consistent with Freud’s (1952) observations. These findings will be discussed further in relation to the aims of my review at the end of chapter three. What is still largely missing from these studies is the preschool child’s perspective on the child’s practical activity during acute illness. In addition, these studies are all quite dated and mostly ignored in the larger body of research on children’s cognitive conceptions of illness, which are discussed in chapter three.
CHAPTER THREE

COGNITIVE REVELATIONS OF WHAT IT IS LIKE FOR CHILDREN TO BE ILL

Grown-ups like numbers. When you tell them about a new friend, they never ask questions about what really matters. They never ask: ‘What does his voice sound like?’ ‘What games does he like best?’ ‘Does he collect butterflies?’ They ask: ‘How old is he?’ ‘How many brothers does he have?’ ‘How much does he weigh?’ ‘How much money does his father make?’ Only then do they think they know him. (Saint-Exupéry, 1943/2000, p. 10)

PRESCOLL CHILDREN’S ‘COGNITIVE’ CONCEPTIONS OF ILLNESS

There is a considerable body of research on children’s conceptions of illness (see Burbach & Peterson, 1986; Rushforth, 1999; Siegal & Peterson, 1999b for reviews). Only a relatively small proportion of this body of research includes data from preschool children. Of the studies that include preschool children many focus on what they do not know about conventional conceptions of illness relative to older children and adults, rather than on what the preschool children do know or what they know in other ways. Furthermore, results and discussions direct attention to the most frequent finding rather than the range of findings in the preschool sample. By focusing on what the studies reveal preschool children do know, I will show how the methods and findings of the body of research that includes preschool children are useful but limited representations of preschool children’s own understandings of illness; the abstract concepts themselves being the primary limiting factor.
Most of this research falls within the domain of cognitive developmental psychology and conceptualises children’s understandings of illness within biological, social, cultural, psychological, moral/religious, and probabilistic terms (Kalish, 1999). Within the biological conception of illness the concepts of contagion and contamination have been used extensively to represent children’s reasoning about the causes of illness (Kalish, 1996a, 1996b, 1999; Solomon & Cassimatis, 1999).

An important finding in most of the literature reviewed below is that children’s cognitive understanding of these concepts changes over time in predictable ways. The prediction is typically that understanding progressively improves in a linear and hierarchical model. The linear, hierarchical model is a presupposition of many developmental theories. Thus, childhood is viewed as a state of Becoming rather than Being (Todres, 2000). The historic depths of the linear hierarchical presupposition in child development is evident in Ariès’ (1960/1962) exploration of the history of childhood in which he describes iconic artworks from the fourteenth to the nineteenth-century depicting “a row of figures representing the various ages from birth to death, and often standing on steps” (p. 24). A risk of holding such a presupposition, is to not even consider that children may understand something, as well as, or even better than, adults do. It is important to be aware of this possible presupposition when critiquing researchers’ interpretations of findings in this body of literature. What is more important is to consider childhood as a state of Being and Becoming. When considering childhood as a state of Being a contrasting presupposition suggested by Gadamer (1993/1996) emerges; that is, that being human requires consideration that “the other may not only have a right but may actually be right, may understand something better than we do” (p. 82).
The progression of children’s cognitive understandings of illness is not the focus of this review and is not generally discussed further unless it is relevant to the knowledge generated about preschool children’s understandings of illness. The focus of this part of the review is on articulating what the cognitive developmental literature reveals about preschool children’s understandings of illness in their own right.

The starting point for the cognitive developmental literature on children’s understandings of illness is typically an adult view of illness as a disease state or process, usually caused by biological agents or malfunctions. The important distinction Svenaeus (2001) makes between disease as a state or process and illness as the lived experience of a person is not made in this literature. Understanding children’s lived experience of illness is my ultimate destination. In reformulating what the cognitive developmental literature reveals about children’s understanding of illness, my point of departure was constrained by my return to the cognitive developmental literature itself. But my direction was influenced by the later stages of analysing my field data which as mentioned in the previous chapter occurred concurrently with reformulating what the literature reveals. However, my return to the literature lead to the identification of the following thematic aspects of illness, evident to varying degrees within the cognitive developmental literature: getting an illness, being ill, pain during illness, the temporal duration of illness, and getting better.

Because of cognitive psychologists’ interest in children’s causative thinking, by far the largest body of literature on children’s conceptions of illness has focused on children’s understanding of how they get an illness. Knowledge about children’s understanding of
being ill, pain during illness, the temporal duration of illness and getting better have been relatively small by-products of the research on children’s causative thinking. Each thematic aspect of illness is discussed below, not as a comprehensive review of all literature, but as a more or less chronological, critical overview of the cognitive developmental research on preschool children’s understanding of illness.

**Getting an illness**

In one of the few early studies to include preschool children, Nagy (1951) interviewed 20 preschool children, as part of a study of 100 Hungarian children. The interview schedule included the question: “What makes us ill?” (p. 6). Nagy says all ten 3-year-olds and eight of the ten 4-year-olds “did not seem to grasp the concept of illness having a cause of general application. They describe only particular causes especially related to their own illnesses” (p. 6). She reports the remaining two 4-year-olds say illness is due to infection. Nagy concluded children aged 3 to 5-years “are incapable [italics added] of understanding the real [italics added] origin of illness. They cannot go beyond symptoms of illness to find a causal and general explanation” (p. 11). The conclusion that these children are incapable of understanding the real origin of illness goes beyond what the study was designed to test and beyond the data presented. Nagy’s findings support the conclusion that these children did not have an understanding of the “real” origin of illness, when “real” is defined in biological, and adult terms. It also supports the conclusions that preschool children have knowledge of illness based on their own experiences of illness; their understanding includes symptoms and may include a notion of infection. Like many of the early studies that did not include preschool children, Nagy found age related
differences in children’s explanations but did not explicitly link those differences to developmental theory.

To explicitly link the development of illness concepts to Piaget’s (1929/1951) stages of development, Simeonsson, Buckley and Monson (1979) studied conceptions of illness in 60 hospitalised American children. The children were in three age groups, the youngest group ranging from 4-years-0-months to 5-years-11-months-old. Children were asked the following three questions related to how children get sick: “How can children get sick? How do children get stomach aches? How do children get bumps or spots?” (p. 78). In addition, IQ was assessed using a receptive language test, and a variety of measures were used to assess Piagetian concepts of conservation, egocentrism, and physical causality. Given the variety of concepts assessed it is clear the questioning of these children would have been prolonged, repeated, and a departure from the convention of everyday conversations (Siegal, Waters & Dinwiddy, as cited in Eiser, 1989). Simeonsson et al.’s findings suggest that preschool children’s conceptions of how they get sick are not abstract, that they tend to be concrete, specific responses reflecting specific acts or events, but can also be global, or undifferentiated. The transformation of children’s responses to questions about the cause of illness into one of three developmentally ordered stages (global responses, concrete responses, and abstract responses) signifies a broad approach to researching children’s understanding of illness through Piaget’s theory of development.

Bibace and Walsh’s (1979; 1980; 1981) influential research on children’s conceptions of illness is even more explicit about transforming children’s explanations into categories that correspond to Piaget’s theory of cognitive development. Utilizing Piaget’s
clinical method, Bibace and Walsh interviewed 160 American children aged 3 to 13-years about their explanations of a range of illnesses and illness experiences including: being sick, colds, measles, heart attacks, cancer, headaches, pain and germs. It is likely the younger children would have had no personal experience of some of the illnesses they were asked about (e.g. heart attacks and cancer). The children’s responses to these questions were classified into six categories and developmentally ordered in accordance with Piaget’s three broad stages of cognitive development (pre-logical, concrete-logical and formal-logical). The six categories in developmental order were Phenomenism, Contagion, Contamination, Internalization, Physiological and Psychophysiological.

A conception of space that differentiates internal (inside) and external (outside) is imposed by the categories Bibace and Walsh (1979; 1980) developed to transform children’s responses into a developmentally ordered hierarchy. Below are the definitions of the six categories with the spatial concepts italicised and an example related to the question “How do people get colds?”

- Phenomenism: “the cause of illness is an external concrete phenomenon which may co-occur with the illness but which is spatially and / or temporally remote.” Example: “From the sun.”
- Contagion: “the cause of the illness is located in objects or people which are proximate to, but not touching, the child.” Example: “When someone else gets near them.”

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7 The pilot phase was conducted with 180 children according to Bibace and Walsh (1979, 1981) and 160 children according to Bibace and Walsh (1980).
• Contamination: “The cause is viewed as a person, object or action external to the child which has an aspect that is ‘bad’ or ‘harmful’ for the body.” Example: “You’re outside without a hat and you start sneezing. Your head would get cold – the cold would touch it – and then it would go all over your body.”
• Internalization: “illness is now located inside the body, while its ultimate cause may be external.” Example: “In the winter, they breathe in too much air into their nose and it blocks up the nose.”
• Physiologic: “although the cause may be triggered by external events, the source and nature of the illness lies in specific internal physiologic structures and functions.” Example: “It’s when you get all stuffed up inside, your sinuses get filled up with mucus. Sometimes your lungs do, too, and you get a cough”
• Psychophysiologic: “Illness is described in terms of internal physiologic processes but the child now perceives an additional or alternative cause of illness, a psychological cause.” (Bibace & Walsh, 1980, pp. 914-915)

In the literature reviewed below many researchers apply this artificial division between internal and external (evident in the above definitions) as a means of transforming children’s responses into developmentally ordered categories. Yet, the division is not questioned. It seems almost inevitable that scientists (and philosophers) make this dualistic distinction between the inside and the outside (Johnson, 1999). As Piaget (1929/1951) points out, it is not a distinction made by the children themselves. Piaget’s (1929/1951) view is that preschool children do not distinguish between internal and external or between

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8 Bibace and Walsh (1980) do not provide an example related to the question: “What is a cold?”
a sign and thing signified. This has been labelled as an externalist view in which there is no distinction between mind, body, and world (Gelman & Wellman, 1991). More recently, a number of findings from Gelman and Wellman (1991) and Gottfried and Gelman (2005), outside the domain of illness causality, have challenged the externalist view by showing that in the context of a range of animals, plants, and machines, preschool children attend to non-obvious features and can and do make clear distinctions between insides and outsides. The finding that preschool children do make distinctions between insides and outsides is not inconsistent with an externalist view if the insides and outsides are determined to be factors internal to this whole (mind, body, world) (Zahavi, 2004). The internal and the external are at some point hinged; from a human physiological perspective the hinge might be at the surface of the skin. It is important not to divest the internal from the external nor to privilege one over the other (Johnson, 1999). Yet, this is exactly what is done in the cognitive developmental literature on children’s understandings of illness, where external explanations are separated from internal explanations and internal explanations are privileged in a linear developmental hierarchy.

In order to test and verify the linear developmental hierarchy of the six categories, Bibace and Walsh (1979; 1980) interviewed a further 72 children in three different age groups about their explanations of the range of illnesses and illness experiences described above. The youngest group comprised 4-year-olds and included 24 children. The children’s explanations were matched to one of the six categories according to the most mature form of explanation they gave at least twice (Bibace, Sagarin, & Dyl, 1998; Bibace & Walsh, 1979; 1980). The authors found variability in the type of explanation within each developmental stage. The 4-year-olds’ explanations were most frequently coded as
Contagion, followed by Contamination, but also included explanations coded as Incomprehensible, Phenomenistic, and Internalization (Bibace & Walsh, 1979; 1980). This variety of explanations was found despite the authors’ conventional practice of categorising individuals’ responses, which did not acknowledge the co-existence of explanations at other levels.

Thus, Bibace and Walsh (1979; 1980) reveal 4-year-old children’s explanations of how you get ill vary between children; but they are more likely to involve external (outside) cues from someone or something else. In contrast, explanations given by 11-year olds in Bibace and Walsh’s (1981) study were seen as more mature and likely to involve internalisation and physiological responses in which the source and nature of the illness is seen as internal. Bibace and Walsh’s (1981) findings could be used to support the argument that children’s understanding of how they get an illness develops progressively from external outside cues to internal inside cues and that they are initially devoid of adult physiological conceptions of illness. However it could be argued that physiological conceptions of illness are developed from the outside looking in. In addition, the distinction between outside and inside is a conceptual transformation imposed by the researchers on the children’s descriptions and as already argued this may not be a distinction the children make.

Although Bibace and Walsh (1979; 1980; 1981) asked children about a range of illnesses and illness experiences including being sick, colds, measles, heart attacks, cancer, headaches, pain and germs they did not analyse their results across illnesses. Recently Myant and Williams (2005) established that preschool children hold differing levels of
understanding about the cause of different ailments (cold, chicken pox, asthma, toothache, bruise and broken leg), in particular they have more knowledge of injuries than illnesses. From this study it is not clear what experiences influence children’s differing levels of understanding.

Continuing the explicit links to Piaget’s theory of cognitive development Kister and Patterson (1980) studied children’s conceptions of the causes of illness at four different grade levels; specifically they studied children’s understanding of contagion. Their sample included 15 American children (mean age 4-years-8-months). Children were interviewed individually about a contagious illness (a cold), a non-contagious illness (a toothache or a headache), and an accident (a scraped knee). To test the children’s understanding of contagion Kister and Paterson asked this forced-choice question: “If a boy your age went to school one day, and the girl sitting next to him had {the ailment}, would he have to be careful [italics added] so he wouldn’t catch [italics added] {the ailment} from her?” (p. 840). In both the context of the non-contagious illness and the accident 10 of the 15 preschoolers replied ‘yes’. Kister and Patterson concluded that preschool children overextend the concept of contagion.

Kister and Patterson (1980) do not consider the validity of their question to actually measure the concept of contagion. Within the question, the word ‘catch’ was presumably the key word in relation to the concept of contagion. However, the preceding phrase ‘be careful’ may have implied prevention to the preschool children rather than contagion. In a similar study, that included preschool children’s understandings of contagious illnesses (cold and chicken pox), non-contagious illnesses (asthma and toothache), and injuries
(bruise and broken leg), Myant and Williams (2005) found that ‘being careful’ was the focus of children’s prevention strategies. Both scraped knees and toothache can be prevented by ‘being careful’ not to fall over or to brush your teeth properly. Thus it is possible that Kister and Patterson’s question measured preschool children’s understanding of prevention rather than contagion.

Kister and Patterson (1980) also assessed whether children believed in immanent justice as the cause of illness and accidents, that is, the belief that illness and accidents are a form of punishment. Since it was described by Piaget (1932/1968) there has been considerable empirical research on immanent justice as a type of moral reasoning used by children (see Jose, 1991 for a review). Piaget (1932/1968) argues that young children’s belief in immanent justice originates “in a transference to things of feelings acquired under the influence of adult constraints” (p. 260). The example Piaget gives is of parents saying “it serves you right” or “that will be a punishment for you” (p. 258), in response to a child having a minor accident. Thus, according to Piaget, children learn indirectly from adults to associate misdeeds with punishment.

Consistent with Piaget’s (1932/1968) now traditional method of questioning children, Kister and Paterson (1980) told children a story in which a child did something wrong and subsequently suffered from an illness or had an accident. In addition, to check whether children simply identified two adjoining events as causally related they also used a control story in which a child did something good (helped his mother) and subsequently suffered a negative consequence (lost some money). They found that 11 of the 15 preschool children “failed” the control story. In other words, they accepted a causal
relation between the child in the story helping the mother and losing money. While the preschool children gave a full range of responses from what the researchers considered the least to the most mature, the majority “failed” the control story. Kister and Paterson conclude that preschool children tend to believe two temporally adjoining events are causally related and argue this is a less mature form of thinking than immanent justice.

However, Kister and Paterson (1980) do not consider the effects on the children’s responses of, the stories format, the adult experimenter, and the questions. The stories start by describing a misdeed, followed by a question highlighting the misdeed. Then the children are told about a temporally related misfortune, and then an adult asks the children whether the two events are related. The children’s responses should be interpreted in the context of the social rules underlying conversations in which listeners try to work out the speaker’s intent (Ceci & Bruck, 1993). Ceci and Bruck (1993) cite a number of studies that show “from an early age, children perceive their adult conversational partners as being cooperative, truthful, and not deceptive [italics added]” (p. 418). In addition, children’s desire to comply with adult authority figures means they are also cooperative, supplying adults with the information they think is being requested (Ceci & Bruck, 1993). Thus, the preschool children in Kister and Paterson’s study may have assumed the misdeed mentioned first by the adult must be relevant to the subsequent question. Furthermore, most studies examining children’s suggestibility have shown that misleading questions are likely to provoke inaccurate acquiescence by a child and that preschool children are disproportionately more vulnerable to suggestion than older children (Ceci & Bruck, 1993; Gilstrap & Ceci, 2005). Consequently, Kister and Paterson might be wrong to interpret the preschool children’s response as a belief that two temporally adjoining events are causally
related or that immanent justice is a cause of illness. An alternative interpretation of Kister and Paterson’s findings, supported by this analysis, is that the preschool children in their study tended to acquiesce to the adults’ suggestions, because of the way this information was presented to the children rather than for other reasons.

Further support for this interpretation is provided by Springer and Ruckel (1992) who point out that Kister and Paterson’s (1980) stories are somewhat leading. Their study provides empirical evidence to support their claim. Using a different question format, Springer and Ruckel (1992) interviewed 20 American children aged 4 to 5-years. They found that most healthy preschool children reject misbehaviour as a cause of illness. Springer (1994) replicated the different question format used by Springer and Ruckel in a study of 34 preschoolers, 17 with cancer and 17 without cancer. Springer again found most preschoolers rejected misbehaviour as a cause of illness. Furthermore, the preschoolers with cancer were as likely as the healthy children to reject misbehaviour as a cause of illness. Similarly, using a scenario format to investigate the moral reasoning skills of healthy and chronically ill 3 and 4-year-olds, Kato Lyon and Rasco (1998) found that except for the chronically ill 3-year-olds the children did not confuse illness and moral transgressions.

To evaluate whether prior evidence of immanent justice beliefs (Jose, 1991; Kister & Patterson, 1980; Piaget, 1932/1968) is based on leading questions Springer and Ruckel (1992) followed up 16 children approximately 10 months after being asked questions in the

9 This critique also applies to Piaget (1932/1968) and to Jose (1991).
new format and asked them the same set of questions, in traditional Piagetian form. They found an increase in the overall proportion of affirmative responses. Springer and Ruckel (1992) attribute this finding to the leading nature of the traditional question format. Thus, their findings support my interpretation that preschool children tend to acquiesce to adult (misleading) suggestions. This highlights not only the difference subtle changes in question format can make to preschool children’s responses, but also the intersubjective nature of questions and answers between adults and children.

In addition to the above arguments Kister and Paterson’s (1980) assertions that preschool children overextend the concept of contagion, and that they tend to believe that two temporally adjoining events are causally related, are refuted by the findings of Siegal’s (1988) second experiment. Siegal told three stories about a child with a scraped knee in random order to 24 Australian preschool children (mean age 4-years-11-months). The results suggest that at least in the case of a scraped knee (one of the examples used by Kister and Patterson) these children did not believe it was caused by sitting next to another person with a scraped knee.

Similarly to the previous studies, Redpath and Rogers (1984) used Piaget’s stages of cognitive development to investigate young children’s concept of illness. Their sample included a group of 30 American preschoolers (mean age 3-years-9-months), six of whom had been previously hospitalised. Each child was assessed on two Piagetian tasks (conservation and physical causality). The children were asked 13 questions regarding medical concepts. The preschoolers’ medical concept scores were significantly correlated with the Piagetian concept score for causality. Redpath and Rodgers’ qualitative analysis
of those questions suggested that preschoolers tended to confuse cause and effect which would be one explanation for the correlation. However, it could also be argued that the tendency to confuse cause and effect might not be so much a tendency to confuse cause and effect as the tendency reported by Freud (1952) not to separate cause and effect.

In a noteworthy departure from previous highly structured interview techniques Robinson (1987) conducted a qualitative study of children’s conceptualisations of health and illness. Robinson sampled 21 Canadian children aged 3-years-11-months to 5-years-6-months. All the children were well and interviewed in a familiar place using a semi-structured interview schedule which included the question “what caused you to be sick?” (p. 96). Robinson found the children explained the cause of illness in a variety of ways congruent with several levels of cognitive understanding reported in the previous literature. Robinson notes that despite the variety of causal explanations given by the preschool children, “the cause was always externally located” (p. 93). This supports Bibace and Walsh’s (1979; 1981) conclusion that preschool children’s explanations of how they get an illness are more likely to involve cues, interpreted by adult researchers, as being external, that is from someone or something else.

In a move towards more child friendly interview techniques, preschool children’s knowledge of contagion and contamination as causes of illness was further examined in experiments by Siegal (1988). Siegal’s second experiment has already been discussed in relation to Kister and Patterson’s (1980) findings. Siegal’s first experiment included 40 Australian preschoolers, mean age 4-years-11-months. The children were shown in random order four videotaped segments where puppets with colds and toothaches explained their
ailments either in terms of (contagion) catching “the ailment when playing with a friend who had the ailment” (p. 1354) or (immanent justice) “through naughty behaviour that included playing with forbidden scissors” (p. 1354). Siegal’s study has two important differences from Kister and Patterson (1980) study. Firstly, the story is told by a video taped puppet rather than an adult authority figure. Secondly, the illness (misfortune) is mentioned first followed by the misdeed.

Siegal (1988) found 93% of preschoolers accepted the causal role of proximity in the transmission of colds and 73% rejected immanent justice as the cause of colds. These findings suggest many, but not all, preschool children have an understanding that colds can be caught when playing with a friend who has a cold. Siegal claims these findings show preschool children have an understanding that colds are contagious. However, whether such an understanding relates to a biological understanding of contagion is not addressed by the experiment. Contrary to Siegal’s (1988) claim that these findings support the conclusion that many preschool children reject immanent justice explanations for colds, the findings actually support a more qualified claim that many preschoolers reject as a cause of colds naughty behaviour that included playing with forbidden scissors.

In contrast, Siegal (1988) found that preschoolers’ responses to the toothache example did not exceed chance, 53% rejected the causal role of proximity in the transmission of toothache and 63% rejected immanent justice as the cause. The differences in the preschooler’s correct causal answers to questions about colds compared to toothaches were statistically significant. This difference might be explained by preschool children’s personal experience of colds that is likely to exceed their personal experience of toothache.
In the second phase of Siegal’s (1988) first experiment the preschool children were told three stories with real illustrations in which a dead cockroach, a clean spoon and a comb with dandruff on it fall in to a glass of milk. Of the 40 children 39 said they would not drink the milk with a dead cockroach inside. Most of the preschoolers thought drinking the milk with the comb inside (28/40) or removed (23/40) would make the child sick. Half the preschoolers thought drinking the milk with the clean spoon inside would make them sick. According to Siegal “many of these spontaneously volunteered that they would be afraid of swallowing the spoon” (p. 1356). With the clean spoon removed most of the preschoolers (29/40) thought the child would not get sick drinking the milk. Despite Siegal’s effort to develop a child friendly interview structure he structured the experiment in a way that was logical to his adult reasoning and was surprised by the children’s fear of swallowing the spoon. This highlights the need to be sceptical of adult reasoning, and despite the difficulties of doing so, to be regardful of children’s possible reasoning.

In a move away from Piaget’s theory of cognitive development, Banks (1990) interviewed 75 healthy children aged 3 to 15-years on topics related to health and illness. Twenty four of these children were aged 3 to 5-years. The children were individually interviewed in their homes or at a nursery school. The questionnaire included the question: “What makes a person sick?” (p. 44). Preschool children gave a variety of answers to the question about what makes a person sick. The most frequent answer involved cold weather or going out with insufficient clothing, but 6% gave answers regarding eating the wrong food, and 25% gave answers Banks regarded as “unusual answers such as ‘spiders,’ ‘ghosts,’ and ‘smoke’ ” (p. 44). Whereas previous authors (Bibace & Walsh, 1979, 1980;
Kister & Patterson, 1980; Redpath & Rogers, 1984) have applied a Piagetian framework either to their findings or the whole study design, Banks questions the appropriateness of applying Piagetian stages of cognitive reasoning to natural phenomena. Banks proposes the “age differences in concepts of illness represent the acquisition of culturally accepted beliefs, rather than application of operational logic” (p. 43).

Even Piaget (1929/1951), in concluding his discussion of children’s reasoning about thoughts, names, and dreams, advocates the need for further research to confirm “that the part played by adult influences may be more definitely separated from the spontaneous and constant conviction of the child” (p. 129). In a series of three experiments to examine preschooler’s understanding of non-observable causes of illness Kalish (1996b) demonstrated that children as young as 3-years-old know about germs. He suggests that, that knowledge must be acquired through cultural and parental influences. Myant and Williams (2005) asked preschool children about the cause of specific illnesses including colds and found they were “more likely to refer to cold weather than contagion to explain the causality of colds” (p. 815). Myant and Williams suggest this is because parents frequently tell children they will catch a cold if they go out in the cold. It is worth noting that the word ‘cold’ has two different meanings, it is used as an adjective to talk about ‘cold weather, cold air,’ etc, but it is also used as a noun to name an illness. Children are required to distinguish between the two meanings. From an experiential point of view it would make as much sense to name the illness ‘warm’ or ‘hot’, since the person feels hot as often as they feel cold. The term ‘cold’ comes from a pre-germ theory era where illness was attributed to cold air or getting a chill. So historical understandings influence the very language adults use to name illness and the explanations they give children. In the domain
of ontology the influences of adults testimony compared with young children’s first-hand experience was assessed by Harris, Pasquini, Duke, Asscher and Pons (2006). Their findings confirm that children’s beliefs extend beyond their first person experience of such entities and vary dependent on the testimony they receive from adults. Thus, if adult testimony endorses to children that you catch a cold by going outside in the cold it is not surprising that children hold such beliefs. Although, even here, Harris et al, Myant and Williams, Piaget, and Banks, view adult influences as outside the child, exerting pressure on and eventually replacing the child’s thinking, rather than seeing the child as part of a social whole to which the child belongs from the very beginning (Vygotsky, 1999).

The continuing influence of Piaget and studies based on Piaget’s work such as Bibace and Walsh (1979; 1981) is evident in Goldman, Whitney-Saltiel, Granger and Rodin’s (1991) study. While this study moved beyond the focus on children’s conceptions of illness causation Goldman et al. did include a question to assess understanding of the ‘cause’ of illness. Goldman, et al. studied 27 American children (age range 4 to 6-years-old). Children were interviewed individually and asked: “How do boys/girls get colds/fevers?” (p. 752). The children’s responses were coded into six categories developed by Perrin and Gerrity (1981) which correspond to Piagetian developmental levels and are similar to those developed by Bibace and Walsh (1981). Some understanding of the causal origin of illness was communicated by 62% of the sample. Most of the children’s explanations were categorised as phenomenalistic and or magical. Goldman et al. also comment that “answers indicated that children viewed illness as something external, which

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10 Children’s beliefs in the existence of cats, germs, Santa Claus, monsters and flying pigs.
some-how impinged on them” (p. 754). However, this interpretation seems to stem from the customary adult distinction of an external world and an internal body and mind, a distinction which is not necessarily that definite in a child’s prereflective experience (van den Berg, 1972).

Despite critique Bibace and Walsh’s (1980; 1981) work continues to be influential, Iannotti and Kapor (1996) used categories almost identical to Bibace and Walsh to categorise the responses of 50 Yugoslavian preschool children to the question “What causes illness?” (p. 263). Most of the preschool children gave responses categorised as phenomenist “claiming that illness is caused by ‘air,’ ‘popcorn’,11 ‘fingers,’ etc” (p. 264). Some of the preschool children’s responses were also categorised as infection. Thus, like other studies using this category system most four-year-olds are seen to fit into Piaget’s preoperational stage of cognitive development.

In the contested area of children’s conceptions of biology (Inagaki & Hatano, 2006), Kalish (1996a; 1996b; 1997; 1998; 1999) undertook a series of studies on causal reasoning related to illness. In recognition that asking children structured open-ended questions, and categorising their responses, may underestimate children’s understanding of illness, these studies involved a series of short (one to three sentence) stories (vignettes) followed by a closed (forced-choice) question to ascertain the child’s causal reasoning. The stories were based on a biological model and conception of illness and often included information about the cause of the illness. The stories were read to the children one at a time. Kalish (1999)

11 The potential significance of popcorn is discussed further in chapter six.
tentatively concludes that preschool children understand “infection as a physical relationship based on the transfer of material particles” (p. 123). However, as Kalish (1997; 1998; 1999) points out, the findings are open to varied and contested interpretations, depending on the explanatory model imposed by the researcher. In a series of five studies with preschool children, Solomon and Cassimatis (1999) apply a different explanatory model but a very similar method of stories plus a forced-choice question and use their results to argue against preschooler’s understanding germs as biological causal agents.

There is debate in the literature about whether the method of using stories plus a forced-choice question captures the complexity of children’s understanding. One criticism is that the forced-choice method does not give children the opportunity to express multiple causes (Raman & Gelman, 2004). Raman and Gelman’s (2004) study makes a new contribution to the literature by studying 41 preschool children across two different cultures (Indian and American), and by using a method that gives the opportunity to choose multiple causes (biological, moral, psychological, or irrelevant) for the origins of illness. Both American and Indian preschoolers most frequently attributed illness to biological causes but also acknowledged multiple non-biological causes, particularly the American preschoolers. Moral and psychological causes were endorsed significantly more by American than Indian preschoolers which lead the authors to postulate that this result may represent a bias in the American children to respond “yes” to the task.

Raman and Gelman (2005) used a different story plus open question method in a series of four studies with preschool children to study their understanding of the transmission of genetic disorders and contagious illnesses. Their results show preschool
children recognise that not all illnesses are transmitted by contagion. Their results also indicate that children recognise leading and misleading cues in the context of the stories researchers tell them.

In summary what is clear from these studies is that children’s understanding of illness causation is more complex than previously thought, and that interpreting children’s understanding is fraught with difficulties. There is considerable variability within and across studies regarding preschool children’s understanding of illness causality. Some of the variability can be attributed to significant limitations in the validity and reliability of methods used to ascertain children’s knowledge of illness causality. Some of the variability can also be attributed to the degree to which preschool children have experience of the illnesses in question, and some of the variability can be attributed to historical and cultural influences. Changes in methods of questioning have lead to changing views about children’s abilities to understand causes of illness. Clearly, children’s understanding of the question, its context, purpose, and relevance has a significant impact on what knowledge is obtained from the children (Siegal & Peterson, 1999a). However, once that knowledge is obtained, the cognitive developmental literature has consistently measured preschool children’s conceptions of illness causality against the prevailing scientific explanation of depersonalised and desituated, physical causality, and found preschool children wanting, while other conceptualisations of illness have largely been discounted.

There is little evidence that causality is a significant component of preschool children’s understanding of illness. Children’s limited understanding of the causes or origins of illness may be linked to their capacity not to distinguish between cause and
effect. As a prereflective experience illness does not present itself in the first place as an event in the world or in the body to which the category of causality can be applied, but as a recreation or reconstitution in which things in the world are experienced differently (Merleau-Ponty, 1945/1962; van den Berg, 1972). Thus a cognitive conception of causality is only one aspect of understanding illness (Robinson, 1987). I now turn to preschool children’s understanding of being ill as revealed in the cognitive developmental literature.

**Being ill**

The distinction between internal and external cues is also evident when it comes to preschool children determining whether or not they are ill. Neuhauser, Amsterdam, Hines and Steward (1978) found that when 4 to 5-year-old children feel a sense of internal locus of control they are more likely to use internal body cues to determine they are ill. The researcher imposed distinction between internal body and external world is also evident in the work of Redpath and Rodgers (1984) who published one of the few studies to analyse the content as well as the form of the children’s answers. They provide a qualitative analysis of children’s answers to the question “What does it mean to be sick?” (p. 35). Their qualitative analysis suggests “most of the preschoolers could not explain what it means to be sick. Rather than describing a change in their bodies, they described a restriction of their activities” (p. 35). Here Redpath and Rogers interpretation is dominated by an adult perspective and theoretical construct that completely usurps that of the child. Lippitz (1986) warned of the danger in psychological research with children of the adult perspective and theoretical constructions dominating those of the child. Redpath and Rogers do not appear to have even considered the possibility that for the preschool children being sick means being restricted in their activities.
The importance of activity in children’s experience of being ill is also evident in Robinson’s (1987) qualitative study where well preschool children were asked “what is it like when you are sick?” and “What things can you do when you are sick” (p. 96). Robinson transformed responses to these questions into a predefined category labelled the “course of illness” (p. 90) but notes it was the richest and most meaningful category in terms of the children’s understanding. The children “explained that most people get sick at some time and that sicknesses vary in severity. … Relative degrees of health and illness were determined by kind of activity, permitted location of activity, and contact with other people” (p. 93). Thus according to Robinson, children judged the severity of the illness by the nature of their activities during the illness, rather than by the nature of the underlying disease.

However, Robinson (1987) also found evidence that preschool children have some understanding of the nature of disease. She also asked the children “How do you know when you are sick?” (p. 96). While this question generated little data, Robinson found “children discussed symptoms such as coughs, headache, fever, earache, sneezing and diarrhea as indicators of sickness … A few children described general malaise” (p. 93). In response to the questions “What do you think sickness does to you?” and “What happens inside when you are sick?” (p. 96) most of the children gave responses emanating from sensory experience which “focused on a global negative body feeling” (p. 93).

Further evidence about children’s understanding of the signs and symptoms of being ill is provided by Banks (1990) who asked 24 children aged 3 to 5-years a number of
questions including “What is a cold?” (p. 44). This question typically (60%) generated a “don’t know” response, while 20% identified a cold as being sick, and a further 20% identified symptoms. The wording of Banks’ question may have under-estimated the children’s knowledge of colds. Phrasing the question slightly differently Goldman et al. (1991) obtained quite different responses. Goldman et al. asked preschool children “Can you tell me something about a cold/fever?” (p. 752). This question was answered in terms suggesting a somatic profile by 89% of the children. Furthermore, the children generally gave specific symptoms for the illness labels provided to them “for example children defined ‘fever’ as having a ‘hot head’ and ‘a high temperature,’ and colds were described as having a ‘runny nose,’ ‘sneezing,’ and ‘coughing’ ” (p. 756).

Iannotti and Kapor (1996) studied 150 Yugoslavian children from three age groups including 50 preschool children (4-year-olds). The interviews conducted at the preschool included the following questions about being ill: “How did you know you were ill? What did you do first when you were ill? How do children feel when they are ill?” (p. 257). Forty-one of the four-year-olds indicated that it was the child who noticed he or she was ill and nine were told by others that they were ill. Twenty-two indicated they had tried to deal with the illness on their own and 28 asked for help. According to Iannotti and Kapor the four-year-olds often understood the question “How did you feel when you were ill?” as “What were you doing when you were ill?” (p. 262). Even though they were ill 14 of the 4-year-olds said they felt well, 16 mentioned unpleasant reactions such as “I vomited” or
“there was a lump in my throat”, and 9 said they were ‘terrified’\textsuperscript{12}, and 11 gave answers categorised as vague (p. 262).

In summary, few studies have asked preschool children specifically about being ill. Those studies that have asked preschool children about being ill demonstrate that children understand being ill in relation to how it affects their activity and in terms that include bodily signs and symptoms. Pain is a potentially important symptom of childhood illness which is addressed next.

**Pain during illness**

As reported in the previous chapter, Mattsson and Weisberg (1970) found that ill preschool children commonly complain of pain and discomfort. Sore throats, sore ears, and sore tummies are common in childhood illnesses. Nevertheless, pain during illness was not commonly represented in the literature on preschool children’s cognitive developmental conceptualisations of illness.

The one exception is Harbeck and Peterson’s (1992) study of developmental levels of children’s understanding of pain in five different age groups. Harbeck and Peterson included a group of 20 preschoolers (aged 3 to 4-years-old) chosen to approximate the Piagetian preoperational level of development. The children were interviewed regarding their understanding of pain using three vignettes “describing an injury (skinned knee), a

\textsuperscript{12} While the authors suggest some of the children were afraid their parents would leave them alone. ‘Terrified’ is a strong word and it might be relevant to note data was collected in the Serbian town of Novi Sad between 1991 and 1992, which marked the beginning of the Bosnian, Croatian, Serbian war.
medical intervention (injection), and an illness related pain (headache)” (p. 140). For each vignette Harbeck and Peterson asked the children “the following three questions: (1) ‘How would you describe this pain to your best friend: What does your {type of pain} feel like?’ (2) ‘Think about the story … why does your {body part} hurt?’ (3) ‘There are a lot of bad things about pain, what is good about this pain?’ ” (p. 140). Responses to the questions were converted into nominal categories developed from the children’s responses and then ordered into a developmental sequence derived from existing theories. For the purpose of statistical analysis Harbeck and Peterson (1992) treated the categorised qualitative data as interval level data. However, given the category system imposed on the children’s qualitative responses it is debatable whether the data would have been more appropriately analysed as ordinal or even nominal level data.

Regardless of the three situations in which the pain occurred, the preschoolers’ descriptions of what their {type of pain} felt like were mostly categorised as, “general label with no additional specific information” (p. 141). Keeping in mind the limitations in the way Harbeck and Peterson analysed the data, the standard deviations for the preschoolers’ description of pain in each situation were relatively large compared with the other age groups indicating a wider spread of responses, that is greater variance in the preschoolers’ descriptions of pain. In fact, the preschoolers’ descriptions of pain in the three situations were likely to have covered the full range of the category system used.

After asking the preschool children to describe the pain, Harbeck and Peterson (1992) proceeded to ask the children “Why does your {body part} hurt?” (p. 140). A proportion of the responses were coded as “unresponsive to the question, instead is a
*description of the pain* [italics added] (examples: beating or pounding in head, stings, burns)” (p. 141). A *Description of the pain* was the question Harbeck and Peterson asked earlier. Medcalf Davenport (2003) has found that preschool children continue to process answers to questions long after testing has moved to other questions. Consequently, Medcalf and Davenport recommend responses should be re-coded if they are later determined to be answers to earlier questions. Interestingly, if responses to the question of “Why does your {body part} hurt?” (p. 140) coded as “unresponsive to the question, instead a description of the pain” (p. 141) had been re-coded as responses to the earlier question, about describing pain, they would have been categorised into what Harbeck and Peterson regarded as the highest developmental level for that question. Thus, Harbeck and Peterson might have underestimated preschool children’s ability to describe pain.

In addition, Harbeck and Peterson (1992) found the categorisation of preschoolers’ descriptions of why a pain hurt did vary significantly, depending on the situation in which the pain occurred. Most preschoolers had the least understanding of why a headache hurts, a better understanding of why a skinned knee hurt, and the best understanding of why an injection hurt. There is an intuitive appeal to this finding in that the concrete cause of both a skinned knee and an injection is more obvious than the cause of a headache. In addition, most preschoolers are likely to have experienced injections (such as vaccinations) and to have scratched or skinned knees or other parts of limbs in the course of play and other activities. Harbeck and Peterson (1992) also found that preschool children do not have an understanding of pain as having a beneficial or positive value – something that is evident in adult and particularly medical, constructions of pain.
Harbeck and Peterson (1992) might also have given too much weight to the distinction between the symptom (pain) and the situation (a skinned knee or having and injection). This is evident when they comment that statements such as “I was playing too rough” or “was hit in the head” (p. 142) exemplify “a response that misses the point and instead recounts causes of the accident or headache rather than causes of the pain” (p. 142). From a physiological and neurological perspective the symptom pain can be separated from the situation in which it occurs, but it can be argued that from an experiential perspective the cause of the situation is the primary cause of the pain and in a causative chain not only precedes but is necessary for any physiological and neurological changes. The categorical separation of situation from the symptom is contrary to Gendlin’s (1991) view that “body-sense and situation are implicit in each other” (p. 81) and might not be part of preschool children’s perception of their embodied being. Thus, it can be concluded from Harbeck and Peterson’s study that preschool children have a situational understanding of why pain hurts, rather than a physiological understanding. This is consistent with van den Berg’s (1972) view that pre-reflective life “has no knowledge of physiology” (p. 51).

Overall, the literature on preschool children’s cognitive developmental conceptualisations of illness pays little attention to children’s understandings of pain. Like the many studies related to children’s understanding of illness causation, Harbeck and Peterson’s (1992) study about children’s understanding of pain raises issues about the methods employed to access and analyse children’s experience. The next aspect of children’s understanding of illness to be considered in this chapter is the temporal duration of illness.
Temporal duration of illness

Few studies have attempted to explore preschool children’s understandings about the duration of illness. Robinson (1987) asked 21 preschool children “are you sick for a long time or a short time?” (p. 96) and found they had realistic understandings of the variation in the duration of different illnesses “as one child said ‘The cough is longer than the vomiting you know’ ” (p. 93). Similarly, Goldman et al. (1991) asked 27 preschool children two time-related questions: “How long will the little boy/girl be sick with a cold/fever? How long will it take him/her to get better?” (p. 752). An understanding that a cold/fever would resolve within a short time was conveyed by 96% of the children. Of those children 64% described the duration of illness to be a realistic finite number of days and assigned a similar length of time to being sick and getting better. A further 36% described the duration of illness in what the authors labelled “subjective and variant time” (p. 756). In the case of two contagious illnesses (chickenpox and colds) and two noncontagious illnesses (asthma and cancer) Williams and Binnie (2002) asked 4-year-olds about the time it would take from exposure to the cause of an illness to getting the illness. For all four illnesses the 4-year-olds most often chose fixed choice answers that indicated some knowledge of a time delay between exposure to the cause and getting the illness. Similarly Myant and Williams (2005) presented vignettes of characters with different illness to 4 to 5-year-olds and asked them “How long would it take for {name} to feel bad?” (p. 809) and “How long would it take for {name} to feel better?” (p. 809). Responses were categorised in a way that indicated the children had some or no understanding of the time course.
Time is a complex phenomenon that has also received little attention in the cognitive developmental literature on children’s conceptualisations of illness. The model that has been used privileges an objectively determined chronological conceptualisation of time and undervalues the lived experience of time during illness (Lippitz, 1983). No attention has been given to how illness affects the child’s perception of their past, present, and future. The last aspect of children’s understanding of illness to be considered in this chapter is their understanding of getting better.

**Getting better**

The distinction between internal and external cues evident in the discussion of getting an illness and being ill, also features in this discussion of getting better. In a study of children’s concepts of healing at two different stages of cognitive development, Neuhauser, et al. (1978) included a sample of twelve 4 to 5-year-olds. The children were given a verbal questionnaire about an illness and an injury involving a cut. The questions included: “How did you know when you were all healed (all better)?”¹³ (p. 337). The children’s explanations for how they knew they were better were transformed in a now familiar way according to whether they described internal body cues, external body cues or outside cues from someone or something else. Neuhauser et al. found the 4 to 5-year-old children were more likely to use outside cues from someone or something else but they also used external body cues and internal body cues to determine when they were well again. Neuhauser et al. conclude that because of their limited capacity for symbolic thought,

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¹³ The words in parentheses were used when asking about an internal illness.
internal cues were not as accessible to these preschool children as concrete external observable cues.

Findings from Simeonsson et al.’s (1979) study which included a group of hospitalised children (aged 4-years-0-months to 5-years-11-months) also indicate that preschool children’s explanations of how they get better tend to be concrete, specific responses reflecting specific acts or events. Preschool children’s responses were also categorised as global or undifferentiated responses, but were not categorised as abstract reasons or principles. Slightly more detail is provided in Robinson’s (1987) qualitative study where she asked preschool children “What makes you better when you are sick?” (p. 96). The children believed getting better from illness required medication, yet they seldom mentioned doctors and did not mention other health professionals at all. Treatments identified by the children included specific acts such as “rest, physical comforting such as hugs and cuddles, medicine to treat symptoms, special foods and drink, including treats” (p. 94). At least some children distinguished between making the body better and feeling better.

To assess preschool children’s understanding of ‘curing illness’ Goldman et al., (1991) asked 27 children: “What will help this little boy/girl get better?” (p. 752). The children’s responses were transformed into one of three categories (two of which are now quite familiar) internal, external or interactive depending on the locus of control of the remedial agent. Some strategy for illness resolution was offered by 92% of the children.

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14 A boy/girl with a cold/fever.
Of the strategies mentioned for resolving the illness 52% referred to an external agent, for example a medicinal agent or a doctor, 8% referred to some internal “personal activity such as ‘resting,’ ‘taking vitamins,’ or ‘eating good food’ as salutary” (p. 755). An interactive response incorporating both an external agent and internal actions was referred to in 40% of the strategies mentioned. Similarly Iannotti and Kapor (1996) asked 50 Yugoslavian 4-year-old preschool children “What do children do to get well?” (p. 257). They provide little analysis of the results other than to say “the youngest children said things such as ‘I drank tea’ or ‘I lay in bed and took medicines’” (p. 267). However, they do acknowledge the important influence of their cultural belief “that health enters the body through the mouth” (p. 267).

These findings suggest that preschool children’s conceptions of how they get better are not abstract, that they tend to be concrete specific responses, possibly related to their own experience and culture. Accordingly preschool children know about a range of things they and other people do that help them get better from illness.

**Methodological critique**

My critique above is an epistemological transformation of the literature which serves to clarify a number of preceding transformations (Reinharz, 1983). Since the 1950s a range of mainly quantitative research methods have been used by cognitive and

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15 Interestingly ‘taking medicines’ was categorised as external and ‘taking vitamins’ or ‘eating good food’ was categorised as internal.
16 Tea in this cultural context was almost certainly some form of herbal or dried fruit tea given with the intent of symptom relief.
17 Reinharz (1983) paper on epistemological transformations in phenomenological research informs my discussion of epistemological transformations in the research reviewed here.
behavioural scientists to generate knowledge about children’s understanding of illness. All the methods involve a series of epistemological transformations. The variety of methods can be divided into two broad approaches which involve slightly different steps.

In the first approach the researchers transform their current knowledge into a series of questions or stories and presents those to the children in an interactive context. That is the first transformation. The children are then free to respond but the responses are effectively limited by the question or story, the interactive context, and their own knowledge, experience, culture, and vocabulary. The children’s response is the second transformation. The researchers then transform the verbal component of the child’s response into one of several conceptual categories drawn from the researchers’ current knowledge. That is the third transformation. The researchers then transform those conceptual categories into a published explanation which captures what the researchers thinks their transformation of the children’s responses says about current knowledge. That is another transformation.

In the second approach the researchers transform their current knowledge into a series of questions or stories and a series of answers (representing different conceptualisations) and present both to the children in an interactive context. That is the first transformation. Providing children with a range of answers gives them an opportunity to demonstrate an understanding that they might not otherwise have the vocabulary to express. In the interactive context the children then respond to the question or story with one or more of the answers provided by the researcher. That is the second transformation. The researchers then transform the answers into a published explanation, which captures
what the researchers think the children’s answers say about current knowledge. That is another transformation.

In both approaches my problem with the existing research is obvious. My aim is different - my aim is to understand children’s experience of being ill, to grasp the meaning of their experiences, and not to always transform their experiences through my own perspective (Meyer-Drawe, 1986). In both approaches, during each transformation, something is gained, usually some extension to an abstract explanatory framework about the form of children’s thinking (Sigelman, Maddock, Epstein, & Carpenter, 1993). On the other hand, something is also lost, usually detail of the content of the child’s experience or knowledge, as well as the chance for adults to grasp children’s experience as children understand it.

Within each approach the methods and the knowledge that is a product of those methods have evolved over time, as researchers have considered and attended to contested claims about the validity of the method to generate knowledge about children’s understanding of illness. Many early studies paid little attention to the interactive context. Consequently, unfamiliar adults subjected children, often in abnormal social and cultural contexts, to repeated, prolonged, non conversational questioning, that may have lacked meaning, and been hard for children to understand because the questions were not related to the children’s everyday experiences (Eiser, 1989). Furthermore, the setting for the research is almost always removed from the home context where most preschool children experience being ill. Findings from recent studies suggest that underestimating the role of language
and social interaction in earlier studies contributed to underestimating children’s capabilities.

Many studies in the first approach, where the content of children’s responses to questions were transformed into theoretical categories, required coders to make some inferences, and did not clearly define mutually exclusive categories. While most of these studies tested interrater reliability on at least a sample of data, few studies discussed how disagreements were resolved. The data are analysed and categorised using an adult frame of reference, possibly by someone not involved in collecting the data. It is little wonder preschool children’s replies are sometimes categorised as *nonsense* when the person categorising them has no sense of the wider context in which they were made. As Meyer-Drawe (1986) suggests “it is no nonsense we recognise, nor a not-yet-sense, but another sense which deviates from our usual experience” (p. 53).

In both approaches little attention has been given to the validity of the questions to measure what they intended to measure. However, studies using both approaches have made significant attempts to compensate for limitations in children’s verbal abilities. Yet, the “forced-choice” interviews that epitomise the second approach used in many of the contemporary studies deny children the opportunity to present their own view. Rather, they ask the children only what the researchers think is important and what fits into their theory (Beekman, 1983).

The changing methods of questioning children have consequently led to changing views about children’s understandings which Raman and Winer (2002) have labelled as the
“naïve child”, the “sophisticated child” and the “irrational adult” (p. 325). However, despite the methodological developments and changing understanding of children’s knowledge about illness, the research questions and answers continue to be formulated, categorised, and interpreted through adult conventions.

The research on preschool children’s understandings of illness has done little to overcome the very real difficulties, if not the impossibility, of adults completely understanding the child’s world. Almost all research on preschool children’s conceptions of illness excludes children’s significant adult caregivers from the research process, presumably to obtain the child’s own views. However, preschool children are still largely dependent on relationships with significant adult caregivers and they are usually a significant part of the child’s world, particularly when they are ill.

Backett and Alexander (1991) went some way to address many of the limitations identified above. They interviewed children in their own homes and used a variety of innovative methods when asking children to talk about health. However, their sample only included three 4-year-olds and the authors acknowledge the schedule worked least successfully with the preschool age group. Furthermore, their findings are not reported by age group. The authors also note they wanted to talk to children on their own terms and time constraints meant an ethnographic study was not possible. There is a need for qualitative research that provides in-depth descriptions of the variety of children’s understandings about being ill (Myant & Williams, 2005). Studying the intricacies of

18 Notable exceptions are Robinson (1987) and Wilkinson (1988).
children’s experiences in situations of health and illness might help to develop new understandings of what it means to preschool children to be ill. However, my review of the behavioural and cognitive literature related to children’s understanding of illness highlights the difficult and challenging nature of research into children’s subjective experiences, especially the meaning of being ill. Thus there is also a need for a research methodology that addresses the issues I have raised above.

**THE NATURE AND EXTENT OF EXISTING KNOWLEDGE**

My first aim in reviewing the empirical literature in these two chapters was to establish the nature and extent of existing knowledge about how preschool children experience being ill. The question of children’s understanding of illness is largely an epistemological question of what counts as knowledge and has been studied primarily from one epistemological framework. That epistemological framework is based on reductionist theories of the mind. The problem with using theories of the mind to understand what children know about illness is the physical nature of being ill. Illness is experienced physically before it is a thing thought about. Cognitive knowledge is derived from other types of knowledge and is only one way humans relate to their world (Anton, 2001).

Most studies investigate preschool children’s thinking related to abstract illness concepts or tied to behaviour. However, there is a difference between conceptual understanding and understanding the meaning of children’s lived experience of illness. In addition, preschool children’s understandings about illness have literally been de-meaned through being positioned at the bottom of an adult imposed hierarchal structure that privileges and compares all other understandings against an abstract objective scientific
conception of illness. Illness is both an abstract concept and a concrete experience. Cognitive developmental science focuses on preschool children’s limited abilities to verbally articulate an abstract understanding of illness and in so doing it devalues an embodied experiential understanding of illness. As Lippitz (1986) points out, the value of concrete understanding lies “with its closeness to perceived reality and with its sensitiveness to concrete changes in it” (p. 62). What is missing, from both the behavioural and cognitive literature is the preschool child’s direct experience of being ill.

**ESSENTIAL FEATURES OF WHAT IT IS LIKE FOR PRESCHOOL CHILDREN TO BE ILL**

My second aim in reviewing the empirical literature in these two chapters was to uncover the *a priori* understandings of the essence of what it is like for preschool children to be ill. According to Merleau-Ponty (1961/1964b) the facts discovered in the empirical research reviewed in these chapters should involve an *a priori* understanding of “the essence of that with which they are concerned” (p. 74). It is clear from the research reviewed that preschool children have a limited cognitive understanding of illness. However, children who have experienced illness cannot not have an understanding of what it means to be ill. Therefore the essence of their understanding of illness must be something other than cognitive.

The importance of children’s movement and activity reported in both the behavioural and cognitive literature suggests that there is a kinaesthetic component to children’s understanding of illness. The behavioural literature suggests there is an intersubjective component to children’s understanding of illness, which perhaps for epistemological and methodological reasons is scarcely evident in the cognitive literature,
except for some limited acknowledgement of parental, cultural, and historical influences on children’s understandings. There is also evidence that children’s understanding of illness is situational. Their level of cognitive knowledge varies depending on the situation, while within a situation they do not separate cause and effect, nor do they separate their felt sense from their situation.

Finally, there appears to be a spatial dimension to understanding illness. Much of the cognitive literature differentiates between internal and external dimensions to determine the level of children’s understanding. Preschool children’s responses to questions about illness tend to be transformed by adult researchers into categories labelled external. Yet it is not clear that preschool children themselves differentiate between internal and external dimensions. However, older children and adults do come to articulate an understanding of illness that differentiates internal and external features and privileges internal features.

Therefore, in summary the question of children’s understanding of illness is largely an epistemological question of what counts as knowledge, and has been studied primarily from a reductionist epistemological framework. Preschool children have a limited cognitive understanding of illness. Older children do come to know and articulate a cognitive understanding of illness that differentiates internal and external features and privileges internal features. However, preschool children’s experience of illness may not differentiate between internal and external and is more than cognitive. My analysis of the behavioural and cognitive literature reveals in a limited way the kinaesthetic, intersubjective, situational, and spatial essence of what it is like for preschool children to be ill that is more than a cognitive understanding.
In chapter six the kinaesthetic, intersubjective, situational, and spatial essence of what it is like for preschool children to be ill, revealed in a limited way by my analysis of the behavioural and cognitive literature, will be developed further in the context of my field data. In the next two chapters I outline the research methodology developed to aid my search for what it means for preschool children to be ill.
CHAPTER FOUR

INVESTIGATING EXPERIENCE AS LIVED BY CHILDREN

Even the others who meant well, who sometimes condescend to converse with children, for the most part no longer had any idea what was important. They too, almost all of them, if they wanted to communicate with us, had laboriously and embarrassingly to reduce themselves to children, not real children but rather to invented, silly caricatures of children. All these grownups, almost all of them, lived in a different world, breathed a different kind of air from us children. (Hesse, 1945/1973, pp. 17-18)

The limits of existing knowledge about how preschool children experience being ill, outlined in chapters two and three, and the importance to health professionals of understanding young children’s experience of short-term passing illness, outlined in chapter one, attest to the need for new knowledge in this area. Current knowledge about how children experience short-term passing illness derives primarily from a dualistic Cartesian epistemology in which knowledge obtained from a private individual mind is viewed as separate from the body and the physical world. My critical review of the empirical literature indicates a phenomenological epistemology, which refutes dualism of mind and body, may shed further new light on the essence of what it is like for preschool children to be ill.

For this study I chose an existential phenomenological methodology guided primarily by the traditions of Maurice Merleau-Ponty. I felt his philosophy of embodiment
could contribute something to my investigation of how young children experience being ill (Merleau-Ponty, 1945/1962, 1942/1963, 1964, 1948/1964, 1964/1968, 1964/1973, 1988). Phenomenological research starts with particular concrete experiences, as lived by persons experiencing them, and arrives at an understanding of those experiences (Merleau-Ponty, 1945/1962; Plager, 1994; van Manen, 1990). Therefore, phenomenology is a suitable methodology to address the aims of this study, which are to identify how young children experience being ill from a short-term passing illness and how they communicate their experience of being ill to others. To address these aims it is first necessary to access young children’s experience of short-term passing illnesses in order to make intimate, detailed observations and descriptions of the young children’s everyday experiences in context (Beekman, 1983). Thus, as will become clear in the description of my method, existential phenomenological research with preschool children has some similarities to the “art of fieldwork” normally associated with ethnographic research (Wolcott, 1995).

Accessing the experiences of young children poses considerable methodological challenge. The accessibility of the young child’s experience to adults is limited in part by the child, in part by the adult, and in part by the norms of adult society. The child has a limited ability to symbolize experience through language, yet language is the principal way in which researchers traditionally access children’s experiences. Adults’ physical, cognitive and experiential development is different from that of the child and these differences limit the adult’s ability to access the child’s experience as the child lives it. Furthermore, young children are dependant on adults, particularly on parents and caregivers who are integral to the child’s world and have privileged access to their children’s experiences (Allen, 1976; van Manen & Levering, 1996b). However, other adults’ -
particularly strangers’ - access to the child’s world is usually severely restricted. Additional challenges confront the researcher when the experience being investigated is the young child’s experience of short-term passing illness. The vast majority of these illnesses occur in the home, which in Western tradition tends to be regarded as a private place. Furthermore, the experience of short-term passing illness cannot be predicted in advance. This chapter details the steps taken and techniques used to address these challenges in the process of gaining access to young children’s experiences of short-term passing illness as lived.

There is a significant ethical dimension to conducting research with young children, which will also be explored in this chapter. In researching lived experience there is no gap between the ethical imperative and the methodological prescription (Beekman, 1983). Therefore, where practical, discussion of ethical issues is integrated into the discussion of gaining access to the young children’s experience. The ethical issues salient to this research are common to qualitative research with participants of any age. However, the issues are complicated primarily by the different power relationships that exist between adults and children and in part by children’s different experiences, understanding and ways of communicating (Morrow & Richards, 1996). The power imbalance exists both between the child and the researcher and between the child and the important adults in their life. The ethical challenge has been to design the research in such a way that it reduces both power imbalances and enables children to participate on their own terms, without undermining parents’ responsibilities and without undue influence from either the researcher or the important adults in the children’s lives (Thomas & O’Kane, 1998).
Gaining ethical access to the child’s experience is, however, only half the challenge. Ultimately I seek to understand the meaning the child attributes to those experiences. Understanding the experiences of young children as they understand them has its own methodological, philosophical and ethical challenges, which although they are intertwined with the challenges of access addressed in this chapter will be discussed separately in chapter five. Merleau-Ponty’s (1961/1964b) phenomenology is a blend of Husserlian and Hegelian approaches “which consists in following man [sic] through his [sic] experiences without substituting oneself for him [sic] but rather in working through them in such a way to reveal their sense” (p. 92). Thus, this chapter details how I followed the children through their experiences without substituting myself for the children, and the next chapter will detail how I worked through them in such a way to reveal their sense.

**HOW AND WHERE TO ACCESS THE CHILD’S EXPERIENCE**

Other researchers have found it takes time for children to incorporate and invite the researcher into their world and while this process can be set in motion the details cannot be planned in advance by the researcher (Beekman, 1983; Graue & Walsh, 1995; Irwin & Johnson, 2005; Lippitz, 1986; Mandell, 1988). Thus, to gain access to the experiences of young children it is first necessary to develop a dialogue with the child through participating in their daily life and interests (Beekman, 1983; Graue & Walsh, 1995; Lippitz, 1986). This process of entry into the field and building a relationship with children is regarded as the crucial factor for successful interpretive research with young children (Beekman, 1983; Corsaro, 1985; Graue & Walsh, 1995; Lippitz, 1986; Mandell, 1988).
A series of assumptions about the child’s experience of short-term passing illness that I brought to this study predisposed me to believe that it would be difficult for a stranger to access the experience of an ill child. Those assumptions included pre-understandings about the child’s tendency to cling to the mother, or other significant caregiver; the ill child’s heightened fear of strange or new things, including people, and parents’ protective concern for the ill child. Given the methodological importance of gaining access to the child’s experience, the reported complexity of gaining access to the experiences of young children, and my own assumptions, I decided to recruit well children who were likely to experience short-term passing illnesses. I hoped that by developing a dialogue with children while they were well it would facilitate later access to their experience of a short-term passing illness. However, gaining access to a child’s experience requires first gaining access to the child.

As phenomenological research starts with concrete descriptions of the experience in context, the setting for this study needed to be in a context where young children experience short-term passing illnesses i.e. the child’s home. Yet, the home is a difficult setting in which to conduct research. The value of the home as a private place is highly regarded (Holstein & Gubrium, 1995). A researcher and a stranger entering the home to understand young children’s experiences crosses a traditional boundary between public and private space (Hood, Kelley, & Mayall, 1996). In addition, a stranger entering the home to spend time with children, particularly a male researcher, had the potential to raise parents’ concerns about the researcher’s intentions and the possibility of risk for the child, including at one extreme abuse of the child. On the other hand, a researcher who is also a nurse entering the home may be perceived by the parents as an agent of official surveillance that
could result in adverse criticism (Hood et al., 1996). In order to establish access to young
children in their homes these potential difficulties had to be addressed.

**Gaining Access to Child Participants**

Access to young children is controlled by a hierarchy of gatekeepers (ethics
committees, community organizations, and parents) exercising their responsibility for
protecting vulnerable children from risks and the power of adults (Hood et al., 1996).
Three institutional ethics committees approved the study. Approval was obtained from the
University of Newcastle Australia, Human Research Ethics Committee (Appendix 1). In
New Zealand ethical review of health and disability research is carried out by regional
health and disability ethics committees, which are accredited by the Health Research
Council of New Zealand. Accordingly, ethical approval was obtained from the
Canterbury Ethics Committee (Appendix 2). As my recruitment strategy involved the Royal New
Zealand Plunket Society their policy required that I also obtain permission from the
Plunket Ethics Committee (Appendix 3). These ethical review processes helped to ensure
that, as far as possible, the young children and I as the researcher were protected from
harm.

**Communities and Community Organisations as Points of Access**

To overcome some of the potential obstacles to accessing children in their homes I
decided to recruit participants from within specific geographical communities. The
rationale for this was that targeting specific communities would enable me to meet with key
stakeholders from community groups, thus providing an opportunity for some members of the wider community to evaluate my research and me before they were invited to advertise the study to families/whanau in their community. I made available to the community groups (and ultimately to the parents of children considering participating in the study) the results of a criminal conviction check through the Department for Courts. I felt the development of support and goodwill among stakeholders in the community would be crucial to gaining access to the young children. Targeting specific communities also provides an avenue for communicating the findings back to those groups at the end of the study.

Communities with a high density of children under five years old were targeted for recruitment. Supermap3 a CDROM database of information derived from the 1996 New Zealand Census (Department of Statistics) was queried in order to identify geographic communities in Christchurch with a high density of children under five. Having identified three distinct geographic communities, 16 organisations involved in the care of young children within those communities were identified. Organisations such as Plunket, kindergartens, play centres, and primary health care providers were approached. One of the geographic communities had a high density of Māori and Pacific Island children. Relevant organisations approached in that community included a Kōhanga Reo and a Pacific health provider. Many of these organisations had parent committees with whom I met. Having

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19 The Royal New Zealand Plunket Society is a national provider of well child health services to children under 5-years-old.
20 These checks are a routine requirement of people having employment contact with young children.
21 Plunket’s well child health services for children under 5-years-old are based in local communities and are delivered by paid staff including specialist well child health nurses and parent volunteers.
22 Kōhanga Reo are Māori preschools that teach Māori language and culture.
met with and explained the research to key people in those organisations, those stakeholders then advertised the study. Advertisements (Appendix 4) inviting parents to contact me were given to parents, placed in community group newsletters and on notice boards. In addition, a short article (e.g. "Study into child's experience of sickness," 2002) (Appendix 5) appeared in community newspapers. The circulation area of the community newspapers included but extended beyond the boundaries of the three geographic communities.

**Gaining access to children through parents**

As a result of the activities outlined above 31 parents (29 mothers and two fathers) of potential child participants contacted me by phone expressing an interest in the study. They were sent an information sheet (Appendix 6) and an information booklet\(^\text{23}\) (Appendix 7) with an accompanying audiotape informing them and their child respectively about the aims of the research and what would be involved for them. Existing guidelines suggest that to protect children adult’s consent should be obtained before the child is approached for consent. However, if adults decide to exclude children, then the children are effectively denied a choice about taking part in the research (Thomas & O’Kane, 1998). In a Canadian study involving 21 children in each of the three age groups (5-6, 7-8, and 9-10-years-olds) Abramovitch, Freedman, Thoden and Nikolich (1991) asked the children “should you be in a study if you liked it and your mother didn’t?” Fifty six percent of the 5-6-year-olds said they should, as did 59% of the 7-8-year-olds and 80% of the 9-10-year-olds. In the same study, most children in all three age groups (63%, 68%, and 76% respectively) said they

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\(^{23}\) Development of the information booklet is discussed in the next section
should not be in a study if they didn’t like it and their mother did. The children’s responses to the questions posed by Abramovitch et al. (1991) indicate that many of these children see that they should have an active choice in making a decision about taking part in research.

The problem of ensuring the voluntary nature of participation and eliminating any duress are complicated by the unequal power relations between children and adults. In a series of four studies, Abramovitch et al. (1991) found that prior permission of parents appeared to introduce pressure on children to agree to take part in the research even if the child did not like the study. In my own experience of recruiting participants for another study, I was unprepared for the fact that a child may feel pressured by a parent to take part (Watson, 1998). Ironically, while the consent of the parent or guardian is required to protect children, it may reduce their freedom to refuse to take part. Therefore, in developing the information sheet for parents and guardians I chose to deal explicitly with the possibility of the child feeling pressured by the parent or guardian to take part in the research. The information sheet explained that the final decision on whether their child took part would be left to their child. The consent of the parent or legal guardian would not be obtained until after the child had indicated their choice.

This study was designed to respect the parent’s right not to allow their child to take part. Thus, the community organisations and parents who acted as gate-keepers for children had the potential to limit the opportunity preschool children had to make decisions regarding either participating or refusing to participate in this research (Hood et al., 1996; Miller, 2000). However, if the parents agreed their child could take part in the study, the study design respected the child’s right to make the final choice about taking part.
The children’s informed choice

I was committed to respecting the child’s right to make the final choice about taking part by providing the children with every opportunity to make an informed decision about the research to the extent appropriate to their level of competence. To that end I reviewed a small body of empirical research exploring children’s competence to give informed consent to take part in research (Abramovitch et al., 1991; Ondrusek, Abramovitch, Pencharz, & Koren, 1998; Susman & Fletcher, 1992). Unfortunately, this research does not provide an objective measure of children’s capacity to consent; rather it reveals only the children’s performance with the information provided under the conditions in which that information was disclosed to the children. Children’s capacity to consent is often assessed as limited, without critical consideration of the information provided, or the conditions in which information about research is disclosed to children. Thus, children’s ability to consent to research is often underestimated. Consequently, careful consideration was given to the information that would be provided to potential child participants and the conditions under which that information would be disclosed.

Success in transmitting information to another person requires consideration of the media to be used to transmit the information, the language used in relation to the other person’s ability to understand it, and the context for transmission. These factors are discussed in turn in relation to the development of the information used to inform preschool children about this study.
Ethical and pragmatic issues determined the most appropriate media for transmitting information about research to the potential child participants. The need for freedom from any form of coercion generally prevents the researcher transmitting information directly to potential child participants. Thus, the researcher is left with written, audio or video media. The cost of producing high quality video information for potential participants was a pragmatic constraint in the context of this research. Therefore, I decided on written information in the form of a booklet (Appendix 7), accompanied by an audio-taped recording of the text of the booklet.

The issue of appropriate language was actually secondary to the issue of the content of the message. The initial general content for the information booklet was based on the principal requirements for informed consent: full understanding, freedom from coercion and deception, the nature and extent of expected involvement, the purpose of the research, actual or potential risks, communicating with families, involving the whole family, promoting understanding and time and timing. Once the initial general content of the information booklet was decided, the language in the text was repeatedly refined. In refining the language consideration was given to preschool children’s language development and comprehension. The language used by preschool children is usually couched within sentences that are simple, active, affirmative and declarative (Smith, 1998). Therefore, a thesaurus was repeatedly used to help simplify words. Sentences were consistently shortened to help maintain simplicity. Because children’s own speech tends to be active, passive sentences were avoided. As revisions to the text were made, the Flesch Readability Scores calculated by Microsoft Word’s grammar checker were repeatedly used
as a rough guide to estimating the ease with which the text could be read\textsuperscript{24}. While useful as a rough guide, like most readability scores, the Flesch scores have limited scope, relying principally on vocabulary (the number of letters or syllables in words) and syntax (the length of sentences and paragraphs) to calculate a readability score (Oakland & Lane, 2004; Powers, Sumner, & Kearl, 1958). My main concern in developing appropriate information to give to the preschool children about the research was their ability to understand it rather than read it. Therefore, once the text of the information was sufficiently refined other factors including the layout and the context for transmission were also considered.

I spent many hours in the children’s section of local libraries reading books and listening to book-tape combinations designed for preschool children. Particular attention was given to the layout, content and sentence structure used in these books. As well as reviewing young children’s storybooks I also focused on books designed to tell children about complex social issues such as birth, bullying, personal safety, illness, divorce and death. While having decided to exclude video as a means of transmitting my information, television programmes targeted at preschool children became regular viewing for a number of weeks. Attention was paid to the content and the way it was delivered.

The layout of the information followed that of many books designed for preschool children. Key factors that were incorporated in the layout of the text were a large font size

\textsuperscript{24} Two scores are calculated, the Flesch Reading Ease score where 100 equates with the easiest and the Flesch Kincaid score which assigns a grade level required to understand the text. The Flesch Reading Ease score on
(16), short line length, limiting the number of words and concepts per page, the use of lots of white space and colourful pictures between paragraphs. In an attempt to match the type with preschool children, a font (Kristen ITC) similar to a young child’s printing was chosen. Thick good quality paper was chosen to increase durability and prevent the bright colours showing through on the other side. Symbols are as powerful as words so careful attention was given to inserting pictures to match the words. Consideration was also given to ensuring the pictures represented children and adults from both genders and a range of ethnicities. The greetings and farewell at the beginning and end of the booklet respectively were written in English, Māori and Samoan.

The context or conditions under which the information is transmitted has a considerable impact on the successful transmission of information. In the context of a preschool child, written medium has the advantage of being a social experience facilitating interaction between an adult reader and the child listener. Parents willing for their children to participate were asked to read the booklet titled ‘It’s Your Choice’ (Appendix 7) and / or play the tape-recorded story to their child to enable the child to have the opportunity to consider participating in the study. To encourage active involvement of the child a few pages in the booklet included questions for the child to answer and one page invited the child to draw a picture. Instructions to parents and guardians on the back page of the child’s information booklet encouraged them to stop and discuss issues with the children as they read the booklet to the child. This shared experience was designed to provide both the parents and the child the opportunity for conversation and checking mutual understanding.

the final version of the booklet was 91.4 and the Flesch Kincaid score was four.
It also demonstrated the importance I placed on the child’s view and enabled the children an opportunity to decline to participate even if the parents were willing (Faux, Walsh, & Deatrick, 1988; Ireland & Holloway, 1996; Mauthner, 1997).

In developing the child’s information booklet I chose to deal explicitly with the possibility of the child feeling pressured to take part in the research. The child’s information booklet was titled “It’s your choice”. One page of the booklet dealt explicitly with the possibility of parental pressure stating “even if your mum or dad or the grown up who looks after you says you can talk with me you might not want to”. A picture of one child and six adults standing in a circle as if discussing something followed these words. Underneath the picture was the statement “remember it is your choice”. The following page informed the child “If you don’t want to share some of your time and your story of what it is like to be sick with me just say no thank you”. This was followed by a picture of a frowning looking face saying “no thank you”. The next sentence informed the child “If you want to share some of your time and your story of what it is like to be sick with me just say yes please”.

The booklet ‘It’s Your Choice’ (Appendix 7) was produced to help parents talk with their child about taking part in the study and to maximise the child’s choice in the process. Preschool children are not ready for a detailed discussion about research thus the booklet does not include a lot of detail about the study itself. They are, however, ready to learn how to make decisions about sharing their time and their experiences with others and how to communicate those decisions to others. The booklet gives the child an outline of the study and simple strategies for communicating their decisions. If the child chose to take
part, a parent was asked to sign a consent form (Appendix 8). Furthermore, during the study the booklet helped to clarify aspects of the study with the children.

**THE RESEARCH PARTICIPANTS AND THEIR INVOLVEMENT**

From the 31 initial contacts from parents who were spoken to on the phone and sent the information sheet, booklet and audio-tape, 10 children consented to participate in the study. The children were aged between 3-years and 5-five-years-old, there were four boys and six girls. The 10 children came from eight two-parent families, with two families having two children who consented to participate. Fifteen of the parents also participated in the research.

Having gained access to the children it was then necessary to build a relationship with the child in order that they might invite me into their world so that I could make intimate, detailed observations and descriptions of their experiences. In order to build trust, demonstrate to the children their involvement was respected, collect sufficient data, and allow for the possibility of the child having a short-term passing illness, repeated contact with each child over a period of time was necessary. Deatrick and Faux (1991) report that repeated observations of preschool children over time yield rich descriptive data about childhood experiences. The actual period of data collection for each child participant varied from two to five months with between five and eight visits spread over that period. Siblings were visited together. In total I visited the children on 49 occasions. The duration of each visit was usually about one hour. During the course of the study 5 of the 10 children became ill. Their illnesses included coughs, fevers, sore throats, vomiting and diarrhoea, and chicken pox. Four of the children (2 boys and 2 girls) that became ill were
visited once while they were ill and the fifth child was visited on three occasions while she was ill.

**Negotiating the Researcher Role**

I entered the homes of the children as an outsider or visitor. Entry into the child’s home therefore necessitated negotiating an acceptable participant-observer role with the children and the parents. In a study set in day care centres, Mandell (1988) advocated that researchers engage with the child in what she describes as the least-adult role “which suspends adult notions of cognitive, social, and intellectual superiority and minimizes physical differences by advocating that adult researchers closely follow children’s ways and interact with children within their perspective” (p. 464). However, Mandell chronicles dilemmas of enacting the least-adult role, with children having difficulty accepting an adult as nondirective, and adults expecting the researcher to make an adult contribution in the context of the day care centre. Van Manen (1990) advocates the researcher assume a relationship that is as close as possible to the child’s experience while retaining alertness to situations that allow the researcher to constantly step back and reflect on those situations. Therefore, I endeavoured to actively participate with the children in the least adult role possible.

The children, the parents, and I needed to be clear about who or what I was in the context of their home. Graue and Walsh (1995) suggest the role of the researcher should be defined and negotiated in relation to the aim of the research and the context of the study. Given the aims of this study, and to minimise the risk of the child seeing me as an adult authority figure, I adopted a non-authoritative role, particularly in relation to the child’s
illness experience. To facilitate both observation and participation I endeavoured to be as free as possible from adult conceptions (Corsaro, 1985; van Manen, 1990). However, Fine and Glassner (1979) suggest “there is no way in which the adult participant observer who attempts to understand a children’s culture can pass unnoticed as a member of that group” (p. 153). Accordingly, on occasions I found the children asking me to take on adult roles such as reading a book. On other occasions, I found myself adopting an adult role, limiting possibilities for the children by saying things like “I think we should ask mum about that first”. My researcher role did vary a little with each child and family, and over time, so my role was not rigidly prescribed and ongoing negotiation with the child and family was important (Mandell, 1988). I use the word negotiation deliberately as it reflects the active and continuous role taken by all three parties, the children, the parents and myself.

My active participant least-adult interactions with the children proceeded at a pace indicated by the behaviour of the child rather than by my needs as a researcher. These interactions aimed to provide children with opportunities to express their views without interference or coercion, and without fear of criticism. I believed responses made by children were likely to be more meaningful if the child initiated the interaction. Every effort was made to ensure the process was enjoyable for the child.

**DATA COLLECTION**

Collecting data relating to the lived experiences of young children raises issues around communication, comprehension, attention span, motivation, accuracy and confidentiality (Doorbar, 1997). These issues required careful consideration. Even within particular age groups, individual children’s communication skills vary, depending on
cultural and experiential factors, self-esteem and confidence (Doorbar, 1997). Furthermore, the children’s understanding is not necessarily reflected in the language they use (Doorbar, 1997). Therefore, I needed to adapt the means of communication so that it was accessible to each child.

To meet the considerations outlined above the following data collection techniques were used: participant observation, interviews, photography, videotaping, drawing, and play. The children were given as much choice as possible about the data collection techniques used. Which techniques were offered to individual children did vary according to my confidence with my researcher role with each child and family, and according to each child’s preference, ability, and response. Each of the data collection techniques was pictured in the child’s information booklet and the children themselves played a role in directing which techniques were used by asking questions about the pictures or exploring the contents of my bag which contained the various pieces of equipment (paper, crayons, camera, audio-tape recorders, video-recorder). While each of these techniques was used it is artificial to itemise them separately for in reality the method of collecting data was one of “close observation” (van Manen, 1990, pp. 68-69) that incorporated one or more of the above techniques from time to time.

Close observation

I use van Manen’s (1990) term “close observation” (pp. 68-69) intentionally, because it accurately reflects the process of data collection used. During the observations, I was on many occasions physically very close to the children. Most of the time was spent playing with them. Young children are not able to generate written descriptions of their
own experiences and have limited ability to engage in conversational interviewing (van Manen, 1990). So to gain access to the experience of children it was necessary to participate in the child’s daily activities, to play with them, talk with them, and generally interact with them as much as possible, and however temporarily, become a part of their lived world. Participant observation in phenomenological research is a close involved observation that tries to break through the distance often created by more experimental observational methods (van Manen, 1990).

Close observation required me to participate as closely as possible, while remaining alert to understanding the meaning of the situation in which I was involved (van Manen, 1990). The periods of close observation were planned to fit in with the child and family’s routine and not to disrupt what they would normally do. Observations were undertaken in the children’s home only when another responsible adult was present. Observations were not undertaken in bathrooms or toilets. Although I did not intend to undertake observations in the children’s bedrooms, bedrooms were a common location for close observations with some of the children. For those children their bedroom was the place where they kept their toys, books, and other objects they wanted to engage me with. Furthermore, for those children their bedroom seemed to be their play space, a space where they felt ‘at home’ and a space they considered as their own. Bedrooms were only used for close observation if I was specifically invited by the child to enter their bedroom and the responsible adult present consented to this.

Initially the unstructured close observations helped to build rapport and trust between the children, their family and myself. However, the primary purpose of the close
observation was for me to gain experiential anecdotes into the child’s experience of being ill. This was done by giving children a chance to express their thinking and ideas not only through speech but also through play, drawings, actions, and all the subtle ways in which young children represent their opinions, feelings and needs to others (Pugh & Rouse Selleck, 1996). Spontaneous play activities, initiated by the child and not directed by the researcher, formed the core of the close observations and are the main source of data. The children tended to involve me in their play rather than play alone. Control of the play rested with the children in the situation. I tried to remain alert to understanding the meaning of the situation, particularly any verbal or non-verbal expressions of the child’s understanding of what was happening. The repeated close observations over a period of time yielded anecdotes (Deatrick & Faux, 1991; van Manen, 1990) relevant to aspects of the children’s illness experience which are explored in detail in chapter six.

As rapport and trust between the children, their family and myself developed, some structured questions were incorporated in the close observations. The content and format of the questions was driven by specific events described by the child or a parent about the child’s experience. Subsequent questions flowed from the dialogue with the child about these events and not from a predetermined path. In other words, the focus of the questions was on events associated with the child’s experience. The parents were particularly helpful in improving my understanding of the child’s experience of illness events, occurring either before or during the study and the nature of the data collected from their child.

The quality of the questions was dependant in part upon the interpersonal relationship established between the child and myself. Therefore, direct questions about the
child’s experience of illness tended not to occur until some trust had been established between the child and myself. Questions tended to be informal and happen naturally from situations in which the child and I were interacting (Deatrick & Faux, 1991). Periods of questioning directly related to an illness experience tended to be short and limited by the child’s response.

The process of asking the children questions about their illness experience attempted to capture the unique perspective of the child. This perspective was more likely to be captured from free recall, or unstructured questions rather than responses to questions posed from an adult perspective. Consequently, questions about illness experiences tended to be open ended. For example, “what happened when you got sick?” If a child made little response to an open question focused on a specific experience, which was common, another more specific question was asked. Specific questions came from comments made by the child’s parents about the child’s past illness experiences. I tried to avoid introducing information not initially introduced by the child or their parent. This was to minimise the risk of children saying what they thought I wanted to hear. The pattern of the children’s responses to questions was such that responses often appeared irrelevant to the latest question asked. However, subsequent examination of transcripts often revealed a continuity of response that may have related to a question or an event that occurred much earlier or even in a previous visit. Thus, the children’s answers to questions did not tend to flow directly from the preceding dialogue with the child. This is consistent with the results of research conducted by Medcalf Davenport (2003) who found that preschool children continued to process responses to questions long after testing had moved to other questions.
Other researchers have found that children’s recall of events can be prompted by external cues rather than questions (Docherty & Sandelowski, 1999). Accordingly, I sometimes used objects already in the child’s home such as a tooth that had been extracted and kept in a special container, a soft toy given by an ambulance officer, special cuddly toys and medical play toys, as prompts to a child’s recall of an illness event. Where such prompts were used I found out about them through the child’s parents. The one illness-related prop I introduced to some of the children was a children’s book titled Who’s poorly too? The ‘get well soon’ book (Gray & McQuillan, 2001) in which a range of animals feel poorly from zany conditions and get better, for example the Dalmatian’s spots came out in stripes. On a few occasions, I read this book to the children and asked them if they had been poorly too. Although the children seemed to enjoy the book it was not particularly useful in generating new data. On some visits, I brought chalk, crayons, paper to draw on, a hand puppet and play dough. When these items were used they were used in play directed by the child. In addition, one or more of the following: audio-tape recorders, instamatic cameras and video-cameras were also introduced into the context of my close observations.

**Audio-tape recorders**

Of the 49 close observation visits with the children, 39 were audio-recorded with the verbal consent of the child. For the first five children I chose not to use the tape recorder on my first visit, and for two of those children I chose not use the tape recorder until my third visit. These decisions were based on first developing rapport with the children and on my own confidence in my participant observer role. One child declined consent to use the tape recorder on my fifth visit with her and her brother, and her request
was respected. On one early visit I had problems with equipment failure and on one visit I chose not to audio-record the visit to reduce my reliance on the audio recording and force me to remain attentive to other aspects of the close observation.

The close observations with preschool children generally involved lots of movement and activity, and the location could range from the living room to the backyard to the bedroom in a matter of minutes. Close observations typically included background noise from televisions, radios, toys, and mothers going about their daily activities. Children’s voices ranged from excited screams to quiet whispers and the pace of their speech was often fast. When the close observations included two children, these issues were further complicated by inattention to adult speech conventions regarding turn taking. Thus the environment for recording my close observations with the preschool children was in dramatic contrast to the ideal, controlled, quiet environments, free from interruptions, typically used for recoding qualitative interviews with adults.

I used up to three mini audio-tape cassette recorders (Panasonic RQ-L30) with lapel microphones at any one time, one for myself and one for each of the children. While the mini cassette recorders were small enough to fit in my pockets, they were too big for most children’s pockets. I had purchased three ‘bum bags’ made of soft fluffy fabric with the pouch in the shape of a Lions face. I had anticipated putting the cassette recorders in the pouch and the children wearing the ‘bum bags’ around their waist so that recordings could literally be made on the run. However, while the children were happy to wear the lapel

25 ‘Bum bags’ are also known as ‘fanny packs’, ‘belt packs’, or ‘hip packs’.
microphones most of the children were reluctant to wear the ‘bum bags’ and preferred to hold the recorder, leave it on the ground, or if possible, put it in a pocket.

The tape recorders had a reactive effect on children and me. The initial effect on me was to focus my attention on verbal content of my interactions with the children. They also put me in a role of teacher as I demonstrated to the children how they worked. Introducing the tape recorders gave the children and me something physical to engage with that I had brought to the context. All the children reacted to the audio-tape recorders, particularly in the early stages of the recording where the children were very interested in hearing themselves on the audio-tape and learning how to play the recording back and turn the recorder on and off. This reaction was often repeated at the beginning of each observation. At other times, for example following a funny sound, children requested to have parts of their tape played back.

Given that I also had an audio-recorder running, at least one recorder was running most of the time. At other times there were up to three recorders running. This required careful labelling of tapes after each visit. While multiple tapes had the advantage of sometimes catching words on one tape that were not clear on another, matching multiple recordings, some of which had been stopped and started and played back, was not an easy task. Given all of these issues, the quality of the audio-taped recordings varied within each close observation and the recordings were particularly difficult to transcribe. Issues relating to transcription and analysis are dealt with in detail in the next chapter.
**Drawing**

Paper and crayons were among the props I introduced. At some stage all the children were offered an opportunity to draw a picture about being ill. Children typically view drawing as a non-threatening and enjoyable activity. Other researchers have noted that young children usually express themselves more naturally and spontaneously through actions rather than through words (Johnson, 1990; Rollins, 1990). Projective techniques such as drawing have been used as a way of eliciting data about events children might find difficult to talk about (Pridmore & Lansdown, 1997; Spinetta, McLaren, Fox, & Sparta, 1981; Woodgate & Kristjanson, 1996). However, I found that children often asked to draw something else, in which case the children drew what they wanted. If the children gave the pictures to me I kept them as potential sources of data, otherwise the children kept their drawings.

**Photography**

All of the children were on at least one occasion offered the opportunity to use a Polaroid (i-zone) instant pocket camera to capture meaningful moments, events, or objects in their experience. On most occasions the children took the photographs themselves but on some occasions they directed me to take photos. Photographs have the advantage of visually capturing a moment of experience, thus providing an immediate focus on a concrete experience (Collier & Collier, 1986; Hagedorn, 1994). The child’s discussion of the photographs provided access to some information not otherwise revealed in verbal communication. All photographs were given to the children at the end of each visit.
Video recording

Video recordings were used to supplement close observations and audio recordings with a view to collecting more detailed non-verbal data in context (Paterson, Bottorff, & Hewat, 2003). Following parental approval, three of the children recruited later in the study were offered the opportunity to be recorded on video-tape. Consequently, parts of six periods of close observation were recorded on video-tape. Of those, four video-tape recordings occurred during visits when a child was ill.

The video recorder was positioned on a tripod at a height about inline with the child’s chest and placed in front of the child to capture their expressions and actions rather than mine. The LCD monitor on the video recorder was inverted so the child could see what was being recorded. Use of the tripod and inverting the LCD monitor had the advantage of not positioning me behind the camera and left me more able than I otherwise would have been to continue to interact with the children during the video-taped observations. However, where the children moved outside the view of the camera, and it didn’t hinder my interaction with the child, I adjusted the view of the camera to include as much of the child’s activity as possible. Although the video camera had an inbuilt microphone, the video recorded observations were also audio recorded as outlined above. If the child asked for something or someone else to be recorded, usually a parent or myself, then I complied with their request. If the child asked or otherwise indicated they wanted the video-recorder turned off, video recording was stopped (more on this in chapter six).

The video recorder had a reactive effect on both the children and me. During video recordings, I found myself adopting more of an adult role, as I became protective of the
relatively expensive video recorder and sought to limit the child’s direct contact with the recorder. All three children reacted to the video recording in much the same way as the children reacted to the audio-taped recordings, particularly in the early stages of the recording where the children were very aware of the recording and interested in seeing themselves on video. Video recording has the obvious advantage of capturing nonverbal and contextual data such as gestures, actions, rhythms, and some environmental influences. While video captures additional data and has been described as the research instrument par excellence (Lomax & Casey, 1998), the constraints and possibilities for analysing this data are discussed in chapter five. Video-tapes will be given to the children and their families at the conclusion of the study.

**Field notes**

In order not to break the spontaneity of interactions, close observations were not recorded as field notes at the time of the interaction. However, some notes were taken on reflection soon afterwards. Field notes usually consisted of brief notes relating to the setting, people, actions and conversations observed, as well as my more subjective reflections, ideas and concerns (Bogdan & Knopp Biklen, 1998).

**Interviews with parents**

As well as informal discussion with parents (mainly mothers) at the beginning, during, and at the end of close observation visits with the children, parents also participated in formal interviews. Both parents from seven of the families and one parent from the other family participated in the formal interviews. Parents were intimately connected with their children and had knowledge of their child’s experience of illness. This background
knowledge was important to understanding the context of their child’s illness experiences. Interviews with parents focused on specific situations that described what seemed to be of concern to the child at the time of past episodes of illness. Interviews began with an open-ended question to elicit a spontaneous description about their child’s past experience of illness. For example, “What seemed to be of concern to your child when s/he was sick?” Subsequent questions flowed from the dialogue with the parent rather than from a predetermined path. Interviews were tape recorded with the written consent of the parents. Some parents chose to review and comment on the transcripts of close observations with their children. Where parents did this it often helped to shed light on some of the child’s comments, particularly those that appeared to make no sense or be out of context.

**ETHICS**

Many of the ethical issues involved in this research have already been discussed, in particular informed consent. However, the remaining issues of confidentiality and freedom to withdraw are explored below.

**Confidentiality of children’s data**

Confidentiality is an essential part of respecting participants in any study. Additionally, participants’ confidence in the assurance of confidentiality can impact on the credibility of the data collected (Coyne, 1998). In research with young children there is a complex paradox between the child’s right to confidentiality or privacy and the parent’s responsibility to supervise and protect their child. Adults commonly expect that they have a right to access any information relevant to the children for whom they are responsible. This is particularly so in regard to younger children. Consequently, young children
frequently have little experience of situations where they have personal privacy, particularly in relation to keeping things from their parents (Abramovitch et al., 1991). Therefore, Abramovitch et al. (1991) suggest that it might be quite difficult for researchers to explain confidentiality to younger children but suggest that special effort should be made to do so.

There is clearly a need to balance the parents’ responsibility to supervise and protect their child, with the young child’s right to confidentiality. New Zealand’s legislative requirements provide a framework that seems particularly applicable to the issue of confidentiality in research involving young children whose understanding and maturity limit their ability to exercise their right to privacy and where the support of parents or guardians is clearly required. Parents in New Zealand do not have an automatic right to all information about their children (Kerkin, 1998). New Zealand’s rights-based legislation such as the Privacy Act ("Privacy Act," 1993) and the Health Information Privacy Code (1994) make no real distinction between their application to adults and to children. However, rule 11 of the Health Information Privacy Code allows information to be disclosed if the intention to disclose the information was openly expressed before collecting the information. Rule 11(2)(b) of the Code allows the disclosure of some information in the context of “a registered health professional to a person nominated by the individual concerned or to the principal caregiver or a near relative of the individual concerned in accordance with recognised practice and the disclosure is not contrary to the individual’s or representative’s expressed request.” More pertinently, Section 22F of the Health Act (1956) requires information to be disclosed to a child’s parent or guardian on request. However, under section 22F of the Health Act requests for information by parents or
guardians can be refused if the refusal is authorised by a code of practice issued under the Privacy Act (1993). Rule 11(4) of the Health Information Privacy Code does set out grounds upon which information may be withheld. These grounds may include the disclosure of information that would be contrary to the individual’s interests, or if the agency has reasonable grounds for believing that the individual does not or would not wish the information to be disclosed. Following the legislative framework, children were informed that all information they shared with the researcher might be disclosed to their parents. This included the parents reviewing and commenting on the photos, audiotapes, videotapes and field notes of the researcher’s visits with their child.

The child’s information booklet (Appendix 7) reinforces to the child that their story of what happens to them when they are sick is special and it belongs to them. Children were told that they could tell their parents anything they wanted about what they did when I visited. Parents were encouraged to ask the child about my visits. I undertook to disclose any information relevant to a child’s participation in the study that was requested by the child’s parents. However, if a child expressly requested that I keep something private, I could still disclose that information if the disclosure was not contrary to the child’s interests.

The issue of confidentiality is made more complex by my responsibility to protect the young child from all forms of harm. Protecting young children from harm has special significance because of their limited ability to protect themselves. This issue places a limit on the degree of confidentiality that can be assured and a limit on the degree of disclosure to parents. A provision was made concerning information that if kept confidential would
result in harm to the child. In such circumstances the researcher would give the relevant information to someone who was in a position to protect the child.

The actions taken to protect children from harm are guided by legal requirements, ethical values and professional standards of practice. In New Zealand law the Children, Young Persons and Their Families Act ("Children, Young Persons, and Their Families Act," 1989) does not require mandatory reporting of child abuse. However, there has been considerable recent debate about the risks and benefits of mandatory reporting of child abuse (Fielden, 2000; NZPA, 2000). The Paediatric Society of New Zealand has had a policy in favour of mandatory reporting for more than a decade (Kelly, 2000). Furthermore, the New Zealand Nurses Organization in its 1993 Standards for Nursing Practice expects that “nursing practice protects clients from physical and psychological danger and avoidable risk” (p. 10). The duty of care requires a nurse researcher to report any suspected child abuse and be able to refer the situation to a properly trained health professional who can advocate for the child. The support of a paediatrician (Appendix 9) was negotiated so that there was a properly trained health professional available to advocate for the child should such a circumstance have arisen.

Subject to the above qualifications all information about the participants was kept confidential. The only people who have access to the photos, audio and or videotapes and the written records are my supervisors and me. A typist who signed a confidentiality agreement (Appendix 10) also had access to the audiotapes. No one else outside the participants’ family was told that the child was taking part in this study unless the child or their parents chose to tell them.
To keep the identity of people private all written records and any publications from this study will use pseudonyms for participants and any third parties mentioned during the course of the study. Despite the use of pseudonyms in publications, it is possible family members or those who know the child well may recognise the child’s story. There is no absolute solution to this dilemma. All data used in this thesis has been closely scrutinised to protect the anonymity of participants and third parties.

**Freedom to withdraw**

Participants must be able to withdraw from the investigation at any time without waiver of any rights and without giving reasons. In one of a series of studies conducted by Abramovitch et al. (1991) children were asked, “What happens if you want to stop being in the study?” Only 38% of the 5-6 year olds correctly identified that they could tell the experimenter and leave, or simply leave and get their mother. In response to a more direct question, “How can you stop being in the study?” 57% of the 5-6-year-olds responded correctly. In a pilot study, Ondrusek et al. (1998) asked 18 children, 5 to 18-years-old who had agreed to participate in a study “Is it OK to stop”, only two of the eight children under 10 years believed it was acceptable to stop taking part in the study. Susman et al. (1992) found that in a sample of 44 participants aged from 7 to 20 years only 40% understood they were free to withdraw from the study. Thus, a substantial percentage of young children in these studies did not know that they could withdraw from the study. Furthermore, in the studies by Abramovitch et al. (1991) and Ondrusek et al. (1998) it appeared the children felt that their parents and/or the researcher might respond negatively if they stopped taking part.
One page of the child’s information booklet for this study dealt explicitly with the fact that the child was able to withdraw from the study stating “If you want to share your story with me and later you change your mind and feel you don’t want to share your story that’s OK”. This sentence was followed by “Just say no thank you and tell your mum or dad or the grown up who looks after you”. A picture of a smiling face saying “no thank you” separated the two sentences. Thus, I attempted to state clearly that the child could change their mind about taking part, that it was OK with me, and to give a simple message about how to withdraw.

In summary, this chapter has detailed the steps taken to overcome the complex and challenging obstacles to gaining ethical access to children’s experiences of short-term passing illness. In the next chapter I detail the steps taken in my attempts to understand those experiences as the children understand them.
CHAPTER FIVE

THE ENIGMA OF UNDERSTANDING CHILDREN’S LIVED EXPERIENCE

It took me a long time to understand where he came from. The little prince, who asked me so many questions, never seemed to hear the ones I asked him. It was things he said quite at random that, bit by bit, explained everything. (Saint-Exupéry, 1943/2000, p. 7)

Here is my secret. It’s quite simple: One sees clearly only with the heart. Anything essential is invisible to the eyes. (Saint-Exupéry, 1943/2000, p. 63)

In chapter four, I focussed on how I gained access to the experiences of preschool children, by following the children through their experiences, which could be characterised as an ethnographic approach. In this chapter my focus is on explicating the development of a phenomenological process I came to use as a means of reflectively appropriating, insofar as I am able, the structure of the meaning of those experiences as lived by the children (van Manen, 1990). The development of this phenomenological process differentiates this research as principally phenomenological. What I am presenting is an ethnographic phenomenology for understanding preschool children. In the ethnographic phenomenology I am advocating, ethnography provides access to the field where the preschool child’s experience is lived, and phenomenology provides the methodology central to understanding the child’s experience. This approach differs from the phenomenological anthropology
advocated by Jackson (1996) and Katz and Csordes (2003) where anthropology is the central concern.

In the previous chapter, I argued the ability of adults to access the experience of preschool children is limited by the child’s limited ability to symbolise experience through language, the differences between adults and children, and preschool children’s dependence on adults. In this chapter, I will show how those very limitations provided positive possibilities for moving to a primordial understanding of preschool children’s intentions, meanings and ways of acting. Consistent with Heidegger’s (1927/1962) and Gadamer’s (1960/1996) descriptions of how interpretive understanding is achieved, the positive possibility in those limitations was worked out by remaining focussed on the child, and constantly examining the legitimacy of those limitations that formed part of my own pre-understandings. The process of repeatedly revising those pre-understandings uncovered the child’s ability to symbolise experience by means other than language, the need to engage *in-between* the different perceptions of adults and children, and the importance of the adult being *situated* in relation with the child. These movements in understanding were prerequisites for subsequently being open to understanding the children’s lived experience, not just within the limits of their language, but also informed by our mutual embodiment within the world. This is a phenomenological process guided by Merleau-Ponty’s constant view, as succinctly stated by Dillon (1997), that language is “a phenomenon founded upon human embodiment within the world, and must be understood within this context” (p. 186). The rest of this chapter outlines the methodological process I followed for apprehending in so far as I am able the structure of the meaning of those experiences as lived by the children from the foundation of our mutual embodiment within the world.
IS IT POSSIBLE TO SEE THE WORLD AS THE CHILD DOES?

Interpreting the experiences of preschool children poses considerable methodological challenges. The key challenge is seeing and interpreting the world as the child does. Saint-Exupéry (1943/2000) in dedicating his classic children’s story The little prince to an adult points out that “all grown-ups were children first. (But few of them remember it.)” (p. not numbered). Taking this idea further, Hermann Hesse (1945/1973), in the autobiographical account of his childhood, asks:

wasn’t it a strange and suspicious thing that among all those ‘big’ people, who after all had been children themselves not long ago, there were so very few who had not completely unlearned and forgotten what a child is, how it lives, works, plays, thinks, what it likes and what it hates? (p. 17)

Thus, while every adult has been a child, it seems at worst the child within us is forgotten and at best the child within us is “the remembered child”, and as such is bound inextricably to the perspective of the person remembering in the present (Lippitz, 1986, p. 56). Similarly, the child within us, as our past, is, according to Husserl (1929/1960), “given only by memory and is characterised in memory as my past, a past present – that is: an intentional modification ... of my living present” (p. 115). The remembered child within me can only be experientially verified by virtue of memories occurring in the present and therefore as a modification of my living present the child I once was is inevitably beyond

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26 Merleau-Ponty (1961/1964b; 1964/1968) uses the phrase intentional transgression rather than intentional modification when referring to this section of Husserl’s (1929/1960) work.
my present grasp (Husserl, 1929/1960). As well as the inevitable limitations of remembering one’s own childhood, histories of childhood illustrate that the child’s world changes over time with social and technological changes (Ariès, 1960/1962; Cunningham, 1995). Consequently, the world of my childhood is likely to be different in some aspects to the world the children in this study experience.

While every adult has been a child, no child has been an adult. Therefore, the child’s standpoint is inescapably different from the adult’s. A point also made clear by Hesse (1945/1973) who complains of “suffering once more from the fact that it was so hard to make oneself understood by grown-ups” (p. 13). Also, Saint-Exupéry (1943/2000) asserts “grown ups are so strange” (p.33). Accordingly, Beekman (1983) claims there are “fundamental differences in the lifeworld structures of young children and adults” (p. 40). Beekman goes on to declare “as long as we see the actions of little children through the models of our shared adult conventionality [italics added], we are not likely to see the world as children, in their own uniqueness, see it” (p. 40). I was not confronted with the true extent of the challenge, if not the impossibility, of seeing and interpreting the world as the child does until I began to transcribe and analyse my data.

**TRANSCRIPTION AS PHENOMENOLOGICAL REFLECTION!**

At first, I began the conventional process of transcribing verbatim the audiotapes from the initial close observation sessions. These early attempts at producing draft transcripts focused on converting the words recorded on audiotape into a text format. Each participant’s words were recorded on a new line in a chronological sequence. My initial underlying assumption was that the language used by the preschool children would be
primary to understanding their experience as they did. How something was said, was seen as of secondary importance, as were the contextual and nonverbal data. Given the nature of my interactions with the children described in the previous chapter, the clarity of the words recorded was sometimes poor. Consequently, the process of producing draft transcripts was time consuming. In addition, I quickly became aware that these initial draft transcripts did not adequately re-present the nature of my interactions with the children and that substantial nonverbal and contextual data needed to be included in the transcripts. Consequently, I added nonverbal and contextual information from field notes and my memory and placed it between double parentheses to the right of the verbal content. As Ochs (1979) identifies “the problems of selective observation are not eliminated by the use of recording equipment. They are simply delayed until the moment at which the researcher sits down to transcribe” (p. 44). The problem of selective observation applies equally to the use of audio and video recording equipment. The audiotape recorder does not hear and the videotape recorder does not see; they both record (Jager, 1971). Here there is an essential distinction between perceiving and recording that will later prove to be decisive.

In an effort to expedite the process of transcription, I decided to use a typist to transcribe from each audiotape-recorded interaction as many words as she was able within a three-hour period.\textsuperscript{27} The focus of the typist was on transcribing the verbal content she could clearly hear. This allowed me to concentrate on the rest of the tape recording particularly poorly recorded parts and the nonverbal and contextual information. At the same time, I checked the accuracy of the transcribed verbal content. Having somebody

\textsuperscript{27} The three-hour period was based on a pragmatic consideration of cost.
else’s hearing of the recordings forced me to listen more critically to my own hearings of what had been recorded. Commencing with a good skeleton of verbal content transcribed by the typist, seemed to help me concentrate on stretches of conversation which were hard to hear the first time, but usually became clear after repeated play back, at normal speed and at reduced speed.

I was relatively happy the draft transcripts accurately recorded the children’s verbal content, my verbal content, and key contextual information relating to the close observations, until I began the process of attempting to seek meaning from the transcripts by uncovering and isolating thematic aspects (van Manen, 1990). Following fruitless attempts to analyse the transcripts I began to question the quality of the transcripts. In the context of the transcripts, much of what the children said appeared to make little or no sense, even though most of it had made sense in my lived experience of the close observations. Sometimes what the children said related to something much earlier in a period of close observation or even to something during a previous close observation. I felt my close observations had allowed me to know some important dimensions of the children’s lived experience but, at this point, I could not conceptualise or articulate them and they did not seem to appear in the transcripts. Something important was still missing in the transcripts, and so for guidance on how to re-present children’s discourse in textual form I turned to Ochs’ (1979) seminal work on the theory of transcription in the field of child language.

In English-speaking culture, written language is decoded from top to bottom and from left to right. Because of this convention, there is a predisposition to interpret verbal
and nonverbal behaviour in light of the preceding text (Ochs, 1979). When examining the speech of young children the expectation that speech is normally reliant on prior talk does not hold (Ochs, 1979). Thus, the immediately prior speech or action particularly of another speaker cannot necessarily be counted on to assist in the interpretation of a child’s verbal or nonverbal act. Ochs suggests the format of a transcript influences the interpretation process and that a transcript of children’s speech should not match that of adult speech. Ochs also suggests conversations between adults and children aged 14-months to 3-years-6-months be presented side by side in parallel columns, making it easier for the reader to see the prior verbal behaviour of the child. Ochs’ central concern is not to dictate a particular transcription format but to raise researchers awareness that the act of transcription has potential consequences for interpretation. Furthermore, Ochs acknowledges that as children acquire communicative skills the transcription format should be adjusted.

Guided by Ochs’ (1979) theory of transcription I adjusted the format of the transcripts. In order to make it easier to see the prior verbal content of the children I decided to use a **bold font for the children’s verbal content** and a regular font for my own verbal content. The use of a bold font for the child's verbal content also helped to overcome my culturally inherited tendency to use my adult verbal content as the point of orientation. Where the interactions with the children involved more than one child, a distinctive bold font was used for each child.

In the earlier drafts of the transcripts, the verbal content was in the foreground in part, because the interactions were audiotape recorded and any field notes of nonverbal behaviour were limited to observations recorded immediately after the interactions, or
memories of nonverbal behaviour recalled during the process of refining the transcripts. The nonverbal context is therefore much less complete than the verbal content. In addition, my early transcription practice of placing nonverbal behaviour within double parentheses to the right of the verbal content further placed the nonverbal behaviour in the background. Typically, the context in which I interacted with the children was one of play where nonverbal behaviour, both the child’s and my own, emerged as an important component. The emergence and the importance of nonverbal behaviour are discussed in detail in the following chapter. Ochs (1979) suggests, "these behaviours should not be relegated to 'bracketed' status" (p. 55). By removing the brackets, presenting the nonverbal behaviour in superscript and in italics I integrated the nonverbal and verbal content while maintaining the ability to distinguish between the two. Placing the nonverbal content in superscript while maintaining the same font size as the verbal text gave the nonverbal behaviour some prominence because of my cultural tendency to decode from top to bottom which went some way to compensating for my adult (researcher) tendency to privilege the verbal content. Rather than placing the nonverbal content to the right of the verbal content as an aid to interpreting the verbal content, careful consideration was given to the placement of nonverbal content either to the left or right of the verbal content to reflect their temporal relationship in the context of the interaction.

The production of the transcripts was extremely time consuming but also tremendously important for three reasons. Firstly, the revised transcripts were much more accurate and effective re-presentations of the close observations. Secondly, I eventually
came to realise the intricacies of the situations would always be *more than* even the most detailed transcript was capable of encompassing. Thirdly, I realised the transcripts would always inevitably be implicit re-presentations of my subjective observations and experience in what were inter-subjective situations. They were not neutral re-presentations, and they were not re-presentations of what the child perceived as present.

Thus, the act of transcription had significant consequences for my attempts to interpret the experiences as the children would. The transcripts were important for capturing the children’s language and aspects of the context in which the language occurred. However, they could not stand on their own as a source for interpreting the lived experience of these preschool children as the children would. Two questions presented themselves. How could I interpret the experiences, as the children would, when all the data I had was *always already* internal to me, my subjective experience revealed to me in interaction with the preschool children? How could I interpret the intricacies of the situations that were always *more than* the transcripts re-presented? I will address each question in turn in the next two sections.

**MERLEAU-PONTY’S PHENOMENOLOGY AS A GUIDE TO REFLECTION**

Merleau-Ponty’s works (in particular 1960/1964; 1961/1964b; 1964; 1964/1968) and Welsh’s (2002) thesis on Merleau-Ponty’s thought related to childhood experience were influential in working out the solution to the question of how to overcome the introspective nature of my data. This could be seen as ironic given that Piaget (1965/1971) rejected Merleau-Ponty’s phenomenology on the basis that it was introspective. However, as Rojecwicz (1987) points out, Piaget misunderstood Merleau-Ponty’s phenomenology.
In the working notes of the unfinished manuscript Merleau-Ponty (1964/1968) was writing before his death, he addresses my problem of understanding children through introspection. Under the heading “the problem of analysis” (p.203) he starts by asking, “Do we have the right to comprehend the time, the space of the child as an undifferentiation of our time, of our space, etc. . . . ?” It is obvious Merleau-Ponty (1964/1968) thinks we do not have the right to comprehend the experience of the child as an undifferentiation of our experience. He goes on to say, to do so “is to reduce the child’s experience to our own, at the very moment one is trying to respect the phenomena. For it is to think it as the negation of our differentiations” (p. 203). Thus, Merleau-Ponty (1964/1968) confirms my first analytical problem and in addition presupposes differences in the experience of the child and the adult. However, the question of how to solve this problem remains.

Merleau-Ponty’s (1964/1968) solution to the problem of analysis as recorded in his working notes is to “recapture the child, the alter ego, the unreflected within myself by a lateral, pre-analytic participation, which is perception, ueberschreiten by definition, intentional transgression. When I perceive the child, he [sic] is given precisely in a certain divergence (écart)” (p. 203). This solution and its methodological implications are not as obvious as the problem now seems, and requires further explanation. There are two interrelated components to the solution, both involving Merleau-Ponty’s position on perception; first perception as a lateral, pre-analytic participation, (intentional transgression) and, second, perception as a certain divergence. Although they are closely
interrelated, I will explore perception as a certain divergence first and then return to perception as a lateral, pre-analytic participation (intentional transgression).

Merleau-Ponty’s (1964/1968) solution suggests the key to understanding childhood experience lies in my unreflected perception given precisely in a certain divergence. In other words, I cannot avoid involving my own unreflected experience and can only uncover thematic aspects of the child’s experience when they are given to me as precise deviations (Meyer-Drawe, 1986). This insight helped to focus my analysis on the relatively few moments in the close observations where my lived experience was one of surprise at what the child said or did in the situation. The surprise emanating precisely from a certain divergence from what I expected. I tended to experience these moments of surprise pre-reflectively as a felt sense, an unclear bodily awareness (Gendlin, 1981), often like an uncomfortable knot in my stomach. Interestingly van Manen (1990) describes phenomenological themes metaphorically as “like knots in the webs of our experience” (p. 90). Lippitz (1986) also indicates a sensual physical nature to understanding; he suggests that adult researchers and children have an obligation to accept each others strangeness as “the necessary, but not sufficient, [italics added] condition with which communication, and through it understanding – as a living sensual-physical process- [italics added] becomes possible” (p. 64). On reflection, these moments of surprise were mostly times when I realised I did not understand the child. For me these moments of surprise and misunderstanding were experienced as a living sensual-physical process, like a separation.

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28 Similarly in a closely related context Husserl (1929/1960) says “precisely if there is something discordant about its behaviour” (p.114).
It is important to note that the perception of a certain divergence comes from being close to the child’s experience in which the divergence is recognised as a separation.

To use the same instructive comparison as Husserl (1929/1960), somewhat like my childhood memories which are a modification of my living present and go beyond my present grasp, my ‘internal perception’ of the child in the divergence was experienced as a modification of my living present and went beyond my present grasp of the situation. Thus, phenomenologically, I experienced the child as an “intentional modification” (Husserl, 1929/1960, p. 115) of myself; or as Merleau-Ponty (1964/1968) would say, “intentional transgression” (p. 203). This is important because Merleau-Ponty’s (1964/1968) solution to the problem of understanding children through introspection requires recapturing the child by intentional transgression.

Recognising moments of divergence from what I expected in the close observations was relatively simple as the felt sense usually remained in me as a meaningful part of the situation, although frequently not recorded as such in the transcripts. Nonetheless, recognising the moments of divergence was not sufficient to make sense of what the child had said or done from their perspective. Understanding is not so much a matter of accepting the strangeness but rather of recognising it and attending to the perception given in a certain divergence, in order to comprehend how what was said or done could possibly make sense. Here there is a presumption that from the child’s point of view what was said or done was an expected, sensible thing to say or do in that situation.
No thought was required to grasp the possibility I was expecting in each situation; it was given to me precisely in the perceived divergence. According to Merleau-Ponty (1964/1968) the “divergence is not a void,” (p.272) it is filled with possibilities. However, this does not help resolve the problem of identifying the possibilities, in particular the possibility that made the words or actions make sense for the child in each situation. The problem of identifying possibilities is compounded when one considers the world of children is open to more possibilities than the adult world, which has established rules and conventions, which serve to limit possibilities (Meyer-Drawe, 1986). Hesse (1945/1973) poignantly describes how adult limits gradually encroach on childhood possibilities.

Slowly out of the unlimited, something limited was coming toward me, the real world of grownups…..Already the many-splendored world of the possible was limited for me, divided into fields, cut up by fences. Gradually the primeval forest of my days was altered, paradise congealed around me. I no longer remained what I was, prince and king in the land of the possible. (p. 20)

Thus, I had what was beginning to look like a familiar problem. How could I identify the possibilities in the situation, which were always more than my experience of the situation presented to me? As all adults were children once, one option was to rekindle memories of lost possibilities from my own childhood experiences but, like Lippitz (1986), I also found it extremely difficult to rekindle childhood memories, particularly from preschool years. Another option was to use artistic sources such as literature, particularly biographies or biographical novels in order to glean the essence of some childhood possibilities (Lippitz, 29

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29 The fact that the felt sense remained in me is important to resolving the problem that the situations were
1986; Meyer-Drawe, 1986; van Manen, 1990). I did seek to glean possibilities through a few literary sources that briefly refer to the preschool years (for example see Burnett, 1982; Hesse, 1945/1973; Moberg, 1957; Potok, 1975). However, despite the literary sources’ ability to capture the essence of some childhood experiences and enhance my understanding of childhood, the knowledge of childhood possibilities extracted from them did not help to identify possibilities that made the children’s words or actions make sense in the situations of perceived divergence. Again, I am left with the problem of situations that appear to be more than my experience of them. I will return to this point under the next heading.

Taking stock of my position, it might seem that I was trapped in a vicious circle. I knew what I expected in the situations but I did not know what the child expected. This also looks very like the other problem I started with, where all the data I had was always already internal to me. This circularity is not so much a vicious circle than what other phenomenological thinkers have called the hermeneutic circle (Gadamer, 1960/1996; Heidegger, 1927/1962; Simms, 1993). While I had returned to the problem of situations that were more than my experience of them, I had made some progress. I had identified specific situations from my experience of the close observations in which I can be fairly sure there was a divergence between my perception of the situation and the child’s perception of the situation. This is not a fall back to the position of developmental theorists drawing comparisons between children and adults. The point is not to compare possibilities, but rather to bracket or suspend my possibility in an attempt to identify always more than the transcripts re-presented and is discussed in the next section of the this chapter.
possibilities in which what the child said or did makes sense. However, it seems inevitable that making sense means making sense to me, rather than to the child in the situation. Thus, in attempting to break from my understanding of the situation I learn what Merleau-Ponty (1945/1962) acknowledges as “the impossibility of a complete reduction” (p. xiv). Therefore, my perception of the situation inevitably places some limits on my ability to see the situations as the children did.

It is clear I see these divergent situations with the children from a particular vantage point. According to Merleau-Ponty (1945/1962) the fact I am situated is not contestable. We must not wonder why being is orientated, why existence is spatial, why, using the expression we used a little while ago, our body is not geared to the world in all its positions, and why its co-existence with the world magnetizes experience and induces direction in it. The question could be asked only if the facts were fortuitous happenings to a subject and an object indifferent to space, whereas perceptual experience shows that they are presupposed in our primordial encounter with being, and that being is synonymous with being situated. (p. 252)

My felt sense of a certain divergence began in a situation and was immediate. While my perception of the situation necessarily imposes some limits on my understanding, Merleau-Ponty’s (1945/1962) description of phenomenology explicitly refers to the importance of the situation in understanding the other.

For the ‘other’ to be more than an empty word, it is necessary that my existence should never be reduced to my bare awareness of existing, but that it should take in also the awareness that one may have of it, and thus include my incarnation in some nature and the possibility, at least, of a historical situation. The Cogito must reveal
me in a situation, and it is on this condition alone that transcendental subjectivity can, as Husserl puts it, be an intersubjectivity. (p. xiii)

Therefore, in order to identify possibilities in which what the child said or did makes sense I must begin not with possibilities from my childhood, or the literature, but in the situation I find myself thrown in.

To summarise thus far, in addition to my felt perception of a certain divergence in particular situations, and recognition that the child’s perception of those situation was probably different to mine, I now know I must begin to understand the children’s experience through my position in the situations. The question remains open: Is it ever possible to move from my perception of the situation to the child’s perception? This question foregrounds a tension that is not unique to this research. It is evident in all phenomenological human science research but it is amplified by my focus on preschool children’s experience (Heshusius, 1991). Therefore, it is not surprising to find further direction on this problem in Merleau-Ponty’s (1960/1964) work The child’s relations with others.

My concern about the possibility of moving from my perception of the situation to the child’s perception is equivalent to my earlier concern about the records of my close observations always being records of my introspective subjective experiences with the children. Both concerns rest on a Cartesian dualistic understanding of self and other, in which my reflective conscious experience is viewed as mine, separate from the conscious experience of any other person and inaccessible to others. Merleau-Ponty (1960/1964) views this as a misunderstanding and says
The problem comes close to being solved only on condition that certain classical prejudices are renounced. We must abandon the fundamental prejudice according to which the psyche is that which is accessible only to myself and cannot be seen from outside. My ‘psyche’ is not a series of ‘states of consciousness’ that are rigorously closed in on themselves and inaccessible to anyone but me. My consciousness is turned primarily toward the world, turned toward things; it is above all a relation to the world. The other’s consciousness as well is chiefly a certain way of comporting himself [sic] toward the world. Thus it is in his [sic] conduct, [italics added] in the manner in which the other deals with the world, that I will be able to discover his consciousness. If I am a consciousness turned towards things, I can meet in the things the actions of another and find in them meaning, because they are themes of possible activity for my own body. (pp. 116-117)

Here again the adult is faced with a particular challenge when the other is a preschool child, particularly a sick preschool child, because the themes of possible activities for my physical body are not necessarily themes of possible activities for the child’s physical body and vice versa. Perhaps the most obvious feature about children is that their physical bodies are in many ways different from adult bodies. Children’s bodies are smaller, lighter, weaker, they are more flexible, they adopt different postures, they have a different physiological rhythm with a faster resting cardiac and respiratory rate, there is less differentiation between the male and female body, visual acuity is less, they have their primary teeth, etc (Johnson,
Moore, & Jeffries, 1978). However, the challenge of working out whether a theme of possible activity for my body is a theme of possible activity for a preschool child’s body and vice versa is not as great as it might seem. The essential thing “is to see that a perspective on the other is opened to me from the moment I define him [sic] and myself as ‘conducts’ at work in the world” (Merleau-Ponty, 1960/1964, p. 117). Those very conducts can reveal differences between themes of possible activity for the body of a child and an adult. Children may use objects in a different manner to adults. For example, for a child a table or chair may be something to stand on in order to get something out of reach because their body is too small, rather than as something to sit on or to eat off. Children may also ‘use’ adults in a different manner to the way they ‘use’ other children, for example, when a child asks an adult to open a container because s/he does not have the strength or dexterity to open it. Despite differences such as these, the conduct of children at work in the world still opens a perspective on them to me.

The problem of understanding the other comes even closer to being solved through what Merleau-Ponty (1960/1964; 1961/1964b) regards as the primordial intractable bond that exists between one’s self experience and the experience of others (Welsh, 2002). A bond between self, other, and understanding is evident in Saint-Exupéry’s (1943/2000) assertion that “grown-ups never understand anything by themselves” (p. 2) and in Merleau-Ponty’s (1961/1964b) assertion that “in order that knowledge may be possible, I must not

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30 Although not directly relevant to this research it is worth noting that in the atypical child bodily abnormalities may alter what activities are possible for that child (Eagle, 2007; Goode, 1994). For example a child with a cleft palate may not be able to form certain words or sounds (Eagle, 2007).
be cut off from myself and from the other” (p.64). To solve the problem of the transfer of a child’s perception to me it is necessary to make clear the nature of the relation of my experience to the experience of the other. According to Merleau-Ponty (1961/1964b) “reflection on the meaning or the essence of what we live through is neutral to the distinction between internal and external experience” (p. 65). In explaining what he means by the above, Merleau-Ponty (1961/1964b) says:

nothing prevents my phenomenological reflection from having a bearing, for example, on another person, since I perceive him [sic] and his [sic] modes of behaviour. Nothing prevents the clarification of the intentions or meanings or ways of acting from referring not only to my own conduct but to that of another whom I witness. Nothing prevents me from explaining the meaning of the lived experience of another person, in so far as I have access to it, by perception [italics added]. (p. 65)

The qualification, in so far as I have access to it, by perception returns my argument to the first part of Merleau-Ponty’s (1964/1968) solution to the problem of understanding children, that is to perception as a lateral, pre-analytic participation. Merleau-Ponty’s (1964/1968) use of the word ‘lateral’ in relation to perception should be understood both as side by side and in the same light as ‘lateral thinking’, that is, a view of perception that is unorthodox and apparently illogical.

For Merleau-Ponty (1960/1964) perception is not an agglomeration of sensations (auditory, visual, tactile, olfactory, or kinaesthetic) but rather an already organised totality
that is not strictly individual. For Merleau-Ponty (1945/1962) perception is embodied because, unlike other external objects, the body has the peculiarity of not being able to be removed from my perception. Emphasizing the absolute permanence of the body relative to other objects, Merleau-Ponty asserts “the presence and absence of external objects are only variations within a field of primordial [italics added] presence, a perceptual domain over which my body exercises power” (p. 92). Understanding the primordial perceptual domain is crucial to perception as a lateral (side by side, apparently illogical), pre-analytic participation, and to my attempts to understand the children’s experience as they did.31

Merleau-Ponty (1960/1964) argues that infants begin life not as self-centred egos, but as a communion with others. The first me according to Merleau-Ponty (1960/1964), is: virtual or latent, i.e., unaware of itself in its absolute difference. Consciousness of oneself as a unique individual, whose place can be taken by no one else, comes later and is not primitive. Since the primordial me is virtual or latent, egocentrism is not at all the attitude of a me that expressly grasps itself (as the term ‘egocentrism’ might lead us to believe). Rather it is the attitude of a me which is unaware of itself and lives as easily in others as it does in itself – but which, being unaware of others in their own separateness as well, in truth is no more conscious of them than of itself. (p. 119)

This is a perceptual communion in which infants are unable to distinguish their bodies from those of others (Jensen, 2002). This absence of a division between self and other (pre-personal perception) is according to Merleau-Ponty (1945/1962) the foundation that

31 Here I am indebted to Welsh’s (2002) systematic exploration of the ‘primordial’ in Merleau-Ponty’s works.
underlies subjectivity and intersubjectivity. Merleau-Ponty (1960/1964) shows how from this stage of indistinction from others the child gradually develops an awareness of self and others as distinct beings. According to Merleau-Ponty (1960/1964) the gradual recognition of oneself as a distinct being from all others develops from and through bodily relations with others. Merleau-Ponty (1960/1964) asserts that the process of distinguishing between self and other “is never completely finished” (p. 119). This supports Welsh’s (2002) claim that the absence of a division between self and other “is not simply an immature stage which is overcome; it’s the basis of all social interaction” (p. 173). As the result of this gradual differentiation between self and other the nature of the communion with others changes (Jensen, 2002). Dillon (1997) explains that “communion is now communion across a distance rather than syncretic participation in undifferentiated oneness” (p. 127). In other words, the communion or connection between self and other now involves difference. Difference is not the antithesis of communion, rather they are reciprocal and have the potential to promote one another (Jensen, 2002).

The circular structure of this discussion has brought me back to a certain divergence but not back to the beginning. In the process I have worked out, within certain limits, a way for adults to interpret experiences as children might when all the data are already internal to the adult, their subjective experience revealed to them pre-analytically in participation with children. To paraphrase and move beyond Merleau-Ponty (1961/1964b, p. 65), the distinction between my experience and the child’s experience is neutral when my reflection is related to the pre-personal void in between our divergent perceptions. Insights from those reflections can apply to the child’s experience because my experience and the child’s experience are interrelated in my participation with them (by an intentional
transgression in which phenomenologically I experienced the child as a modification of myself). Macmurray (1961) sums up this position well when he says

human experience is, in principle, shared experience; human life, even in its most individual elements, is a common life; and human behaviour carries always, in its inherent structure, a reference to the personal other. All this may be summed up by saying that the unit of personal experience is not the individual, but two persons in personal relation; and that we are persons not by individual right, but by virtue of our relation to one another. The personal is constituted by personal relatedness. The unit of the personal is not the ‘I’, but the ‘you and I’. (p. 61)

Within certain limits the question of how to overcome the introspective nature of my data is now resolved. I now know: my introspective experience and the child’s experience are interrelated in my participation with them; I must begin to understand the children’s experience through my position in the situations; and the key to understanding childhood experience lies in my unreflected perception given precisely in a certain divergence.

On the other hand Merleau-Ponty (1964/1968) contends that each person has only a partial and incomplete view of the sense of the self, the other, and the world. He suggests we are never able to see or touch another being in its entirety. Thus, something is lost and always incomplete when we attempt to enter into the world of others or alternatively the world of others is always more than we are able to understand. This brings me back to the need to address the problem of how I can interpret the intricacies of the situations that are always more than the transcripts re-present.
THINKING WITH WHAT IS ‘MORE THAN’ USING GENDLIN’S PHILOSOPHY OF THE IMPLICIT

Having resolved one problem I seem to have made the other problem worse. I now know: the intricacies of the situations were always more than the transcripts could represent; the possibilities that made the children’s words or actions make sense for the children in the situations were always more than my experience of the situation presented to me; and that the child’s world would always be more than I would understand. Given these limitations, how could my interpretations do justice to the child’s experience? Here the writings of Gendlin (1962; 1973; 1978/79; 1981; 1991; 1992a; 1992b; 2003; 2004a; 2004b; Gendlin & Hendricks, 2004) were instructive in working out how to let the more than function in my thinking.

Merleau-Ponty’s (1964/1968) solution suggested the key to understanding childhood experience lies in my unreflected perception given precisely in a certain divergence. As already discussed, my bodily felt sense gave me an unreflected and precise perception of a certain divergence in situations. Furthermore, Merleau-Ponty’s (1964/1968) solution suggested I must begin to understand the children’s experience through my position in the situations. Gendlin (1991) contends “body–sense and situation are not just two things. Situations are not without the people whose situations they are. One’s body-sense is part of (happens in, makes and re-makes, carries forward, is …) the situation” (p. 82). Thus Gendlin argues “the body-sense is not subjective, not just internal, not private; it is the implicit situation” (p. 82).
As I have already indicated I experienced situations where I felt a certain divergence, which were always more than what I could re-present. In these divergent situations, I had a strong felt sense of something promising, an unclear lead worth pursuing, but no theme or concept seemed to fit or work. Reflecting on my attempts to uncover meaningful thematic aspects from my field data I found myself returning again and again to these situations. With each return to these situations, my felt sense of something promising did not dissipate or change. However, at times my frustration grew, nothing I thought, read, or wrote evoked a sense of the situation that felt tolerable. Something implicit in my felt sense of the situations enabled me to reject one thematic idea after another. My felt sense of something promising in the situations was opaque, but the fact nothing felt tolerable implied the presence of an intricate, implicit order, I sensed but did not know how to describe (Gendlin, 2004b). My felt sense of the something promising in these divergent situations demanded (Gendlin would say implied) something more precise that continued to be felt but not articulated. None of the themes took my felt sense of something promising forward (Gendlin would say “carried the implying forward” (p. 133)); my felt sense remained unchanged there within me.

From the above reflections it is clear that there was an interactive process between my bodily felt sense, the situation, and the language that would describe it (Gendlin, 1991, 2004b). My thinking from the language in the transcripts did not match my felt sense of the situation. In addition, my felt sense of the situation recognised the inadequacy of my

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32 I am indebted to Kathleen Galvin and Les Todres from Bournemouth University for introducing me to the
thinking emanating from the language. Furthermore, my felt sense implicitly held something valuable that needed to be said. However, I did not know how to think or speak from an unclear bodily felt sense.

The idea of thinking from an unclear bodily sense was a questionable project on the edge of my understanding of thinking, but one that proved decisive. According to Gendlin (2004a) first it must be recognised that no established word or phrase will ever be able to say what needs to be said. The person can be freed from trying to “translate” the felt sense into regular sayings. Yet what the person wanted a word to mean can be expressed but only in one or more whole sentences that use words in a fresh and creative way. In certain kinds of sentences a word can go beyond its usual meaning, so that it speaks from the felt sense. When one has tried several words and found that each of them fails to say what needs to be said, fresh sentences can say what one wished the word to mean. Now it turns out that each of the rejected words gives rise to very different fresh sentences. Each pulls out something different from the felt sense. In this way, with some further developments, what was once one single fuzzy sense can engender six or seven Terms. These terms bring their own interrelations, usually a quite new patterning. This constitutes a whole new territory where previously there was only a single implicit meaning. One can move in the field created by these terms. (p. 3)
In this quote Gendlin is referring to the practice of “Thinking At The Edge” (p. 1), which has come from his philosophy of the implicit. Thinking At The Edge (TAE) is a systematic approach, the first five steps of which enabled me to begin to write and think from what was my original unclear bodily felt sense, in need of being said. The first five steps focus on the original felt sense of a knowing (Depestele, 2004). The following section outlines how I worked through the first five TAE steps.

**TAE steps 1-5: Thinking from the felt sense**

The instructions below in italics are direct quotes for each step given by Gendlin and Hendricks (2004) but they have been abbreviated. The normal text is my response as I worked through the steps described by Gendlin and Hendricks. My responses to the instructions may at first appear a bit odd and illogical. In part that is the TAE process, and in part it is due to the fact that anyone reading this does not have my bodily felt sense, was not bodily in the situations in which it arose, and does not have access to the transcripts of those situations. Then again, the intent of each step is to explicate the knowledge implicit in my felt sense and bring into the public domain what I knew from my felt sense but could not say (Depestele, 2004).

“**Step 1:** let a felt sense form.... From your felt sense, write the central crux in **one short sentence, with one key word or phrase, ... underline the key word**” (p. 12).

Children know more than they can say.

“**Write down one instance**” (p. 12).

A young child with raised intracranial pressure positioned himself in the knee chest position. How did the child know to get into this position? How did the child know this
position would reduce his intracranial pressure? Adult neurology would recommend the opposite i.e. raising the head. Yet there is physiological evidence this position would be helpful in reducing the pressure. At some level the child must know this, but how? There seems to be a contradiction or opposition between the child’s knowledge and conventional wisdom.

“Step 2: Find what is more than logical in your felt sense….Find what does not make the usual logical sense and write an illogical sentence….you can write a paradox” (p. 13).

Children know less than adults and also know more than adults.

“Step 3: Notice that you don’t mean the standard definition of words. Write the usual dictionary definition of the underlined word in step 1” (p. 13).

More = “existing in greater or additional quantity, amount or degree” (Sykes, 1982, p. 657).

“and notice it is not what you mean” (p. 13).

My point is not so much that they know ‘more’ in terms of quantity, amount or degree but that they know something different. But it is ‘more’ because adults don’t seem to know it, recognise it, or they undervalue it. Here the words “seem to” are important.

“Take out the underlined word and write your sentence with a blank slot” (p. 13).

Children know … than they can say

“Return to your felt sense and let another single word come to say what you mean” (p. 13).

Children know different than they can say

“Write the usual definition of the second word” (p. 13)
Different = “able to be distinguished, unlike the other nature, form or quality” (Sykes, 1982, p. 267). This partly gets it but the problem is that the ‘different’ I am thinking about is not able to be distinguished, at least not usually. The difference is usually distinguished as less not more. The bit that partly gets to what I mean by ‘different’ is that it is unlike the other nature, form or quality.

“Return to your felt sense and let a third word come” (p. 13).

Children know other than they can say

“Write the usual definition of the third word” (p. 13)

Other = “not the same as one or more or some already mentioned or implied, separate in identity, distinct in kind, alternative or further or additional” (Sykes, 1982, p. 723). I think the ‘other’ is not the same as what they can say. But I don’t think the ‘other’ is separate in identity or necessarily distinct, this links with the problem of distinguishing I raised above. ‘Alternative’ also does not capture it, ‘alternative’ to me implies a choice between at least two and I don’t think children have a choice about this knowing. I think it comes naturally. This links to the next point - I don’t think the ‘other’ they know is further or additional, in fact I think it is closer and foundational rather than additional.

“Accept the fact that there is no established word for this knowing. No word fits. None should, if this is new” (p. 13).

“Step 4: Write a sentence or fresh phrase to say what you wanted each of the three words to mean. Put the original first word back in the slot in your sentence from step 1 (p. 14).

Children know more than they can say.
“… write a fresh sentence or phrase to say what you had wished the single word to mean, what this word pulls out from your felt sense which the other two do not” (p. 14).

Children know some things words cannot explain.

The meaning of ‘more’ I wanted is, the something words can not explain. Children know in unusual ways unlike adults. This is not correct, it is not unusual for the children, but it is for adults, it is as if adults have forgotten.

“Now put the second word in the slot” (p. 14).

Children know different than they can say.

“Write a phrase or sentence to say what it pulls out from the felt sense” (p. 14).

Children like the usual way they know.

The meaning of ‘different’ I wanted was not different at all but like the usual. It is only different from an adult perspective.

“Do this with the third word” (p. 14).

Children know other than they can say.

Children know inside out.

The meaning of “other” I wanted was inside out rather than outside in. That is, inside out is other to outside in which is adults’ normal way of perception.

“Step 5: Expand what you wanted each word to mean by writing fresh, linguistically unusual sentences. Using the main words or phrases from step 4, write a somewhat odd sentence … in order to expand even further what you now mean by each of the words or phrases” (p. 14).

Expanding even further on the phrase something words cannot explain from step 4, I now mean must be impossible to articulate with words. The articulation of the something must
be achieved by something other than words. Although I meant articulate as “divide into words” (Sykes, 1982, p. 49), articulate also has a bodily meaning as “connect by joints” (Sykes, 1982, p. 49), and it is a bodily meaning that words cannot explain. Joints also link to my outside in, after all outside and inside must be joint somewhere. Impossible to articulate is also important. It is not so much that it is impossible to articulate this something in words, but that any articulation must be imperfect because the something being articulated is felt. But words can convey feelings! It seems like I am being elusive about what this something is perhaps because its very nature is elusive to me but not to children. Thus my somewhat odd sentence is:

Other than words, elusive joints articulate bodily meaning.

Expanding even further on the phrase like the usual way from step 4, I now mean is a preference for what is a normal or natural way of knowing. ‘Way’ has many meanings including passage, route, unimpeded opportunity to advance, custom, manner of behaving (Sykes, 1982) all of which have some relevance here. Thus my somewhat odd sentence is:

An unimpeded opportunity to advance is the preferred passage. There is a whole lot I haven’t said here about how children’s lack of words is an impediment for them. There is also a lot I haven’t said about how adults may be impeded by their own preference for a different passage.

Expanding even further on the phrase Inside out from step 4, I now mean inside out has connotations of the wrong way, which is exactly what I am trying to avoid. It is only wrong if you presuppose inside in and outside out. But what if it doesn’t matter whether the inside is in or out? Or the outside is out or in? What if it does matter? What if inside
should be out and outside should be in? What if there is no inside and outside? What if it is reversible? Presuppose suggests an order. If we presuppose inside out then my somewhat odd sentence is: Inside out is reversible by outside in.

“Write a ‘string’ of the three original words and the main fresh phrases in the underlined slot in your sentence from step 1” (p. 15).

Children know more, different, other, elusive joints, articulate, bodily meaning, unimpeded, opportunity, advance, preferred passage, inside out reversible outside in… than they can say.

“Play with the grammar and order. Eliminate excess words until you have a sentence you like” (p. 15).

Children know bodily meaning inside out unimpeded by other; it is their preferred passage to articulate in advance of what they can say.

While the sentence above does not say all of my bodily felt sense an idea has emerged from the bodily felt sense. It emerged with a sense of excitement and relief because it changed the felt sense and carried it forward in a way that literally allowed me to proceed with analysing my field data where previously nothing seemed to fit. According to Gendlin (2004a) “statements that speak-from the felt sense can be recognised by the fact that they have an effect on the felt sense. It moves, opens and develops” (p. 1) which is exactly what happened to me.

The first five TAE steps outlined above are not the end of the TAE process Gendlin and Hendricks (2004) describe. Step six involves collecting instances. Step seven allows the instances to contribute more detail. Step eight involves crossing the real instances and
finding patterns. Step nine involves writing freely about what you have understood. The
TAE process also includes steps 10-14 that relate to building theory but these go beyond
the aims of this thesis. In chapter six instances, actual situations from my field data will
contribute detail to the implicit knowing that has only just begun to be uncovered in steps
1-5. Each new situation is considered for what it contributes to communicating the implicit
knowing of my felt sense in order to make it more communicable.

In summary, there will always be parts of the children’s experience I will never be
able to reach or understand (Johansson, 2003). However, even when the data are always
already internal to me, I can (within limits) interpret the experiences as the children would.
As Gendlin (2004b) says “Phenomenology has no problem going beyond a single person’s
private experience, because experiencing is inherently an interaction process in a situation
with other people and things. What appears is neither internal nor external, neither just
private not just interactional” (p. 147). While the children’s experiences will always be
more than I can re-present, the first nine steps of the TAE process (Gendlin & Hendricks,
2004) enable me to think with my felt sense, which was more than the transcripts re-
presented. Thus through a combination of Merleau-Ponty’s and Gendlin’s ideas I evolved a
process that enabled me to capture the essence of what it means to preschool children to be
ill.
CHAPTER SIX

CHILDREN UNDERSTAND ILLNESS INSIDE-OUT

So I grope in one direction and another, as best I can. In the end, I’m sure to get certain more important
details all wrong. But here you’ll have to forgive me. My friend never explained anything. Perhaps he
thought I was like himself. But I, unfortunately, cannot see a sheep through the sides of a crate. I may be a
little like the grown-ups. I must have grown old. (Saint-Exupéry, 1943/2000, p. 13)

I have shown in my analysis of the literature in chapters two and three that
preschool children have a limited cognitive understanding of illness and may not
differentiate between internal and external. I have also shown how the behavioural and
cognitive literature reveals in a limited way the kinaesthetic, intersubjective, situational and
spatial essence of what it is like for preschool children to be ill. In chapter five I began to
explicate aspects of my original felt sense of situations I experienced in the field, using the
first five steps of the process of Thinking At The Edge (Gendlin & Hendricks, 2004). This
culminated in the idea that children know bodily meaning inside out unimpeded by other
and that it is their preferred passage to articulate in advance of what they can say. In this
chapter I follow in a less structured way steps six to nine of Gendlin and Hendricks’ (2004)
process of Thinking At The Edge. In chapter five I also established the methodological
significance of situations in which I perceived the children precisely in a certain
divergence. In this chapter I give detailed attention to specific instances where I perceived
the children precisely in a certain divergence, each divergence being the focus of analysis
which enabled my understanding of what it is like for preschool children to be ill. In doing so my felt sense is carried forward and expanded. Thus, my aim is to further articulate the implicit knowing from my felt sense, the children’s language, and the situations in which I perceived a divergence, in order to convey what it is like for young children to be ill, and how they communicate their experience of being ill to others.

In this chapter I begin by highlighting the ambiguity inherent in situations, particularly situations where children and adults experience things in a different way. I then elaborate on my felt sense presenting the essential theme of my phenomenological description, which is that preschool children, understanding illness inside-out, unimpeded by others. This theme fits many situations. Inside-out is deliberately ambiguous. Do I mean that for children inside and outside are inseparably linked as the hyphen implies? Do I mean that preschool children understand illness internally (inside) and express that understanding externally (outside)? Do I mean that preschool children know illness in completely the opposite way to adult pathophysiological conceptions, which view illness from the outside in? Do I mean that children know illness thoroughly? To some extent, I mean all of the above. As I will show in this chapter, the inside-out theme appears in different and divergent instances during my close observations with the children. Therefore, this single theme takes on different meanings depending on the situation. Detailed exploration of further instances carries my felt sense forward, to show that, in illness, as in health, and in advance of what they can say, preschool children move their bodies in ways that bring forth and express their felt sense of situations from the inside-out. Finally, I show how adults can begin to understand children’s experience of illness from the
outside-in and by focusing on their own felt sense in intimate situations with ill children, from the inside-out.

**MIS-UNDERSTANDING THE CHILD’S WORLD**

My immediate experience of surprise at some of the children’s statements or actions reveals possible differences in our respective views of the world. The brief excerpt below from the transcript of my second visit with Ivan (lines 66-69) provides an illuminating example of possible differences in our respective views of the world.

P Who was your friend that did the photos at Tūroa?

I Um Martin.

P Martin.

I He’s a man.

I thought it odd for Ivan to state that Martin was a man. This appeared to me to be an obvious statement of Martin’s masculine sex. I did not consider Martin could be anything other than a man. Straus (1966a) suggests that “one might consider every statement as an answer to a question implicitly posed” (p. 168). I assumed the question implicitly posed by Ivan’s statement “He’s a man” was: Is Martin a man or a woman? Merleau-Ponty’s (1945/1962) position is that in order to understand others I must be revealed in a situation. The situation I was in, was one of an adult male researcher asking a four and a half year old boy I had only met once before, about a friend I did not know at all. On reflection, I can see the possibility of an alternative question implicitly posed by Ivan’s statement, that is: Is Martin a man or a boy? At the time of the conversation, I did not consider that possibility. Ivan’s statement “He’s a man” is unlikely to be a statement of the obvious sex of the friend and more likely to be an answer to the implicitly posed question: Is Martin a man or a boy?
the answer to which would not be evident without Ivan’s statement “He’s a man”. Comprehending this implicit question enables me to follow a train of thought that makes Ivan’s statement “He’s a man” a sensible and understandable point of clarification. Based on my failure to comprehend Ivan’s implicit question I misinterpreted Ivan’s statement as an unnecessary clarification of Martin’s sex rather than, as an informative clarification that Martin was a man and not a boy.

Straus (1966a) suggests there are intimately connected relationships between the questioner and their world, between the questioner and the person questioned and between the question and the answer. Exploring the relationships that Straus suggests are intimately connected reveals something of both Ivan’s world and mine. I have suggested two possible implicitly posed questions that stem from Ivan’s assertion (answer), “He’s a man”. In the case of the implicitly posed question: Is Martin a man or a woman?, I was implicitly the questioner and in my world I differentiate people as male or female. The dominance of the distinction between the two sexes in the adult world is evident when we consider the first question asked about a newborn baby (or an ultrasound scan of a foetus) is often, is it a boy or a girl? Furthermore, for centuries adults have dressed children in ways that distinguish boys from girls (Ariès, 1960/1962).

In the case of the implicitly posed question: Is Martin a man or a boy?, Ivan was implicitly the questioner and in his world he differentiates people as children or adults. This possibility is not surprising when we consider Merleau-Ponty’s (1945/1962) view that we first meet the other through their body. The differences and contrasts between a female and a male preschool child’s body are barely noticeable unless the genital region is
exposed. In addition, the sexual non-differentiation of the child is an ancient idea. Jung’s (1941/1963) phenomenology of the child archetype in mythology identifies hermaphroditism as one aspect of the child archetype. In comparison, the differences and contrasts between the child’s body and the adult body are distinctive particularly in relation to size and strength but also in relation to the sexes.

Ivan’s statement “He’s a man” anticipated a question I did not even consider in my immediate experience of the situation. I am not arguing that children do not differentiate between females and males, or that adults do not differentiate between children and adults; that would be absurd. The question implicit in Ivan’s statement indicates not an absolute difference between our respective worlds but rather a difference in the order of things. For Ivan it would appear the difference between child and adult precedes the difference between female and male.

As well as revealing something of the child’s world, this excerpt also reinforces the fact that I tend to interpret the children’s language and behaviour by analogy with my own experience of the world. In doing so I presuppose what I am trying to understand. Thus, interpretation can lead to misunderstandings when children experience the world differently. However, this need not be a problem, as long as I conceive my perspective and point of view as my embodied insertion into the world, not as constituting the truth, but as my situated understanding (Merleau-Ponty, 1945/1962). If I conceive my perspective and point of view this way then the perspective and point of view of the children is also consequent upon their embodied insertion into the world, inevitably in a different place. Therefore, I must be open to the inherent ambiguity in situations.
AN INTRODUCTION TO UNDERSTANDING ILLNESS INSIDE-OUT

Early in my fourth visit with Sharon before I had turned on the tape recorder, she said something to me about popcorn stuck in her throat. Once I had turned on the tape recorder I tried, initially unsuccessfully, (lines 18-23) to get Sharon to repeat what she had told me.

P You were telling me about the popcorn in your throat.

S Yeah, so let's do draw.

P You want to draw a picture? Sharon picks up a stamp What's that?

S That's a little stamp.

P A little stamp Sharon stamps the piece of paper oh who's that?

S That's Santa.

A little later (lines 42-51), during the same close observation, I had another attempt to get Sharon to tell me about the popcorn in her throat.

P Oo and what did you do when you had popcorn in your throat?

S I, I ate the popcorn.

P Mm

S And it got stuck in my throat.

P Mm

S Yep

P And then what did you do?

S I tell my Mummy.

P Ah ha
S  And then we had to go to the doctor.

During my subsequent interview two months later with Sharon’s mother Kay and her father Richard (Lines 71-83) the following exchange took place.

K Yeah. When she ((Sharon)) had the tonsillitis her telling me that she had popcorn stuck in her throat would be about the most specific thing she has ever told me.

P I was going to ask you about that, it was on my list of things because I was listening to that ((Sharon had talked about popcorn stuck in her throat on an earlier visit, visit four)) and I thought that’s a great description because that’s exactly what the tonsils look like and I guess I wondered if that came from you or the doctor

K No

P or whether it came from

K It came her

R From her

K It came directly from her

Sharon’s mother verifies that when Sharon had tonsillitis Sharon came to her and said she had popcorn stuck in her throat. Both parents are adamant that this description came from Sharon and not from them or the doctor. Here Sharon appears to believe that she ate some popcorn, it got stuck in her throat, she told her mother and then she had to go to the doctor.

Sharon’s statement is open to multiple interpretations. It could be interpreted as childish or imaginative non-sense. In chapter three I discussed the seminal work of Bibace and Walsh (1980) who might have classified Sharon’s comment as ‘Phenomenism’, in which case popcorn would be interpreted as a temporally remote, external, concrete phenomenon attributed with causing the illness. Alternatively, they might have classified it
as ‘Internalization’, in which case the illness is located inside the body (the throat), but caused by an external agent (popcorn). However, such interpretations reveal no-thing about how Sharon understands illness.

It is possible, perhaps even probable, that Sharon had previously felt popcorn stuck in her throat and that having inflamed tonsils felt similar to that experience. Therefore, by analogy, Sharon interpreted the two sensual experiences as the same. This would support the idea that children understand illness based on their previous sensual experiences.

It is also possible that Sharon had never felt popcorn stuck in her throat, but rather that Sharon correlates the felt tactile sense of her sore inflamed throat with a visual image of popcorn (inflamed tonsils can look very much like popcorn). At first this possibility might seem unlikely, but it warrants further consideration. For this to be possible, Sharon would have to be able to perceive her felt tactile sense of a sore throat as a visual image of popcorn. Adults can touch an unseen object and determine its visual shape, so the notion of perceiving a sense in one modality such as touch and transferring it to another such as vision is not difficult to grasp. Although, this example of an unseen felt sore throat transferring to a vision of popcorn may seem to be at the extreme end of plausibility. However, Meltzoff and Borton (1979) have demonstrated that 29-day-old infants are capable of a similar transference from an oral tactile sense to a visual sense.

Meltzoff and Borton (1979) studied 32 infants ranging from 26 to 33-days-old. They placed an oral tactile stimulus in the form of a pacifier with either a sphere-with-nubs or a smooth-sphere in the infants’ mouth for 90 seconds, without the infant seeing the
tactile stimulus. The oral tactile stimulus was removed (without the infant seeing the tactile stimulus), the infants were then presented with both visual shapes and the infants’ visual fixation was observed. Results demonstrated that 24 of the 32 infants fixated on the shape matching the oral tactile stimulus they experienced longer than on the non-matching shape. The results were significantly different from chance (p<0.01). The experiment was repeated with a second sample of 32 full term infants 27 to 31-days-old, with similar results (Meltzoff & Borton, 1979). If 29-day-old infants can visually discriminate the shape of an unseen object from an oral tactile experience of the object it seems plausible to conclude it is possible that a preschool child can perceive a visual image of popcorn stuck in her throat from the oral tactile experience of inflamed tonsils during an episode of tonsillitis.

Meltzoff and Borton’s (1979) experiments do not explain how it is possible for very young infants to match an experience in one sense, touch, with an experience in another sense, vision. However their findings suggest the sense modalities are not independent. Gendlin (1991) briefly discusses these experiments and suggests, the body does not first relate these bits of sense data and then put them together. On the contrary, each part of the perceptual field receives its significance from a whole or gestalt (Merleau-Ponty, 1964/1973). The boundary that primordially separates similar things, such as one pacifier from another pacifier, is according to Dillon (1997) “the edge of the gestalt that defines each as a perceptual theme” (p. 240). Applying this line of thinking Simms (2001) offers the following explanation of Meltzoff and Borton’s results:

Perhaps we can come closer to an answer if we perform a brief imaginative variation and feel our way into the infant’s experience. What is it like to touch and see the pacifiers in the given circumstances? The nubby pacifier I feel in my mouth
has contours of touch that rise and fall, a form that my tongue traces, my mouth feels. It calls me to specific action, modifies my sucking, calls for my attention, invites my tongue to travel its grooves and rises. The two pacifiers I see invite my eyes to trace their shape. The spherical one I glide over, but the other one leads my eyes up and down is shadowy crevices. Its form, its gestalt, is like the one I touched, up and down, interesting, rough and I spend more time following its invitation, explore it some more. Infants prefer to explore the pacifier they have just touched. . . . Underlying the newness of what is seen is the familiar gestalt, the contour of a thing already traced with the tongue. (pp. 36-37)

Thus according to Simms (2001), the infant’s ability to match the sense of touch with a visual sense is not an abstract representation in the mind but a consistency in how the pacifier is experienced in the world, whether it is experienced through touch or sight.

Applying a similar line of thinking helps to explain how the ‘thing’ stuck in Sharon’s throat could acquire its identity as “popcorn” rather than as some other object, such as inflamed tonsillar tissue, or peas or any other object? The What I call tonsillitis is distinct from normal tonsillar tissue or other forms of sore throat, before I come to know the biomedical label. The distinction is given in the felt sense of the body, more specifically, tonsillar tissue. In the same way, it is not only language that distinguishes between sharp and blunt; the difference can be felt. Inflamed tonsillar tissue has a particular irregular shape, size, and texture that contribute to its felt sense. Popcorn has an irregular shape, size, texture, taste, smell and colour. Popcorn also has a gestalt; a

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33 My response to this question is informed by Dillon’s (1997, pp. 238-242) discussion of appropriation.
perceived whole that is more than the sum of its parts. It is popcorn’s gestalt, which
distinguishes popcorn from other objects. After all, different flavours and colours can be
added to popcorn and it is still popcorn. In the situation of inflamed tonsillar tissue, it is
not difficult to see how without intellectual effort a child could appropriate the gestalt of
popcorn for inflamed tonsillar tissue. The gestalt of popcorn does not distinguish between
the internal felt sense of tonsillitis and the external visual image of popcorn rather there is a
coherence of the two things in the child’s experience of the world. The word ‘popcorn’ in
this situation and in the context of the other words in Sharon’s sentence has a univocal
meaning in which the gestalt of popcorn reveals a remarkable ‘inner’ bodily sensibility of
the shape, size and texture of the inflamed tonsillar tissue in Sharon’s throat.

Returning to the language Sharon used to describe her experience of what
biomedical science would label as tonsillitis, I can now reveal something of Sharon’s
knowledge. Recall Sharon said, “it (popcorn) got stuck in my throat”, which was verified
by her mother saying, Sharon told “me that she had popcorn stuck in her throat.” Given
that language is used to discriminate among things, working backwards through Sharon’s
statement reveals significant knowledge of tonsillitis. The word ‘throat’ discriminates
among body parts. The word ‘my’ discriminates between self and other. The word ‘in’
discriminates among positions within space. The word ‘stuck’ discriminates among things
that are fixed to a surface and things that can be moved. The word ‘got’ discriminates
among things one obtains and things one always had. The word ‘popcorn’ discriminates
between objects with the gestalt of popcorn and objects with a different gestalt. Sharon’s
statement signifies important features that distinguish tonsillitis from other conditions - it
occurs in the throat in a fixed location, is obtained and has the shape size and texture of popcorn.

When others interpret children’s speech from their own experience of the world it creates an impediment to understanding. For adults, words are a familiar way of describing experience and words such as popcorn and tonsillitis have acquired distinct conceptual meanings. In interpreting language adults tend to presuppose those meanings are common to all. Conversely, for young children words are new; many words are still open both to apprehending and conveying conceptual and existential meaning to others (Merleau-Ponty, 1945/1962, pp. 174-199). In attempting to interpret children’s speech it is important to recognise their openness to giving words meaning according to their own experience of things in the world. While the significance of words is conveyed outside us, Merleau-Ponty (1945/1962) argues there is an essential relationship between language, thought and their living significance. Therefore, in order to begin to understand the meaning children give words, it is important to take part in their world and look for their living significance in a context of action (Merleau-Ponty, 1945/1962). Accordingly, I have shown that for young children the word “popcorn” is open to acquire the existential meaning of “tonsillitis” because the gestalt of popcorn already bears the essence of the sensory experience of inflamed tonsillar tissue.

All the interpretations above are not at the extreme end of plausibility. Rather, they are consistent with each other and with empirical and phenomenological evidence for the unity of the senses in the body (Dufrenne, 1953/1973; Gendlin, 1991; Merleau-Ponty, 1960/1964; Réé, 2000). It is not essential to know whether Sharon had previously
experienced popcorn stuck in her throat, and, by analogy, interpreted tonsillitis as the same experience, or whether she was able to correlate the felt tactile sense of her sore inflamed throat with a visual image of popcorn, or whether the gestalt of popcorn was appropriated for inflamed tonsillar tissue. In each interpretation Sharon’s description of tonsillitis as popcorn stuck in her throat reveals an ability to very precisely relate an inner felt sense to a previous experience from the inside-out, unimpeded by others.

**CHILDREN’S GESTURES UNDERSTAND ILLNESS INSIDE-OUT**

Piaget (1929/1951) suggests preschool children “know nothing of the nature of thought” (p. 37) because they do not locate thought in the brain or the mind. Piaget does not consider the possibility of thinking in any other way, such as thinking in movement (Sheets-Johnstone, 1999, pp. 483-518). In this section I explore one instance of a child’s gestural communication that not only carries forward my **felt sense** but also introduces the idea that children’s gestures understand illness inside-out, which is an idea I develop further in the next section.

As reported in chapter five, the initial transcripts of the audiotapes that recorded the verbal language during my interaction with the children failed to adequately re-present the quality of my interaction with them. This signalled the need to pay closer attention to features of the interaction other than spoken language. In particular, I started to add in the situational context in terms of what we were doing at the time of the speech. As outlined below, until the gestural exchange broke down it did not become clear that bodily gestures were also an important but taken for granted and largely unnoticed aspect of each interaction.
The following extract from the transcript of my second visit with Ivan (the first child recruited into this study) is the first instance I noticed of many in which the child participants communicated with their bodies.

I Why is this taking too long (six second pause)

P ((I am not sure what Ivan was referring to as taking too long))

I Ivan pulls up one leg of his pants above his knee, looks at his leg and then at me

P ((I understand Ivan is trying to show me something but I do not know what. I think this is an odd thing to do and I feel slightly uncomfortable about Ivan exposing a part of his body to me but do not say anything as I try and work out why Ivan has done this))

I Eczema!

P Eczema! (pause) I look more closely at Ivan’s leg

You have got eczema haven’t you.

I Very itchy! Ivan looks at his leg but didn’t scratch his skin

What was the condition that allowed me to look at Ivan’s leg but not see the eczema? My thoughts were on what Ivan was trying to communicate and what his mother might think was going on. Furthermore, I did not know what Ivan was referring to when he said, “Why is this taking too long?” While I was looking at his leg, I was clearly not attending to what I was seeing nor was I involved in the situation in the same way that Ivan was. I noticed this bodily communication, in part, because it was so obvious and, in part, because I did not understand it. I perceived Ivan’s action of pulling up the leg of his trousers and exposing his knee and lower leg to me as a communicative gesture directed at me. However, I did
not know the meaning of this gesture; in fact, it puzzled me. I felt Ivan’s gaze on me, as if I should understand, and that made me feel uncomfortable and objectified. I also felt uncomfortable with Ivan exposing his leg to me, and I wondered what his mother might think was going on. In turn, I gazed at Ivan’s leg, transforming it into an object and searching cognitively for a meaning behind the gesture. With each passing second I felt physically more uncomfortable. I did not see the eczema around his knee, perhaps because I withdrew into my own thoughts when I did not understand the gesture. Ivan presumably expected me to see the eczema but I did not, until he said “eczema”. While I felt relieved when Ivan said “eczema” I also felt stupid, wondering how I had not seen the eczema.

On reflection, I began to understand Ivan’s experience through the implicit link between his bodily gesture, language, and the situation (Gendlin, 1991). The situation in which Ivan exposed his leg to me occurred in the context of Ivan as a participant in a research project in which I as the researcher was interested in finding out about what it is like for Ivan to be ill. In a later interview with Ivan’s parents, they explained that Ivan’s eczema was his most persistent health problem and the main reason that he would visit the doctor. It is possible that Ivan’s question “why is this taking too long?” is a reference to me getting on and finding out about what it is like for him to be ill, and that his gesture of showing me his eczema was a way of focusing our interaction. Here again I appear to have interpreted Ivan’s experience from my own experience of the world. This interpretation is much more likely to be a reflection of my anxiety about how long it would take to understand what it is like for Ivan to be ill. Understanding and seeing things from my own experience of the world seems to make me blind to possibilities from Ivan’s position in the situation (Buynendijk, 1974, p. 38).
Bracketing out this possibility, and seeing Ivan’s language, his bodily gesture, and the situation as a whole, reveals another possibility in which what Ivan said and did makes sense. It is more likely that Ivan’s question, “Why is this [italics added] taking too long?” refers directly to what he was trying to show me through his gesture – in other words his eczema. In my first draft transcript of this section of my interaction with Ivan I had typed “Why is this taking so long?”. Careful listening to the original recording made it clear that what Ivan actually said was “Why is this taking too long?”. The distinction is subtle but perhaps important in terms of Ivan’s understanding of eczema. The word “so” would have given explanatory emphasis to the word “long”. In other words, emphasising that eczema itched for a long time. However, the word “too” is more explicit in stating the length is intolerable, excessive, longer than desirable or admissible (Sykes, 1982). In this interaction, Ivan tells me, not only that eczema is very itchy, but also that it itches for longer than is desirable. This shows an understanding of eczema as a temporal process the duration of which exceeds his expectations.

The exploration above once again supports Straus’ (1966a) suggestion that there are intimately connected relationships between the questioner and their world and between the question and the answer. At the time I did not understand, or answer, Ivan’s question. The answer implicit in Ivan’s question “Why is it taking too long?” is that eczema is an illness that itches for too long. The answer implicit in Ivan’s question indicates an understanding of the world in which things like eczema have an expected duration.

I am grateful to Professor Diana Keatinge one of my supervisors for pointing this possibility out to me.
Mandler (2004) suggests that “what things do is the core of their meaning, and for some time in infancy it is the only meaning that is available” (p.87). For Ivan, what eczema does is itch. Therefore, for Ivan, at least part of what it means to have eczema is to itch for longer than is desirable. Furthermore, this meaning fits the pattern in which eczema is also understood from the inside-out, unimpeded by others.

Ivan’s understanding shows that eczema as a lived experience establishes its own ‘internal’ feeling (very itchy). Another participant, Karen, had also experienced eczema. In an interview with Karen’s parents, Erin, Karen’s mother shows that eczema as a lived experience also establishes an ‘external’ pattern of behaviour. Erin says “she (Karen) sits down and will scratch, (we) just can’t do anything about it” (lines 178-179). When I reflect on my own experience of eczema I also find it establishes a pattern of action, making me scratch. Because eczema establishes its own pattern of behaviour mostly I do not think I am itchy and then scratch the itch, rather, I find myself scratching the itch, or moving towards the part of my body that itches in order to scratch it, and then I think I should not scratch. There is a sensual satisfaction in scratching that at least temporarily relieves the itch, which has been confirmed by research demonstrating that scratching reduces the itch sensation and the histamine-induced blood flow changes (Yosipovitch, Fast, & Bernhard, 2005).

The meaning of eczema as itchy is not dependent on language it is “first and foremost a corporeal concept” (Sheets-Johnstone, 1999, p. 505) expressed in the action of scratching. Furthermore, the feeling (very itchy) and the action (scratching) are not two
distinct entities severed from each other. The action (scratching) does not exist prior to and independent of the feeling (very itchy). The visible action (scratching) is an original of the invisible feeling (very itchy). Prior to language at least, I have only one means of representing my very itchy feeling, which is to scratch it. In fact, the location and quality of the itch is evident in the location of the scratch and the energy, speed, and range of movement of the scratching action. Thus the gesture of scratching understands the meaning of eczema as itchy inside-out.

The example above of Ivan pulling up one leg of his pants to show me his eczema is the first bodily gesture I documented as intentionally communicative. However, there are numerous examples earlier in the interview where without any verbal cues I appeared to correctly interpret much more subtle bodily actions. To further understand the breakdown of bodily communication outlined above it is useful to examine a situation during the same period of close observation where the bodily communication worked. For example, the way Ivan looked at his tape recorder and at me, which I interpreted as a request to turn off the tape recorder. As seen below, the non-verbal cues were so taken for granted I did not even note them in the transcript (lines 152-155).

I Oh, I see the other one (pause). ((Not sure what Ivan is referring to, possibly the third tape recorder in my carry bag))

P Do you want to stop it and hear what it says?

I Yeah.

I did not make any mention of Ivan’s communicative gestures in the transcript, yet my lived experience of the situation was that Ivan had obviously indicated he wanted to stop the tape. How he indicated this or even the fact he indicated this went unrecorded and
unnoticed at an intellectual level until I reflected on the incident in which Ivan’s gestural communication broke down. This is just one of many examples in which I verbally responded in a taken for granted way to Ivan’s communicative gestures. On reflection, these earlier examples of bodily communication involved me noticing Ivan’s face and his look when we were closely engaged in activities together. There may have been other subtle cues involving parts of Ivan’s body other than his face, but I do not recollect them. This facial communication went totally unrecorded, yet appears relatively transparent in that Ivan’s affirmative reply to my question about turning off the recorder indicates I accurately interpreted the non-verbal cues. In the example of Ivan exposing his leg to me it is likely that Ivan read the confusion on my face and clarified his non-verbal communication with the word “eczema”. The importance of the face in human expression is clearly evident in Plessner’s (1987) assertion that:

In the face man [sic] expresses himself [sic] in an immediate way; the face is, within limits, the zone where the entirety of personal existence is mirrored; including the factor of being seen. As the exposed front which we, with eyes and voice, constantly turn towards our neighbor, it is accentuated and understood contrapunctual to the other parts of the body concealed by clothing. (p. 51)

That the face is accentuated and understood before other parts of the body is confirmed by the contrasting ways I understood the situation involving Ivan’s leg and the situation involving his face. My close observations with the children were filled with facial and nonfacial gestures many of which I appeared to understand. However, a number of situations arose where I misunderstood children’s nonfacial gestures. The extent of gestural interaction in my close observations, the fact they were often a point of divergence and the
idea I have introduced above that children’s gestures understand illness inside-out, all indicate that children’s gestures is an area worth exploring further.

**CHILDREN GESTURE IN ADVANCE OF WHAT THEY CAN SAY**

In this section I explore a range of situations to show how children frequently use parts of their body other than their face to articulate things in advance of what they can say. The following excerpt from my fourth visit with Sharon (lines 51-55) records her gestural communication.

S  And then we had to go to the doctor
P  Mm  (pause).  What did you tell the doctor?
S  I tell the doctor, um, I had a, *Sharon places index finger and middle finger of her left hand in her right armpit* un under, a thing like under my arm

In the context of Sharon talking about what happened during a visit to a doctor, her gesture of putting her index and middle fingers under her armpit clearly indicated that while she was at the doctor’s the thing under her arm was a thermometer. Sharon did not appear to have the word ‘thermometer’ but her gesture clearly communicated a thermometer in advance of what she could say. Similarly Roth and Lawless (2002) have shown in a series of videotaped studies of school children learning about abstract scientific concepts that “gestures first arise from earlier sensorimotor actions and observation. These gestures precede language at a macro level and are increasingly correlated with appropriate words” (p. 351) as can be seen in my description of the next situation.
During my sixth close observation with Sharon she was unwell and had been vomiting. She asked me to read her a book about dragons. While I was reading to her the video camera was recording. The following excerpt from the transcript (lines 208-212) records her gestural communication:

S They go, they go, they go moves hand to her wide open mouth with thumb and index finger going just into her open mouth and then moves her hand away from her mouth spreading her fingers apart. Aghh

P Aghh

S Yeah and they, and they breathe fire out of their mouth.

Although Sharon found the words “they breathe fire out of their mouth”, the video recording clearly shows her using her hand to imitate the way fire comes out of a dragon’s mouth. Furthermore, prior to the gestural communication Sharon appears to be searching for the right words. She says “They go, they go, they go” and then she makes the gesture. My verbal attempt to imitate Sharon in making the “Aghh” sound missed the vital point of what she was trying to communicate, that is, that dragons breathe fire out of their mouth. Whether her gestural expression assisted in finding the words as suggested by Butterworth and Hadar (1989 as cited in Roth & Lawless, 2002) or whether the words were unnecessary until I missed the vital point remains unresolved.

The previous two examples show how children use parts of their bodies other than their face to communicate through gesture in advance of what they can say. Not every gesture has a communicative intent in the linguistic sense (Best, 1978, pp. 138-162) of the
two previous examples, where the expressive gestures effectively substituted for words. For example, during my third close observation with Sam, he had a cold, and copious nasal discharge draining onto his upper lip, which on a number of occasions he skilfully wiped away with his tongue. I do not believe Sam intended this gesture to communicate anything to me. This gesture was certainly not a request to get a tissue to wipe his upper lip. In fact, on a number of occasions Sam ignored my suggestions of a tissue and continued playing with the trains. While not every gesture has a communicative intent, every gesture reveals something about a child’s way of *being-in-the-world* (Boss, 1987/2001, pp. 89-91). In this case, Sam clearly had an internal sense of the nasal discharge building up on his upper lip and an established action for dealing with it. The gesture with his tongue caused the least disruption possible to the activity he was engaged in. The use of his tongue kept his hands free for playing with the trains. I have seen other children (and adults) wipe nasal discharge away with their forearm but in this instance, the use of the forearm rather than the tongue would have impeded Sam’s involvement with the trains. Here, despite having a cold, Sam’s gesture with his tongue let him carry on with his activity of playing with the trains unimpeded by the copious nasal discharge. This example fits with the pattern of children understanding illness inside-out, unimpeded by others, including in this case the illness itself.

In chapter five I briefly mentioned the instance of a child with raised intracranial pressure who positioned himself in the knee-chest position. This instance coincided with the early stages of my research. The child (approximately 18 months old) presented to the hospital (where I was working) with an acute onset of vomiting, irritability and lethargy. In describing their child’s presentation, the parents noted the child’s recent tendency to
position himself prone with his head on the floor, his knees under his chest and his bottom in the air (knee-chest position). This was the only unusual characteristic of this child’s presentation. Otherwise, his signs and symptoms were typical of those encountered in a number of common childhood illnesses, in particular gastroenteritis. Following routine investigations and oral rehydration fluids the child was discharged with instructions for the parents to bring the child back if the vomiting did not resolve itself. The child’s parents brought him back the next day with continued vomiting. To cut a long story short, a cranial CT scan revealed the child had a cerebral tumour which raised his intracranial pressure and caused the vomiting.

This case both intrigued and concerned me. I wondered if I had missed something on the first day the child presented. The only thing I felt I could have paid more attention to was the child’s tendency to position himself in the knee-chest position. Furthermore, I began to wonder why the child would position himself this way. I had been taught lowering the head was contraindicated in patients with raised intracranial pressure. In addition, Wong et al. (1999) report lowering the head intensifies the symptoms of raised intracranial pressure. Why then would a child put himself in a position that would make his symptoms worse? This question lead me to search the electronic database Medline combining the key terms position and intracranial pressure. As a result I found an article by Straussberg, Amir and Varsano (1993) reporting three cases of children under five-years-old with increased intracranial pressure who presented with “a natural preference to lie in the knee-chest position” (p. 99). Straussberg et al. assume the knee-chest position reduces pressure in the right atrium allowing for a greater flow from the superior vena cava, consequently increasing the drainage of blood from the dural sinuses, thus reducing
cerebral volume and therefore intracranial pressure. Thus, I seemed to have a plausible explanation for why a child with raised intracranial pressure might have a natural preference to lie in the knee-chest position.

But what constitutes natural and how does a child come to know they get some relief from the symptoms of raised intracranial pressure in the knee-chest position? One explanation might be that children spontaneously move around in a variety of positions until they find a position in which they feel better. This explanation implies the child’s voluntary movement into the knee-chest position is learnt from repetition of chance movements associated with instant changes in the child’s sense of well-being. There is evidence that changes in posture and variations in blood pressure can cause instantaneous modifications in cerebral blood flow (Savin et al., 1995; Savin, Siegelova, Fisher, & Bonnin, 1997). Therefore, although it may seem unlikely, it is possible that the adoption of a knee-chest position could lead to a small but rapid reduction in cerebral blood volume, and consequently large and rapid reduction in intracranial pressure, and therefore a rapid improvement in well-being. This is possible because the relationship between intracranial pressure and cerebral volume is a three-phase hyperbolic curve in which phase one is a flat portion with normal intracranial pressure; phase two is the exponential portion with normal intracranial pressure where slight increases in volume are not tolerated; and phase three is the steep portion with raised intracranial pressure (Vernon-Levett, 1998). Given the relationship between volume and pressure, as volume reaches the point where pressure begins to rise, small reductions in volume can cause large reductions in pressure. This possible explanation is consistent with the view that it is through movement that we know ourselves and think (Sheets-Johnstone, 1999, pp. 496-517). In other words, the gesture
understands illness inside-out. Similarly, it is an understanding of the knee-chest position in the context of raised intracranial pressure that fits the pattern of children understanding illness from the inside-out, unimpeded by others.

Now I present another possible explanation that also relies on learning from the child’s past experience, in this case as an infant/foetus in the process of being born. The knee-chest position bears a close resemblance to the position of the infant/foetus as the head passes through the dilated cervix and vagina during birth. Birth is perhaps the only time during which an infant may have experienced raised intracranial pressure. Sheets-Johnstone (1999, pp. 496-507) supports her thesis of the primacy of movement by demonstrating how studies of infant development indirectly confirm that infants think in movement. According to Sheets-Johnstone “even as a fetus in utero, it has a tactile-kinesthetic sense of its own body as an articulable, essentially dynamic form” (p. 501). The natural preference of children with raised intracranial pressure to move into the knee-chest position may therefore be related to a primal recognition of its position, in utero, during the process of being born.

A second possible explanation might be that the motor behaviour of assuming the knee-chest position is an unlearnt neurophysiological reflex response to the stimulus of raised intracranial pressure\(^\text{35}\). According to this mechanistic explanation, an internal factor, in this case probably a specific level of intracranial pressure, controls or triggers the motor centres responsible for assuming the knee-chest position. In the first chapter of his first

\(^{35}\) I am thankful to Prof. D. J. Mellor, Massey University for suggesting this possibility to me.
book, Merleau-Ponty (1942/1963) argues against understanding reflex behaviour as mechanistic. The mechanistic model takes “the stimulus as an objective entity existing independent of the organism” (Keeping, 2006, p. 183). Based on Merleau-Ponty’s work Keeping (2006) proposes a “conception of instincts as meanings implicit in the body’s very structure” (p. 187). The human body is structured so that within very narrow limits certain norms are favoured, such as temperature and intracranial pressure. These norms make the body’s environment meaningful. For example, when body temperature rises above the set point of the hypothalamic thermoregulatory centre we feel hot. When intracranial pressure rises above normal levels our head feels heavy.

According to Keeping (2006) “the meaning of the situation is itself the behaviour that the situation elicits” (p. 184). The idea that the meaning of raised intracranial pressure as a heavy head is evident in preschool children’s behaviour of adopting the knee-chest position is evident in Plato’s *Cratylus*, where Socrates says:

> Suppose that we had no voice or tongue, and wanted to indicate objects to one another, should we not, like the deaf and dumb, make signs with the hand and head and the rest of the body? . . . We should imitate the nature of the thing; the elevation of our hands to heaven would mean lightness and upwardness; *heaviness and downwardness would be expressed by letting them drop to the ground* [italics added]. (as cited in Rée, 2000, pp. 119-120)

Thus the behaviour of some children with raised intracranial pressure of dropping their head to the ground, putting their knees under their chest and their bottom in the air (knee-chest position) imitates the nature of the head as heavy. The meaning of raised intracranial pressure as *a heavy head* is not dependent on language; it is “first and foremost a corporeal
concept” (Sheets-Johnstone, 1999, p. 505) expressed in the action of the knee-chest position. In advance of what pre-school children can say, raised intracranial pressure establishes a feeling (heavy head) and a pattern of behaviour (knee-chest position), which conveys their felt sense of the situation from the inside-out.

As discussed in chapter five, themes of possible activity for the child’s body are not necessarily effortless themes of possible activity for the adult body, and vice versa. This became particularly evident to me during my close observations with the children, which included lying, crawling and rolling on the ground, sitting cross legged, squatting, running, swinging on ropes, hanging upside down by the legs, hanging from bars, bouncing on beds and jumping and rolling on trampolines. In fact, my orientation to the world was different in my observations with the children. This became particularly evident when I realised I could draw good floor plans of the parts of the children’s houses I had been in, but I had very little detail about what was in the room above knee height. Young children are frequently already close to and parallel with the ground. Consequently, the locomotive development of an infant or young child may present the knee-chest position as a meaningful expression of a heavy head. In contrast, the upright posture of the adult impacts on their expressive attitude (Straus, 1966b) and therefore an adult’s locomotive abilities may present other possibilities. I wonder how many times the knee-chest position in preschool children goes unnoticed as a sign of raised intracranial pressure because it does not coincide with the inner possibilities of an adult body.
Interestingly, the knee-chest position is also spontaneously assumed with therapeutic effect by infants and toddlers with tetralogy of Fallot\(^{36}\) experiencing cyanosis and dyspnea on exertion, where as older children with tetralogy of Fallot tend to squat (Guntheroth, Mortan, Mullins, Baum, & Wash, 1968; Lurie, 1953; Taussig, 1947). In this case the different bodily gestures, knee-chest position, or squatting, is contingent on locomotive development, but also on the situation. According to Taussig (1947, p. 119) most children with extreme exhaustion will assume the knee-chest position.

Obviously in the case of children with tetralogy of Fallot the knee-chest position is likely to have quite a different meaning than it does for children with raised intracranial pressure. As Best (1978) suggests, “the meaning of a particular action cannot be explained by a narrow concentration upon the physical movement in isolation” (p. 136). The meaning of a gesture is given in the wider situational context. Taussig (1947) describes the wider situational context in the case of a five year old boy with tetralogy of Fallot who could run a few steps and would then squat down. When he tried to run farther, he would not only squat down but fall forward to lie for a moment in a knee-chest position and then get up and run again. (p. 133)

In contrast, the three cases of the knee-chest position in children with raised intracranial pressure reported by Strausserberg et al. (1993), and the one case from my own experience, occurred in a context that included lethargy and vomiting. My point here is not to begin to interpret the possible meaning of the knee-chest position in children with tetralogy of Fallot but rather to point out that the manner in which the gesture is lived, and the situations in

\(^{36}\) A congenital heart condition with four features first described by Fallot in 1888 (Taussig, 1947).
which it occurs, must be considered in interpreting the meaning of gestures. This would equally apply to interpreting the meaning of the dystonic posturing, characterised by arching the head, neck, and trunk, which has been shown to increase oesophageal peristalsis in children with gastroesophageal reflux (Puntis, Smith, Buick, & Booth, 1989 as cited in Olguner, Akgür, Hakgüder, & Aktug, 1999).

The examples of bodily gestures in preschool children with eczema, colds, raised intracranial pressure, tetralogy of Fallot, and gastroesophageal reflux highlight that, these illnesses have a feel, that children have a bodily sensibility of the feeling created by the illness, and that bodily sensibility is meaningfully present in their gestures during situations of illness (Schulkin, 2006). Thus the examples I have given show that in illness as in health, and in advance of what they can say, preschool children move their bodies in a way that carries their felt sense of situations from the inside out, unimpeded by others.

**ADULTS UNDERSTANDING CHILDREN INSIDE-OUT**

In this section, I focus on the *link* between the inside and the outside, and its significance for adults understanding children. The conventional pattern of observing children from the outside is extremely important. I have already shown that preschool children move their bodies to express their felt sense of illness situations from the inside-out. Adults are most familiar with noticing things on the outside and children depend on adults for care during all but the mildest illness.

Many parents talked about noticing changes, sometimes quite subtle changes in their children’s movements. In the following excerpt from the transcript of my interview
with Davina’s parents (lines 276-281), her mother Lois talked about detecting earache through quite subtle changes in Davina’s movements.

L No, the way she walks it’s sort of the way she does her rolly polys and I’ve noticed she tends to be a bit more [-?] like she’ll um maybe walk into things where normally she would have just missed it or she just sort of seems she can’t pull herself out of things as quickly.

P Right

L It, it does seem quite subtle, but yeah.

This example shows how parents notice a difference in relation to the child’s normal pattern of movement. Children’s characteristic rhythm of movement is an important part of their self-identity (Feldstein, 1976).

Others know children through their bodies, not just the physical features of their body, but also the characteristic ways their bodies interact with their environment. The child’s body and its way of being in the world is an inseparable aspect of the child’s self (Gadow, 1982). In the interview with Davina’s parents her father David (line 188) says

D She’s pretty quiet, and um, lethargic, clingy, and just not herself really.

David’s comment that Davina was “just not her self” is typical of comments parents make, particularly when talking about the emergent stages of a child’s illness. When parents make comments like this they frequently point out ways in which their children’s interactions with their environment are different from normal, for example, being quiet, lethargic, and clingy. According to Lefebvre (1992/2004, pp. 9-18) our bodies are a bundle of many different natural rhythms (awake/sleep, respiratory, cardiac, thermoregulatory, hunger, thirst etc.) entwined in social rhythms, which in health have a normal pattern. The
parents also frequently reported how illness changed their child’s sleeping and eating habits (awake/sleep and hunger rhythms). Physical illness imposes itself on the natural rhythms of the body and changes them. A child’s natural rhythm is a part of their identity along with their physical appearance. Therefore, when illness changes their rhythm, their identity changes, they are just not themselves. Carnavale (1997) suggested that in critical illness nearly every aspect of what constitutes the child’s self is afflicted and therefore the critically ill child goes through a process of unmaking and remaking the self. Here my analysis suggests that the self of children with short term passing illness also undergoes at least some mild transformation.

In my own interactions with the children when they were ill I came to notice another dimension of the child’s nonverbal world, a spatio-temporal dimension, which of course had been there from the beginning. When the children were ill my close observations were inevitably confined to a much smaller space, and the level of activity and pace of the activity felt slower. When the children were ill with a short term passing illness their everyday existence changed; it was more confined. Thus the sick child clings to a much smaller space, which has an intersubjective dimension. This confinement narrows the world to a more proximate and intimate dimension (Jager, 1971). There is a shift in emphasis “from the world-at-large to the body” (Jager, 1971, p. 234). In healthy states we tend to take our body for granted, so much so that it seems not to be there (Grange, 1985). In health, “the outside dominates the inside-outside relationship” (Lefebvre, 1991, p. 315). In illness, the shift in emphasis from the outside world to the internal body lets the body show what it feels from itself.
Some transformation in the way children interact with their environment seems necessary for children to label themselves as ill. During my fifth close observation with Nigel he had signs of active chicken pox but did not consider himself ill and during my third close observation with Sam he had signs of a cold but did not consider himself ill. In both the above observations, I did not notice any obvious change in the spatial and temporal way the children interacted with their environment. They appeared to be themselves. This suggests a distinguishing feature of children being ill is not being yourself evident through changes in the way their bodies interact with the environment.

As we have already seen, it can be very difficult to interpret what the child’s body means when in illness it shows what it feels from itself. This difficulty is exemplified in the following excerpts from the transcript of my interview with Catherine and Daniel’s parents Jane and Peter. Peter described Catherine during her most recent illness as being “out of sorts” (line 33) and “all quiet and sort of you know quite grizzly and sulky” (lines 43-44) and then goes on to say how frustrating it is (lines 48-57):

Pt  It’s frustrating because, um, if, if it’s, an adult, you know, they can say well
P  yeah
Pt  well actually, you know, it’s my throat, um yeah, it’s worse when they don’t have the language, or haven’t got enough language, to sort of say sore throat.
P  yeah
Pt  and you know she’s sort of past that stage now at least she can say which part hurts as far as vocabulary goes but yet she just doesn’t [-?-?-:].
J  How hard is this behavioural thing?
Jane’s question is not so much a question but a statement of how hard it is to interpret children’s behaviour when they are ill. Similar comments occurred in all my interviews with parents. The reality is that it is very hard for adults, even parents who know their children well, to know what it is like for a young child to be ill from the outside. The outside and the inside is a false distinction and parents never know their children just from the outside. The inside and outside are always in relation.

The relational link between the inside and the outside and its role in understanding is exemplified in the following exploration of another instance during my close observations. My sixth close observation with Sharon was on a day when she was sick; she had vomited earlier in the day. We were in the lounge, sitting on the floor next to a child-sized couch that had been set up like a bed in front of the television. At Sharon’s request I had been reading her some books. The video recorder was recording our interaction. As the excerpt from the transcript (lines 272-289) below shows, Sharon put the cap on the lens of the video recorder. My felt sense of the situation was that Sharon was going to vomit. Consequently as a researcher I felt torn, I wanted to capture her vomiting on video but I felt an ethical obligation not to video record Sharon without her continued consent.

*S looks down, puts left index finger in her left ear twists it around three times,*

*removes her finger from her ear*  
*Yeah*  
*leans forward reaches for the cap on the video camera lens.*

*P You want to have a look at that?*

*S Puts the cap over the lens*
P: That'll stop it. Do you want me to turn it off? ((I didn’t want to turn off the video camera. I felt certain Sharon was going to vomit soon. I thought it would be great data to have on camera. However, I was ethically obliged to ask Sharon if her action of putting the cap on the lens of the video camera indicated she wanted the camera turned off, but as can be seen below even after getting her reply I did ask Sharon a second time))

S: Yeah.

P: Shall I turn it off.

S: Yep

P: OK. There we are. Is it off?

S: No. Now it’s off?

P: Now its off, off yup.

One minute and 37 seconds after placing the cap on the video camera lens Sharon says “I got a sore tummy” (line 310) and 27 seconds later Sharon vomits, three times in close succession.

My strong felt sense of the situation was that Sharon was going to vomit. A number of questions arose from this situation. Did Sharon know she was going to vomit? Did Sharon put the cap over the video camera lens because she knew she was going to vomit and didn’t want it recorded? If Sharon knew she was going to vomit how did she know? How did I know Sharon was going to vomit? Had I unconsciously perceived some objective external evidence that caused me to have that inner subjective feeling? I know for sure Sharon wanted the video camera turned off, both her actions (putting the cap on the lens) and her verbal response to my repeated question make that much clear. From
Sharon’s actions and words I cannot be certain about why she wanted the video camera turned off. I know from my own experience of vomiting that my body usually gives me some warning signs, from the inside, before I vomit. Those internal bodily signs usually give me time to get to a container to vomit in to. Because of my own bodily experience of vomiting I can see the possibility that Sharon might have known she was going to vomit at the time she put the lens cap on the video camera. That is two minutes and four seconds before she vomited. Of course there are other possibilities; the timing of the two events could have been a coincidence. Perhaps the more interesting question to arise from this situation is how did I know Sharon was going to vomit?

How was it possible for me to know with a *felt sense* of certainty over two minutes in advance that Sharon was going to vomit? One possibility follows a cognitive reasoning process. My detection of my *felt sense* that Sharon was going to vomit corresponded with her movement to put the cap on the lens of the video recorder. In this possibility, I would not think of Sharon’s movement in terms of a kinaesthetic experience but rather in terms of her aim (turning off the camera), and her motivation (not to be recorded). I could carry this explanation forward in terms of an intellectual understanding and argue that in the context I used a rapid reasoning process to determine that one possible motivation for Sharon not wanting to be recorded was that she knew she was going to vomit. Although I sometimes reason this way my *felt sense* of the situation was much more precise and immediate, suggesting another explanation.

Another possible explanation relates to the neurological discovery of mirror neurons (Rizzolatti, Fogassi, & Gallese, 2006). Mirror neurons provide a neurological mechanism
for an individual’s understanding of someone else’s actions and intentions. In other words, the actions and intentions of others are intersubjectively accessible through mirror neurons. Mirror neurons in the brain register the visually observed movements of another person in exactly the same way, only weaker, as if the person had moved themselves (Rizzolatti et al., 2006). Thus, according to Rizzolatti et al. (2006) the person observing someone else has a visceral understanding of what the other person is doing because mirror neurons enable them to experience it in their own mind. Lohmar (2006) suggests the discovery of mirror neurons means “new and concentrated attention” should be paid to “our feelings and sensations when we see bodily movements of other people” (p. 8). My felt sense that Sharon was going to vomit has some characteristics that would fit this explanation. My felt sense that Sharon was going to vomit was quite exact in that I felt certain she was going to vomit and that it would be soon. While my felt sense that Sharon was going to vomit was strong it was much weaker than the sensations I would normally get prior to vomiting. However, my felt sense while quite exact was not a co-sensing in a visceral way. My felt sense at the time Sharon put the cap on the lens was nothing like the sensations of nausea and abdominal discomfort I might experience prior to vomiting. While the mirror neuron explanation locates my felt sense of the situation within my physical body, the link to the outside is limited to a stimulus-response mechanism that ignores much of the context and complexity in the situation (Welsh, 2006). The mirror neuron explanation goes some way to integrating my felt sense, but ultimately fails to match or carry it forward.

37 Although the same cannot be said for when she actually did vomit.
Another possible explanation relates to my interactions with Sharon in the situation. On reflection after the situation I thought I must have unconsciously perceived some objective external evidence that caused me to have the *felt sense* that Sharon was going to vomit. My disappointment at not being able to record Sharon vomiting on video was moderated when I realised I must have captured on video the objective external evidence that caused me to have that inner subjective feeling. I watched and listened to the video numerous times looking for the objective external evidence I was sure would be there. I also watched the video in slow motion so I could attend to every movement in detail. I watched the video without sound attending only to the visual stimulus. I listened to the video recording without watching it, attending only to the sounds; and I listened to the corresponding audiotape recording. When I could not find the evidence, I watched the video many more times, each time attending to different parts of Sharon’s body, her face, her mouth, her eyes, her neck, and her trunk. Despite these efforts, I found no objective external evidence for my *felt sense* that Sharon was going to vomit. The objective evidence seemed to refute my *felt sense* of the situation. However, reflecting on the way I had been attending to my analysis of the video recording revealed the multiple components implicit in the situation, the visual, including movements of each part of Sharon’s body, and the auditory, all of which I attended to separately. Given the lack of objective evidence I began to think about the details of the situation that were lacking in my analysis so far.

The video camera and audiotape had recorded the visual and auditory components of the situation over a set period of time and in a specific space but these recordings did not correspond to my perception of the situation. This highlights an essential distinction between recording and perceiving. My perception of the situation was never exclusively
visual or auditory or even a combination of the two. I thought about my senses, and what the recordings lacked. Obviously in this situation the sense of smell could have contributed to my sense that Sharon was going to vomit. By combining the visual and auditory record and adding the possibility of a smell I still did not reconstruct the complexity and intimacy of the situation. Keeping my experience of the situation in mind there was also the history of Sharon vomiting earlier in the day, the bowl, in the room, in case she vomited again, and my past experience of children vomiting. The situation contained many more details that I could continue to set out, but I could never give all the details. The important point is that my reflective analysis of the situation identified all these separate details but my pre-reflective experience of the situation was as one quite specific felt sense that Sharon was going to vomit. The error in my analytical gaze, to date, was to think the details functioned separately rather as a “pre-separated multiplicity” (Gendlin, 1991, p. 89) or as an “unseparated multiplicity” (Gendlin, 2004b, p. 144). My felt sense was implicit in the situation as a pre-separated multiplicity, which strongly and precisely implied a further event (Gendlin, 1991, pp. 87-96), in this case the event was Sharon vomiting. My felt sense that Sharon was going to vomit did not require a cognitive reasoning process, or necessarily mirror neurons, but was rather implicitly and precisely implied in the situation (as an unseparated multiplicity). This example demonstrate how by focusing on their felt-sense adults in intimate situations with ill children can have a sense of what it is like for young children to be ill from the inside-out.

In this chapter I have used a small number of actual instances from my close observations, parental interviews, and nursing experience to contribute further detail to some aspects of the implicit knowing that emerged as a felt sense of what I had learnt from
all the situations with the children and their parents. In doing so I have explicated the essential theme of my thesis that preschool children understand illness inside-out, unimpeded by others. My aim was to communicate what it is like for young children to be ill, and how they communicate their experiences of being ill to others. I have shown that preschool children understand illness as lived from the inside-out. What it is like for them to be ill depends to a certain extent on how the illness makes them feel on the inside. I have shown that preschool children have an ability to very precisely relate an inner felt sense of an illness to a previous experience from the inside-out, unimpeded by others. I have shown that in advance of what they can say their bodies move directly to carry their felt sense of an illness from the inside-out. In the process I have contributed further detail to the kinaesthetic, intersubjective, situational and spatial essence of what it is like for preschool children to be ill that was revealed in a limited way by my analysis of the behavioural and cognitive literature in chapters two and three. In addition, I have shown how adults can understand children’s experience of illness from the inside-out. In the final chapter I will examine the application of these ideas with particular reference to the discipline of nursing, while also giving consideration to other disciplines that work with and research preschool children.
CHAPTER SEVEN

INSIGHTS AND IMPLICATIONS FROM THE INSIDE-OUT

*Grown-ups never understand anything by themselves, and it is exhausting for children to have to provide explanations over and over again.* (Saint-Exupéry, 1943/2000, p. 2)

This research began from my need as a nurse to understand how young children experience being ill and how they communicate their experience of being ill to others. In the process of searching for what it means to preschool children to be ill, I have uncovered the presence of embodied knowledge about illness inside children, and revealed how children’s embodied knowledge is expressed outside through their bodies. I have shown that preschool children have considerable embodied knowledge about illnesses they have experienced, which contrasts with and extends existing understandings about the deficits in preschool children’s disembodied knowledge of illness. Uncovering the presence of children’s embodied knowledge about illnesses they have experienced opens a new direction for further enquiry. Furthermore, in the process of re-searching for what it means to preschool children to be ill, I have developed an ethnographic phenomenological methodology, which is a form of what Todres (2007) refers to as “embodied enquiry” (p. 5). This novel combination of ethnographic method and phenomenological methodologies goes some way to addressing the methodological difficulties inherent in attempts to understand the world as children do.
In this final chapter, I review key outcomes of my search for what it means to preschool children to be ill described in the previous chapters. I focus on the outcomes relating to children’s experience of illness, and conducting research with preschool children. In doing so I explore the insights and implications, particularly for nurses and researchers, but also for others who encounter children in their daily lives.

**CHILDREN’S EXPERIENCE OF ILLNESS**

In chapter three, my analysis of the cognitive literature demonstrated that preschool children have only a limited cognitive understanding of illness. However, the cognitive developmental literature has had a major influence on what information is given to young children in health care settings and on how that information is given. The Piagetian literature tended to focus on what children do not know and consequently significant restrictions were placed on what young children were told about illness. The contemporary literature has increasingly recognised that children know more about illness than they have previously been given credit for (Rushforth, 1999). This literature has been used to guide efforts to find developmentally appropriate ways to explain abstract disembodied knowledge of biological illness processes and concepts to children. However, the contemporary literature still focuses on children’s understanding of illness as an abstract concept rather than their understanding of illness as lived. Careful consideration needs to be given as to whether an abstract understanding of what is happening to an ill child will add any value (for the child) to what they already understand, based on their lived experience of the illness. Where such an understanding might add value for the child then the existing literature on how preschool children conceptualise illness is of some value.
This thesis has shown that children experience illness before they conceptualise it, and that the abstract concept of illness is first given as lived experience. My analysis has shown that preschool children have a direct bodily understanding of illnesses they have experienced and that they carry that understanding in the way they move their bodies. Of key importance for practitioners is the recognition that children carry, in their lived bodies, a substantial understanding of illness situations. It is critical that health professionals working with preschool children, and researchers studying children’s understanding of illness, begin to shift their focus from what preschool children know about illness as an abstract concept or their physical bodies as objects, to children’s understanding of illness as lived through their bodies and their bodies as lived. What is needed is a wider and fuller conception of illness that incorporates illness as lived. There is a need for further research on young children’s experience of specific illnesses and interventions. Such research could be used to explain children’s embodied knowledge of illness to adults caring for children, so that they can be more responsive to children’s situated needs.

The idea that preschool children know little about illness, and that their answers to adult’s questions about illness prove that, has been opened to question. This has been achieved through turning to the children themselves and seriously attending to their situation while attempting to suspend adult presuppositions. Children’s bodily sensibility is caught up in the illness not as an abstract concept but as a lived experience inseparable from the rest of their world. Their understanding of illness is derived from their bodily sensibility and does not require language to be formulated. This pre-linguistic understanding of illness is not primitive or deficient; rather it is an understanding that
knows illness directly. In other words, in advance of what they can say, children understand illness inside-out, unimpeded by others.

As the example of popcorn stuck in the throat demonstrates, the language preschool children use to describe illness is likely to reflect their pre-linguistic lived bodily understanding of illness rather than an abstract understanding of illness. Furthermore, they may use words in unorthodox ways when the gestalt for the word corresponds to the gestalt of their bodily sensibility. Children do not suffer from illness as defined by medical and nursing text books; rather, they suffer from illness as lived in relation to their bodies in an intersubjective world (van den Berg, 1972, p. 85). Thus in illness situations it is important to consider how preschool children’s statements or questions could possibly make sense. This requires professionals and lay carers to presume children’s statements are sensible (even if they do not yet, or never make sense, from our perspective). It requires that children’s statements be taken seriously, and it requires adults to constantly question their own preconceptions about what the child said, and remain alert for clues in the situation that reveal possible meanings for the child - possibilities our own preconceptions may have suppressed.

In the light of my analysis, it is evident that in illness preschool children express their views not just verbally, but first and foremost with their bodies. I first highlighted the importance of bodily movement in children’s experience of illness in chapter two through the work of Freud (1952), and my analysis of the behavioural studies which showed the effects of illness on children’s routine activities. The meaning of being sick, as a restriction on children’s activities, is also evident in my analysis of the cognitive literature in chapter
three, examined under the thematic aspect of being ill. In chapter six, the importance of children’s movement is taken further in my analysis of children’s gestures, which show an understanding of illness in advance of what they can say. Thus, the child’s experience of illness is meaning-full but that meaning is not dependent on language (Broom, 2007).

Health professionals and parents need to be attentive to the fact that children’s actions and movements may be embodied expressions of their views on the illness. In other words, they may be full of meaning. In the example of the scratch in eczema and the knee-chest position in raised intracranial pressure, this research has identified that actions and movements can re-present the child’s sensuous understanding of the illness, from the inside-out, unimpeded by others. This is not about body language, it is about embodied thinking, and thinking in movement (Sheets-Johnstone, 1999). Children’s right to express their views, have their voices heard, and be given due weight in accordance with their age and maturity is enshrined in Article 12 of the United Nations Convention on the Rights of the Child (United Nations High Commissioner for Human Rights, 1989). Therefore, wherever possible, children must be enabled to move their bodies freely because without that freedom they are, in part, silenced. Even with the freedom to move there is no guarantee children’s unspoken gestures will be heard or understood.

This whole thesis is an attestation to the difficulties adults face in understanding the world as children do. I have conceded that it is not possible to completely understand young children’s experience of the world as the child would, but there are also some clear indications from this research about how at least a limited understanding can be obtained. This thesis provides evidence of the intersubjective nature of understanding. The child’s
bodily actions do not occur in isolation. As Broom (2007) notes the “experiencing body lives in a context, in an environment, in the world” (p. 159). Inevitably, others are an important part of that world for preschool children. In intimate situations children’s actions and movements are always in relation to others. To understand situations as children might, adults need to come very close to children and be involved with them in situations with which they are concerned, while remaining attentive to divergent perceptions of the situation. This coming close to children and being involved with them resembles the being-there and being-with which are common themes of the nursing literature on presence as a nursing intervention (for examples see Finfgeld-Connett, 2006; Fredricksson, 1999; Gardner, 1992; Pederson, 1993). Several studies have documented the positive role of parental presence in the context of children having medical procedures (see Piira, Sugiura, Champion, Donnelly, & Cole, 2005 for a recent systematic review). However, as Pederson (1993) claimed, there continues to be little research about nursing presence with children and so this remains an area for further research.

Being-there and being-with are pre-requisites for understanding but are not sufficient on their own. Drawing on the work of Gendlin (1978/79), I have shown how my felt sense in a situation is a form of immediate understanding. The knowledge in this felt sense is relational, it is linked to my being-there and being-with the children in the situation and implicitly knows something more than my experience of the situation. This bodily felt sense must be attended to because it gives access to what is more than an individual experience of a situation. There is a need for parents and health professionals to be attentive to their felt sense of intimate situations with children because that felt sense carries
an implicit understanding of the situation and may uncover something of the child’s understanding of the situation.

It is clear from my research and the literature that when children are ill their way of acting and moving in the world is different. They are not ‘themselves’ when they are ill. Their normal actions and movements in the world, in part, define their selves. However, it is necessary to know what normal actions and movements are, in order to detect the difference (Spicker, 1976). Therefore, nurses and other health professionals working with ill children should know the actions and movements that can be expected of healthy children, at different stages of development. It also makes sense for health professionals to ask parents who know their children well if they have detected any differences in the way their ill child acts and moves in the world. Changes in the pattern of children’s actions and movements over the course of the illness are an indication of the progression of the illness itself. Such changes in movement need to be carefully observed and recorded. What I am suggesting about observing and recording the pattern of children’s movements is similar to how nurses and other health professionals have long understood biological body rhythms as indicators of both health and illness. Historically, a considerable amount of nurses’ time has been spent observing and recording biological body rhythms (e.g. height, weight, temperature, pulse, respirations, blood pressure, food and fluid intake, and urine and faecal output). Similar to interpreting the meaning of changes in other body rhythms, a change in body movement, is never interpreted in isolation. At a minimum, its meaning comes from its variation from what is regarded as normal. But more importantly, its meaning is analysed in the context of the repetition of rhythmic movements for that child, in other words, in the context of that child’s pattern of movement over time. Children’s actions and
movements provide an important focus for assessment about the progression of the illness itself. More importantly, such observations will help health professionals to carefully listen to children’s non-verbal communication and therefore they should be in a better position to see their meaning and respond appropriately (Broom, 2007, pp. 69-82).

Children’s movements can also more or less adequately compensate for the physiological effects of illness. In chapter six, I discussed the compensatory effects of movement and posture spontaneously adopted by young children with various diseases. The knee-chest position in association with raised intracranial pressure has been shown to reduce cerebral blood volume (Straussberg et al., 1993). The knee-chest position in tetralogy of Fallot has been shown to correct hypercyanotic spells (Guntheroth et al., 1968; Lurie, 1953; Taussig, 1947). Scratching in eczema has been shown to decrease histamine-induced skin blood flow and itch intensity (Yosipovitch et al., 2005). Dystonic posturing in gastroesophageal reflux has been shown to increase oesophageal peristalsis and promote clearance of acid from the lower oesophagus (Olguner et al., 1999). Furthermore, the clinical relevance of movement and posture in a variety of diseases has been reviewed by Martin-Du Pan, Benoit and Girardier (2004). Their review included the significant decrease in the prevalence of sudden infant death syndrome since recommendations to position infants on their side or back to sleep. These examples indicate that paying closer attention to children’s posture and movements in illness may help to identify patterns of movement, or postures that may more or less adequately compensate for the physiological effects of illness.
In chapter one, I mentioned children’s rights to effective communication, and to make informed choices to the extent appropriate to their level of competence. My analysis of how children experience illness suggests a need to extend what is currently regarded as appropriate content to inform young children about illness, diagnostic tests, and therapeutic interventions. To be effective, communication must connect with the child’s lived understanding of their world. Leventhal (1975, as cited in Kestenbaum, 1982, p. 22) suggested that health practitioners need to consider “three types of statements (sensory feeling, bodily change, future self)” to help patients connect diagnostic and therapeutic interventions to the patient’s experience of the world. My findings confirm and extend at least the first two aspects suggested by Leventhal. Knowing that children’s experience of illness is lived in how their bodies feel, move, and occupy space, all of which have an intersubjective component, extends the sensory information that children need to know to make sense of the natural course of an illness, and any diagnostic, or therapeutic interventions.

Current evidence suggests the most appropriate content for informing children about forthcoming diagnostic or therapeutic interventions includes procedural and sensory information (Jaaniste, Hayes, & von Baeyer, 2007). This research broadens the scope of what is typically regarded as sensory information. Children need to know how an illness, diagnostic test, or therapeutic intervention will feel. ‘Feel’ includes the full range of sensuous experience from the inside-out: what they will see, hear, taste, smell, what they will feel from the outside, tactile sensations (e.g. heavy, hot, sharp, etc.), and what they will feel on the inside, proprioception (e.g. full tummy, an urgent need to pee etc.). When considering how something might feel in illness it is important to be aware that illness
shifts the sensual emphasis from the outside world to the internal body and in the process heightens bodily awareness.

Children need to know how their body’s ability to move itself through space and time will be affected by the illness, diagnostic test or therapeutic intervention, because a child’s movement through space and time is integral to the child’s current self. When considering how a child’s ability to move their body in time and space might be affected it is important to consider that their biological development already presents possibilities for movement in time and space that may be different from those presented to adults. The kinaesthetic sense of movement includes: the speed of movement, the range of movement, the tension in movement etc. (e.g. swift, slow, smooth, clumsy, jerky, weak, heavy, hesitant etc.) (Sheets-Johnstone, 1999, pp. 55-57).

Children also need to know how their relationship with significant others will be affected. Just as the child’s movement is integral to the child’s current self, so too is the child’s participation with others. The sensuous nature of the information required by children also suggests how this information should be given to the children, in other words in a sensuous and situational way. Little is known about the most appropriate timing for providing preschool children with information such as this. However, my own experience with children in this study and the work of Medcalf Davenport (2003) suggests that preschool children continue to process information long after adults have moved onto other things. Providing children with this sort of information must be a transactional social process in which the child plays an active role in shaping the information provided (Jaaniste et al., 2007). It is possible this type of information, delivered appropriately, could reduce
children’s fear, and enable them to become active participants in their care, although this remains to be researched.

The ideas about the lived experience of illness, presented in this thesis are not new; rather they are newly detailed, in their application to the lived experience of illness in preschool children. Preschool children understand illness as lived from the inside-out, unimpeded by others. This is quite different from the objective scientific view of illness, which is derived from the outside. Both perspectives are legitimate. Adults have tended to interpret children’s understanding of illness from the objective scientific point of view, found them wanting, and attempted to teach children this perspective. Consequently, children come to know and articulate an understanding of illness derived from the outside-in. However, young children primarily understand illness through their everyday functioning in the world. Children’s understanding of illness is not something primitive or lacking but rather a fundamental pattern of the human experience of illness.

I have suggested that by focusing on their own felt sense, adults in intimate situation with ill children can begin to understand what it is like for young children to be ill. Again, the role of the felt sense in understanding is not new, Gendlin (1981) has written about it extensively. However, it is newly detailed in its application to understanding what it is like for children to be ill. This represents a relatively new way of thinking in terms of communicating with and understanding children that will be important for all the diverse groups of people whose role it is to communicate, interact with, and support young children in one context or another.
Aspects of the ethics and art of researching with preschool children have been carefully documented in chapters four, five, and six. The effort taken to inform children of their choices, and respect their right to decide on the nature of their participation throughout the research process, was at times frustrating. For example, when children wanted to draw something other than a picture about being ill, or when my plans to use ‘bum bags’ to hold the tape recorders didn’t work out, or when the children didn’t seem to hear my questions. However, my commitment to respecting the children’s right to choose eventually reaped rewards, as the example of Sharon putting the lens on the video camera demonstrates. During my close observation with the children the information booklet titled “It’s your choice” was at times used by the children to direct my attention towards certain activities, thus it seemed to help the children shape their interactions with me. Unfortunately, I do not know what role it played for the 23 children whose parents were sent the information booklet but did not consent to participate.

The process of data collection was essentially one of close observation. The anecdotes collected during periods of close observation with the children were essential to the research. Furthermore, the time spent in close observation with the children while they were well proved decisive in understanding the significance of movement when children are ill. This highlights the importance of researchers observing healthy children to illuminate features of the ill child (Spicker, 1976). However, I do not want to underestimate the importance of parent’s participation in research with preschool children. Parents were often in a position to inform me about historical and contextual information unknown to me but always already at work in the situations before I observed them.
Phenomenology has been characterised as a movement that keeps on redefining itself (Spiegelberg, 1971). Phenomenological researchers have historically relied largely on spoken language as their source of data (Danaher & Briod, 2005). Consequently, it is a research methodology that has had limited use in relation to the preverbal child and in younger children with limited verbal abilities. However, the subject of the child was of more than a casual interest in Merleau-Ponty’s phenomenology. I have found engaging with the writings of Merleau-Ponty very helpful both in overcoming the introspective nature of my data and in evolving a research methodology for understanding children. Similarly, engaging with the writings of Gendlin was essential to uncovering the intricacies of the situations which were always more than the transcripts could re-present and to showing me that the more than was implicit in my embodied felt sense of the situations. This embodied understanding provided a methodological path of embodied enquiry (Todres, 2007) into situations were I felt a certain divergence between myself and the child. Thus, by engaging with the writings of Merleau-Ponty and Gendlin I was able to take forward the methodological challenge of understanding the world as children do.

I have shown that interpreting the meaning of young children’s language and actions as they would is an extremely complex, and ultimately impossible, but not futile task. Furthermore, I have shown that children’s movements and their bodily actions in situations with others are a point of access to understanding their experience at least in a limited way. As Serlin (1996) suggests “action occurs between mover and witness and, as such, is a text” (p. 28) open to interpretation. An action is a way of seeing and being seen that reveals the invisible through the visible (Serlin, 1996).
The following explanation of how I attempted to reveal the child’s invisible understanding of illness through their visible actions\textsuperscript{38} is informed by Merleau-Ponty’s (1961/1964a) view that things have an internal equivalent in me; they arouse in me a carnal formula of their presence. Why shouldn’t these correspondences in their turn give rise to some external visible shape in which anyone else would recognise these motifs which support his own inspection of the world? Thus there appears a “visible” of the second power, a carnal essence or icon of the first. It is not a faded copy. (p. 164)

In a similar vein, I suggest illness (e.g. eczema, or brain tumour) has an internal equivalent in children; illness arouses in children an internal invisible sensuous impression of its presence (e.g. itchy skin, or heavy head). This internal sensuous equivalent of illness produces some external visible action (e.g. scratching, or knee-chest position), which the child recognises because it corresponds with and supports the child’s embodied view of the world. Therefore, the child’s actions in an illness situation carry the sensuous essence of the illness for the child.

As a researcher, nurse, or parent, I should be able to see the child’s external visible action. However, what I recognise the action as, depends on my own embodied view of the situation, which is inevitably different from the child’s embodied view of the situation. Furthermore, the child’s actions have an internal invisible equivalent in me; they arouse in me a sensuous impression of their presence. Thus, there appears to be, in me, a third order

\textsuperscript{38} Actions include words.
invisible sensuous essence, of the child’s second order visible action that arose from the child’s first order invisible sensuous impression of the illness. My third order, invisible, sensuous impression, is a faded copy of the first in the child. It is a faded copy because, my body is not in the child’s position, and it is not the child’s body. This necessarily imposes some limits on my understanding. However, my invisible, sensuous impression is still a copy of the child’s first internal, invisible, sensuous impression of the illness. I have referred to my invisible sensuous impression as a felt sense of the situation. My felt sense should never be reduced to my bare awareness of the child; it takes in, and is inseparable from, my situation with the child. Merleau-Ponty (1942/1963) states an inner sense “cannot be conceived part by part and must be conceptualised all at once as an indecomposable essence” (p. 171) or as Gendlin (1991) would say a “pre-separated multiplicity” (p. 91).

The world of the sick child was “out there” to be seen, only a faded copy was in me as a felt sense, so to understand the felt sense I had to look for an explanation “out there” (Kohák, 1978 as cited in Kestenbaum, 1982, p. 14), in the situations where the children interacted with me and their world. To interpret my felt sense of the child’s experience I had to overcome my own position, which was achieved partially by imaginative variations which took into account the child’s position in the situation and in particular the locomotive development of the child’s physical body. As Todres (1990) explains “it is this holistic, pre-verbal sense of ourselves-in-relation that enables us to have or not a sense of recognition as to whether an interpretation or verbal description ‘fits’ or not” (pp. 36-37). My felt sense held more than what I could otherwise articulate in the situations with the
children. Gendlin’s (2004a) process of Thinking At The Edge offered a way of articulating my *felt sense* that was bound experientially to the child’s experience.

The ideas about how to conduct phenomenological research in this thesis are not new - Finlay (2005) and Todres (2007) have made similar suggestions – rather, they are newly detailed in their application to conducting phenomenological research with preschool children. Furthermore, they extend the scope of the phenomenological research tradition in nursing (see Crotty, 1996; Madjar & Walton, 1999; Thomas & Pollio, 2002 for examples), which has relied heavily on verbal data. The move away from reliance on verbal data opens up an opportunity for the phenomenological study of infants, neonates and possibly even the unborn child. I have not gone down the phenomenological path without also looking at the empirical literature. What I saw in my analysis of the field data informed my analysis of the empirical literature and vice versa. If phenomenological research is to push the boundaries further into the early stages of life it must incorporate results from the empirical science to uncover what they reveal, at least in a limited way about the essence of what they study (Merleau-Ponty, 1961/1964b).

Finally, the research on which this thesis is based has its origins in my nursing practice with children and grew out of a need to understand how preschool children experience being ill and how they communicate those experiences to others. Therefore, it seems appropriate to end this thesis where I began by returning to an example from my nursing practice. I recall an example from one of my first days as a nurse in a paediatric setting, after many years nursing adults. An infant and her mother arrived unannounced on the ward from the emergency department. I remember meeting the child and mother in the
corridor. The mother seemed calm but the child was limp, pale and lethargic. As a novice paediatric nurse, I did not know much about sick children but I knew enough to know this infant was not well. I put the child and mother in a single room, gave the child some oxygen, called a senior colleague for assistance, and within minutes the infant was receiving high concentrations of oxygen in an incubator. I was pleased I had recognised the severity of the infant’s situation, but I was shocked by what I did not know, and full of admiration for my senior colleague, who seemed to assess the situation with ease, and knew exactly what to do. On reflection, I now know that I recognised the seriousness of the situation through the knowledge hidden in my lived experience of healthy infants as animate beings, and this infant was inanimate. Accordingly, when I assess a child, one of the things I expect to see, in a healthy child, is movement. This reflection and observation is little more than what Piaget (1929) declares every child knows. In a study of what children understand by the concept of “life”, Piaget found not a single case “of a child who failed to bring in also the idea of activity and movement” (p. 204). Likewise children’s activity and movement have been significant themes in this thesis.

In the end, this thesis is for preschool children, particularly those children that frequently experience illness. Yet, the thesis is written for grown-ups, which might seem inside-out. I have a serious justification: Inside-out is reversible; it is also outside-in. Which is why the quotes from Hesse (1945/1973) and Saint-Exupéry (1943/2000) at the beginning of each chapter can go to the heart of what this thesis is about. I wrote this thesis for the children grown-ups care for and study. I hope the children will see in the actions of those grown-ups who have read this thesis, that they no longer have to work so hard to make themselves understood by grown-ups.
APPENDIX ONE: UNIVERSITY OF NEWCASTLE ETHICS APPROVAL

The University of Newcastle  
HUMAN RESEARCH ETHICS COMMITTEE

Certificate of Approval  
for a research project involving humans

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<td><strong>Chief Investigator/Project Supervisor:</strong></td>
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<td>(First named in application)</td>
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| **Other Investigators:** | **Professor Diana Keatinge**  
| | **Mr Paul Watson** |
| **Project Title:** | **What is it like for young children to be ill?** |

In approving this project, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the *National Statement on Ethical Conduct in Research Involving Humans, 1999*, and the requirements within this University relating to human research.

<table>
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| **HREC Approval No:** | **H-123-9601**  
| **Date of Approval:** | **20 June 2001** |
| **Approval valid for:** | **5 years**  
| **Progress reports due:** | **Annually** |

**Comments or conditions:**

Approved with comments.

Amendments to *Information sheet for parents and guardians*.

[a] The Committee requested that someone in New Zealand be identified who could act as a supervisor or mentor to Mr Watson and who could be contacted if parents/guardians wanted to discuss or verify details of the project with someone other than Mr Watson.

[b] In the complaints paragraph, the email address could be added for the Human Research Ethics Officer at The University of Newcastle, which is [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).

**Signed:**  
Ms S J O'Connor  
Secretary to the Committee
APPENDIX TWO: CANTERBURY ETHICS COMMITTEE APPROVAL

2 October 2001

Mr PB Watson
4 Derwent Street
Bryndwr
Christchurch 8005

Dear Paul

What is it like for young children to be ill?
Investigators: Paul Watson, Prof I Madjar (Supervisor), Prof D Keatinge, Jane O’Malley
Ethics reference no: 01/06/081
Information sheet/consent form version 17 September 2001

Thank you for the revised information sheet. Ethical approval is now confirmed for the above study.

Approval is until 30 September 2004. The Committee will review the study annually and notify you if it withdraws approval. It is your responsibility to forward a progress report in August each year. Failure to do so may result in withdrawal of ethical approval. A final report is also required at the conclusion of the study. Report forms are available from the administrator.

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way. Please quote the above ethics committee reference number in all correspondence.

The Committee wishes you well with your research.

Yours sincerely

Sally Cook
Ethics Committee Administrator
APPENDIX THREE: PLUNKET ETHICS COMMITTEE APPROVAL

Royal New Zealand Plunket Society (Inc.)

Mr Paul Watson
4 Dervent Street
Bryndwr
Christchurch

30 May 2001

Dear Mr Watson

What is it like for young children to be ill?

The above proposal was discussed at this week’s meeting of the Plunket Ethics Committee. I am pleased to inform you that your proposal has been approved subject to the following provisos.

1. Details of the paediatrician be provided to the Committee (p 9). Appendix 5 was not in the papers provided to the Committee.

2. You state that "...the researcher could still disclose that information if the disclosure was not contrary to the child’s interests". The Committee considers that this information ‘will be’ disclosed under these circumstances.

3. The information sheet should be less wordy and shorter; in addition, its language should be simplified. This sheet should have a New Zealand contact number (that of the Health and Disability Services Consumer Advocate) at the bottom in a prominent place.

4. An information sheet should be provided for Plunket staff in the three Christchurch areas you intend using in your research.

5. You are recommended to attend Plunket staff meetings in these areas so that you can discuss the project with the staff, since clients may approach them with questions.
6. Since termination of the relationships with children in the study may be complex, the Committee suggests that you give this matter some thought well in advance. How will you explain this to the children in a meaningful way?

7. The Committee wishes to be informed when the Newcastle University Human Research Ethics Committee has given approval for this project to proceed.

8. While the Committee was very impressed with the thoroughness of your application the amount of work appears to be very considerable. You may need to reassess this as the project proceeds.

This letter provides you with ethical approval. You need to contact Ms Gill Sinclair, Area Manager, Area 15 Canterbury, regarding approval for Plunket staff to be involved in the project.

Yours sincerely

D. Gareth Jones
Chairman, Plunket Ethics Committee
What is it like for young children to be ill?

Do your children / tamariki get sick from time to time?

- Are your children aged between 2 and 5?
- Do they get occasional coughs, colds, sore throats, earaches or similar illnesses?
- Would you be willing to let your children take part in a research project aimed at finding out what it is like for young children to be sick? It is hoped the findings of the research will help health professionals and families/whanau caring for young children.
- Could your family help? Your child does not need to be sick at present to take part in this study. Your family would be visited at home regularly over 1 to 6 months. Information would be kept confidential and there would be no costs to you in taking part.

If you are interested in finding out more about the research please contact Paul Watson ph 359-1803.

The Canterbury Ethics Committee, the Newcastle University Human Research Ethics Committee and the Plunket Ethics Committee have approved this study, which is part of a PhD.
APPENDIX FIVE: COMMUNITY NEWSPAPER ARTICLE

Study into child’s experience of sickness

Understanding how pre-school children feel when they are ill should help health professionals care for them better, says a Christchurch health researcher.

Paul Watson, a registered nurse and lecturer at the Christchurch Polytechnic Institute of Technology, is researching what it is like for preschool children to be ill. The work is part of his PhD.

“Preschool children often get short-term illnesses such as coughs, colds, sore throats, sore ears and other infections and because of this they are major users of health services,” Mr Watson says.

“But we actually know very little about how children view the experience, we tend to rely on their parents or caregivers to give us whatever information we need.”

Mr Watson believes that a better understanding of what it is like for preschool children to be sick will result in improved care.

“Little research has been done to help us understand the illness experience of preschool children in their terms.

“Children are likely to benefit if health professionals and parents understand more clearly how they experience being ill.”

Mr Watson is interested in hearing from families with children aged between two and five who might be interested in taking part in his study.

Children do not need to be sick at present to take part in this study. Participating families will be visited in their home regularly over one to six months, and all information will be kept confidential.

The Canterbury Ethics committees have approved the study and there will be no cost to the families involved.

For more information, contact Mr Watson on 359-1803.

("Study into child's experience of sickness," 2002)
APPENDIX SIX: INFORMATION SHEET

Paul Watson, PhD Candidate
4 Derwent St Christchurch, NEW ZEALAND
Phone (03) 359-1803

Supervisors: Professor Irena Madjar & Professor Diana Keatinge
Faculty of Nursing Newcastle University
NSW 2308 AUSTRALIA
Phone (0061) 2-4921-7043

Jane O’Malley, Senior Lecturer
Department of Psychological Medicine
Christchurch School of Medicine
Phone 372-0400

What is it like for young children to be ill?
Information sheet for parents and guardians

Hello, Kia ora, Talofa,
I am Paul Watson, the father of two boys. I work as a nurse lecturer at Christchurch Polytechnic Institute of Technology. This study of what it is like for young children to be ill is part of my PhD studies at the University of Newcastle, Australia. You are invited to consider allowing your preschool child to choose if s/he wants to take part in this study. This information sheet explains the reasons for doing this study and what would be involved for you and your child if you both agree to take part. You will want to think carefully about this and may wish to discuss this study with other people (e.g. family / whanau, hapu or iwi) before making your decision. Please feel free to contact me if you or your child have any questions.

Aims of the study
Preschool children often get short-term illnesses such as coughs, colds, sore throats, sore ears and other infections. As a result, children are major users of health services, yet their opinions about their illnesses are rarely sought. Nurses and doctors tend to rely on adults, usually parents to give a report of their child’s illness. Adult reports are important but the child’s own views may also contain important and relevant information. Little research has been done to help us understand the illness experience of preschool children in their terms. Children are likely to benefit if health professionals and parents understand more clearly how they experience being ill.

Therefore, this study aims to find out how young children experience being ill from short term passing illnesses. It also aims to identify how young children communicate their experience of being ill to others. There will be 25-30 children aged 2 to 5 years and their parents/caregivers who normally speak English at home taking part. Children younger than 2, children with a chronic or life threatening illness and children who do not normally speak English at home will not be able to take part. People who meet the above criteria will be selected for the study by responding to advertisements in newspapers and community locations for preschool children.

What is involved?
It is likely that I will need to visit your home about once a week over one to six months. Each visit will vary from about 15 minutes up to an hour. I will visit only at those times when a parent, guardian or responsible adult is at home. The date, time and
length of each visit will be arranged to suit you, your child, and other family members. At first, I would like to visit your child while s/he is well. These visits would involve me taking part in your child’s normal activities (playing with them, talking with them and generally doing what interests them) and will enable your child and you to get to know me. I may need to take notes or tape record part of these visits. I would also like to talk to you about your child’s experiences of illness. These interviews would focus on situations that describe what seemed to be of concern to your child.

It is impossible to predict if, or when, your child might get sick. If your child does not get sick, my visits will stop after six months, or sooner, if you or your child decide to withdraw from the study. If your child becomes sick, then their experience of that illness would become the focus of my visits. My aim will be to provide your child with a chance to express his/her views on what it is like to be ill. I would also like to tape record part of these visits. Children may choose to share their experiences in many ways, such as by letting me be present, playing, talking, or drawing. Your child may also like to use (or ask you to use) a tape recorder, camera or video to record events in their illness experience. These would then be used to help your child and me to talk about their experience.

You will be given opportunities to review and comment on the audiotapes, videotapes, photographs and/or written records of my visits with your child. If you agree, I would like to tape record your comments and then make a typed record of them. I will return the tape and/or typed record of your interviews so you have a chance to review, edit or erase any comments you do not wish me to use in my study.

Consent for children
The final decision on whether your child takes part will be left to your child. Enclosed with this information is a booklet and tape-recorded story titled ‘It’s Your Choice’. The booklet’s back cover has more information on talking to your child about this study. If your child chooses to take part a parent or legal guardian will be asked to sign a consent form.

Confidentiality
Your child needs to know before they make a choice about taking part that any information they share with me, I may talk about with you (the child’s parent, guardian or caregiver). I encourage parents, guardians and caregivers to ask their child about my visits. I will give parents, guardians or caregivers any information they request that is relevant to their child’s part in the study. In the unlikely event that a child expressly requests that I keep something private, then I could still tell a parent, guardian or caregiver that information, unless the disclosure is against the child’s interests.

I appreciate that by taking part you will be allowing me into your home and the privacy of your family. I will respect that privacy by keeping all information about your child, your family, and yourself confidential. The only exception to this rule would be if I came across any information that indicated your child or any other children in the home were at serious or imminent risk in which case I would advise appropriate authorities.

The only people who will have access to the photographs, audio and/or videotapes and the written records will be myself and my supervisors who live in Australia and will not know you. Your names will not be revealed to them. A typist, who will sign a confidentiality agreement, will have access to the audiotapes to transcribe them. Your
names will not appear on the tapes or in the transcripts. To keep the identity of people private all written records and any publications from this study will use false names for people who take part and those mentioned during this study. The tapes and written records will be stored in a locked cabinet or as password-protected files on a computer at my home. I will keep a password-protected back-up copy of computer files at another secure place. When the study is finished, the audiotapes, videotapes, photographs and negatives will be returned to you to keep for your child. If you do not wish to keep these items, they will be destroyed. None of the photographs or other visual images taken of your child will be included in the thesis or other publications. A copy of the written records will be sent to the Faculty of Nursing at the University of Newcastle in Australia to be held securely for 10 years as required by research regulations.

**Risks and Benefits**

There may be no immediate or direct benefits to your child, your family or you from taking part in this study. However, there may be benefits to other children and their families in the future if nurses and other health professionals know more about what it is like for young children to be ill. There are no costs or financial benefits from taking part.

**Ethical Approval**

This study have been reviewed and approved by the Canterbury Ethics Committee, the Royal New Zealand Plunket Society Ethics Committee and the Newcastle University Human Research Ethics Committee.

**Voluntary participation**

Taking part in this study is your and your child’s choice. If you both agree to take part, your child and you have the right to decline to answer any question and are free to pull out at any time without needing to give a reason. The quality of health care you or your child receive will not be affected in any way.

**Queries concerns or complaints**

If you have any queries or concerns about you or your child’s rights in this study, you may contact a Health and Disability Services Consumer Advocate, phone 377-7051. If you want to discuss or verify details of this project with a local person other than myself, you can contact Jane O’Malley who is acting as a field supervisor ph 372-0400.

The University of Newcastle requires that you are informed that if you have any complaint about the way this study is conducted you may discuss it with me or my supervisors. or if an independent person is preferred, the University’s Human Research Ethics Officer, Research Branch, The Chancellery, University of Newcastle, Callaghan NSW 2308, Australia, ph (0061) 2-4921-6333, email Human-Ethics@newcastle.edu.au.

Thank you for considering your and your child’s participation in this study. Please contact me if your child decides that he or she wants to take part.

Kind regards and best wishes

Paul Watson       Professor Irena Madjar       Professor Diana Keating       Jane O’Malley
Researcher         Supervisor                           Supervisor                             Supervisor

**Information Sheet: 17 September 2001**

*What is it like for young children to be ill?*
It’s Your Choice

A book to help children decide if they want to take part in a study about what it is like for young children to be sick.

By Paul Watson
Hello, Kia ora, Talofa
My name is Paul Watson.

I live in Christchurch with my family.
Some of the time I work as a nurse with sick children.

And some of the time I learn new things at a special school called a university.
Everyone changes as they grow up and new things happen to them. So it is hard for grown-ups like me to remember what it is like to be young.
Part of what I have to learn at university is what it is like for children to be sick at home.

The best way for me to find out how children understand being sick is to ask children like you.

Ask Me!
I can speak for myself you know!
It is nice to have some people reading this book with you. If you want to you can draw a picture of everybody who is here.

You are all welcome.
I have written this book to help you decide if you want to share with me some of your time and your story about what it is like for you if you get sick.
You are probably not sick now.

But most children get sick quite a few times each year with coughs, colds, sore throats, sore ears and things like that. You usually only feel unwell for a short time.

Can you remember being sick?
I would like to spend some time playing and talking with you at your place. That way you and your family can get to know me.

Then you might feel happy to talk with me later if you get sick with a cough, cold, sore throat, sore ears or some illness like that.
If you did get sick later, I would like to hear your story about what it was like for you to be sick. There are many ways you could tell me your story.

We could talk,

play games,

draw pictures,

take photos,

or make video or tape recordings

about you being sick.
No two people see the world in the same way.

Some people like the Tweenies and some people like Blues’ Clues.
The way you see the world comes from what happens to you each day. No two people have the same things happen to them.

So you have something special that belongs to you. It’s your story of what happens to you.
Your story on what happens to you when you are sick is special and it belongs to you.

Or you might not want to share your stories.

You might like to share your stories about what happens to you.
You don't know me. You might know you should not talk to strangers unless mum or dad or the grown-up who looks after you says you can.

Does your mum or dad or the grown-up who looks after you say you can spend some time with me at your place and share your story about being sick?
Even if your mum or dad or the grown-up who looks after you says you can talk with me you might not want to.

Remember it is your choice.
If you don’t want to share some of your time and your story of what it is like to be sick with me just say NO THANK YOU.

If you want to share some of your time and your story of what it is like to be sick with me just say YES PLEASE.
Remember your story on what happens to you when you are sick is special and it belongs to you.

If you want to share your story with me and later you change your mind and feel you don’t want to share your story that’s OK.

Just say NO THANK YOU and tell your mum or dad or the grown-up who looks after you.
Do you have any questions about what I have said?

Your mum or dad or the grown-up who looks after you can probably answer your questions.

If they do not know the answer to your questions they can contact me and I can answer them.
I hope this book helps you decide if you want to share your story about being sick with me. Thank you for listening.

Good-bye, E noho r a,
Tof a
Dear Parents and Caregivers

It’s Your Choice has been written in order to help you talk with your child about taking part in my study about what it is like for young children to be ill. You will not find a lot of detail about the research in this book. Preschool children are not ready for detailed discussions about research. They are ready, however, to learn how to make decisions about sharing their time and their experiences with others and how to communicate those decisions to others.

Thus I encourage you not just to play the tape and / or read this book to your child but to share the book together. You may find it useful to stop and discuss issues as they come up.

Its Your Choice points out to children that their view of what happens to them is special. This is a deliberate strategy because children often try to please adults by providing the answers they think the adult wants. For this study it is important for me to find out your child’s understanding of what it is like to be ill.

When you have finished reading It’s Your Choice and talking about the research with your child please let me know your child’s decision.

Kind regards

Paul Watson
APPENDIX EIGHT: CONSENT FORM

Consent Form

What is it like for young children to be ill?

Researcher
Paul Watson
PhD Candidate, Newcastle University
4 Derwent St, Bryndwr
Christchurch, New Zealand
Ph (03) 359-1803

Supervisors
Professor Irena Madjar
& Professor Diana Keatinge
Faculty of Nursing, Newcastle University
NSW 2308, Australia
Ph (0061) 2-4621-7043

Statement by the Parent or Guardian:

• I have read and I understand the information sheet dated 17 September 2001 for parents and guardians of children taking part in this study to find out what it is like for young children to be ill.

• I have read (and or played the tape of) the booklet ‘It’s Your Choice’ to my child.

• My child and I have had the chance to talk about this study with the researcher and other people or groups (e.g. hapu or iwi) that my child and I consider will help my child make this choice. I am satisfied with the information my child and I have been given.

• I understand the final decision about taking part in this study is my child’s choice.

• I am satisfied that my child has freely chosen to take part in this study.

• I understand my child and I can pull out of this study at any time and it will have no effect on our health care.

• I understand my child and I can decline to answer any question in this study.

• I understand my part and my child’s part in this study is confidential and no material that could identify my child, my family or me will be used in any reports on this study.

• I know who to contact if my child or I have any questions or concerns about this study.

• I understand that I will be given opportunities to review, and comment on the audio / videotapes / photos of my child and the records of the researcher’s visits with my child.

• I understand I will be given the chance to review, edit or erase my audiotaped comments.

Consent Form: 17 September 2001

What is it like for young children to be ill?
• I understand that at the completion of the study the audiotapes, videotapes and photos will be returned to me to keep for my child. If my child or I do not wish to keep them they will be destroyed.

• I understand that the Canterbury Ethics Committee, the Royal New Zealand Plunket Society Ethics Committee and the Newcastle University Human Research Ethics Committee have approved this study.

• I consent to my child being audiotaped. Yes / No

• I consent to my child being photographed / videotaped (please circle). Yes / No

• I consent to my comments being audiotaped. Yes / No

• I am aware that there will be a significant delay between my child’s involvement in the research and the publication of results.

• I would like to receive a summary of the results when they are available and would like the opportunity to discuss the results of the study. Yes / No

I ........................................................................................................ (enter your full name) hereby consent to ................................................................. (enter the full name of your child) my ............................... (enter the child’s relationship to you) taking part in this study under the conditions set out in the information sheet, of which I have a copy.

Signed (Parent / Guardian): ................................................................. Date: ......................

Signed (Researcher): .................................................................................. Date: ......................

Project explained by: .................................................................

Parent/Guardian’s copy / Researcher’s copy (delete as applicable)

Consent Form: 17 September 2001

What is it like for young children to be ill?
29 May 2001

TO WHOM IT MAY CONCERN:

re: Mr Paul Watson 4 Derwent Street Bryndwr Christchurch

My name is Dr Russell Austin. I am a Developmental Paediatrician working at Christchurch Hospital with a particular interest in the field of Child Protection. During the course of his study, I would be more than happy for Paul Watson to refer any Child Protection concerns to me.

Yours faithfully

RUSSELL AUSTIN
Developmental Paediatrician

PAEDIATRIC DEPARTMENT, CHRISTCHURCH HOSPITAL
Private Bag 4710, Christchurch, New Zealand.
Telephone: (03) 364 0730  Fax: (03) 364 0919
APPENDIX TEN: CONFIDENTIALITY AGREEMENT

Confidentiality Agreement

What is it like for young children to be ill?

Researcher: Paul Watson
PhD Candidate, Newcastle University
4 Derwent St, Bryndwr
Christchurch, New Zealand
Ph (03) 359-1803

Supervisors: Professor Irena Madjar and Professor Diana Keating
Faculty of Nursing, Newcastle University
NSW 2308, Australia
Ph (0061) 2-4621-7043

Statement by typist

- I understand that the material I am typing for this research project contains confidential information and I will discuss it only with the researcher (Paul Watson).
- To make sure confidentiality is maintained I will ensure that no other person has access at any time to the material I am using.
- I will ensure that all typed documents are password protected.
- On completion of transcription, I will ensure that all copies of the material are returned to the researcher (Paul Watson), including hard copies, tapes and computer discs.
- Once copies of the material are returned to the researcher (Paul Watson), I will delete from the computer hard drive any documents that relate to this research.

Typist’s full name: .................................................................

Signed (Typist): ................................................................. Date: ..............

Witness full name: .................................................................

Signed (Witness): ............................................................... Date: ...............
REFERENCES


Wise, B. (2002). In their own words: The lived experience of pediatric liver transplantation. *Qualitative Health Research, 12*(1), 74-90.


